



POSITIVELY AWARE
HIV Treatment and Health

TRANSGENDER AND HIV

*Alexandra
Billings*

ON HOLLYWOOD, HIV,
AND HER CHICAGO ROOTS

**HORMONE THERAPY AND
DRUG INTERACTIONS**

**PROFILES AND
PERSONAL STORIES**

HAART 2.0

JULY / AUGUST 2008
THE JOURNAL OF TEST POSITIVE AWARE NETWORK

PLUS



INDICATION

PREZISTA (darunavir) is a prescription medication. It is one treatment option in the class of HIV (human immunodeficiency virus) medicines known as protease inhibitors (PIs).

PREZISTA is always used with 100 mg ritonavir (Norvir®) in combination with other HIV medicines for the treatment of HIV infection in treatment-experienced adult patients, such as those with HIV resistant to more than one PI.

- The use of other medications active against your HIV in combination with PREZISTA/ritonavir (Norvir®) may increase the likelihood of your overall treatment response. Your healthcare professional will work with you to find the right combination of other HIV meds
- The long-term benefits and side effects of PREZISTA therapy are unknown at this time. It is important that you remain under the care of your healthcare professional

PREZISTA is not approved for the treatment of HIV infection in adult patients who have

never taken HIV medications before or in pediatric patients.

PREZISTA does not cure HIV infection or AIDS, and does not prevent passing HIV to others. Please read Important Safety Information below, and talk to your healthcare professional to learn more about PREZISTA.

IMPORTANT SAFETY INFORMATION

- Do not take PREZISTA if you are allergic to PREZISTA or any of its ingredients, or ritonavir (Norvir®)
- Please refer to the ritonavir (Norvir®) Product Information (PI and PPI) for additional information on precautionary measures
- **Taking PREZISTA with certain medicines could cause serious and/or life-threatening side effects or may result in loss of its effectiveness. Do not take PREZISTA if you are taking the following medicines:** astemizole (Hismanal®), terfenadine (Seldane®), dihydroergotamine (D.H.E.45®, Migranal®), ergotamine (Wigraine®, Ergostat®,

Cafergot®, Ergomar®), methylergonovine, cisapride (Propulsid®), pimozone (Orap®), midazolam (Versed®), triazolam (Halcion®), rifampin (Rifadin®, Rifater®, Rifamate®), lopinavir/ritonavir (Kaletra®), saquinavir (Invirase®), lovastatin (Mevacor®), pravastatin (Pravachol®), simvastatin (Zocor®), carbamazepine (Tegretol®, Carbatrol®), phenobarbital, phenytoin (Dilantin®, Phenytek®), or products containing St. John's wort

- Before taking PREZISTA, tell your doctor if you are taking sildenafil (Viagra®), vardenafil (Levitra®), tadalafil (Cialis®), atorvastatin (Lipitor®), atorvastatin/amlodipine (Caduet®), or rosuvastatin (Crestor®). **This is not a complete list of medicines. Be sure to tell your doctor about all the medicines you are taking or plan to take, including prescription and nonprescription medicines, vitamins, and herbal supplements**
- Tell your healthcare professional if you are taking estrogen-based contraceptives. PREZISTA might reduce the effectiveness of estrogen-

Belief { in myself in my doctor in my care

PREZISTA, in combination with Norvir® (ritonavir) and other HIV meds, may help lower viral load and raise the number of T cells.



- Individual results with PREZISTA treatment may vary. The effect of PREZISTA therapy on viral load and T-cell count has been evaluated in 2 studies that lasted 24 weeks. The long-term benefits and side effects of PREZISTA therapy are unknown at this time

Ask your healthcare professional if PREZISTA is right for you.

 **PREZISTA™**
(darunavir) tablets

Please visit www.PREZISTA.com

- based contraceptives. You must take additional precautions for birth control, such as a condom
- Before taking PREZISTA, tell your healthcare professional if you have any medical conditions, including allergy to sulfa medicines, diabetes, liver problems (including hepatitis B or C) or hemophilia
 - Tell your healthcare professional if you are pregnant or planning to become pregnant, or are breastfeeding
 - The effects of PREZISTA on pregnant women or their unborn babies are not known. You and your healthcare professional will need to decide if taking PREZISTA is right for you
 - You should not breastfeed if you have HIV or are taking PREZISTA
 - Liver problems, which may be life-threatening, have been reported with the use of PREZISTA. It was not always clear if PREZISTA caused these liver problems. Patients with liver disease such as hepatitis B and hepatitis C may have worsening of their liver disease with PREZISTA.
- Your healthcare professional should perform blood tests prior to and during your treatment with PREZISTA
- Skin rashes ranging from mild to severe or life-threatening have been reported in some patients receiving a PREZISTA-ritonavir regimen. Contact your healthcare professional if you develop a rash
 - High blood sugar, diabetes or worsening of diabetes, and increased bleeding in people with hemophilia have been reported in patients taking protease inhibitor medicines like PREZISTA
 - Changes in body fat have been seen in some patients taking anti-HIV medicines. The cause and long-term health effects of these conditions are not known at this time
 - As with other protease inhibitors, taking PREZISTA may strengthen the body's immune response enabling it to begin to fight infections that have been hidden. Patients may experience signs and symptoms of inflammation that can include swelling, tenderness or redness

- The most common side effects include diarrhea, nausea, headache, and common cold. If you experience these or other symptoms, talk to your healthcare professional. Do not stop taking PREZISTA or any other medications without first talking to your healthcare professional

PREZISTA should always be taken twice a day with and at the same time as 100 mg ritonavir (Norvir®), in combination with other anti-HIV medicines as prescribed by your healthcare professional. PREZISTA should also be taken with food (the type of food is not important).

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see Important Patient Information on the next page.

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IMPORTANT PATIENT INFORMATION

PREZISTA™* (darunavir) Tablets

Patient Information about

PREZISTA (pre-ZIS-ta)

for HIV (Human Immunodeficiency Virus) Infection

Generic name: darunavir (da-ROO-nuh-veer)

ALERT: Find out about medicines that should NOT be taken with PREZISTA. Please also read the section “Who should not take PREZISTA?”.

Please read this information before you start taking PREZISTA. Also, read the leaflet each time you renew your prescription, just in case anything has changed. Remember, this leaflet does not take the place of careful discussions with your doctor. You and your doctor should discuss your treatment with PREZISTA the first time you take your medicine and at regular checkups. You should remain under a doctor's care when using PREZISTA and should not change or stop treatment without first talking with a doctor.

WHAT IS PREZISTA?

PREZISTA is an oral tablet used for the treatment of HIV (Human Immunodeficiency Virus) infection in adults. HIV is the virus that causes AIDS (Acquired Immune Deficiency Syndrome). PREZISTA is a type of anti-HIV drug called a protease (PRO-tee-ase) inhibitor.

HOW DOES PREZISTA WORK?

PREZISTA blocks HIV protease, an enzyme which is needed for HIV to multiply. When used with other anti-HIV medicines, PREZISTA may reduce the amount of HIV in your blood (called “viral load”) and increase your CD4 (T) cell count. HIV infection destroys CD4 (T) cells, which are important to the immune system. The immune system helps fight infection. Reducing the amount of HIV and increasing the CD4 (T) cell count may improve your immune system and, thus, reduce the risk of death or infections that can happen when your immune system is weak (opportunistic infections). PREZISTA is always taken with and at the same time as 100 mg of ritonavir (NORVIR®), in combination with other anti-HIV medicines. PREZISTA should also be taken with food.

DOES PREZISTA CURE HIV OR AIDS?

PREZISTA does **not** cure HIV infection or AIDS. At present, there is no cure for HIV infection. People taking PREZISTA may still develop infections or other conditions associated with HIV infection. Because of this, it is very important for you to remain under the care of a doctor. Although PREZISTA is not a cure for HIV or AIDS, PREZISTA can help reduce your risks of getting illnesses associated with HIV infection (AIDS and opportunistic infection) and eventually dying from these conditions.

DOES PREZISTA REDUCE THE RISK OF PASSING HIV TO OTHERS?

PREZISTA does **not** reduce the risk of passing HIV to others through sexual contact, sharing needles, or being exposed to your blood. For your health and the health of others, it is important to always practice safer sex by using a latex or polyurethane condom or other barrier method to lower the chance of sexual contact with any body fluids such as semen, vaginal secretions, or blood. Never re-use or share needles.

Ask your doctor if you have any questions on how to prevent passing HIV to other people.

WHAT SHOULD I TELL MY DOCTOR BEFORE I TAKE PREZISTA?

Tell your doctor about all of your medical conditions, including if you:

- are allergic to sulfa medicines.
- have diabetes. In general, anti-HIV medicines, such as PREZISTA, might increase sugar levels in the blood.
- have liver problems, including hepatitis B or C.
- have hemophilia. Anti-HIV medicines, such as PREZISTA, might increase the risk of bleeding.
- are pregnant or planning to become pregnant. The effects of PREZISTA on pregnant women or their unborn babies are not known. You and your doctor will need to decide if taking PREZISTA is right for you. If you take PREZISTA while you are pregnant, talk to your doctor about how you can be included in the Antiretroviral Pregnancy Registry.
- are breastfeeding. Do not breastfeed if you are taking PREZISTA. You should not breastfeed if you have HIV because of the chance of passing HIV to your baby. Talk with your doctor about the best way to feed your baby.

WHO SHOULD NOT TAKE PREZISTA?*

Together with your doctor, you need to decide whether taking PREZISTA is right for you.

Do not take PREZISTA if you:

- are allergic to darunavir or any of the other ingredients in PREZISTA
- are allergic to ritonavir (NORVIR®)
- take any of the following types of medicines because you could experience serious side effects:

Type of Drug	Examples of Generic Names (Brand Names)
Antihistamines (to treat allergy symptoms)	astemizole (Hismanal®) terfenadine (Seldane®)
Ergot Derivatives (to treat migraine and headaches)	dihydroergotamine (D.H.E. 45®, Migranal®) ergonovine ergotamine (Wigraine®, Ergostat®) Cafergot®, Ergomar® methylergonovine
Gastrointestinal Motility Agent (to treat some digestive conditions)	cisapride (Propulsid®)
Neuroleptic (to treat psychiatric conditions)	pimozide (Orap®)
Sedative/hypnotics (to treat trouble with sleeping and/or anxiety)	midazolam (Versed®) triazolam (Halcion®)

CAN PREZISTA BE TAKEN WITH OTHER MEDICATIONS?*

Tell your doctor about all the medicines you take including prescription and nonprescription medicines, vitamins, and herbal supplements, including St. John's wort (*Hypericum perforatum*). PREZISTA and many other medicines can interact. Sometimes serious side effects will happen if PREZISTA is taken with certain other medicines (see “Who should not take PREZISTA?”).

Tell your doctor if you are taking estrogen-based contraceptives. PREZISTA might reduce the effectiveness of estrogen-based contraceptives. You must take additional precautions for birth control such as a condom.

Tell your doctor if you take other anti-HIV medicines. PREZISTA can be combined with some other anti-HIV medicines while other combinations are not recommended.

Tell your doctor if you are taking any of the following medicines:

Type of Drug	Examples of Generic Names (Brand Names)
Antiarrhythmics (to treat abnormal heart rhythms)	bepiridil (Vascor®) lidocaine (Lidoderm®) quinidine amiodarone (Cordarone®) digoxin (Lanoxin®)
Anticoagulants (to prevent the clotting of red blood cells called platelets)	warfarin (Coumadin®)
Anticonvulsants (to treat epilepsy and prevent seizures)	carbamazepine (Tegreto®, Carbatrol®) phenobarbital phenytoin (Dilantin®, Phenytek®)
Antidepressants	trazodone (Desyrel®)
Anti-infectives (to treat bacterial infections)	clarithromycin (Biaxin®)
Antifungals (to treat fungal infections)	ketoconazole (Nizoral®) itraconazole (Sporanox®) voriconazole (Vfend®)
Antimycobacterials (to treat bacterial infections)	rifabutin (Mycobutin®) rifampin (Rifadin®, Rifater®, Rifamate®)
Calcium Channel Blockers (to treat heart disease)	felodipine (Plendil®) nifedipine (Adalat®) nicardipine (Cardene®)

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IMPORTANT PATIENT INFORMATION

Type of Drug	Examples of Generic Names (Brand Names)
Corticosteroids (to treat inflammation or asthma)	dexamethasone (Decadron [®]) fluticasone propionate (Advair Diskus [®] , Cutivate [®] , Flonase [®] , Flovent Diskus [®])
HMG-CoA Reductase Inhibitors (to lower cholesterol levels)	atorvastatin (Lipitor [®]) lovastatin (Mevacor [®]) pravastatin (Pravachol [®]) rosuvastatin (Crestor [®]) simvastatin (Zocor [®])
Immunosuppressants (to prevent organ transplant rejection)	cyclosporine (Sandimmune [®] , Neoral [®]) tacrolimus (Prograf [®]) sirolimus (Rapamune [®])
Narcotic Analgesics	methadone
PDE-5 Inhibitors (to treat erectile dysfunction)	sildenafil (Viagra [®]) vardenafil (Levitra [®]) tadalafil (Cialis [®])
Selective Serotonin Reuptake Inhibitors (SSRIs) (to treat depression, anxiety, or panic disorder)	paroxetine (Paxil [®]) sertraline (Zoloft [®])

Tell your doctor if you are taking any medicines that you obtained without a prescription.

This is **not** a complete list of medicines that you should tell your doctor that you are taking. Know and keep track of all the medicines you take and have a list of them with you. Show this list to all of your doctors and pharmacists any time you get a new medicine. Both your doctor and your pharmacist can tell you if you can take these other medicines with PREZISTA. Do not start any new medicines while you are taking PREZISTA without first talking with your doctor or pharmacist. You can ask your doctor or pharmacist for a list of medicines that can interact with PREZISTA.

HOW SHOULD I TAKE PREZISTA?

Take PREZISTA tablets every day exactly as prescribed by your doctor. You must take ritonavir (NORVIR[®]) at the same time as PREZISTA. The usual dose is 600 mg (two 300 mg tablets or one 600 mg tablet) of PREZISTA, together with 100 mg (one 100 mg capsule) of ritonavir (NORVIR[®]), twice daily every day. It may be easier to remember to take PREZISTA and ritonavir (NORVIR[®]) if you take them at the same time every day. If you have questions about when to take PREZISTA and ritonavir (NORVIR[®]), your doctor can help you decide which schedule works for you.

Take PREZISTA and ritonavir (NORVIR[®]) with food. The type of food is not important. Swallow the whole tablets with a drink such as water or milk. Do not chew the tablets.

Continue taking PREZISTA and ritonavir (NORVIR[®]) unless your doctor tells you to stop. Take the exact amount of PREZISTA and ritonavir (NORVIR[®]) that your doctor tells you to take, right from the very start. To help make sure you will benefit from PREZISTA and ritonavir (NORVIR[®]), you must not skip doses or interrupt therapy. If you don't take PREZISTA and ritonavir (NORVIR[®]) as prescribed, the beneficial effects of PREZISTA and ritonavir (NORVIR[®]) may be reduced or even lost.

If you miss a dose of PREZISTA or ritonavir (NORVIR[®]) by more than 6 hours, wait and then take the next dose of PREZISTA and ritonavir (NORVIR[®]) at the regularly scheduled time. If you miss a dose of PREZISTA or ritonavir (NORVIR[®]) by less than 6 hours, take your missed dose of PREZISTA and ritonavir (NORVIR[®]) immediately. Then take your next dose of PREZISTA and ritonavir (NORVIR[®]) at the regularly scheduled time.

You should always take PREZISTA and ritonavir (NORVIR[®]) together with food. If a dose of PREZISTA or ritonavir (NORVIR[®]) is skipped, do not double the next dose. Do not take more or less than your prescribed dose of PREZISTA or ritonavir (NORVIR[®]) at any one time.

WHAT ARE THE POSSIBLE SIDE EFFECTS OF PREZISTA?

Like all prescription drugs, PREZISTA can cause side effects. The following is **not** a complete list of side effects reported with PREZISTA when taken either alone or with other anti-HIV medicines. Do not rely

on this leaflet alone for information about side effects. Your doctor can discuss with you a more complete list of side effects.

Your healthcare professional should do blood tests prior to initiating combination treatment including PREZISTA. Patients with liver diseases such as hepatitis B and hepatitis C may have worsening of their liver disease with PREZISTA and may need more frequent monitoring of blood tests. PREZISTA has been reported to cause liver problems which may be life-threatening. It was not always clear if PREZISTA caused these liver problems because some patients had other illnesses or were taking other medicines.

Mild to moderate rash has been reported in 7% of subjects receiving PREZISTA. In some patients, PREZISTA has been reported to cause a severe or life-threatening rash. Contact your healthcare provider if you develop a rash. Your healthcare provider will advise you whether your symptoms can be managed on therapy or whether PREZISTA should be stopped.

As with other protease inhibitors, PREZISTA may cause side effects, including:

- high blood sugar (hyperglycemia) and diabetes. This can happen in patients taking PREZISTA or other protease inhibitor medicines. Some patients have diabetes before starting treatment with PREZISTA which gets worse. Some patients get diabetes during treatment with PREZISTA. Some patients will need changes in their diabetes medicine. Some patients may need new diabetes medicine.
- increased bleeding in patients with hemophilia. This may happen in patients taking PREZISTA as it has been reported with other protease inhibitor medicines.
- changes in body fat. These changes can happen in patients taking anti-HIV medicines. The changes may include an increased amount of fat in the upper back and neck, breast, and around the back, chest, and stomach area. Loss of fat from the legs, arms, and face may also happen. The exact cause and long-term health effects of these conditions are not known.
- immune reconstitution syndrome. In some patients with advanced HIV infection (AIDS) and a history of opportunistic infection, signs and symptoms of inflammation from previous infections may occur soon after anti-HIV treatment is started. It is believed that these symptoms are due to an improvement in the body's immune response, enabling the body to fight infections that may have been present with no obvious symptoms.

The most common side effects include diarrhea, nausea, headache, and common cold.

Tell your doctor promptly about these or any other unusual symptoms. If the condition persists or worsens, seek medical attention.

WHAT DO PREZISTA TABLETS LOOK LIKE?

PREZISTA 300 mg tablets are orange, oval-shaped, film-coated tablets mentioning "300" on one side and "TMC114" on the other side.

PREZISTA 600 mg tablets are orange, oval-shaped, film-coated tablets mentioning "600" on one side and "  " (curved triangle with a dot) on the other side.

HOW SHOULD I STORE PREZISTA TABLETS?

Store PREZISTA tablets at room temperature (77°F (25°C)). Short-term exposure to higher or lower temperatures [from 59°F (15°C) to 86°F (30°C)] is acceptable. Ask your doctor or pharmacist if you have any questions about storing your tablets.

This medication is prescribed for your particular condition. Do not use it for any other condition or give it to anybody else. Keep PREZISTA and all of your medicines out of the reach of children. If you suspect that more than the prescribed dose of this medicine has been taken, contact your local poison control center or emergency room immediately.

This leaflet provides a summary of information about PREZISTA. If you have any questions or concerns about either PREZISTA or HIV, talk to your doctor.

For additional information, you may also call Tibotec Therapeutics at 1-800-325-7504.

Rx Only

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LET'S GET MOVING.

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**AIDS
RUN
WALK**
SEPTEMBER 20, 2008

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Photo provided courtesy of Alexandra Billings.

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A model, photographer, or author's HIV status should not be assumed based on their appearance in *Positively Aware*.

You can view these (and other stories from previous issues) online at www.tpan.com and www.positivelyaware.com

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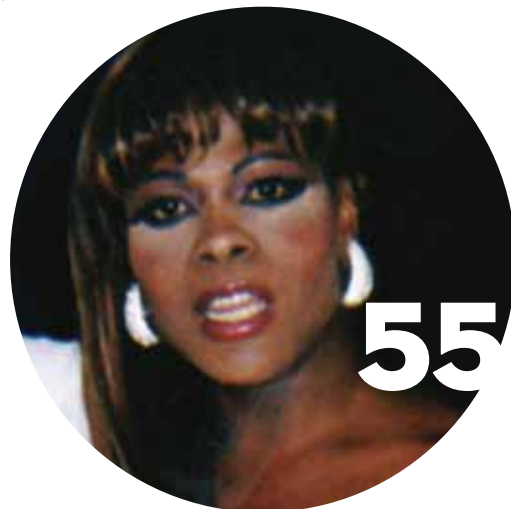
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MORE THAN JUST ANOTHER BRICK IN "THE WALL"

WANT A PIECE OF TPAN?

TPAN is growing and we need your help! Not only are we expanding our variety of programs to include the new POWER (Positive Outcomes for Wellness, Education and Recovery) Program, as well as thinking ahead towards future growth, but we're also expanding our physical space into 5541 N. Broadway. There, we will have room for new staff members, a meeting room large enough for 75 people, modern equipment and facilities that will serve us well for years to come.

But, as you can imagine, all of that costs money. True to our long history of being peer-led, we are creating a grassroots campaign to support this growth. One of the large walls in the new space is made of bricks - we are inviting everyone to buy a brick in the wall at whatever level is right for them. In order to show our gratitude and acknowledge your ownership of TPAN's future, the bricks will bear the names of every contributor who wants their name, or the name of someone they donate in honor or memory of, to appear there. We believe that even the smallest donation deserves to be recognized for helping to make this exciting growth possible.

If you would like to donate, you can do so in several ways:

By mail: Use the form below and send a check or money order to TPAN at 5537 N. Broadway, Chicago, IL 60640.

Online: By credit card, go to www.tpan.com and click on "The Wall"

In person: forms and donation envelopes are available at reception

There are four levels of giving:

Bronze: \$5-\$99; **Silver:** \$100-\$249; **Gold:** \$250-\$499; **Platinum:** \$500 and above. And, yes, your donation is tax deductible!

Additionally, there are other opportunities to become a conference or counseling room sponsor starting at \$1,500. Contact Ron Schnorbus, Director of Development, at 773-989-9400, ext. 229, for more information.

If you've ever felt that TPAN has helped you or someone you know to live a healthier, more informed, more empowered life, now is your chance to help us to continue to do that for all who enter here. Thanks for being part of TPAN's continued success!



YES! I WANT MY PIECE OF TPAN!

Name _____

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Is your donation in honor or in memory of someone?

How would you like your donation to appear on the "The Wall"? (please print legibly): _____

I prefer to donate anonymously.

Bronze: \$5 to \$99 **Silver:** \$100 to \$249 **Gold:** \$250 to \$499 **Platinum:** \$500 and above **Donation Amount:** \$ _____

Payment method: Cash Check/MO Credit Card

Credit card # _____ Expiration _____ Code _____

TPAN PROGRAMS AND MEETINGS

- Support Groups
- Rapid HIV Testing
- Yoga, Reiki and Massage
- Needle Exchange Program
- Buddy Program
- Access Medical Clinic at TPAN
- PULSE, an HIV-positive Weekly Social
- Positively Aware Party at Hydrate
- POWER (Positive Outcomes for Wellness, Education, and Recovery)
- TEAM (Treatment Education Advocacy Management)
- SMART Sex—Prevention and Outreach Program
- Monthly Educational Forums and Trainings

For detailed descriptions of programs, including dates, times, and locations, visit www.tpan.com and click on Client Services, or call (773) 989-9400.

TPAN EVENTS

- Aware Affair Gala: Superheroes
Saturday, September 13th, 2008
MCA Loft
visit www.tpan.com
- Chicago Takes Off
Saturday, March 7th, 2009
Two shows!
visit www.tpan.com
- Other Special Events

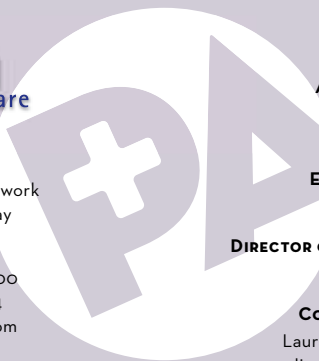


For detailed descriptions of these and other TPAN events visit www.tpan.com and click on Events, or call (773) 989-9400.



Test Positive Aware Network
5537 North Broadway
Chicago, IL 60640

phone: (773) 989-9400
fax: (773) 989-9494
e-mail: tpan@tpan.com
www.tpan.com



EDITOR

Jeff Berry

ASSOCIATE EDITORS

Keith R. Green
Enid Vázquez

EXECUTIVE DIRECTOR

Rick Bejlovec

DIRECTOR OF EDUCATION AND ADVOCACY

Matt Sharp

CONTRIBUTING WRITERS

Laura Jones, James Learned,
Jim Pickett, Sue Saltmarsh

MEDICAL ADVISORY BOARD

Daniel S. Berger, M.D., Patrick G. Clay, Pharm.D.,
Rupali Jain, Pharm.D., and Ross M. Slotten, M.D.

ART DIRECTION

Russell McGonagle

ADVERTISING INQUIRIES

publications@tpan.com

DISTRIBUTION

Joe Fierke
distribution@tpan.com

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TPAN recommends that all medical treatments or products be discussed thoroughly and frankly with a licensed and fully HIV-informed medical practitioner, preferably a personal physician.

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A Decade Delayed

When we at *Positively Aware* began planning this issue on Transgender and HIV well over a year ago, I loved the idea but must admit I wondered at the meeting whether there would be enough to fill an entire issue (I always like to play devil's advocate). My doubts were immediately squelched with a resounding, "Yes, absolutely!" from my fellow writers, and it turns out, for once, they were right.

We don't hear much about the course of HIV among the transgender community and, as psychologist Walter Bockting pointed out during his interview, the progress made thus far is "a decade delayed." There seem to be a number of reasons for this. For one, we don't even know how many transgender individuals there are in the U.S., since it's not tracked by the census. Additionally, there is scant research that has been done to date, partly because the CDC surveillance data doesn't even exist. And what little funding for research or prevention that has been available was for programs mainly created or already in place for "men who have sex with men." One thing is clear—the current category under which funding is appropriated is inadequate for transgender individuals. And they deserve a place at the table as the prevention and care programs are designed and implemented, in order to effectively address the unique needs and challenges that face their community.

As my colleagues and I delved into the topic at hand, it immediately became clear that there was a steep learning curve that we ourselves needed to overcome before we could even begin. First there was the confusing terminology. Then, what exactly should we include, and what could we leave out? What assumptions were we willing to make about what our readers already knew? And could we talk about HIV and transgender without giving some added background on transgender-specific issues that were broader than just HIV? These and many other questions lingered for months over our minds like a dark cloud, but finally the cloud began to lift and dissipate as our work neared completion.

We understood it was essential that we remain sensitive to the transgender community in our approach to the material, while presenting the information to our readers in a positive and affirming manner. Just keeping my pronouns straight during an interview soon became a challenge. I found myself pausing to think long and hard before even asking a question. I had to ask myself more than once, would I ask someone else this same question? Was the question really relevant to the story, or was I just curious? It was a humbling self-revelation.

In the stories that follow we learn that there are some ways HIV is affecting the transgender community that in many ways parallel how HIV has affected and made its inroads into other communities as well. These include stigma, low self-esteem, violence, poverty, homelessness, and substance abuse, all of which oftentimes lead to an increased risk for HIV. There are additional co-factors and behaviors that are unique to certain subgroups within the trans-

gender community, such as the sharing of needles used for injecting hormones and silicone.

Sadly enough, one thing that still lingers is the existence of stigma and discrimination within the GLB community itself towards the "T" that falls at the end. This is something that really stood out for me as I researched and talked with others about this issue. It also presents us with a unique opportunity, because it is the one thing that, luckily, we have in our power to change.

Ultimately I began to realize that our stories were virtually one and the same. I recognized the stigma, the pain, and the shame in these stories. In many ways they mirrored my own experience as a child growing up gay—the feelings of isolation, of separation, of not fitting in.

I learned that transgender is much more than a man wanting to become a woman, or a woman wanting to become a man. It doesn't start or end there, but encompasses an entire rainbow and spectrum of experiences and behaviors. And more often than not, the lines between gender and sexual orientation are constantly being blurred, with terms like gender queer and bi-gender inching their way into my vocabulary. This made the entire subject not only more challenging, but also immensely rewarding and fulfilling.

During the course of the three interviews I undertook for this issue, I would find that my emotions would surface unexpectedly, and for no apparent reason. My eyes would suddenly fill with tears, even though all three interviews were very different from one another. There seemed to emerge a common thread of humanity and soul-searching in all of these stories that follow. I feel an enormous sense of pride in my brothers and sisters for the courage and grace that they have displayed in sharing them with us.

All of it makes for what I believe is a fascinating exploration of HIV, human sexuality, and gender expression—and to the place where they intersect with our humanity. I want to thank the many people who have graciously given of their time, energy, and talents to contribute to this issue. It is my hope that you, too, will discover the commonality amidst the struggles in these stories, struggles which our communities share, and which one day we can overcome if we join together in the fight.

Take care of yourself, and each other.

Jeff Berry
Editor
publications@tpan.com

READERS FORUM



CLARIFICATION

The photos of Mo'Nique which appeared on pages 37–39 of the March/April issue were by Pierre R. Cameron. *Positively Aware* apologizes for the oversight.

YOUTH ACTIVISM

I've enjoyed reading *Positively Aware* for a few years now and have always enjoyed your publication's coverage of issues relevant to HIV/AIDS. However, your editorial in the May/June 2008 [Editor's Note: Four Minutes to Save the World] came as a slap in the face. As a young person, your depiction of young people as "too busy changing their MySpace page," etc. to care about the HIV epidemic is unfair and simply not true. Many folks my age (26) and younger are out there doing what they can to fight this disease. From raising money for local organizations to, yes, doing Internet outreach to other youth using pages like MySpace. We're out there beside the rest of you fighting. And given that about half of all new infections are in our age group, we realize that we're fighting for the lives and health of our generation. Your publication should be encouraging youth involvement and organizing, not writing us off in a flip editorial.

Jesse Pack, Worcester, MA

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Write to: *Positively Aware*,
5537 North Broadway
Chicago, IL 60640

Fax: (773) 989-9494

E-mail: readersforum@tpan.com

I always enjoy your [Jeff Berry's] articles in *Positively Aware*. Today after putting the finishing touches on a new blog entry (<http://blog.myspace.com/index.cfm?fuseaction=blog.view&friendID=371361125&blogID=390385698>) I was amazed to open the brown envelope that arrived from Chicago, read your editorial, and discover that we both had activism and a bit of nostalgia for the past on our minds. My entry deals with the admittedly lighter topic of activism and gay rights contrasted over 15 years. My belief is that activism for gay rights is less visible because good progress has been made. Though you point out several areas of society where there are tremendous problems related to HIV/AIDS, I suspect the explanation is similar. Good progress has been made and people are only motivated into action when the tipping point is reached. Despite 12 or 13 years of ART [antiviral therapy], I have lost three close friends. I know HIV/AIDS is still a giant problem. I think another explanation that I hint at in my blog is technology. You reference this in your editorial too. I think part of the answer is that we need to encourage and motivate people to feature HIV/AIDS in their online, social-networking world. I have read about the coming Fourth Tier of prescription insurance coverage that requires individuals to pay a percentage of cost for expensive medicines. I suspect many more individuals, including myself, will be very close to the tipping point when that day comes.

George Perry, via the Internet

I just read your Editor's Note in the May/June issue. I've been working in the field of HIV since 2001. My first foray into the field was when I was serving as a Peace Corps Volunteer in Southern Africa. When I returned Stateside, I lost my first HIV job due to funding and budget cuts. I moved on and became a case manager. I dealt with people on a personal level and got

to understand their situation and their story. I now live in New York City and am employed as an HIV health educator. There seems to be a major component missing in this fight, the reinvention you mention in your article. The way we did prevention 15 years ago is not the same way that necessarily works today. We have become a society of gadgets and I believe that in order to reach the demographics of those being at increased risk of becoming infected, we need to reach them where they are at. That's why I've taken the initiative to incorporate interactive education into my life. I host a show weekly on www.modmylife.com. It's an interactive website where users enter a suggestion. It gets voted on and the winning vote is performed live using hidden cameras. While not all of these "Mods" are necessarily funny, tactful, or related to HIV education, some of them are. And while I'm not trying to make light of a serious situa-

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PA ONLINE POLL

MAY / JUNE POLL RESULTS

Where do you find your support and strength?

COMMENTS

- From other HIV-positive people
- Friends
- My guy, the two social poz groups and the Living Positive support group at TPAN
- I get support from my friends who know I'm HIV positive—both gay and straight. My strength comes from God.
- HIV community where patients share information about their treatment, outcomes, and quality of life. www.patientslikeme.com



JULY / AUGUST POLL QUESTIONS

Are you on HIV therapy?

Are you currently taking any complementary or alternative therapy?

VOTE AT
WWW.POSITIVELYAWARE.COM

tion, the group of people with the highest rate of becoming infected with HIV is 13 to 24 year olds. This group seems to respond best to such antics. It's much like the cola advertisements at the beginning of a movie and the sight and smell of buttery popcorn, the kind of ads that make you want to leave your seat for that refreshing thirst quencher. This is the same group of people that didn't know what it was like back in the 1980's and 1990's. These are the same types of interactive educational tools that I feel will make people stop reaching for that soda and reach for a condom. I wanted to share with you one of the ways I've been attempting to reinvent prevention education and I hope you enjoy.

Cheetos: <http://www.modmylife.com/mod/2299>

Santa: <http://www.modmylife.com/mod/833>

Jason Wilder Evans, via the Internet

ANAL CANCER

Thanks, Matt [Sharp], for "The Papilloma Chronicles" [May/June 2008]. I have been going through some HPV situations and it is really good to get some real life perspectives on this. Thank you for your openness and honesty about your experiences. I am sure I am not the only one who truly appreciates your words.

Daniel Gebhardt, ACTU, Cleveland, Ohio

PRISON TATTOOS

I've been incarcerated since 1999 for robbery with a firearm and I am scheduled to be released in 2009. In January 2008 I was informed that I am infected with HIV. I never thought in my life I would test positive for HIV, because I didn't engage in the most common activities to put myself at risk to catch the disease in prison, or at least I thought. I was born in 1972 in Baltimore, and moved to Florida with my parents and older brother in order to start a new life in 1996. My brother died at the end of '96, and my new life turned back into my old life of gang warfare and excessive drug and alcohol abuse. I never used intravenous methods to get high and the only drug I used was marijuana, the normal anti-depressant in recreational circles. I never engaged in sexual activities with males in the penitentiary or in the free world.

When I first came into the prison system with a 10-year mandatory sentence to serve, I was still very angry and I got into fights, a gang, and tattoos. I mainly associated HIV and AIDS with homosexuals or the intravenous drug use scenarios because those are the most common ways I know of contracting the disease, but I can only suspect I contracted HIV through fighting or acquiring tattoos in a controlled environment. In just the last few years of my incarceration, I've been able to reform my mind to prepare for my future release back into society. I no longer associate with a gang, I

no longer smoke marijuana, I haven't drank alcohol since the night I was arrested in '99, and I continue to educate myself. With the changes that I have made in my term of incarceration also comes the value of life and the desire to be a better person than what I used to be. I do have the support of my family, and the wonderful mother of my 15-year-old son; she's been a very helpful friend. I received *Positively Aware* from Project Response Inc., an HIV organization based here in Florida. The organization also sent me a lot of reading material to educate myself on medical care, treatment, and living with being infected with HIV. The stories I've read in *Positively Aware* are very inspiring and encouraging, and provide me with a more in-depth perception on coping and living with HIV, and keeping optimistic and positive about the future. I may have committed a crime and I'm a convicted felon in prison, but I'm also a newly informed infected human being who is afraid of not being able to make it home to my family because the medical department isn't concerned about my being infected with HIV. I receive psychological counseling at this facility, but they also seem to think that I have no reason to be concerned about the lack of medical attention. I have had no HIV follow-up. I don't know my viral loads like I should, or my CD4 count. When will it eventually be too late?

Name withheld, Florida ☙

NEWS BRIEFS



by Enid Vázquez

NEW CODING GUIDELINES FOR HIV TESTS

From the American Academy of HIV Medicine (AAHIVM): AAHIVM, in partnership with the American Medical Association (AMA), has just released a new CPT coding guide to help health care providers and their billing staffs become familiar with the proper coding for submitting claims forms related to routine HIV Testing. This Guide was developed and published as part of a grant from the U.S. Centers for Disease Control and Prevention (CDC) to help implement the agency's Revised Recommendations for HIV Testing of Adults, Adolescents and Pregnant Women in Health-Care Settings. CDC released its revised recommendations in 2006, and since that time AAHIVM, AMA and several other national partners have worked to convene several topic-specific, peer-level workgroups to help health care providers understand the importance of routine testing, and to help address any barriers they may have to incorporating routine HIV testing in their respective health-care settings. One of the challenges the workgroup has highlighted is submitting and understanding the proper coding requirements for routine HIV testing, so the Reimbursement Workgroup developed the coding guide to help providers and their staff navigate this often confusing process. The brochure is available as a downloadable PDF from the AAHIVM website. "This brochure is an excellent step forward in helping all health care providers, both HIV-expert and non-experts, submit their medical claim forms for patient consults that include a rapid HIV test," said Litjen Tan, Ph.D., director of infectious diseases, immunology, and molecular medicine at the AMA. AAHIVM member Sharon Valenti, NP, AAHIVS, who also serves as President of the Association of Nurses in AIDS Care (ANAC) of Southeast Michigan, said, "We are looking forward to a wide distribution of this guide so that health care providers in all settings can more confidently make the choice to screen for HIV disease in all of their patient care activities."

FINANCIAL ASSISTANCE WITH LIPODYSTROPHY

From a reader and advocate: My name is Gregg Cassin and I've been living with HIV for over 25 years. I am the chairperson of the national AIDS service organization AIDS, Medicine and Miracles (please see our websites for more information.) My letter is regarding the thousands of people dealing with the horrible and disabling condition of lipoatrophy and lipodystrophy. A decade ago California State Assembly Bill AB 1621 was amended (in 1998) to give people with HIV who are suffering from facial wasting the same right to insurance-paid reconstructive procedures as a woman having a mastectomy. The goal was mandating that insurance companies see facial wasting, etc. as disfiguring, life-altering conditions that should be treated. As with breast reconstruction, insurance companies had seen facial wasting and other lipoatrophy and lipodystrophies as purely cosmetic. Years later we have

come to understand the devastating effects of these conditions causing increased occurrences of depression, anxiety, isolation, and even suicidal thoughts.

My own personal experience living in San Francisco's Castro district tells me that few people know about it and fewer are benefiting from it. I've asked several doctors, case managers, and social workers about insurance coverage of facial restoration treatments and almost all give the same response, "Insurance won't pay." It's troubling that few know about the bill, follow up with any questions, or request more information from me. It seems that it is hard for most people to even believe that there is such a bill. It is troubling to me that this issue continues to not be addressed by doctors, HIV advocates and activists, the HIV/gay media, and "filler" companies. This makes treatment only available to the wealthy few who can afford to pay out-of-pocket. Sadly, I know of only three people who have gotten it covered by insurance—one by Medicare, one by Kaiser, and one by Blue Cross. All three had their procedures done several years ago. I think this is incredibly unfair that there are so many truly suffering from real depression, anxiety, and worse that results from this condition. I'm appealing to you for some assistance in getting this issue addressed so that people can get some real help. Please respond as soon as possible. Thank you very much." *Positively Aware* recommends that people visit www.facialwasting.org for assistance on this topic. See below.

LIPODYSTROPHY RESOURCES

From Program for Wellness Restoration (PoWeR): PoWeR released the results of the largest on-line patient survey performed to date on lipodystrophy options and resources along with a free Spanish translation of their book "Built to Survive." The survey of 776 individuals summarizes the main therapeutic options used in the HIV community, along with a list and ratings of providers who specialize in reconstructive procedures for HIV-related body changes. The excitement and hope for a longer life that accompanied the arrival of Highly Active Anti-Retroviral Therapy (HAART) has been tempered by accounts of humps, bellies, and facial wasting. ... many people living with lipodystrophy have turned to the Internet for advice, treatment, and support in hopes of reversing some of the devastating effects of this stigmatizing syndrome. Visit www.powerusa.org.

HIV CRUISE RAISES MONEY

From www.hivcruise.com: Last October, a group of 225 HIV-positive men and women went sailing away from the worries of the disease while obtaining key health information and raising funds for HIV non-profit projects. In this 10th year, the retreat raised \$6,000 for the non-profit Program for Wellness Restoration (PoWeR) for their project to support the HIV international program of Doctors

Without Borders. More than \$30,000 has been raised over the past 10 years. "It is great to have people who have been challenged for years with fears of death enjoy life in the company of others who are in the same boat as they are," said Nelson Vergel, PoWeR founder, AIDS activist, and lecturer on the cruise. Dr. Michael Wohlfieler, a leading South Florida HIV physician and featured speaker on the cruise, said, "As a doctor who treats hundreds of HIV patients, I must say that spending a week with so many people having fun while being helped with medical information is an ideal scenario." Sam, a long-term survivor from San Francisco, said, "We remember all too well when the virus was considered more or less a signal that it was time to get one's affairs in order. Thankfully those days are behind us. A week like the one I had on this cruise reminds me that life is rich and full and when the good times roll it can be downright amazing." This year's cruise over Halloween will travel from Ft. Lauderdale with stops at Grand Turk (Turks and Caicos), St. Maarten, St. Thomas, and Princess Cays, according to cruise organizer Paul Stalbaum. "We will actually have separate fun activities for gay and straight groups, with some intermingling," he said. For more information contact Stalbaum at 1-800-735-0401 ext. 241, or e-mail Paul@universal-travel.com. Visit www.hivcruise.com for the gay group and www.positivecruise.com for the heterosexual group.

UNIVERSITY STUDENTS FIGHTING THE SPREAD OF HIV WITH MOBILE MEDIA

Visit www.positivelyaware.com to read the press release.

FROM *Positively Aware's* ONLINE NEWS BRIEFS

NEWLY UNSEALED DOCUMENTS SHED LIGHT ON NORVIR PRICE HIKE

The judge in the ongoing federal class action lawsuit against Abbott Laboratories, Inc., the makers of Norvir and Kaletra, recently ordered the unsealing of documents regarding the pharmaceutical company's 400% price increase of Norvir in 2003. "We're appalled by the callous disregard for HIV/AIDS patients that Abbott displayed in the documents they tried to keep secret," said Steve Abrecht, Executive Director of the SEIU Health and Welfare Fund. The documents show that Abbott executives planned to justify the price increase by suggesting that it was "no longer feasible for Abbott to continue manufacturing Norvir capsules" at their original price. One executive, Jesus Leal, noted that this plan and rationale had a significant weakness—"exposure on price if forced to open books." Abbott also considered making Norvir available at its original price only in a foul-tasting liquid form that its own executives acknowledged tastes like "someone else's

vomit." They even considered completely halting the production of Norvir altogether, forcing millions of patients to switch to Kaletra. "These documents show that Abbott put profits ahead of the need of seriously ill HIV/AIDS patients in quintupling Norvir's price," said Alex Sugerman-Brozan, director of Prescription Access Litigation. "This information would never have come to light if not for this lawsuit, demonstrating that litigation is sometimes the only means to uncover such schemes and hold drug companies accountable." When asked to comment a spokesperson from Abbott stated, "The re-pricing of Norvir was legal and captured the value of this important medicine based on its new role in the marketplace." The Judge's ruling and copies of the unsealed documents can be found at http://www.prescriptionaccess.org/lawsuitssettlements/current_lawsuits?id=0022.—*Keith R. Green*

VIRACEPT (NELFINAVIR) NEWS

Pfizer, Inc., the manufacturer of the HIV protease inhibitor drug Viracept (nelfinavir), issued a Dear Healthcare Professional letter in May. The letter states that the drug meets the new final limits established by the U.S. Food and Drug Administration (FDA) for prescribing to all patient populations, including pediatric patients and pregnant women. Earlier, concerns were raised over the level of an impurity that is a naturally occurring result of manufacture, but the issue was in European supplies, not in the U.S.—*Keith R. Green and Enid Vázquez* ✚



XVII INTERNATIONAL AIDS CONFERENCE BLOG

Read Associate Editor Keith R. Green and PA columnist Jim Pickett's blog from the XVII International AIDS Conference in Mexico City, August 3-8, www.positivelyaware.com

ASK THE
AAHIVM
HIV
SPECIALIST™

This issue's Specialist
Anthony Mills, M.D., AAHIVS



NEWLY DIAGNOSED AND STARTING THERAPY

I am 34 years old and from Brazil, and was diagnosed HIV-positive on March 6th of this year. Today I went to the doctor and for the first time got my CD4 count, viral load, and CD8 results. They are not good: my CD4 is 245, viral load was 188,000, and CD8 was 680. My doctor prescribed me zidovudine/lamivudine (Combivir) and efavirenz (Sustiva). My question is about her prescription since she's not an Infectious Disease specialist but a pediatrician—trained by the Brazilian public health system to deal with HIV-positive patients. Nothing much can be done apart from asking for help. In April 2007, my blood tested negative for HIV. After taking the test in March of this year, I got the bad news about being HIV-positive. Should I start taking my HAART prescription or should I wait?

Also, what do you know about KP-1461 by Koronis Pharmaceuticals in the U.S.? Is this a real potential for a cure within the near future?

Signed,
Bewildered in Brazil

Dear B in B,

I'm sorry to hear about your recent HIV diagnosis, which I know is never easy. I tell my patients the important thing to remember is that having HIV does not necessarily mean that your life will be any shorter, or any more difficult. We have made amazing advances in the treatment of HIV in the past few years, and I believe all HIV patients can live very long and full lives. What it does mean is that you will need to see your doctor regularly, have your blood tested regularly, and possibly take medication at some point to help your body fight the HIV. It sounds like you have a good doctor taking care of you and her recommendations

seem appropriate. Here in the U.S. we have two organizations that issue guidelines that suggest to health care providers when to start antiviral therapy. Both organizations currently recommend that patients with fewer than 350 T-cells initiate therapy regardless of how long they have been infected. Every person is different in how his or her individual body responds to HIV and how well they are able to fight the virus without medications. Some people are able to go for many years without needing meds, but most need the help of HIV medications eventually. The timing of the start of therapy is most often based on the T-cell level. The regimen she has selected for you is one that we have much experience with and has been proven to be an excellent regimen in many clinical trials, as well as in our daily practice. So my answer to your first question is yes, I would agree with your doctor that you should start medications to treat your HIV, and I agree with her recommended therapy.

Your second question about the new Koronis investigational drug is a more difficult one to answer. The Koronis drug theoretically works by causing the virus to mutate or change itself at a very high rate, and the hope is that it will change into a form that would be harmless to the human body. The concept is very exciting and we are all anxious to see the results, but the trials are in very early stages and nothing can be said about its effectiveness at this point, or about its safety. [Editor's note: As Positively Aware went to press, development of KP-1461 was suspended after an analysis of current data failed to show activity against HIV.] (For more information see "KP-1461" in the September/October 2007 issue of PA.)

Anthony Mills, MD, AAHIVS
Los Angeles, CA ☪

Dr. Mills is an HIV specialist in private practice in Los Angeles. Visit www.tonymillsmd.com.

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If you are living with HIV, you have a lot of choices to make when seeking care and treatment. One of your most important choices is your healthcare practitioner—so why not choose someone who is knowledgeable about HIV and experienced in its treatment?

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LOCATE AN HIV SPECIALIST™

Your search for an HIV Specialist™ is easy with AAHIVM's online Find-A-Provider directory at www.aahivm.org. Just click on the "Find-A-Provider" window on the homepage, key in your location, and click on the search button for a list of HIV Specialists™ near you.

Due to space limitations, not all submitted questions can be answered in this column, but every effort is made to ensure you receive the information you have requested. For more information about AAHIVM, call 202-659-0699 or visit www.aahivm.org.

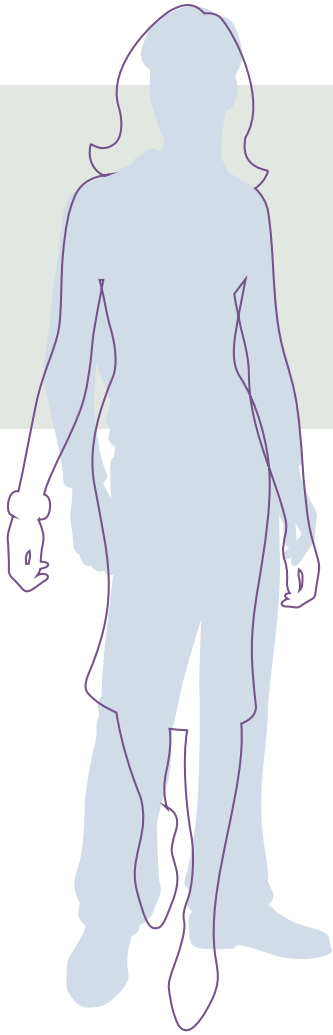
Photo by Jim Cox

SUBMIT YOUR QUESTIONS FOR ASK THE HIV SPECIALIST TO AAHIVM@TPAN.COM



He knows he has HIV. He doesn't know his HIV puts him at risk for kidney disease.

Ask your doctor about your risk factors and the impact that HIV may have on your kidneys.



The Invisible

A quick look at the HIV/AIDS epidemic in a group often overlooked

by Gretchen P. Kenagy, Ph.D., MSW

the midst of the AIDS epidemic. Too often, they have been missing from HIV prevention efforts, left out of or denied treatment options, avoided in HIV/AIDS research, and discounted in HIV surveillance. Many have literally disappeared in death, victims not only of AIDS, but of societal misunderstanding and indifference.

I have been working as a researcher, educator, advocate, and friend to the transgender community for 12 years. I began this journey by studying HIV/AIDS among transgender people in Philadelphia. It used to be that every conversation about transgender people included the question: What does transgender mean? The transgender movement has made great advances in securing civil rights for transgender people and, in the process, has educated Americans on what it means to be transgender. Questions remain, but now, most people seem to be familiar with the term. I have always liked the definition my trans-activist friend wrote in 1997: "...gender-identity is the manner in which we think of ourselves, our internal conviction about being men or women, male or female, masculine or feminine (and both or neither)." I may have added confusion rather than clarity here. This quote says "gender identity" and I am attempting to describe the term transgender. It seems that the recently acquired familiarity I mentioned may still need elaboration.

The language used to describe the term transgender is constantly changing and no single definition can wholly capture its meaning. Despite this, a common set of terms and definitions does exist. "Transgender" encompasses gender identity and gender expression. Gender identity describes the gender with which people identify. Gender expressions are the activities and behaviors people use to express their gender identity. While not all transgender people

identify their gender as male or female, two gender identity categories, also called gender vectors, have been widely used by transgender people and in the transgender literature. Male-to-Females (MTFs) are people whose birth-assigned gender is male, but whose gender identity is female, and female-to-males (FTMs) are people whose birth-assigned gender is female, but whose gender identity is male.

It is important to be able to define transgender in order to understand transgender and HIV/AIDS. So, what do we know about the impact of HIV/AIDS on the transgender community? We know a little. What do we know about HIV infection and HIV risk among transgender people? We know a little. How have we done with regard to addressing HIV/AIDS among transgender people? The answer, simply put, is not well enough.

Since the late 1990s, many needs assessment studies have been conducted in U.S. cities and locales including Atlanta, Boston, Chicago, Houston, Los Angeles, Minneapolis-St. Paul, New York, Philadelphia, Washington, D.C., and San Francisco. Together, the findings from these studies paint a picture of HIV/AIDS among transgender people and the picture, especially among the most vulnerable within the community, is bleak.

The needs assessment studies have consistently found high levels of HIV infection among male-to-female (MTF) transgender people, particularly MTF sex workers. High HIV infection rates among MTFs were found across the country. The lowest level (4%) was found in Minneapolis-St. Paul. In Chicago and Philadelphia, 15% and 19% of adult MTFs self identified as being HIV-positive. Twenty-two percent of MTFs surveyed in New York and Atlanta were HIV-positive. Higher rates were found in Hous-

In 1996, *Newsline* magazine devoted a section of its April issue to "AIDS in the Transgender Community." HIV-positive transgender women, all of whom had been sex workers at some point in their lives, were profiled. Nora, a peer educator and substance abuse counselor for the Gender Identity Project at the Lesbian and Gay Community Services Center was asked the following with regard to HIV/AIDS services: "How do you think transgender people fit into the big AIDS picture?" She had this to say:

"There is invisibility. People don't think about transgender people in the picture of AIDS. In [Greenwich] Village, for years, for decades there were transsexuals, male to female, which is what I'd like to talk about—the Village has always had tons of them. Basically on every block lived one or a few of them. Slowly, the AIDS epidemic came up, and it engulfed everyone. I can tell you that now that I've been living here; there is nothing, there is hardly anything."

The word invisibility has been used repeatedly to describe transgender people in

ton (27%), Washington, D.C. (32%), and San Francisco (25%, 35%, and 47% in various reports). Among a sample of MTF sex workers in Atlanta, 68% were HIV-positive.

HIV-risk factors include lack of or inconsistent use of protection during sex, high numbers of sexual partners, and injection drug or hormone use, including needle sharing. Among MTFs, HIV/AIDS is disproportionately affecting racial minorities, particularly African Americans. Related issues of violence, discrimination, and lack of transgender-specific HIV/AIDS services to prevent and treat HIV/AIDS are contributing to HIV risk and are having a damaging impact on the overall health of the transgender community.

While almost all HIV studies of transgender people include MTFs, inclusion of FTMs in studies is not as common. The limited data shows that, compared to MTFs, HIV-infection levels among FTMs are low (e.g., 2% in San Francisco and 3% in Washington, D.C.). The available data on HIV risk, though, gives cause for concern. For example, a colleague and I analyzed data from two needs assessment studies in Philadelphia and Chicago, which included FTMs, to compare risk for HIV infection between MTFs and FTMs. We found that compared to MTFs, FTMs were significantly less likely to have used protection the last time they had sex and significantly more likely to have engaged in recent high-risk sexual activity. Our findings suggest that FTMs are at risk for HIV/AIDS and we have called for a thorough examination of these risk factors.

For several years, there has been talk about conducting a national needs assessment to study HIV among transgender people. This study would be useful as long as it is not in lieu of other research in this area. Because let's face it, we know that transgender people have many needs when it comes to HIV/AIDS. We need to study the impact of HIV prevention programs, HIV/AIDS medications, and a host of other related issues rather than checking and double-checking that, in fact, transgender people need help. They do.

Of course, conducting research in this area is not an easy task. The political climate over the past seven years has been reluctant to put resources toward stopping the spread of HIV/AIDS in the transgender community. The current political climate appears to be moving toward change and I am hopeful that change will include advances in HIV/AIDS prevention and treatment ser-

vices for transgender people as well as much needed research. What steps can be taken to do this? Here are a few:

- Include transgender people as a separate category in the CDC HIV/AIDS Statistics and Surveillance system. The CDC combines transgender people with the men who have sex with men (MSM) HIV/AIDS surveillance category. Therefore, there is no way, at the national level, to track HIV/AIDS among transgender people. In addition to limiting knowledge about transgender people and HIV/AIDS, this unfortunate categorization also negatively impacts the HIV funding directed toward this community.
- Target all transgender people in HIV prevention strategies. Prevention messages need to include all transgender people at risk and this includes transgender men.

- Increase—significantly—funding for HIV/AIDS prevention, treatment, and research.

Recently, I attended a graduation ceremony. I had the privilege of watching my students walk across the divide from student to professional and begin a new chapter in their lives. I was filled with pride and happiness for their achievements—the ones past and the many that will come.

As the ceremony proceeded, I couldn't help but think of the transgender people I know who are courageously working to transform society; working to make society safe for all transgender people and to stop the devastating impact of HIV/AIDS in their community. They are truly living out the ambitious calls to change the world put forth by the graduation speakers. I also thought of the transgender people I knew who never had the chance to achieve dreams, like earning a degree, because of HIV/AIDS.

Transgender people must be counted, not discounted, included, not excluded, in the nation's efforts to prevent and treat HIV/AIDS.

- Bring more HIV-positive transgender people into care and provide them with top quality HIV treatment regimens.
- Educate physicians and other health care professionals on transgender identity and health.
- Provide transgender-specific HIV/AIDS prevention and treatment services.
- Broaden the scope of research on HIV/AIDS among transgender people. Research on transgender health must move forward to include a broader array of studies including the effects of HIV/AIDS medications and transgender hormonal therapy and evaluation studies to assess program outcomes.

When the graduation ceremony ended, I felt that our work has just started. There are still many transgender people who are vulnerable and at risk. Transgender people must be counted, not discounted, included, not excluded, in the nation's efforts to prevent and treat HIV/AIDS. We must work to ensure that all transgender people have the opportunity to pursue their dreams and do not fall prey to very preventable obstacles like HIV/AIDS. ✚

Gretchen Kenagy, Ph.D., MSW, is a Senior Research Associate at the American Medical Association and owner of GPK Consulting in Chicago, which offers services including evaluation research, grant writing, and academic presentation and teaching skills for health and human service professionals, academicians, and graduate students in the social and behavioral sciences. Visit www.gpkconsulting.com.



Transgender Therapy and HIV

Two complicated conditions rolled into one

by Enid Vázquez

Andrew Halbur, a pharmacist specializing in HIV, lost a patient he adored when she stopped taking her antiviral meds.

The patient, in her mid-thirties, was a transgender woman (male-to-female, or MTF) who was taking estrogen, a female hormone. Transgender women on hormonal therapy normally take a high dose of estrogen, but if they're also on anti-HIV medications, they sometimes have to take an even higher dose. This increases the risk of having a complication.

It appears that she stopped taking her HIV medications, including Kaletra, but did not adjust her estrogen to a smaller dose. Within two months, she had died of a stroke.

"She was absolutely one of my favorite patients. She was a riot," says Halbur.

Halbur works for Walgreens Specialty Pharmacy at the Howard Brown Health Center in Chicago, which serves the gay, lesbian, bisexual, and transgender community. "We think three patients had strokes because they stopped HIV drugs and their estrogen went super high," he said. Two died and the third survived, but with complications, including paralysis on half of her face.

Paralysis on one side of the body is common with strokes, which are similar to heart attacks, but occur in the brain. Slurring

of speech and walking with a limp, as well as disfigurement, can result. Strokes are commonly caused by blood clots, and high levels of estrogen increase the risk of a blood clot. Like heart attacks, they may be so minor that a person doesn't realize they had one, but the risk of more serious trouble later on is increased.

"They have to really understand the safety issues of hormones," says nurse practitioner Bethsheba Johnson of the Luck Care Center on the far South Side of Chicago. "Estrogen, as we know, has side effects. It can cause blood clots and other things. Then if they're on estrogen and HIV-positive, they might end up with a higher dose, which can be dangerous with blood clots. Blood clots, cardiac events, pulmonary embolism—they can die. We tell them they can't smoke if they're on estrogen, because it increases the risk of blood clots."

The treatment protocol produced by the Tom Waddell Health Center (TWHC), which focuses on transgender care as part of the Department of Health in San Francisco, reported that, "A number of them [their patients] obtained [hormones] on the street (often illegally imported) or from a few unscrupulous medical providers who administered drugs but did not monitor their patient's health or provide preventive services or treatment for other serious health conditions."

Said Halbur, “People are using illegal drugs or have no medical follow-up, so we don’t know the number of problems that exist. How do you make a connection if she goes to an ER for a blood clot when she never had a primary physician? If someone has a stroke, do they realize it’s from the estrogen, or do they think it’s from using drugs or from aging? We have no data.”

COMPLICATED THERAPY

Cross-gender hormone therapy is considered safe, with the proper precautions, and fortunately for transgender people with HIV, there is no conflict in the treatment of both conditions. For example, people can start hormones and HIV therapy at the same time.

According to the “AAHIVM Fundamentals of HIV Medicine” by the American Academy of HIV Medicine, “Experience suggests that there is no reason not to treat HIV-infected transgender individuals in a similar fashion to those without HIV,” although it goes on to say that research is limited.

The manual also refers to a report from a well-known surgeon suggesting that HIV-positive patients seeking transsexual surgery should preferably have at least a 200 CD4+ T-cell count and an undetectable viral load for at least three months.

The Standards of Care of the World Professional Association for Transgender Health (WPATH, formerly known as the Harry Benjamin International Gender Dysphoria Association) states: “It is unethical to deny availability or eligibility for sex reassignment surgeries or hormone therapy solely on the basis of blood seropositivity for blood-borne infections such as HIV, or hepatitis B or C, etc.”

That doesn’t mean that therapy is easy. Like HIV treatment, transgender medical care by itself is often complicated.

To begin with, there is no therapy approved by the U.S. Food and Drug Administration (FDA) for transgender people to ease their chosen transition. Instead, hormones approved for other conditions are prescribed to them off-label.

In off-label usage, a medication that has been shown to have benefit for a condition is prescribed even though it hasn’t been researched and approved for that condition. Male and female hormones are prescribed in transgender therapy because they have been shown to help them in their transition to become more masculine or more feminine.

With limited research, the medical protocols (or standards) that exist for transgender hormonal therapy are those that health care workers specializing in this therapy have pulled together based

on their experience. Moreover, insurance—if available—does not cover off-label medications. Furthermore, response to therapy depends on age, genetics, and other individualized factors, making hormonal therapy a matter of extensive laboratory monitoring.

Cross-gender hormone therapy is considered safe, with the proper precautions, and fortunately for transgender people with HIV, there is no conflict in the treatment of both conditions.

With transgender patients coming to their HIV treatment center (the majority of them MTF), Johnson and her husband, clinic director Dr. William Johnson, tried to quickly figure out what there is to know about therapy in this population. They learned about the many things they needed to measure on a blood test before prescribing hormones. They had to investigate the potential drug interactions between hormonal therapy, HIV drugs, and the anti-depressants she says are very commonly needed in this population. They learned that transgender individuals use high doses of hormones, but that several HIV medications lower the blood levels, calling for even higher doses to be prescribed. And then there’s all the monitoring that needs to be done a month after hormone therapy begins and then regularly after that.

“It’s a whole complex mess of which blood levels to check and on monitoring the dose,” Johnson said.

SHADES OF HIV

The Johnsons are no strangers to underserved populations, like the transgender community. It’s what their clinic is all about. They were already familiar with the stigma and discrimination facing their patients for being HIV-positive, and often, for being gay.

The adverse conditions facing transgender people are astoundingly similar.

- They face stigma and discrimination for being gender different and sexually different.
- As a result, they are often closeted.

- Their fertility and adoption rights are often discounted or denied.
- They are vulnerable to violence, including partner violence, and threats of outing.
- They may suffer from feelings of being unlovable due to their different status, which in turn may lead them to tolerate unprotected high-risk sex.
- Transgender therapy, like HIV treatment, is expensive and also complex, requiring patient education.
- Like HIV treatment, transgender therapy is life-long.

“While medical attention is increasingly focused on visible transgendered members of various communities, the amount of social support, legal resources, medical research, and, most grievously, legitimate employment opportunities, remain severely limited,” the protocol continues. “Identifying an employment history is important because some patients feel that they are unemployable in mainstream jobs and lean towards sex work because in their mind this is all they can do as a transgender person. Or, they may have had a great employment record, but while transitioning or post transition find it difficult to find work.”

“I think all the care for transgender people is just horrible,” said Johnson. “They’re stigmatized. From the receptionist on—the snickering. It’s still a huge problem. We see gay people get stigmatized, and you have this population that’s even more stigmatized. We get calls from pharmacists who don’t want to give hormones to our patients. They call us and say, ‘This is a man.’”

For those who can overcome all of the barriers that face them, the search for hormones might lead to better care. The TWHC protocol reports that, “Treatment with hormones is frequently an incentive for patients to address their HIV disease.”

According to the Academy’s manual, “Transgender individuals are frequently victims of prejudicial behaviors, and are often distrustful of authority figures. Therefore, clinicians should begin taking patient history by using simple courtesies, such as asking patients what name they use and which pronouns they prefer, and always using the appropriate pronoun is essential. Research findings indicate that many transgender

individuals engage in high-risk behaviors, including unprotected sex and sex work (many have no other viable source of income); in addition, they are frequently homeless, and have high rates of drug and alcohol misuse (Reback and Lombardi 1999; Clements-Noelle et al 2001). These behaviors can adversely affect the physical and emotional health of individuals with HIV, as well as their ability to adhere to antiretroviral regimens. Social and mental health support is frequently critical to the well-being of these patients... .

“All transgenders, regardless of their HIV status, are medically underserved,” the transgender section of the AAHIVM manual concludes. “Medical training currently does not include education in transgender needs; in addition, clinical research in this population is lacking. Prevention efforts are important to address mental health and substance abuse issues, as well as specific needs for HIV care.” ✚

For those who can overcome all of the barriers that face them, the search for hormones might lead to better care.

According to the Waddell protocol, multiple studies have found a high rate of HIV in transgender individuals around the world. Often, reports are looking specifically at sex workers, and find that the rate of HIV is higher in the transgender population.

Although the vast majority of transgender individuals may need some kind of transition, including therapy and perhaps surgery, in order to live a better life, the protocol lists several reasons why transgender individuals lack adequate health care. “This group has historically been averse to accessing medical services for a number of reasons, including: prior negative experience in clinic settings, expectation of discriminatory treatment, the requirements of psychiatric treatment and, in some cases, reticence to reveal illegal occupational activities or undocumented immigration status.” Under psychosocial aspects of care, it states, “Like other marginalized groups, TG patients may present with history of trauma, with resentment against institutions, and with multiple vulnerabilities.”

HIV

I WANT TO GET THE WORD OUT

- **No refrigeration required.¹**

¹Exposure to high humidity outside the pharmacy container for longer than 2 weeks is not recommended.

- **Can be taken with or without food.¹**

- **Once or twice daily dosing,¹ ask your doctor.**

Once daily is not recommended for treatment-experienced patients.¹

KALETRA[®]
(lopinavir/ritonavir)
REAL LIFE. REAL RESULTS.

KALETRA is not a cure for HIV infection. Individual results may vary.

TALK TO YOUR DOCTOR TODAY AND GO TO KALETRA.COM TO LEARN MORE

Indication¹

KALETRA[®] (lopinavir/ritonavir) is a type of medicine called an HIV-1 (human immunodeficiency virus-1) protease (PRO-tee-ase) inhibitor. KALETRA is always used in combination with other anti-HIV medicines to treat HIV-1 infection. KALETRA is a combination of two medicines. They are lopinavir and ritonavir. KALETRA is for adults and for children aged 6 months and older.

Important Safety Information¹

KALETRA does not cure HIV-1 infection or AIDS and does not reduce the risk of passing HIV-1 to others.

Do not take KALETRA if you are allergic to KALETRA or any of its ingredients, including lopinavir or ritonavir.

You must tell your doctor about all medicines you are taking or planning to take, including those without a prescription, and herbal products.

Do not take KALETRA with the following medicines, as they can cause serious problems or death: dihydroergotamine, ergonovine, ergotamine, and methylergonovine, such as Cafergot[®], Migranal[®], D.H.E. 45[®], Ergotrate Maleate, Methergine, as well as Halcion[®] (triazolam), Orap[®] (pimozide), Propulsid[®] (cisapride), or Versed[®] (midazolam).

Do not take KALETRA with rifampin, also known as Rimactane[®], Rifadin[®], Rifater[®], or Rifamate[®], or products containing St. John's wort (*Hypericum perforatum*). These medicines may lower the amount of KALETRA in your blood.

Do not take KALETRA with the cholesterol-lowering medicines Mevacor[®] (lovastatin) or Zocor[®] (simvastatin) because of possible serious reactions. There is also an increased risk of drug interactions between KALETRA and Lipitor[®] (atorvastatin) and Crestor[®] (rosuvastatin). Talk to your doctor before you take any of these cholesterol-reducing medicines with KALETRA.

Talk to your doctor before you take Viagra[®] (sildenafil), Cialis[®] (tadalafil), or Levitra[®] (vardenafil), since the interaction with KALETRA and these medicines may result in an increase in their side effects.

If you are taking oral contraceptives ("the pill") or using the contraceptive patch to prevent pregnancy, you should use an additional or different type of contraception since KALETRA may reduce how well the oral or patch contraceptives work.

You should not take KALETRA once a day with the following medicines: Sustiva[®] (efavirenz), Viramune[®] (nevirapine), Agenerase[®] (amprenavir), fosamprenavir, Viracept[®] (nelfinavir), phenobarbital, phenytoin (Dilantin[®] and others) and carbamazepine (Tegretol[®] and others). Your doctor may change your dose of KALETRA if you are taking these medicines.

If you are taking Mycobutin[®] (rifabutin), your doctor will lower the dose of Mycobutin[®].

If you are using or before you begin using inhaled Flonase[®] (fluticasone propionate), talk to your doctor about problems these two medicines may cause when taken together. Your doctor may choose not to keep you on inhaled Flonase[®].

KALETRA oral solution contains alcohol. Talk with your doctor if you are taking or planning to take metronidazole or disulfiram. Severe nausea and vomiting can occur.

When preparing a dose of KALETRA oral solution for your child, you should carefully measure the dose of KALETRA as instructed by your healthcare provider. This will reduce the possibility of giving too much or too little medicine, which could cause serious harm to your child or cause the medicine not to work well. KALETRA should not be given once-daily to children.

All strengths of KALETRA tablets should be swallowed whole and not chewed, broken, or crushed. The most commonly reported side effects of moderate severity that are thought to be drug-related are: abdominal pain, abnormal bowel movements, diarrhea, feeling weak/tired, headache, and nausea. Children taking KALETRA may sometimes get a skin rash. This is **not** a complete list of reported side effects.

Pancreas and liver problems, which can cause death, have been reported in patients receiving KALETRA. Tell your doctor if you have nausea, vomiting, or abdominal pain, which may be signs of pancreatitis, or if you have or have had liver disease, such as hepatitis B or C.

Some patients receiving KALETRA have had large increases in triglycerides and cholesterol. The long-term chances of getting complications such as heart attacks or strokes due to these increases in triglycerides and cholesterol caused by protease inhibitors is not known at this time. Diabetes and high blood sugar have occurred in patients taking protease inhibitors. Changes in body fat have been seen in some patients receiving antiretroviral (anti-HIV) therapy. The cause and long-term health effects of these conditions are not known at this time. Some patients with hemophilia have increased bleeding when taking protease inhibitors. The effects of KALETRA on pregnant women or their unborn babies are not known. Mothers should not breast-feed if they are taking KALETRA. KALETRA tablets should be stored at room temperature. Exposure of this product to high humidity outside the pharmacy container for longer than 2 weeks is not recommended. Refrigerated KALETRA oral solution remains stable until the expiration date printed on the label. If stored at room temperature up to 77°F (25°C), KALETRA oral solution should be used within 2 months. Avoid exposure to excessive heat.

¹ KALETRA Prescribing Information.

Please see important patient information on adjacent page.

1-866-KALETRA (525-3872)

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

The people depicted in the photo above are models and are being used for illustrative purposes only.

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**CONSUMER BRIEF SUMMARY
CONSULT PACKAGE INSERT FOR FULL PRESCRIBING INFORMATION**

KALETRA[®]

**(lopinavir/ritonavir) tablets
(lopinavir/ritonavir) oral solution**

ALERT: Find out about medicines that should NOT be taken with KALETRA. Please also read the section “MEDICINES YOU SHOULD NOT TAKE WITH KALETRA.”

Patient Information

KALETRA[®] (kuh-LEE-tra)

Generic Name: lopinavir/ritonavir (lop-IN-uh-veer/rit-ON-uh-veer)

Read this leaflet carefully before you start taking KALETRA. Also, read it each time you get your KALETRA prescription refilled, in case something has changed. This information does not take the place of talking with your doctor when you start this medicine and at check ups. Ask your doctor if you have any questions about KALETRA.

Before taking your medicine, make sure you have received the correct medicine. Compare the name above with the name on your bottle and the appearance of your medicine with the description provided below. Contact your pharmacist immediately if you believe a dispensing error has occurred.

What is KALETRA and how does it work?

KALETRA is a combination of two medicines. They are lopinavir and ritonavir. KALETRA is a type of medicine called an HIV-1 (human immunodeficiency virus) protease (PRO-tee-ase) inhibitor. KALETRA is always used in combination with other anti-HIV-1 medicines to treat people with human immunodeficiency virus (HIV-1) infection. KALETRA is for adults and for children age 6 months and older.

HIV-1 infection destroys CD4⁺ (T) cells, which are important to the immune system. After a large number of T cells are destroyed, acquired immune deficiency syndrome (AIDS) develops.

KALETRA blocks HIV-1 protease, a chemical which is needed for HIV-1 to multiply. KALETRA reduces the amount of HIV-1 in your blood and increases the number of T cells. Reducing the amount of HIV-1 in the blood reduces the chance of death or infections that happen when your immune system is weak (opportunistic infections).

Does KALETRA cure HIV-1 or AIDS?

KALETRA does not cure HIV-1 infection or AIDS. The long-term effects of KALETRA are not known at this time. People taking KALETRA may still get opportunistic infections or other conditions that happen with HIV-1 infection. Some of these conditions are pneumonia, herpes virus infections, and *Mycobacterium avium* complex (MAC) infections.

Does KALETRA reduce the risk of passing HIV-1 to others?

KALETRA does not reduce the risk of passing HIV-1 to others through sexual contact or blood contamination. Continue to practice safe sex and do not use or share dirty needles.

How should I take KALETRA?

- You should stay under a doctor’s care when taking KALETRA. Do not change your treatment or stop treatment without first talking with your doctor.
- You must take KALETRA every day exactly as your doctor prescribed it. The dose of KALETRA may be different for you than for other patients. Follow the directions from your doctor, exactly as written on the label.
- Dosing in adults: The usual KALETRA dose for adults is 400/100 mg (given as two yellow KALETRA tablets (200 mg lopinavir/ 50 mg ritonavir) or 5 mL of KALETRA oral solution) twice a day (morning and night), in combination with other anti-HIV-1 medicines. The doctor may prescribe a KALETRA dose of 800/200 mg (given as four yellow KALETRA tablets (200 mg lopinavir/ 50 mg ritonavir) or 10 mL of KALETRA oral solution) once-daily in combination with other anti-HIV-1 medicines for some patients who have not taken anti-HIV-1 medications in the past.
- Dosing in children greater than 6 months of age: Children greater than 6 months of age can also take KALETRA. The child’s doctor will decide the right dose based on the child’s weight. KALETRA should not be administered once-daily in children.

- KALETRA tablets (all strengths) should be swallowed whole and not chewed, broken, or crushed.
- KALETRA tablets can be taken with or without food.
- When preparing a dose of KALETRA oral solution for your child, you should carefully measure the dose of KALETRA as instructed by your health care provider. This will reduce the possibility of giving too little or too much medicine which could reduce the effectiveness of therapy or cause serious harm to your child.
- Take KALETRA oral solution with food to help it work better.
- Do not change your dose or stop taking KALETRA without first talking with your doctor.
- When your KALETRA supply starts to run low, get more from your doctor or pharmacy. This is very important because the amount of virus in your blood may increase if the medicine is stopped for even a short time. The virus may develop resistance to KALETRA and become harder to treat.
- Be sure to set up a schedule and follow it carefully.
- Only take medicine that has been prescribed specifically for you. Do not give KALETRA to others or take medicine prescribed for someone else.

What should I do if I miss a dose of KALETRA?

It is important that you do not miss any doses. If you miss a dose of KALETRA, take it as soon as possible and then take your next scheduled dose at its regular time. If it is almost time for your next dose, do not take the missed dose. Wait and take the next dose at the regular time. Do not double the next dose.

What happens if I take too much KALETRA?

If you suspect that you took more than the prescribed dose of this medicine, contact your local poison control center or emergency room immediately.

As with all prescription medicines, KALETRA should be kept out of the reach of young children. KALETRA liquid contains a large amount of alcohol. If a toddler or young child accidentally drinks more than the recommended dose of KALETRA, it could make him/her sick from too much alcohol. Contact your local poison control center or emergency room immediately if this happens.

Who should not take KALETRA?

Together with your doctor, you need to decide whether KALETRA is right for you.

- Do not take KALETRA if you are taking certain medicines. These could cause serious side effects that could cause death. Before you take KALETRA, you must tell your doctor about all the medicines you are taking or are planning to take. These include other prescription and non-prescription medicines and herbal supplements.

For more information about medicines you should not take with KALETRA, please read the section titled “MEDICINES YOU SHOULD NOT TAKE WITH KALETRA.”

- Do not take KALETRA if you have an allergy to KALETRA or any of its ingredients, including ritonavir or lopinavir.

Can I take KALETRA with other medications?*

KALETRA may interact with other medicines, including those you take without a prescription. You must tell your doctor about all the medicines you are taking or planning to take before you take KALETRA.

KALETRA can be taken with acid reducing agents (such as omeprazole and ranitidine) with no dose adjustment.

MEDICINES YOU SHOULD NOT TAKE WITH KALETRA:

- Do not take the following medicines with KALETRA because they can cause serious problems or death if taken with KALETRA.
 - Dihydroergotamine, ergonovine, ergotamine and methylegonovine such as Cafegot[®], Migranal[®] D.H.E. 45[®], Ergotrate Maleate, Methergine, and others
 - Halcion[®] (triazolam)
 - Orap[®] (pimozide)
 - Propulsid[®] (cisapride)
 - Versed[®] (midazolam)
- Do not take KALETRA with rifampin, also known as Rimactane[®], Rifadin[®], Rifater[®], or Rifamate[®]. Rifampin may lower the amount of KALETRA in your blood and make it less effective.
- Do not take KALETRA with St. John’s wort (hypericum perforatum), an herbal product sold as a dietary supplement, or products containing St. John’s wort. Talk with your doctor if you are taking or planning to take St. John’s wort. Taking St. John’s wort may decrease KALETRA

levels and lead to increased viral load and possible resistance to KALETRA or cross-resistance to other anti-HIV-1 medicines.

- Do not take KALETRA with the cholesterol-lowering medicines Mevacor® (lovastatin) or Zocor® (simvastatin) because of possible serious reactions. There is also an increased risk of drug interactions between KALETRA and Lipitor® (atorvastatin) or Crestor® (rosuvastatin); talk to your doctor before you take any of these cholesterol-reducing medicines with KALETRA.

Medicines that require dosage adjustments:

It is possible that your doctor may need to increase or decrease the dose of other medicines when you are also taking KALETRA. Remember to tell your doctor all medicines you are taking or plan to take.

Before you take Viagra® (sildenafil), Cialis® (tadalafil), or Levitra® (vardenafil) with KALETRA, talk to your doctor about problems these two medicines can cause when taken together. You may get increased side effects of VIAGRA, CIALIS, or LEVITRA such as low blood pressure, vision changes, and penis erection lasting more than 4 hours. If an erection lasts longer than 4 hours, get medical help right away to avoid permanent damage to your penis. Your doctor can explain these symptoms to you.

- If you are taking oral contraceptives (“the pill”) or the contraceptive patch to prevent pregnancy, you should use an additional or different type of contraception since KALETRA may reduce the effectiveness of oral or patch contraceptives.
- Efavirenz (Sustiva™), nevirapine (Viramune®), Agenerase (amprenavir) and Viracept (nelfinavir) may lower the amount of KALETRA in your blood. Your doctor may increase your dose of KALETRA if you are also taking efavirenz, nevirapine, amprenavir or nelfinavir. KALETRA should not be taken once-daily with these medicines.
- If you are taking Mycobutin® (rifabutin), your doctor will lower the dose of Mycobutin.
- A change in therapy should be considered if you are taking KALETRA with:
 - Phenobarbital
 - Phenytoin (Dilantin® and others)
 - Carbamazepine (Tegretol® and others)

These medicines may lower the amount of KALETRA in your blood and make it less effective.

KALETRA should not be taken once-daily with these medicines.

- If you are taking or before you begin using inhaled Flonase® (fluticasone propionate) talk to your doctor about problems these two medicines may cause when taken together. Your doctor may choose not to keep you on inhaled Flonase®.
- *Other Special Considerations*
KALETRA oral solution contains alcohol. Talk with your doctor if you are taking or planning to take metronidazole or disulfiram. Severe nausea and vomiting can occur.
- *If you are taking both didanosine (Videx®) and KALETRA*
Didanosine (Videx®) can be taken at the same time as KALETRA tablets without food.
Didanosine (Videx®) should be taken one hour before or two hours after KALETRA oral solution.

What are the possible side effects of KALETRA?

- This list of side effects is **not** complete. If you have questions about side effects, ask your doctor, nurse, or pharmacist. You should report any new or continuing symptoms to your doctor right away. Your doctor may be able to help you manage these side effects.
- The most commonly reported side effects of moderate severity that are thought to be drug related are: abdominal pain, abnormal stools (bowel movements), diarrhea, feeling weak/tired, headache, and nausea. Children taking KALETRA may sometimes get a skin rash.
- Blood tests in patients taking KALETRA may show possible liver problems. People with liver disease such as Hepatitis B and Hepatitis C who take KALETRA may have worsening liver disease. Liver problems including death have occurred in patients taking KALETRA. In studies, it is unclear if KALETRA caused these liver problems because some patients had other illnesses or were taking other medicines.
- Some patients taking KALETRA can develop serious problems with their pancreas (pancreatitis), which may cause death. You have a higher chance of having pancreatitis if you have had it before. Tell your doctor if you have nausea, vomiting, or abdominal pain. These may be signs of pancreatitis.
- Some patients have large increases in triglycerides and cholesterol. The long-term chance of getting complications such as heart attacks or

stroke due to increases in triglycerides and cholesterol caused by protease inhibitors is not known at this time.

- Diabetes and high blood sugar (hyperglycemia) occur in patients taking protease inhibitors such as KALETRA. Some patients had diabetes before starting protease inhibitors, others did not. Some patients need changes in their diabetes medicine. Others needed new diabetes medicine.
- Changes in body fat have been seen in some patients taking antiretroviral therapy. These changes may include increased amount of fat in the upper back and neck (“buffalo hump”), breast, and around the trunk. Loss of fat from the legs, arms and face may also happen. The cause and long term health effects of these conditions are not known at this time.
- Some patients with hemophilia have increased bleeding with protease inhibitors.
- There have been other side effects in patients taking KALETRA. However, these side effects may have been due to other medicines that patients were taking or to the illness itself. Some of these side effects can be serious.

What should I tell my doctor before taking KALETRA?

- *If you are pregnant or planning to become pregnant:* The effects of KALETRA on pregnant women or their unborn babies are not known.
- *If you are breast-feeding:* Do not breast-feed if you are taking KALETRA. You should not breast-feed if you have HIV-1. If you are a woman who has or will have a baby, talk with your doctor about the best way to feed your baby. You should be aware that if your baby does not already have HIV-1, there is a chance that HIV-1 can be transmitted through breast-feeding.
- *If you have liver problems:* If you have liver problems or are infected with Hepatitis B or Hepatitis C, you should tell your doctor before taking KALETRA.
- *If you have diabetes:* Some people taking protease inhibitors develop new or more serious diabetes or high blood sugar. Tell your doctor if you have diabetes or an increase in thirst or frequent urination.
- *If you have hemophilia:* Patients taking KALETRA may have increased bleeding.

How do I store KALETRA?

- Keep KALETRA and all other medicines out of the reach of children.
- KALETRA tablets should be stored at room temperature. Exposure of KALETRA tablets to high humidity outside the pharmacy container for longer than 2 weeks is not recommended.
- Refrigerated KALETRA oral solution remains stable until the expiration date printed on the label. If stored at room temperature up to 25°C (77°F), KALETRA oral solution should be used within 2 months.
- Avoid exposure to excessive heat.

Do not keep medicine that is out of date or that you no longer need. Be sure that if you throw any medicine away, it is out of the reach of children.

General advice about prescription medicines:

Talk to your doctor or other health care provider if you have any questions about this medicine or your condition. Medicines are sometimes prescribed for purposes other than those listed in a Patient Information Leaflet. If you have any concerns about this medicine, ask your doctor. Your doctor or pharmacist can give you information about this medicine that was written for health care professionals. Do not use this medicine for a condition for which it was not prescribed. Do not share this medicine with other people.

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Seeking Validation

Transitioning is a celebration of who you are

by Pamela McCann

Transgender individuals seek validation from society for the gender they know they are. This search for validation is one of the most important motivators for an all too often ignored population. Even individuals with family support for their transition and the financial resources to transition in socially and medically approved means face immense challenges. For transgender persons without adequate medical insurance or a support network, transitioning is a truly daunting task.

Silicone, street hormones, and trial-and-error too often form the transition regimen for individuals without the access to health care and the thousands of dollars needed to pursue gender transition in compliance with the World Professional Association for Transgender Health's Standards of Care. Just a discussion of the risks of silicone injections is not helpful. The real issue is affordability and availability of medical services and access to supportive counseling for a healthy gender transition.

For those who do not question their gender identity, it is hard to imagine what transgender persons go through to garner society's validation. Many transgender persons are so driven for validation from soci-

ety that if a potential partner approaches them for a high-risk but validating behavior, the transgender person is too often unable to negotiate a healthier alternative.

Gender is social, not sexual. A transgender person needs to be accepted by the bus driver, by the store clerk, by everyone he or she comes in contact with. And trans people work very, very hard to elicit that acceptance.

The transgender person knows that they must both look like and act like the gender they need to be. Looking the part means cross-gender hormone therapy—estrogen for males to female, testosterone for females to male. Hormones work quite well, but they take a while, especially to reform the male body after the onslaught of testosterone during puberty.

Some transgender people, however, need more immediate validation, while others cannot afford the cost of a long-term hormone regimen. Individuals without access to supportive psychological counseling to help them cope with the stress of transitioning, or those without the insurance or financial resources to pay for hormones, often turn to less-expensive street drugs or alternatives to hormones, like

silicone injections, to re-shape their bodies. The risks of street hormones or silicone injections, while significant, are not the issue. The issue is access to affordable health and mental health services. This is a public health problem.

Programs like those at Howard Brown Health Center in Chicago, where Lois Bates works (see *Body and Soul* sidebar), are needed to cut the risks faced by the transgender population. Because of the sliding scale charged, some trans women pay less for their transgender medical care than many others who have insurance will spend on co-pays.

Cross-gender hormone therapy can run from \$150 to \$200 a month and a battery of needed twice yearly lab tests can cost \$1,200 a year. Insurance will sometimes pay for the tests but not all of them, especially the ones testing for male and female hormone levels in the same person. The cost can be significant even with insurance. Those transgender persons deciding to seek sex reassignment surgery (SRS), typically have to foot the entire bill without any insurance payments, a bill that can easily cost more than \$25,000.

In spite of the challenges, the rejections and the costs that transgender people often tell about in their stories, they typically end their story with "I would not have done it any other way." Transitioning is a celebration of who you are.

Getting validation, a fancy way of saying what the transgender community calls passing, is not just about how you look physically. Gender-appropriate deportment and mannerisms will overcome many aspects of gender-incorrect physical traits more often than we think.

The path is very hard work, but for many of those who persevere, there is the finality of achieving their goal—gender recognition. Several Websites catalog the stories of successful—sometimes very successful—transgender persons. These are stories of MTFs [male-to-female] and FTMs [female-to-male] who are doctors, lawyers, police officers, actresses, professors, cosmeticians, investment consultants, etc.

But even for these very successful individuals, as for all members of the transgender community, discretion is always needed. For the gay community, it's healthy to be out and to be open about who you are. Being out doesn't work as well for the transgender community. Transgender persons want to be validated most of the time for being

women or men, not necessarily for being transgender. It is not helpful, given current societal acceptance, for a transgender person to be out.

The rejection transgender persons face in society can even impact individuals with good jobs and access to health insurance. Working transgender persons sometimes forgo insurance coverage, even when available, for fear of negative reprisals from their employer who many times has access to insurance claim details. Transgender persons have reported losing their jobs just for filing a health care claim. Work-related issues are beginning to lessen, though. Some employers even cover the cost of SRS [sexual reassignment surgery] for their transgender employees. One transgender person who had a particularly bad time when she transitioned on the job some years ago recently said that her former employer has dramatically changed their policies, “to ensure they have access to the high-tech talent pool they needed.”

With all the discussion about transitioning, the long-term dynamics of the transgender experience often gets lost in the intensity of making the initial gender change. Transitioning is a life-long activity, and hormone therapy needs to be continued even with SRS. Transgender persons must take an active interest in their own health care. Transgender persons must ensure that medical providers know of their gender history, since many diseases and medications are sex specific (transitioning does not change a person’s sex chromosomes.) Providers, even your dentist and your chiropractor, must know your genetic sex. This candor with health care providers is sometimes hampered by a transgender person’s previous interaction with the system. Too many stories circulate of providers with a less than supportive attitude towards their transgender patients. A negative interaction, especially if repeated over time or with different providers, can create a reluctance to seek medical help until too late.

Just about every culture we know has references to transgender persons. Ancient Roman society had a place for gender expression. Indigenous American cultures did too. French nobleman Chevalier D’Eon, and counselor to King Louis XV, transitioned “on the job” in court from monsieur to mademoiselle! More recently we have seen films such as the English production from the late 1990’s, “Different for Girls,” and the popular American film,

“TransAmerica.” Even that icon of interior décor, IKEA, produced an ad for the European market featuring a transgender person (you can still see this ad, “Redecorate Your Life,” at www.commercialcloset.org).

Transgender persons are a challenge to one of society’s most fundamental assumptions. They are an underserved population, and are susceptible to high-risk behaviors

but, above all, they are just people wanting to be themselves. ☩

Pamela McCann is an administrator and advocate for the Office of LGBT (Lesbian, Gay, Bisexual, and Transgender) Health at the Chicago Department of Public Health, and herself a transgender woman.

BODY AND SOUL

by Enid Vázquez

With all the discrimination, including that from medical providers, standing in their way, transgender individuals still seek the body that satisfies their soul. If clinics and pharmacies are unwelcoming, and costs prohibitive, treatment is readily available on the streets.

“I’ve seen people with cheekbones put in, not necessarily by doctors,” Chicago nurse practitioner Bethsheba Johnson says of the transgender male-to-female (MTF) patients she lovingly calls her “divas.” (See page 20.)

She’s heard about the backrooms in unsterile conditions, where injections of free (not encapsulated) silicone rounds hips, butts, and breasts. She hears of the “parties” where transgender women gather to get their injections, one after another.

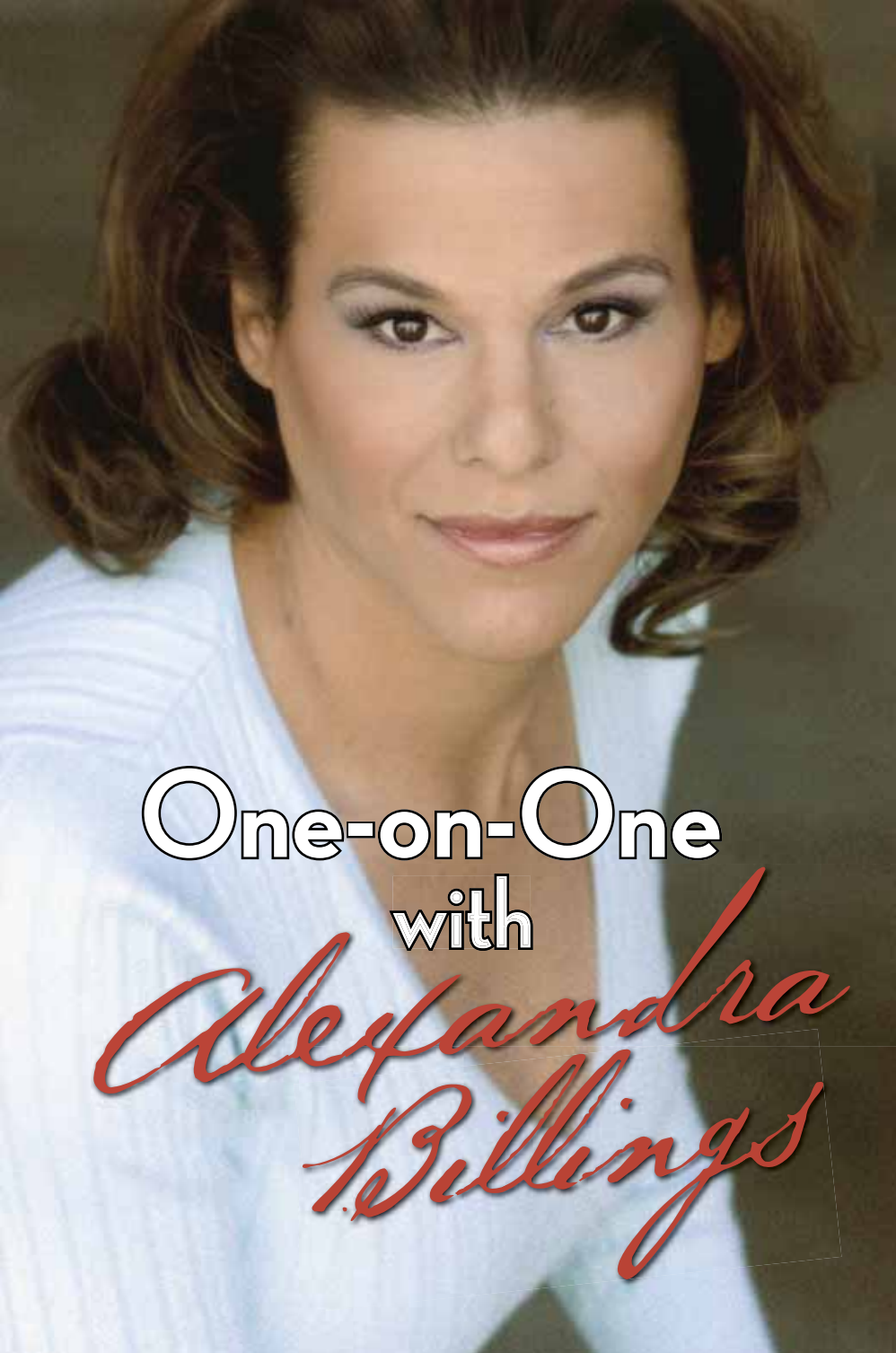
“It scares me,” said Johnson.

According to the treatment protocol produced by the Tom Waddell Health Center (TWHC), which focuses on transgender care as part of the Department of Health in San Francisco, “Invasive procedures such as silicone-like injections were available underground, in cases creating severe local tissue damage. We have patients who have been permanently disfigured by these injections, which often mix industrial grade silicone and/or other substance such as paraffin and oil. ...The immediate dangers of these injections include: soft tissue infection, risk of contaminated needles transmitting disease such as HIV, hepatitis, or MRSA, and foreign substance reaction. The long term dangers include: recurrent inflammation, migration of the foreign matter from the injected site, disfigurement such as nodules, granulomata, and pain syndromes.

“Treatment is palliative [relieving pain and discomfort]; there is no effective way to remove unencapsulated silicone from body tissue,” the protocol continues. “Silicone injections into breast tissue make mammograms ineffective. We see the damaging sequelae of silicone and other substances on an infrequent but regular basis.”

“They are so desperate,” said Johnson, who provides psychosocial care. “They want immediate results. They don’t want to take a couple of years to get the curves. They want them now.”

In her presentation “Trans 101: Misunderstood and Misinterpreted,” transgender Chicagoan Lois Bates (see profile on page 49) explains that, “In the trans community, appearance and pass-ability is very important. It is very important to maintain body image and it is valued above other important aspects of life. The body image process may vary due to an individual’s economic ability to support a regular regimen or see an accredited professional. Some regimens and procedures may be covered by insurance or government aid. Individuals with private insurance have an easier and faster path of transitioning. Individuals with no insurance and lower economic ability may seek medications and regimens from black market sources.” ☩



One-on-One with

Alexandra Billings

The star of stage and screen talks to PA about the importance of love, humor, and her Chicago roots

Interview by Jeff Berry

SHOULD I CALL YOU ALEX, OR ALEXANDRA—WHICH DO YOU PREFER?

Oh, please, call me Alex—Alexandra has way too many syllables in it.

AND CAN I ASK HOW OLD YOU ARE, AND HOW LONG YOU'VE BEEN HIV-POSITIVE?

Sure, you can ask. Can I lie? I'm 26. Not really, I just turned 45. And I've been HIV-positive—gosh, you'd think I'd know this—for 20-something years.

ARE YOU ON ANY THERAPY?

Should I be? Do I sound like I need therapy?

NOT THAT KIND OF THERAPY!

Okay, you scared me. Yes, I am, and I've only changed medications twice. But here's the interesting thing—I was on one of the early clinical trials, a [placebo-controlled] study where everyone was on AZT. And they either gave you a sugar pill or Norvir, and I came to find out later I was [in the placebo group], so I was [basically on AZT mono-therapy].

SO DO YOU FEEL THAT LIVING WITH HIV HAS GIVEN YOU ANY INSIGHT OR UNIQUE PERSPECTIVE IN YOUR WORK AS AN ACTOR, OR THE ROLES YOU'VE PLAYED ON E.R. OR GREY'S ANATOMY? [ON BOTH SHOWS SHE GUEST-STARRED AS A PRE-OPERATIVE TRANSEXUAL, ONE WITH TESTICULAR CANCER AND THE OTHER WITH BREAST CANCER.]

Well, that's an interesting question—no one's ever asked me that before. It's not something that I consciously think about, but I'm certain that it has. When I was diagnosed, my wife was with me at the doctor's office when the doctor came in and told me, and at that time it was most assuredly a death sentence, there was no ques-

Photo courtesy of Alexandra Billings

tion about it. You had a certain time to live, and these medications, these brand new things that were coming out, they had no idea whether they were going to work, or what they were going to do to you in the long run, they still really don't know that. But at the time there was a huge question mark that we were living under. When I was twenty-something and diagnosed—being told that my life was going to be cut short by a matter of half my lifetime sort of stays with you. But I think, in a roundabout answer to your question, absolutely it informs my acting in the sense that I was very young—I'm still very, *very* young—and having been told that you have a fatal illness, you don't ever forget that. So I think I understand more than actors who haven't been through that sort of situation what dire circumstances really are. I think in that way, yes. I don't necessarily go into any scene taking that with me. I try not to consciously do that, because I want to be present in the scene that I'm attempting to play. But I think I carry it with me all the time—not only in my acting life, but in my [personal] life as well.

HAVE YOU EVER ENCOUNTERED ANY STIGMA OR DISCRIMINATION WHEN SEEKING ROLES, EITHER AS A TRANSWOMAN OR SOMEONE LIVING WITH HIV?

You know, I really haven't. But here's the difference—you know, it's funny, because people tend to think that show business is extremely different than any other kind of business. And it's really kind of isn't, in the sense that when I go in for a job interview, it's not something that I talk about in the interview, which is basically an audition. So it's not something that I bring up. If I were asked, I certainly would, but it's never something that comes into play. Now, I have been on sets where I've talked to the crew, or even occasionally to other actors, just because most everyone now either knows someone or has someone close to them who is HIV-positive. And so inevitably in the artistic community, sometimes it comes up. And if I feel the situation is right I'll say something, but usually when I say something about my own HIV status, it's very rare that I'm faced with any opposition or negative feelings.

Now that's changed, because 16 years ago, it was a very touchy subject. I was still talking about it, because I have a big mouth, and I was in rehearsal for a play, and I was talking to a friend

of mine about it, and another actor had overheard. And he was very social with me up until that point, and he literally, physically, steered away from me, and pretty much didn't talk to me through the run of the play. But it's different now, it's very different now. And I'll tell you, it's different in a good way, and it's different in a bad way. It's different in a good way because I think everybody is familiar in some way with it, sadly enough. But in a negative way, I think people tend to think we're cured. I think that people

WE'RE KIND OF THE POSTER CHILDREN FOR WHY THIS BAN AGAINST GAY MARRIAGE IS ABSOLUTELY RIDICULOUS.

assume that these pills are magic bullets, and that everything's peachy. And thus, as I'm sure you're aware, the rate of infection is back up. They're having unsafe sex, and people think, especially the new generation that's coming up, they think, "Well, we're just taking pills, which is like aspirin, I can just pop these pills—I mean, even if I get it—it's fine." It's strange, it's a double-edged sword, I don't think people hear it very well, but I think the acceptance people feel is some kind of casual relation to the actual disease, which I think is the negative part of this—attitude.

YOU AND YOUR WIFE CHRISANNE [BLANKENSHIP] DID A ONE-WOMAN SHOW TOGETHER?

Yes, Chrisanne and I wrote a show called "Before I Disappear" which is an autobiographical piece that also had original music in it, and she not only helped develop the piece, but also wrote all the lyrics to the original songs. We did it in Chicago, Boston, off-Broadway, and in Hollywood.

HOW LONG HAVE YOU BEEN IN YOUR RELATIONSHIP WITH CHRISANNE?

We met when I was 14. We were both in high school, and we've remained best friends ever since, so we've known each other 31 years. We've been married for 11 years, and we were engaged for a year.

I HAVE READ THAT YOU HAD A COMMITMENT CEREMONY, BUT ARE YOU LEGALLY MARRIED?

I love when people ask me this question, this is my favorite question. Well, see, here's the thing. No, we're not—we can't be, because we're two females [*Editor's note: This interview took place several weeks before the recent ruling on same sex marriage by the Supreme Court of California.*]. Which is kind of astounding, when you think about it, because had we gotten married when we were both 19 or 20 years old, we would be legally married. So we're kind of the poster children for why this ban against gay marriage is absolutely ridiculous. Because if you say to us, "Well, you could be legally married at 19," and then you fast-forward five, six years, and all of a sudden you say, "No, we have to take your marriage license back, I'm sorry, you're female now." It makes no sense, we're still the same people. It literally makes absolutely no sense at all. What would they have done, revoke our license? It's not a fishing license, for heaven's sake, it doesn't expire—it's crazy. It's absolutely insane.

YOU CAN'T SURVIVE—YOU CAN'T BE IN THIS LIFE—AND NOT HAVE A SENSE OF HUMOR.

IT WOULD BE REALLY INTERESTING TO HAVE THAT TESTED AT SOME POINT.

You know, we thought about this, we thought really hard about this. Because there was a time when it was legal in certain states. And then five, six years ago Bush was trying to make his amendment to the constitution, and all that crazy stuff. When you're transgender, they don't change the sex on your birth certificate—that usually remains the same. So whatever it says on your birth certificate is what remains there. Now if I wanted to try and challenge the law, I could say to the state of California, which is where I was born, "Look, I was born male, I want to get married. So I want you to make my marriage license from the facts that you have on my birth certificate." Now this was before I got my name changed, of course. I could have, I think, said, "It says male, that's what I am, here's my wife, and we want to get married." And see if they would have actually married us. I don't know. But then, in a sense, it would be denying who we really are, because that's not who we are.

WHAT ARE SOME OF THE THINGS YOU CREDIT FOR YOUR SUCCESS AS AN ACTOR, FOR YOUR LONG-TERM RELATIONSHIP, AND YOUR

CONTINUED GOOD HEALTH? SOME OF THOSE THINGS PROBABLY SOMEHOW TIE TOGETHER, I WOULD IMAGINE.

Oh, absolutely. You know, when you said that I was thinking: luck, and hard work—and that's really it for all three of them. Show business is 80% luck, and a relationship is 80% luck, and the rest of it is hard work. Both of them take work. But in my view, they don't take as much work, as, you know, a little bit of magic dust, I think.

HOW IMPORTANT IS HUMOR TO YOU?

You can't survive—you can't be in this life—and not have a sense of humor. I don't like people who don't have a sense of humor. And it's not necessarily about, "Oh, I find that thing funny." It's more about—you have to be able to laugh at yourself. You have to. If you don't find parts of yourself funny, you need to get off the boat.

WHAT QUALITIES DO YOU VALUE MOST IN OTHER PEOPLE?

A sense of humor, most definitely, that's the first one; honesty; and humility. I like people who are humble. Not false humility, because I've seen that, a lot. But true humility, where you realize your own gifts, but at the same time you don't take them so seriously that they bring you charging head first into the middle of the room screaming, "Look at me, I'm fantastic!" Those kinds of people drive me crazy.

WHAT QUALITIES DO YOU DISLIKE MOST IN OTHER PEOPLE?

Ego. Negativity, I don't particularly like negative people. I don't mind realists, because I married a realist. But I don't like negative people. I don't like people who look at every situation and are, you know, like Eeyore in Winnie the Pooh? "*We'll never make it.*" I don't know—it doesn't solve anything as far as I'm concerned. You don't have to look at the bright side of everything, but I don't like negative people. And I don't like people who form an opinion before a situation has happened—any kind of opinion. I like people who sort of wait until the situation happens, live in the situation, and then figure out the outcome as they go.

WHAT ADVICE WOULD YOU GIVE TO OTHER TRANSGENDER INDIVIDUALS, ESPECIALLY YOUNGER FOLKS, WHO MAY BE STRUGGLING WITH THEIR IDENTITY, OR JUST COMING OUT?

Be honest. Don't make up a past. Don't try and fit in to a world that you're making up in your own head. If you're a male to female transsexual, or a female to male transsexual, don't pretend you're something you're not. Don't lie to people. Don't say to them, "I'm male, I was born male—this is what I am. You're not. You're a transgender male, or you're a transgender female. And that's great. It doesn't mean you're not female, it doesn't mean you're not male. It just means you're a different kind of male, a different

In combination with other antiretroviral agents for the treatment of HIV-1 infection in adults

You control your life.
Take an active role in
your HIV treatment.

Once a day TRUVADA can help get you to undetectable and keep you there. As part of an HIV regimen, the meds in TRUVADA can:

- Be taken with or without food
- Reduce viral load and increase CD4 cell count

Ask your doctor if TRUVADA can be part of a complete once a day regimen.


Truvada® 

200 mg emtricitabine · tenofovir disoproxil fumarate 300 mg

TRUVADA is the #1 Prescribed HIV Med*

TRUVADA does not cure HIV infection or prevent passing HIV-1 to others.

USE OF TRUVADA:

TRUVADA is indicated in combination with other antiretroviral agents (such as non-nucleoside reverse transcriptase inhibitors or protease inhibitors) for the treatment of HIV-1 infection in adults.

TRUVADA must be used as part of combination therapy. TRUVADA should not be used with ATRIPLA® (efavirenz 600 mg/emtricitabine 200 mg/tenofovir disoproxil fumarate [DF] 300 mg), VIREAD® (tenofovir DF), EMTRIVA® (emtricitabine), Combivir® (lamivudine/ zidovudine), Epivir® or Epivir-HBV® (lamivudine), Epzicom® (abacavir sulfate/lamivudine), or Trizivir® (abacavir sulfate/lamivudine/zidovudine).

IMPORTANT SAFETY INFORMATION:

Contact your healthcare provider right away if you experience any of the following side effects or conditions while taking TRUVADA:

- Nausea, vomiting, unusual muscle pain, and/or weakness. These may be signs of a buildup of acid in the blood (lactic acidosis), which is a serious medical condition

- Light colored stools, dark colored urine, and/or if your skin or the whites of your eyes turn yellow. These may be signs of serious liver problems (hepatotoxicity), with liver enlargement (hepatomegaly), and fat in the liver (steatosis)
- If you have HIV and hepatitis B virus (HBV) and stop taking TRUVADA, your liver disease may suddenly get worse. Do not stop taking TRUVADA unless directed by your healthcare provider
- If you have had kidney problems or take other medicines that can cause kidney problems, your healthcare provider should do regular blood tests to check your kidneys
- It is not known whether long-term use of TRUVADA causes damage to your bones. If you have had bone problems in the past, talk to your healthcare provider before taking TRUVADA

Changes in body fat have been seen in some people taking TRUVADA and other anti-HIV medicines.

The most common side effects of the medicines in TRUVADA when taken with other anti-HIV medicines are dizziness, diarrhea, nausea, vomiting, headache, rash,

and gas. Skin discoloration (spots and freckles) may also occur.

Discuss all medicines you take with your healthcare provider and be aware:

- Your healthcare provider may need to follow you more closely or adjust your therapy if you are taking Videx® or Videx® EC (didanosine), Reyataz® (atazanavir sulfate), or Kaletra® (lopinavir/ritonavir) with TRUVADA

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Patient Information on next page, including "What is the most important information I should know about TRUVADA?"

*Based on data from PFAST retail monthly data, September 2005–January 2008, Wolters Kluwer Health.

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Patient Information

TRUVADA® (tru-VAH-dah) Tablets

Generic name: emtricitabine and tenofovir disoproxil fumarate
(em tri SIT uh bean and te NOE' fo veer dye soe PROX ii FYOU mar ate)

Read the Patient Information that comes with TRUVADA before you start taking it and each time you get a refill. There may be new information. This information does not take the place of talking to your healthcare provider about your medical condition or treatment. You should stay under a healthcare provider's care when taking TRUVADA. **Do not change or stop your medicine without first talking with your healthcare provider.** Talk to your healthcare provider or pharmacist if you have any questions about TRUVADA.

What is the most important information I should know about TRUVADA?

- **Some people who have taken medicine like TRUVADA (nucleoside analogs) have developed a serious condition called lactic acidosis** (build up of an acid in the blood). Lactic acidosis can be a medical emergency and may need to be treated in the hospital. **Call your healthcare provider right away if you get the following signs or symptoms of lactic acidosis.**
 - You feel very weak or tired.
 - You have unusual (not normal) muscle pain.
 - You have trouble breathing.
 - You have stomach pain with nausea and vomiting.
 - You feel cold, especially in your arms and legs.
 - You feel dizzy or lightheaded.
 - You have a fast or irregular heartbeat.
- **Some people who have taken medicines like TRUVADA have developed serious liver problems called hepatotoxicity**, with liver enlargement (hepatomegaly) and fat in the liver (steatosis). **Call your healthcare provider right away if you get the following signs or symptoms of liver problems.**
 - Your skin or the white part of your eyes turns yellow (jaundice).
 - Your urine turns dark.
 - Your bowel movements (stools) turn light in color.
 - You don't feel like eating food for several days or longer.
 - You feel sick to your stomach (nausea).
 - You have lower stomach area (abdominal) pain.
- **You may be more likely to get lactic acidosis or liver problems** if you are female, very overweight (obese), or have been taking nucleoside analog medicines, like TRUVADA, for a long time.
- **If you are also infected with the Hepatitis B Virus (HBV)**, you need close medical follow-up for several months after stopping treatment with TRUVADA. Follow-up includes medical exams and blood tests to check for HBV that could be getting worse. **Patients with Hepatitis B Virus infection, who take TRUVADA and then stop it, may get "flare-ups" of their hepatitis. A "flare-up" is when the disease suddenly returns in a worse way than before.**

What is TRUVADA?

TRUVADA is a type of medicine called an HIV (human immunodeficiency virus) nucleoside analog reverse transcriptase inhibitor (NRTI). TRUVADA contains 2 medicines, EMTRIVA® (emtricitabine) and VIREAD® (tenofovir disoproxil fumarate, or tenofovir DF) combined in one pill. TRUVADA is always used with other anti-HIV medicines to treat people with HIV infection. TRUVADA is for adults age 18 and older. TRUVADA has not been studied in children under age 18 or adults over age 65.

HIV infection destroys CD4 (T) cells, which are important to the immune system. The immune system helps fight infection. After a large number of T cells are destroyed, acquired immune deficiency syndrome (AIDS) develops.

TRUVADA helps block HIV reverse transcriptase, a chemical in your body (enzyme) that is needed for HIV to multiply. TRUVADA lowers the amount of HIV in the blood (viral load). TRUVADA may also help to increase the number of T cells (CD4 cells). Lowering the amount of HIV in the blood lowers the chance of death or infections that happen when your immune system is weak (opportunistic infections).

TRUVADA does not cure HIV infection or AIDS. The long-term effects of TRUVADA are not known at this time. People taking TRUVADA may still get opportunistic infections or other conditions that happen with HIV infection. Opportunistic infections are infections that develop because the immune system is weak. Some of these conditions are pneumonia, herpes virus infections, and *Mycobacterium avium complex* (MAC) infection. **It is very important that you see your healthcare provider regularly while taking TRUVADA.**

TRUVADA does not lower your chance of passing HIV to other people through sexual contact, sharing needles, or being exposed to your blood. For your health and the health of others, it is important to always practice safer sex by using a latex or polyurethane condom or other barrier to lower the chance of sexual contact with semen, vaginal secretions, or blood. **Never use or share dirty needles.**

Who should not take TRUVADA?

- Do not take TRUVADA if you are allergic to TRUVADA or any of its ingredients. The active ingredients of TRUVADA are emtricitabine and tenofovir DF. See the end of this leaflet for a complete list of ingredients.
- Do not take TRUVADA if you are already taking ATRIPLA™, Combivir (lamivudine/zidovudine), EMTRIVA, EpiVir or EpiVir-HBV (lamivudine), Epzicom (abacavir sulfate/lamivudine), Trizivir (abacavir sulfate/lamivudine/zidovudine), or VIREAD because these medicines contain the same or similar active ingredients.

What should I tell my healthcare provider before taking TRUVADA?

Tell your healthcare provider if you:

- **are pregnant or planning to become pregnant.** We do not know if TRUVADA can harm your unborn child. You and your healthcare provider will need to decide if TRUVADA is right for you. If you use TRUVADA while you are pregnant, talk to your healthcare provider about how you can be on the TRUVADA Antiviral Pregnancy Registry.
- **are breast-feeding.** You should not breast feed if you are HIV-positive because of the chance of passing the HIV virus to your baby. Also, it is not known if TRUVADA can pass into your breast milk and if it can harm your baby. If you are a woman who has or will have a baby, talk with your healthcare provider about the best way to feed your baby.
- **have kidney problems or are undergoing kidney dialysis treatment.**
- **have bone problems.**
- **have liver problems including Hepatitis B Virus infection.**

Tell your healthcare provider about all the medicines you take, including prescription and non-prescription medicines, vitamins, and herbal supplements. Especially tell your healthcare provider if you take:

- Videx, Videx EC (didanosine). Tenofovir DF (a component of TRUVADA) may increase the amount of Videx in your blood. **You may need to be followed more carefully if you are taking TRUVADA and Videx together.** Also, the dose of didanosine may need to be reduced.
- Reyataz (atazanavir sulfate) or Kaletra (lopinavir/ritonavir). These medicines may increase the amount of tenofovir DF (a component of TRUVADA) in your blood, which could result in more side effects. You may need to be followed more carefully if you are taking TRUVADA and Reyataz or Kaletra together. TRUVADA may decrease the amount of Reyataz in your blood. If you are taking TRUVADA and Reyataz together, you should also be taking Norvir (ritonavir).

Keep a complete list of all the medicines that you take. Make a new list when medicines are added or stopped. Give copies of this list to all of your healthcare providers and pharmacist **every** time you visit your healthcare provider or fill a prescription.

How should I take TRUVADA?

- Take TRUVADA exactly as your healthcare provider prescribed it. Follow the directions from your healthcare provider, exactly as written on the label.
- The usual dose of TRUVADA is 1 tablet once a day. TRUVADA is always used with other anti-HIV medicines. If you have kidney problems, you may need to take TRUVADA less often.
- TRUVADA may be taken with or without a meal. Food does not affect how TRUVADA works. Take TRUVADA at the same time each day.
- If you forget to take TRUVADA, take it as soon as you remember that day. **Do not** take more than 1 dose of TRUVADA in a day. **Do not** take 2 doses at the same time. Call your healthcare provider or pharmacist if you are not sure what to do. **It is important that you do not miss any doses of TRUVADA or your anti-HIV medicines.**
- When your TRUVADA supply starts to run low, get more from your healthcare provider or pharmacy. This is very important because the amount of virus in your blood may increase if the medicine is stopped for even a short time. The virus may develop resistance to TRUVADA and become harder to treat.
- Do not change your dose or stop taking TRUVADA without first talking with your healthcare provider. Stay under a healthcare provider's care when taking TRUVADA.
- If you take too much TRUVADA, call your local poison control center or emergency room right away.

What should I avoid while taking TRUVADA?

- **Do not breast-feed.** See "What should I tell my healthcare provider before taking TRUVADA?"
- **Avoid doing things that can spread HIV infection** since TRUVADA does not stop you from passing the HIV infection to others.
 - **Do not share needles or other injection equipment.**
 - **Do not share personal items that can have blood or body fluids on them, like toothbrushes or razor blades.**
 - **Do not have any kind of sex without protection.** Always practice safer sex by using a latex or polyurethane condom or other barrier to reduce the chance of sexual contact with semen, vaginal secretions, or blood.
- ATRIPLA, Combivir (lamivudine/zidovudine), EMTRIVA, EpiVir or EpiVir-HBV (lamivudine), Epzicom (abacavir sulfate/lamivudine), Trizivir (abacavir sulfate/lamivudine/zidovudine), or VIREAD. **TRUVADA should not be used with these medicines.**

What are the possible side effects of TRUVADA?

TRUVADA may cause the following serious side effects (see "What is the most important information I should know about TRUVADA?"):

- **Lactic acidosis** (buildup of an acid in the blood). Lactic acidosis can be a medical emergency and may need to be treated in the hospital. **Call your doctor right away if you get signs of lactic acidosis.** (See "What is the most important information I should know about TRUVADA?")
- **Serious liver problems (hepatotoxicity)**, with liver enlargement (hepatomegaly) and fat in the liver (steatosis). Call your healthcare provider right away if you get any signs of liver problems. (See "What is the most important information I should know about TRUVADA?")
- **"Flare-ups" of Hepatitis B Virus infection**, in which the disease suddenly returns in a worse way than before, can occur if you stop taking TRUVADA. Your healthcare provider will monitor your condition for several months after stopping TRUVADA if you have both HIV and HBV infection. TRUVADA is not approved for the treatment of Hepatitis B Virus infection.
- **Kidney problems.** If you have had kidney problems in the past or take other medicines that can cause kidney problems, your healthcare provider should do regular blood tests to check your kidneys.

- **Changes in bone mineral density (thinning bones).** It is not known whether long-term use of TRUVADA will cause damage to your bones. If you have had bone problems in the past, your healthcare provider may need to do tests to check your bone mineral density or may prescribe medicines to help your bone mineral density.

Other side effects with TRUVADA when used with other anti-HIV medicines include:

- Changes in body fat have been seen in some patients taking TRUVADA and other anti-HIV medicines. These changes may include increased amount of fat in the upper back and neck ("buffalo hump"), breast, and around the main part of your body (trunk). Loss of fat from the legs, arms and face may also happen. The cause and long term health effect of these conditions are not known at this time.

The most common side effects of EMTRIVA or VIREAD when used with other anti-HIV medicines are: dizziness, diarrhea, nausea, vomiting, headache, rash, and gas. Skin discoloration (small spots or freckles) may also happen with TRUVADA.

These are not all the side effects of TRUVADA. This list of side effects with TRUVADA is **not complete** at this time because TRUVADA is still being studied. If you have questions about side effects, ask your healthcare provider. Report any new or continuing symptoms to your healthcare provider right away. Your healthcare provider may be able to help you manage these side effects.

How do I store TRUVADA?

- **Keep TRUVADA and all other medicines out of reach of children.**
- Store TRUVADA at room temperature 77 °F (25 °C).
- Keep TRUVADA in its original container and keep the container tightly closed.
- Do not keep medicine that is out of date or that you no longer need. If you throw any medicines away make sure that children will not find them.

General information about TRUVADA:

Medicines are sometimes prescribed for conditions that are not mentioned in patient information leaflets. Do not use TRUVADA for a condition for which it was not prescribed. Do not give TRUVADA to other people, even if they have the same symptoms you have. It may harm them.

This leaflet summarizes the most important information about TRUVADA. If you would like more information, talk with your healthcare provider. You can ask your healthcare provider or pharmacist for information about TRUVADA that is written for health professionals. For more information, you may also call 1-800-GILEAD-5 or access the TRUVADA website at www.TRUVADA.com.

Do not use TRUVADA if seal over bottle opening is broken or missing.

What are the ingredients of TRUVADA?

Active Ingredients: emtricitabine and tenofovir disoproxil fumarate

Inactive Ingredients: Croscarmellose sodium, lactose monohydrate, magnesium stearate, microcrystalline cellulose, and pregelatinized starch (gluten free). The tablets are coated with Opadyr II Blue Y-30-10701 containing FD&C Blue #2 aluminum lake, hydroxypropyl methylcellulose 2910, lactose monohydrate, titanium dioxide, and triacetin.

Rx Only

May 2007

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kind of female. And that is a gift, so accept that. Accept what you are, and think of it as a gift, think of it as a present somebody gave you, instead of this awful, terrible thing that you have to hide. It'll make life much easier, believe me—and much more funny.

CAN YOU TELL US ANY PROJECTS YOU'RE CURRENTLY WORKING ON?

I have a couple of things that I'm working on that, unfortunately, I can't really talk about.

ANY FEATURE FILMS POSSIBLY IN THE WORKS?

I'm sorry—oh God, it sounds so secret, doesn't it? *"I'm working on this experiment."* You'd think I was doing something really important, like figuring out a cure for something, it's so not that important—but legally, I can't.

ARE ANY OF THE ROLES THAT YOU CREATED ON E.R. OR GREY'S ANATOMY CONTINUING ROLES? I ONLY SAW CLIPS AND WASN'T ABLE TO VIEW THE ENTIRE EPISODE TO SEE IF YOU DIED.

Yeah, wouldn't that be nice? No, unfortunately I died, in both of them. I'm dead. Unless they figure out a way to reanimate me, that'd be good.

WHERE DO YOU SEE YOURSELF TO YEARS FROM NOW?

Oh dear, hopefully not getting any more Botox. This is going to sound so metaphysical and "new-agey" but, I try not to look ahead. I hope that I'm working, and that I'm happy, and that I'm well. If those three things are in play, I'm good to go. I really am. I'm fine. I have a terrible fear of being caught up in the youth-obsessed nature of this town [Los Angeles]. Every time I go out to dinner, I see women who have the exact same face—do you know what I'm saying? The same lips, the same forehead, and I keep saying to myself, "Okay, don't get caught up in that, or you're going to end up looking like Mary Tyler Moore." And we don't want that to happen, do we?

NO, WE DON'T WANT THAT TO HAPPEN.

No, we really don't, no.

ANYTHING ELSE YOU'D LIKE OUR READERS TO KNOW?

Yes, there is something. I have to tell you, when I was first diagnosed, I was a wreck. My life had literally fallen apart, and I mean by the seams. I don't mean something nasty had happened, I mean my world had turned upside down and split—right at the seams. And Chrisanne and I had no idea about this disease, we had no idea what to do, we had no idea where to turn to, we were completely and utterly confused, and we assumed that I was dying.

And we went to TPAN [Test Positive Aware Network], and, I'll never forget this, we went to the Wednesday night beginners

meeting. And, God, I'm getting choked up thinking about it. Sitting in that room, with all those newly diagnosed HIV-positive people—with a doctor leading the meeting, who I assumed had volunteered his time—*saved my life.* [Editor's note: That was Dr. Ron D'Amico, who faithfully volunteered his time every Wednesday for years. He is now working in New York City.] It truly saved my life. And I'm not exaggerating. I went to those meetings, I think, for a good two or three years when I was first diagnosed. And TPAN, and what they did, and what they stood for, was a lifeline for me. And so the only thing I want other people to know is how important, first of all, TPAN is, as a whole, as an organization; and second of all, is that when you're newly diagnosed, the first thing that you've got to do is reach out—and talk about it.

ACCEPT WHAT YOU ARE, AND THINK OF IT AS A GIFT, THINK OF IT AS A PRESENT SOMEBODY GAVE YOU, INSTEAD OF THIS AWFUL, TERRIBLE THING THAT YOU HAVE TO HIDE.

WELL, I GOT ALL CHOKED UP.

And I'm not kidding you, Jeff, honestly. There are times when I'm in [Chicago], I'll pass that building, and I'll start to well up. It was just extraordinary. And I'll be honest with you, I didn't know something like that existed—none of us did. Ross Slotten was my doctor, my family doctor, for 15-something years—and he's now, actually, a very good friend of mine, and a very good friend of the HIV community. I think if I remember correctly, and I could be wrong about this, but I think he was the one who suggested you guys.

OH, REALLY? WOW—HE'S MY DOCTOR. TALK ABOUT SIX DEGREES OF SEPARATION.

Is he really? Oh! He's terrific, isn't he? What a bedside manner, I tell ya. And you know, that's the other thing, too—find a really good doctor. And shop around. We just got really lucky. I actually got Dr. Slotten from Chillii Pepper, from the Baton [Show Lounge]. Chillii Pepper said, "I have a great doctor, he's a great guy—and he's a specialist for HIV too."

But TPAN saved my life, truly—and my sanity. ☘

Alexandra Billings currently lives in Los Angeles with her wife, Chrisanne, and their two kitties. For more information visit www.alexandrabilings.com.



Challenges of the Young and Transgender

**A PHYSICIAN DESCRIBES
A POPULATION NEAR AND
DEAR TO HIS HEART**

BY KEITH R. GREEN

When Robert Garofalo, MD, MPH, first started working with transgender youth in the mid-1990's, he questioned whether or not it was ethical to initiate hormone therapy in those who were under the age of 18. Upon meeting 15-year-old Ebony, however, his questioning shifted to how ethical it was *not* to do so.

Ebony had been living as a girl since the age of seven. She dressed in girls' clothing and went to school every day as a girl. Her parents, supportive and genuinely concerned with the well-being of their child, got her into therapy when she first began to challenge the gender orientation she'd been assigned at birth. It was the therapist who approached Garofalo about starting Ebony on hormones.

There was one major problem, though. Even though he was a graduate of the New

York University School of Medicine, Garofalo had no training or experience with prescribing hormones for the purpose of changing a person's gender, especially someone as young as Ebony.

He admits that he was extremely reluctant at first, but the encounter with Ebony opened up his heart and his mind.

"We know that gender identity is something that is formed during childhood," he explains. "So, for eight years Ebony had been living as a girl and saw herself as a girl. It was pretty obvious that this wasn't just a fad or a phase that she was going through, nothing was going to change. So was it really ethical to delay starting hormones until she turned 18? I mean, what is so magical about the age of 18?"

Garofalo currently serves as the Director of Adolescent Medicine at Howard

Brown Health Center (HBHC) in Chicago. The guidelines for initiating hormone therapy in transgender youth at HBHC recommend holding off until the individual is at least 18 years of age. He suggests, though, that this has more to do with the laws around parental consent than anything else.

"I don't have an absolute lower age limit," he says. "I take each case on an individual basis."

In addition to having the parents of a young transgender person involved, which is often times a challenge in and of itself, Garofalo feels that such decisions should be made in collaboration with a therapist and even a case manager if possible.

Most transgender youth, he says, would prefer that he give them a checklist of requirements or things that they will

need to do in order to get him to prescribe hormones for them. He contends, however, that it's simply not that easy.

"There are lots of factors that go into the ultimate decision," he says. "Depending on the youth, I may want them to see a therapist for six months or maybe just two or three sessions or maybe two years. Not that there is anything wrong with them, but to make sure that there is nothing else going on with regards to their lives or their experiences that is in any way unstable, so that we can try to stabilize that before transition is started. And also to make sure that they have some realistic expectations about what a transition is going to be like."

The part about expectations, he believes, may be the most important piece of therapy. It is critical for transgender persons seeking to begin hormone therapy to understand it as a process—starting on hormones tomorrow will not result in a fully-developed person of the opposite gender in three weeks.

Also in the back of his mind is the fact that information regarding the biologic effects of giving someone hormones before they've actually gone through puberty are relatively unknown. Things such as bone density or bone development haven't been well studied in transgender youth who begin hormone therapy at an early age. And, while it is believed that there are only mild interactions between antiretroviral therapy and hormones prescribed for gender reassignment, the potential for long-term side effects as a result of combining the two is not very well understood at all.

In fact, knowledge about this "overlooked and misunderstood" community in general is very limited. And Garofalo's concern for these young people runs much deeper than determining the appropriate time to begin hormone therapy in them or even HIV prevention and care, for that matter. The needs of young transgender people, he suggests, are far more extensive than many people realize.

"I feel that a lot of places are interested in serving transgender youth, but only

when they become HIV-positive, because that's where all the funding is," he explains. "But this community has primary care and prevention needs certainly long before they could have put themselves at risk of becoming HIV-positive. I don't think they're being well served when we only see them through an HIV prism."

Realistically speaking, the odds that a young transgender person could prioritize

As a gay man, Garofalo can completely relate to the challenges that young transgender people face with accessing respectful services and culturally competent health care. He is keenly aware, though, of the fact that being transgender is a totally different construct from being gay.

"When I was a young person, if I wasn't ready to be out about my identity because I didn't think that my family could handle it

"A LOT OF PLACES ARE INTERESTED IN SERVING TRANSGENDER YOUTH, BUT ONLY WHEN THEY BECOME HIV-POSITIVE, BECAUSE THAT'S WHERE ALL THE FUNDING IS."

HIV prevention and treatment among the exhaustive list of other issues and concerns facing them—including, but not limited to, finding gainful employment, establishing healthy social support networks, negotiating relationships with family and friends, and the stigma associated with simply being a transgender person—are slim to none.

"Yes, HIV is a part of this puzzle, but we really need to see them as whole individuals. And that extends far beyond their identification as HIV-positive individuals or people at risk for HIV," said Garofalo.

The problem, though, is that culturally competent services for transgender youth, especially for anything not relating to HIV, are extremely rare. This is largely due to the fact that the limited amount of resources available for services to this population comes by way of money allocated for HIV-specific services. And, until recently, even that money was lumped into the same chunk of resources that were allocated for services geared towards men who have sex with men (MSM).

or financially I didn't think I could be on my own or for whatever reason, if I wanted to hide my sexuality or my identity, I could do that," he says. "And we could argue whether that's healthy for me or not in the long run, but at least the option was mine. For transgender people, on the other hand, who feel like they are trapped inside the wrong body, they don't really have that choice."

"The transgender youth community is really one that has challenged me as a clinician, and as an academic, in ways that are much more gratifying and, at times, frustrating than any other population of youth that I've worked with," he says. "Because the challenges and the stigma that they face are exponentially more difficult in some ways than even those which gay men face."

That said, Garofalo is committed to ensuring that transgender youth have access to the services they need in order to live productive, healthy lives.

"Health care is a human right," he says. "And everyone deserves access to quality healthcare and to services." ✚

Ginger Valdez

*Glamour and grit,
advocacy and outreach*

by Enid Vázquez



Ginger Valdez shows up for a *Positively Aware* photo shoot in a suit.

“They think we’re all prostitutes with our cleavage showing. I’m going to show something different,” she says. And she does, her manners as elegant as her style.

Ginger is a drag performer—her words—and a costumer, but she’s also an advocate for transgender people, including those who, like herself, are living with HIV.

“I grew up poor, in a *casero*—a housing project in Puerto Rico—more than 50 years ago,” she recounts. At the age of seven, she was raped by a 14-year-old boy. “A lot of people believe that gave me the tendency to like boys, but that’s not true. I liked boys before then.”

At age 13, she began to dress in drag—her words. Her father was away a lot and she only worried about hiding her feminine appearance from her mom. At the age of 14, while her father was away working at the Fontainebleau Hotel in Miami, she fell asleep in her room still wearing make-up and women’s clothing, with a male friend her own age crashed out in the living room. “No one was naked, but my mom got mad and threw me out.”

Ginger says that unlike most transgender women she has met, it was her father who always accepted and supported her, but not her mother. “My mother didn’t want to deal with it,” she says. When her father returned, she was gone.

She went to live with a friend her age who had already begun to live as a transgender girl, invited by the friend’s mother to stay in a spare room until something better came along.

A placement glitch kept her from entering high school and she later earned the equivalent of a G.E.D. in Puerto Rico. Instead of school, she began performing in drag shows. The choreographer for the traveling show of famed Puerto Rican entertainer Johnny Rodriguez was going to throw out the fancy sequined and feathered costumes worn in the show when a friend suggested he keep the dresses and start operating drag performances.

They needed a dancer, and Ginger had studied tap, jazz, and salsa dancing. Because she was a minor, they needed permission from her parents, and her father wrote a letter giving his permission for her to work in the show. “That’s how I became Ginger Valdez,” she says. But, she says, she never denies that she is José Cruz—“I’m very proud of being José Cruz.”

At that time, being a drag queen was illegal. Johnny Rodriguez managed to get a government license for the show at his theater, El Cotorrito (“the little parrot”), she says, because he provided free graphic design work for the party in power. But with all the glamour that came with her career also came the violence of gay bashers, and she says she “went to hell and back” in her experiences.

The show travelled to New York City and Chicago as well as the Dominican Republic, appearing only in theater lounges, not nightclubs. When she was 21 and performing in New York, she met a man and decided to stay with him. She spent more than a decade in New York City. She was already taking hormones to become more feminine.

“He was 42 and very handsome. He had been in relationships with drag queens before. He was responsible and didn’t smoke or drink. A friend of mine told me I should stay with him, that he worked and could take care of me,” said Ginger.

And he did take care of her. Ginger was happy to stay in New York because she felt she had “nothing to return to in Puerto Rico. My mother didn’t want to have anything to do with me.”

Photo © Russell McGonagle

She stayed with him several years. Later she met another man, a younger one. She dated him for a few months when someone told her he was HIV-positive. “I went to go get tested and sure enough, I was HIV-positive, and my life changed, not for worst, but for better. I began to take care of myself. I learned everything I could about HIV and medicine, and this was in the ’80s when there weren’t any medicines for HIV.” She has been positive for 22 years.

She came to Chicago in 1992 for a couple of months when Miss Kitty, who ran Latino drag shows, invited her. The two had met at El Cotorrito. Ginger ended up staying in Chicago, but performance work here paid much less than it did in New York. “I did the wrong thing and started boosting in the stores.” She ended up serving a short prison sentence for shoplifting.

Afterwards, in addition to her performance work, she was hired by the HIV service agency Minority Outreach Intervention Project (MOIP). She reached out to the transgender community with a program called TransAction, including a weekly support group she held in her home. She says 24 transgender women attended each week. When the agency closed, she went to work with another HIV organization, Vida Sida, for three years. In 2000, she received an award for transgender leadership from ALMA, the Association of Latino Men in Action, an educational, social, advocacy, and support group for gay, bisexual, and questioning men. She is still a “den mother” of sorts, providing support to other transgender women, including sterile syringes for their hormone injections.

Ginger says Chicago is the most segregated city she has ever seen, with even different Latino groups being hostile to each other, and in the gay community, hostility between gay men and the transgender population. “The gay community never understands the transgender community. It’s due to one [person, or negative stereotype] that the others are judged.”

She says that, “If I had the chance to go back and start over, I would not be transgender. A gay man can get a job. They do not allow you to get a job if you’re transgender. It’s like, ‘To be transgender, you made a mistake and we’re going to punish you.’ There’s a lot of discrimination. It’s very obvious. They want a sister or a Caucasian. There’s discrimination even in the Latino community. With all my knowledge, I cannot get a job because of my appearance. And in Chicago, being Latino and being transgender are two strikes against me.”

But, she says, she’s also gay. She doesn’t understand how people can feel trapped in the wrong body. “How can you tell you feel like a woman if you’re not a woman? That’s impossible.” Yet, she says that “I always felt feminine. I didn’t like men’s things. I liked women’s things; I always liked cooking and sewing.”

She has three friends who underwent surgery to become women, but now feel uncomfortable in their former gay bar hangouts. “They get treated worse,” she said. “It’s horrible. They get taunted for being women and asked why they don’t leave.

“No matter what, you’re a man. Even if you have the surgery, you’re still MTF (male-to-female) and they still consider you a man. Somewhere in a corner of the computer, they still put that you were a man,” she says. “I’m not trying to burst your bubble, but see the truth.”

What she sees in the transgender community are people who were runaways because they were rejected by their family, and so they were unable to finish their education and became “hustlers”—sex workers or drug dealers.



SHE DATED HIM FOR A FEW MONTHS WHEN SOMEONE TOLD HER HE WAS HIV-POSITIVE.

“The transgender community is the most misunderstood population in this [gay] community. And if they have HIV, they can’t even go get services because of the way that they’re treated.” She believes that community organizations need to learn how to work with transgender people. “They can get hormones at Howard Brown [Health Center, serving the gay, lesbian, bisexual, and transgender community], but they need places where they can get help. Hormones are good, but they need housing, they need medicine. And not everyone who’s HIV-positive can take hormones.”

For herself, she says, “My life is very peaceful because I’m very secure in who I am.”

For her baby sister’s wedding, she cut her hair and put on a man’s suit. She did not know the family her sister was marrying into and wanted to be “respectful.” Her sister said, “What are you doing? Are you crazy!” She said she was expecting her wedding dress to be outdone by the dress her older “brother” wore. Although her sister was mad about her clothing choice, Ginger wouldn’t budge, although true to her nature, she was still feminine. “People thought I was a lesbian,” she said. “I did it out of respect, and still somebody tried to get *grosero* (rude) with me. My sister, who’s a cop and tough, threw him out. I didn’t even look at him.”

Ginger says that, “*el hábito no hace el monje.*” The habit does not make the monk. It does not matter what you wear, you will be who you are. ✚



An Interview with Walter Bockting, Ph.D.

A leading expert on HIV in the transgender community explains why there's more work to be done

by Jeff Berry

Psychologist Walter Bockting is the author and editor of several books, including two on transgender people with HIV. He recently spoke with PA about some of his research and work within the transgender and HIV. Bockting points out that transgender challenges our conventional understandings of sex, gender, and sexual orientation, and forces us to develop more effective HIV interventions for all. Bockting is Associate Professor at the Program in Human Sexuality, Department of Family Medicine and Community Health at the University of Minnesota Medical School in Minneapolis. He coordinates the University of Minnesota Transgender Health Services, and is the current President Elect of the World Professional Association for Transgender Health.

Visit www.positivelyaware.com for a much longer, unedited transcript of this interview.

ARE THERE ANY DATA ON THE OVERALL DEMOGRAPHICS OF THE TRANSGENDER COMMUNITY, OR THE PREVALENCE OF HIV WITHIN THE TRANSGENDER COMMUNITY?

The demographics are hard to determine for transgender people because it's not included in the census. It's also not been included in surveillance data until recently, when a separate category was created for transgender persons.

According to a recent meta-analysis, the prevalence of HIV infection is between 12-28% (12% self reported and 28% tested positive). A higher incidence was found among African American male-to-female [MTF] transgender persons. Overall, the transgender community probably has a lower rate than 12%, because in the studies we've seen so far researchers are targeting more vulnerable groups. It may be closer to between 2-11% who are HIV-positive, but again that is why the CDC re-

cently agreed to track transgender people better, because we've got to get a better picture of the prevalence of HIV in this population.

WHAT LED YOU TO BECOME INVOLVED IN THE WORK YOU ARE DOING?

In my clinical practice in the early nineties we began to see more and more transgender persons testing positive in Minnesota. At that time there was nothing out there targeting that specific group—the existing programs and methods didn't suit them, and we found that people were falling through the cracks.

As HIV clinics began to see more transgender HIV-positive people and no protocol for their care, no standards of care, there were concerns about the impact of hormone therapy on their immune status, whether it was safe to continue hormones for an HIV-positive person, whether sex reassignment surgery [SRS] should be performed on an HIV-positive person. So there were those types of questions and we responded to these.

[A resolution was adopted in the nineties by the World Professional Association for Transgender Health, which states: *The availability of sex reassignment surgery should not be denied solely on the basis of blood seropositivity for blood borne infections (such as HIV, hepatitis B or C, etc.)*]

The issues today are that some surgeons who see the surgery as elective still hesitate to perform it on an HIV-positive patient. Now there is a standard that if it's medically necessary, then of course you perform surgery on an HIV-positive person, you take their status into account, but you work with that. So it [became] an opportunity for the surgeon to look at the individual as more of a whole person, especially in the early stages of the epidemic because patients then had a greater sense of urgency, fearing that their illness might shorten their life. At that point we saw clients who really panicked. It was very important for them to have this issue

addressed, and to have the reassignment completed before they would pass on.

WHAT ARE SOME OF THE UNIQUE ISSUES FACING TRANSGENDER PEOPLE THAT YOU FEEL CONTRIBUTE TO THE HIGHER RATE OF HIV IN THIS POPULATION?

Many of the issues are related to stigma. For example, it's not that difficult for MTF transgender persons to find men to have sex with, because there are enough men who are interested in that. But for them to find a longer-term, committed relationship, that is more challenging because there are few men who are willing to publicly acknowledge that they have a transgender fiancée, so there is quite a bit of stigma that extends to the partners. On the one hand I think it's real, on the other hand it's also a very strong perception among transgender women related to their issues of low self-esteem as a result of growing up in a world with few role models. They worry about, "Am I lovable?" or "Does anyone want me?" As a result, sex is a very strong affirmation of being wanted, attractive, and of their femininity.

IN ONE OF THE INTERVIEWS IN YOUR BOOK IT STATES THAT MANY TRANSGENDER PEOPLE MAY HAVE SEX TO FEEL DESIRABLE, OR TO FEEL LOVED, OR TO BE VALIDATED AS A MAN OR A WOMAN.

Yes, and they may even go through a time where they feel compulsive about sex, because they want to feel better when they are lonely and struggling with self-esteem issues. But I think also because of the perception that they are relieved that they have found someone who, in their view, despite the fact that they are transgender, want to spend the night with them. And then after having disclosed, what is often already obvious, that they are transgender, and finally having found someone who wants to be with them even if it's just for one night, then on top of that to insist on a condom, that's risking rejection a second time. And if on top of that they

Photo courtesy of Walter Bockting, Ph.D.

are revealing they are HIV-positive, that's like risking rejection three times. That's what the qualitative research indicates, that it does compromise sexual negotiation because they don't want to risk that rejection, and they are in desperate need of love, affection, and company, because they are rejected—often by family, and by society.

WHAT DO YOU FEEL ARE SOME OF THE UNIQUE NEEDS OF FTMS VS. MTFs AS IT RELATES TO TRANSGENDER AND HIV OVERALL?

Among MTFs, the prevalence [of HIV] is higher, and I think part of that is because there are many more MTFs who have sex with men than FTMs [female-to-male]. Nevertheless, in my studies 18% of FTMs do have sex with men, which is an under-recognized phenomenon. And I think in that group, as opposed to FTMs overall, you find that they engage in very similar levels of risk behavior than MTFs engage in, such as unprotected vaginal and anal intercourse. Especially in the beginning when they come out, they adopt norms that exist in the MSM community, including multiple partners and sex as a way of celebrating sexual freedom, and they want to measure up.

ARE THERE ANY UNIVERSAL CONCEPTS OR LESSONS LEARNED IN HIV PREVENTION AMONG MSMs THAT CAN BETTER INFORM US ON HOW TO REACH THE TRANSGENDER COMMUNITY—AND CAN YOU EVEN CALL IT A COMMUNITY?

I think you can definitely call it a community. I'm not saying there isn't room for further community building, but there is definitely a strong transgender community. The Internet has definitely played a major role in the development of that. I think that there's a need to affirm transgender identity and sexuality.

We know that hormones play a role in how transgender people's sexuality changes over time. We know that a male who gets feminizing hormones experiences a decrease in libido and develops a greater sense of vulnerability. The same thing for FTMs: when they take testosterone, they finally get what men have been talking about. But I think further along in their transition, they integrate both their male and female experience, and they're really actualizing an identity and a sexuality that transcends that dichotomy.

They have their own fantasies, their own behaviors, distinct from what non-transgender women and men experience.

IS THAT DIFFERENT, THEN, FROM BI-GENDER?

Bi-gender means people who value both the male and female gender role. During the week they may identify primarily with the husband or father role, and on the weekend they take the time to spend in the female role, and in each identity they may have their own friends, social circles, and sexual partners. Even transsexuals who want to change as much as possible, become a woman as much as possible, even they are recognizing today that they are gender queer, like a bi-gender person is. Both of them don't fit in the established, simplified categories of men vs. women. They're both transgender; it doesn't mean that they are experiencing the same things.

We are now recognizing that a MTF transsexual is not simply a woman, or woman may not be the best way to describe that person's experience, but instead realize that this person is transgender. That person probably has more in common with a bi-gender person, whereas in the past, bi-gender was a term used to describe a person who didn't switch from one category to the other but had a foot in either one. And so in prevention, I think there is an acknowledgement that we need to be careful, and not tie a lot of these risks and behaviors to a particular identity, but to see that these are people with desires, who are interacting with other people. And it's probably still best to describe that behaviorally, and then ask people the meaning associated with those behaviors. Whereas if you move from prevention towards care, it does make sense to bring these diverse groups together and affirm a transgender identity, and seek coalitions with the gay, lesbian, and bisexual communities, because that's the way for people to come together because they still face similar challenges, such as social stigma associated with their gender non-conformity. They have differences, but they also have a common agenda. So that's why the prevention has focused on affirming transgender identity and community.

You can help people manage stigma as best as possible, but at the same time there need to be interventions to reduce

stigma overall. These interventions need to be targeted at populations and institutions.

IS THAT A BARRIER, SINCE A LOT OF THE PREVENTION FUNDING GOES TO CATEGORIES TRADITIONALLY FUNDED BY THE CDC?

The problem in the past was that with the surveillance categories determined by the CDC, funding was allocated based on those numbers to specific groups. So even though at that time, transgender persons who were positive were subsumed under MSM, when the funding was given to MSM, we were not eligible, because transgender persons didn't fit the definition of MSM that was being used, or the client didn't identify as a man, or didn't feel at home in an intervention that was designed for MSM.

There has been a major surge in primary prevention, which is good, but I think we have to go back and pay attention to the 28% who are positive. They haven't gotten the attention that they deserve.

We've just started developing a transgender and HIV online intervention to be created over the next four years that is being funded by the National Institutes of Health. We are now putting together a survey of men who have sex with transgender people to understand the risk behavior of these men better.

IT'S GOOD TO KNOW THAT THE WORK IS BEING DONE.

It is—it's just a decade delayed. The first intervention we did was an eroticizing safer sex workshop within the context of transgender people's risk factors, but we've moved beyond that. The workshops we do today deal with transgender health in a very broad sense, so it's not just focused on specific risk behaviors, but it's also focused on other parts of their health and their self-esteem, their identity and sexuality in a broader sense. I think it took MSM longer to go from the basic prevention to finally promoting positive sexuality; I think in the transgender community we've made that transition a little quicker. We've recognized a little quicker how HIV for many transgender people is not their first priority, how they have overriding health needs and social issues to deal with, and unless you address that, you're not going to make a difference in terms of the transmission of HIV. ✚

POLICING GENDER AND SEXUALITY TRANSGENDER SEX WORKERS, HIV, AND JUSTICE BY DARBY HICKEY

To hear some tell it, the gay and lesbian rights movement has accomplished much without the help of transgender communities who are trying to ride to justice on the coattails of gay and lesbian activism. This reconfiguration of history could be heard most often recently in the justifications of some gay and lesbian activists for the exclusion of gender identity and expression from the federal Employment Non-Discrimination Act (EDNA) voted on in the House of Representatives

able—but others reject the use of the word in this way. In this article I will use it in the latter sense and use trans as the more umbrella term.

Sex work is a term usually used to describe a wide range of commercial sex activities from escorting to porn to exotic dancing—but also used sometimes as a synonym for prostitution. It was coined by activist Scarlet Harlot in an attempt to create a stigma-neutral word for what many see as a legitimate way of making a

as sex workers by police. These attitudes are also related to historical criminalization of trans and lesbian, gay and bisexual people for “wearing clothing of the opposite sex” and the like.

“It’s ultimately all about policing gender and sexuality, policing folks’ ability to be in charge of their own bodies,” says Myrl Beam, Transgender Care Coordinator at Howard Brown Health Center, a large community-based organization in Chicago. Beam spends a significant part of his work with the Broadway Youth Center program at the organization, which includes a drop-in center for LGBT and homeless youth, many of who engage in sexual exchanges of various kinds.

Police profiling of trans women is a major problem everywhere, and being institutionalized in new laws in some places, like San Francisco. New proposals by San Francisco Mayor Gavin Newsome that say you can’t stand outside of a night club for longer than two minutes are “targeting trans women working in the [Tenderloin neighborhood], mainly women of color,” says Blake Nemeć, adding that “other new anti-homeless ordinances [are building on a] history of police abuse and brutality of trans women sex workers.”

Nemeć is Transgender Service and Harm Reduction Training Coordinator at St. James Infirmiry, a sex worker clinic and community group started by sex worker activists in the 1980s. In Washington, D.C., a recent study of policing of sex work found that trans people were much more likely than others to report negative experiences when seeking help from the police, report being treated worse than others when arrested, and report many fears of police including violence and humiliation. Although D.C.’s Police Chief recently issued landmark new orders for treatment by police (including a line that being transgender is not grounds for being considered a criminal), the information detailed in the report “Move Along: Policing Sex Work in Washington D.C.” revealed serious levels of


“WALKING WHILE TRANSGENDER” IS THE ALMOST CONSTANT PROFILING OF TRANSGENDER AND TRANSSEXUAL WOMEN (PARTICULARLY WOMEN OF COLOR) AS SEX WORKERS BY POLICE.

last summer. But the truth is that trans communities—including transgenders, transsexuals, *travestis*, drag queens, and other gender non-conforming folks—were at the forefront of the events that many in LGBT communities consider the beginning of the modern gay and lesbian rights movement. Resistance to police oppression at New York City’s gay Stonewall Inn in 1969, and three years earlier in San Francisco at the Compton’s Cafeteria riots, featured trans people front and center. Not coincidentally, many of those trans people also did sex work.

Transgender is a term used by some as an umbrella for a number of different identities of people who transgress social norms about gender—but it is also a term used by some people to identify themselves as someone whose gender-identity does not conform with their legal or socially designated “sex.” For these people transgender and transsexual are basically interchange-

living by trading sexual services for a fee. In some countries around the world the sex worker rights movements are strong and well developed. India boasts some of the largest sex worker unions which can mobilize thousands in protest, Brazilian sex worker groups are key stakeholders in the country’s development of HIV policy, and sex workers in Thailand are opening their own model workplaces. The movement in the United States is still developing, but in many places trans people, particularly trans women, have played a key role in pushing for the rights of those engaging in sex work.

Many trans people, particularly trans women, engage in sex work to make a living, but it is a frustrating stereotype that all trans women are sex workers. “Walking while transgender” has been coined as a term in many locales to describe the almost constant profiling of transgender and transsexual women (particularly women of color)



police mistreatment and abuse of transgender people in the name of enforcing prostitution laws.

“Trans folks, trans youth, need to be put at the center of all of our conversations about queerness and justice,” says Myrl Beam, noting that in Chicago, “trans folks have less of a voice in the ‘gay’ community response to issues. Because of issues of race and class in Chicago, issues like police brutality, affordable housing, [and] universal health care are not seen as important to [the] mainstream lesbian and gay movement in Chicago but they are important to trans communities.” Trans people face extraordinary levels of violence in many different settings—from physical violence to extreme discrimination in employment and housing, to rejection by families. In D.C., like other areas of the country, this violence is particularly severe for transgender women of color, and those doing sex work, such as Bella Evangelista. A Salvadoran immigrant, Evangelista was murdered in 2003 by a man who had paid her for sex. In the face of such violence and tragedies, trans people are extremely resilient and resourceful. For example, the murders of Evangelista and other trans women in D.C. in 2003 led to renewed community organizing and a blossoming of new trans efforts, including the creation of the D.C. Trans Coalition, which has succeeded in changing local non-discrimination laws to include trans people. “There are multiple ways in which gender transgression is punished,” says Myrl Beam. “[Let’s] connect that to the fantastic ways that trans folks survive and the cultural things that folks do, so that we don’t have a one-dimensional pathologized pitying view of trans people.”

Beam echoes the frustration of other trans activists over the ways that people talk about trans people, sex work, and HIV. “The fact that trans youth in general are only ever talked about within the lens of HIV is one of the major disservices done in our approach and understanding of trans youth.” Similarly, Blake Nemecek likes to flip the script on the idea that trans women doing sex work are

VIEWING SEX WORKERS OF ALL GENDERS AS KEY ALLIES IN THE FIGHT AGAINST HIV IS CRITICAL, SAY ACTIVISTS.

TRANS PEOPLE ORGANIZING TO END CRIMINALIZATION AND IMPRISONMENT

In October 2007, more than 200 trans people and allies gathered in San Francisco at the Transforming Justice conference. The focus was to build a national movement to end the criminalization and imprisonment of trans communities. Different Avenues was present at the event as well as representatives from trans groups from across the country including the Transgender, Gender Variant & Intersex Justice Project in San Francisco, Sylvia Rivera Law Project in New York City, La Gender in Atlanta, Q-Team in Los Angeles, and many more.

The attendees spent two days learning and sharing about the issues facing trans communities impacted by the prison industrial complex. On the final day of the conference, participants developed the following points of unity:

1. We recognize cycles of poverty, criminalization, and imprisonment as urgent human rights issues for transgender and gender non-conforming people.
2. We agree to promote, centralize, and support the leadership of transgender and gender non-conforming people most impacted by the prisons, policing, and poverty in this work.
3. We plan to organize to build on and expand a national movement to liberate our communities and specifically transgender and gender non-conforming people from poverty, homelessness, drug addiction, racism, ageism, transphobia, classism, sexism, ableism, immigration discrimination, violence, and the brutality of the prison industrial complex.
4. We commit to ending the abuse and discrimination against transgender and gender non-conforming people in all aspects of society, with the long-term goal of ending the prison industrial complex.
5. We agree to continue discussing with each other what it means to work towards ending the prison industrial complex while addressing immediate human rights crises.

In the months since, groups in various parts of the country have continued to push this vision forward by having regional meetings. For more information visit www.transformingjustice.org or contact the TGI Justice Project, 1095 Market Street, Suite 308, San Francisco, CA, 94103; Tel: (415) 252-1444.

"THE FACT THAT TRANS YOUTH IN GENERAL ARE ONLY EVER TALKED ABOUT WITHIN THE LENS OF HIV IS ONE OF THE MAJOR DISSERVICES DONE IN OUR APPROACH AND UNDERSTANDING OF TRANS YOUTH."

spreading HIV to others. "A trans woman may get locked up and because of rape and pimping by prison guards she may become HIV-positive," says Nemeč, "but that's not because of her actions and her decision to engage in sex work, that's because of the prison industrial context. Trans women sex workers we see are very knowledgeable, organized, have condoms and lube, and use them."

Viewing sex workers of all genders as key allies in the fight against HIV is critical, say activists, such as those who organized to attend the recent International Harm Reduction Alliance conference in Barcelona, Spain. In a statement about the conference, the International Sex Worker Harm Reduction Caucus said, "Sex worker leadership and empowerment are essential in fighting HIV and discrimination. Sex workers are their own best resource—they should be at the forefront of developing and implementing the programs and policies that impact their lives. It is only by empowering sex workers to speak for themselves and developing sex worker leadership that stigma and rights violations will be stopped." St. James Infirmary and Different Avenues representatives were part of the caucus, as well as other sex workers from across the U.S. and other countries.

That peer leadership approach is critical for groups like St. James Infirmary, Broadway Youth Center, and Different Avenues. Blake Nemeč says St. James Infirmary is pioneering a unique approach for San Francisco—peer-led intake at the clinic. Instead of a social worker or a doctor conducting the initial intake and perhaps asking questions and probing for information that the trans person may feel is irrelevant, Nemeč and another trans person are the first points of contact and take a more holistic approach. After the person seeking services is made to feel welcomed and acknowledged for all the issues they may be dealing with is when a clinician works to assess specific medical needs. That's crucial at Broadway Youth Center too, says Myrl Beam. "It's really important that folks see other trans folk in the space when they come in."

By combining harm reduction, LGB/Trans positive approach, anti-oppression, and an analysis of trauma, Beam says the drop-in also works on a holistic level. Both St. James Infirmary and Broadway Youth Center also take it to a level beyond simply providing services—similar to Different Avenues which is guided by a vision of helping community members to achieve both health and justice, on their own terms. For example, a young African-American trans woman came into Different Avenues the

other day seeking help with changing her legal name, which led to a discussion about trans community organizing going on in D.C., and she expressed a great desire to get involved. Before she left she took a bag full of condoms and lube, and was enthused about the experience.

"Some of the most important things to me are understanding political context for lives of trans youth," says Myrl Beam. "We need to talk about why trans youth are homeless, all the intersecting oppressions of race, class, immigration, and all this different stuff, it's incredibly important." To that end people need to have an understanding of the intersection of the work for trans rights and sex worker rights, and they are key to each other. "Trans rights and sex worker rights both have a base in feminist politics in that they are about stopping people from telling you what to do with your body," says Blake Nemeč. And both are key to HIV work. For Beam, it's about a struggle to "be in charge of your own body," which benefits everybody, whether trans, sex worker, or not. ✚

Darby Hickey is a national transgender and sex worker rights activist based in Washington, D.C. She is co-director of Different Avenues, a peer-led program working for health, safety, and rights to counteract and prevent HIV, violence, and discrimination. Darby also has extensive experience as a reporter and writer. She has written for Spread Magazine, Colorlines, Left Turn, the Independent, DC North, and other publications. For three years Darby reported on Capitol Hill and the D.C. area for Free Speech Radio News, the country's only worker-run, national progressive radio news service. Additionally, Darby sits on the board of Transgender Health Empowerment, a local service agency in Washington, D.C.

Teo's Journey

A TRANSGUY STRUGGLES WITH ADDICTION AND ISOLATION, AND DISCOVERS WELLNESS AND HIS IDENTITY ALONG THE WAY

BY JEFF BERRY



Teo always knew he wanted to be a boy. As a young child he would go on what he describes as magical journeys just to achieve that result. “Once when I was maybe seven, I went to my grandfather and said I wanted to be a jockey. He told me to sleep curled up tight on my pillow, so I would stay short. I did that for a month straight—in my child’s perception if I became a jockey, boyhood came with it.”

He always knew there was something different about him, but never had any language for it. At school he says he was constantly forced into playing hopscotch or some other game with the girls, and it didn’t make any sense to him. But at least at three o’clock he was able to go back to his neighborhood and play football with the other boys.

During adolescence, as his hormones began to kick in and his body began to change, he couldn’t understand what was happening to him. “The trauma of that really sent me spiraling,” he says, and he went cold. “It sent me into this path of annihilation. I was suicidal, but I didn’t want to die—I literally wanted to annihilate myself. I didn’t want to feel anything, or to exist anymore. It’s hard to sit with today, that level of what I felt.”

Teo, who turned 41 in June, has been HIV-positive for 13 years, and was diagnosed with AIDS seven years ago. But he finds it hard to separate his journey as a transguy from his becoming infected with HIV. His life experience of living with self-loathing, of never feeling right in his own skin, left him feeling disposable and unwanted. “It was literally a daily battle—every morning, when I would get out of bed, there was this bargaining about not putting a gun to my head.

“Had I felt like I belonged when I was younger, had I known that someone like me could have had a home in the world, I doubt very much that I would have ended up in the places I did that led to my contracting HIV.”

Teo came out as a lesbian at the age of 16, and lived in the butch-dyke community, and says, “You know, it worked—I’m very grateful today that I had some place to be. But it never was home, I never could quite relax into my own self or the community enough, because it never really felt true to who I was.”

As he started to physically and mentally transition in 2002, and got into the rhythm of living his life as a guy, a huge weight was lifted off of his shoulders. But prior to then, while still in his early 30s, he sort of danced around the decision. “There wasn’t really even this idea that it was possible, I sort of knew what my dream would have been, but I didn’t know there was an avenue to that. And then I started to meet transguys, and I was like, ‘Oh. Uh-oh.’”

During this same period his HIV continued to progress—his T-cells dipped below 200, and his viral load was out of control. In 2001, with a T-cell count of 33, he says he was done. “I knew the bottom line was that I didn’t want to die a girl. That was, I think, what gave me the freedom to make that choice. I saw where I was headed, and I knew I wasn’t happy, I knew I wasn’t healthy, and it was a chance for me to finally make a choice that was just for me. I could not care as much what other people thought, probably because I didn’t know that I was going to be around a long time to watch it.”

He was in therapy at the time, he says, because he was struggling with anxiety and depression, not because of gender transition. “I was sort of blissfully naïve. I didn’t know that I was supposed to have a letter and all this other stuff. And in the summer of 2002, I walked in to see the endocrinologist, and I said, ‘I’m 35 years old. I’ve been sober for well over a decade. I’ve had therapy. I’m going to be neurotic the rest of my life, that’s just a given. And look at me. I’m this very masculine-looking butch dyke, and this isn’t working.’”

“Right then and there he wrote a prescription for testosterone. And I walked out the door.”

Photo courtesy of Teo



He continued in therapy afterwards because his life was changing so rapidly. “For the first time in my life I finally felt like I was getting something I wanted, and something I needed—and I was terrified that somebody would take it away from me. When it came time for chest surgery, I was terrified that they would tell me I couldn’t because of my immune system. Or that I wouldn’t be able to find a surgeon who was willing to operate on me. I was so afraid that somebody was going to get in my way. I had an inkling of what joy felt like, and I was terrified that I was not going to be allowed to go any further.

“I think the paradox of all that was that as I started to transition, I started to feel more at home in my own skin, and I stopped being at war with myself. I started to like who I was, I became more invested in me, and more invested in my own well-being. Actually I got physically healthier. Some of that was probably stress reduction, but I could kind of see myself growing old as a man, where I could not *ever* envision myself being an old woman, so there was nothing for me to fight for before. And now, I cared about my future, I cared if I survived, I could actually see my physical self, in my future, in a way that I couldn’t before.”

While Teo doesn’t view transgender as a stopping place for him, he also feels it’s a very personal experience for every transperson. “If I fill out a form that says male, female, or transgender, I check the male box. I’m living in the world as a small, hippie, crunchy, yoga-practicing guy. That’s kind of what I look like and how I fit in.

“If you ask me to pin down a label, I’ll use queer more often than not. I wouldn’t use straight; I have friends who do but that doesn’t feel home for me. So it’s still pretty new in terms of being out, and what kind of guy I want to be in the world—if you ask me 10 years from now that might be a different thing.”

Living as male has been both a gift and some hard work, says Teo. “I had to learn all new social skills, body language, and sometimes even actual language—apparently guys on a construction sight don’t generally announce they are going to pee. I added ‘I am going to the head’ as part of my lingo.”

While Teo says he sometimes misses being in a community of women, and some of the emotional and physical intimacy that goes along with that, for the most part he prefers the company of other guys. “I think I’m a little bit more comfortable with gay men in that way, because they’re familiar to me. I’m a whitewater kayaker—I spend my time with a group of guys who don’t know my history. A few of them know now, but for the most part they don’t.

“I don’t know that the queer community is more accepting of me,” adds Teo, “I just think that they don’t notice me. If you’re in San Francisco, sure, but if you’re in Connecticut, where transguys don’t even exist on the horizon of possibility, then—you know, I’m just as likely to get killed in a bathroom, or bashed, as a transwoman. I’m very leery of that. I certainly go unnoticed in a lot of ways, if I’m careful, but I’m screwed in the bathroom if my towel drops, because I pass so well that now all of a sudden there’s a reaction. Maybe if I

Photo courtesy of Teo

was a little more obvious, people, men in particular, wouldn't feel that knee-jerk reaction."

Today Teo is happily married to a woman whom he met a little after he started transitioning. "I often joke that I am the poster child for why our marriage laws are messed up. Prior to transition, I couldn't legally marry my now wife, but I also could not be fired from a job based on being queer.

"In Connecticut, all that is required for a marriage license is a photo ID. My license has my new name, and my gender is listed as male. I walked into town hall and got a marriage license. Mind you, all of this is predicated on some privilege—being able to afford the legal name change, access to a therapist who would write me a letter to change my gender marker at the Department of Motor Vehicles, and the ability to navigate the various government systems involved.

"However, now legally married, there is no legislation in Connecticut that would prevent an employer from firing me due to being trans. There is a human rights ordinance ruling that suggests it falls under sex discrimination, but no one has tested it in court to my knowledge."

Nevertheless, even with all of the many advances in transgender rights, Teo agrees we've still got a long way to go. "I do think that in some ways, in terms of civil rights, in terms of awareness, in terms of community, the trans community is 15, 20 years behind," says Teo.

A few years ago, while in Canada and around the time of the SARS epidemic, he came down with a high fever and was extremely ill. "All I knew was that I had to drive home. The idea that looking the way that I did—looking male, being vulnerable, not sure what was going on with me, not sure that I would stay conscious—I couldn't let myself go to a strange E.R. where there was no one to advocate for me. I drove 15 hours to get home, so that my girlfriend, now my wife, could help me.

"Even as sick as I was [when I got home], I waited four or five days, because I didn't have the emotional energy to go to the E.R. And when I finally went to the E.R., I start telling people that I'm on testosterone, and this is who I am, because I know that someone's going to listen to my chest, and I haven't had chest surgery yet, and I have to come out. What people think they can ask you—all of a sudden, the fact that I'm going through gender transition is on the table. I'm here because my lungs hurt, because I have a fever, because I'm diagnosed with AIDS. It has nothing to do with my gender. But you get treated like this guinea pig. People who have no business being around you start showing up to ask questions, because they're curious."

And finally, says Teo, there is the constant argument about how he got HIV. "Like, it's none of your business. You don't need to know that. 'Well, you may have had a drug history.' Then ask me if I had a drug history. 'Well, then how did you get HIV?' None of your damn business!"

He says it's painful to watch, what people feel like they can do and say to you. "And you're always left with that question: Am I going to get okay medical care here?"

"It's funny, because I don't have that same experience around being transgender, and how I walk in the world. I don't normally

tell people, but if I do tell them, I don't feel disempowered by that, I don't feel ashamed by that. But I still struggle around the HIV piece, because of the reaction I've gotten, where people have pulled back, they've been afraid. My dad won't tell his family, my family at large doesn't know. Even a couple of years ago my dad said, 'Well, we haven't told everybody [about your HIV status], because then they won't come to Thanksgiving dinner.'"

When asked what's the single most important thing he'd like readers to remember, Teo responds, "I think I've learned this as a human being. I think the details can be different, and I think we need to know the details, particularly as care providers. We need to know the details of someone's life, or the details of a particular set of people's experiences, so that we have some framework. But I think the details aren't as important as what's common, or that humanity—reaching for people's humanity, that sense of connection, of interconnectedness, rather than the details that separate my experience from yours.

**"I STARTED TO LIKE WHO I WAS,
I BECAME MORE INVESTED IN ME,
AND MORE INVESTED IN
MY OWN WELL-BEING."**

"[When] I sit with a provider who I really feel is right there, and who lets me own my own information, and treats me like a holistic, whole human being—I know it when I see it, and I know it when I feel it, and it feels incredibly safe. And it feels like I can be held, and I can be cared about. It lets me be a part of that process, and I think that that's the thing that I want people to walk away with."

Today his T-cells hover at somewhere between 400 and 500, and his viral load is undetectable. "I found some medication that worked. I do a lot of stuff now to physically take care of myself, and I'm doing okay." While still on disability, he periodically works as a consultant, leading sensitivity trainings for care providers that deal with issues specific to the transgender population.

Teo says he doesn't see a clear delineation between his physical, emotional, and spiritual health. "Paying too much attention to one and neglecting the others is a recipe for disaster, from my personal experience." He stays active, surrounds himself with people whose values resonate with him, and regularly practices yoga—mostly Vinyasa—and meditation. "Yoga has been healing for my body and mind, especially as a transgender person. I spent so much of my life actively trying not to be present, being at war with my physical form, that to practice being in the same space and time emotionally, spiritually, and physically, has been a gift.

"This isn't an easy journey, but it isn't one I would trade for anything," say Teo. "If the HIV meds interfered with testosterone and I had to choose—the HIV meds would be out the door, pronto. Again—my choice, not every other transperson's choice.

"I look in the mirror and see this reflection that finally looks familiar in its newness—I like what I see looking back at me. I am at home." ✚



A Transgender Therapy Primer

Basic information for hormonal treatment and drug interactions

by Enid Vázquez

Transgender individuals may use male or female hormones to make them more masculine or more feminine. Therapy is not just for physical changes. It has been found to greatly reduce psychological distress. Transgender hormonal therapy is taken for life.

Female-to-male transgender individuals, or FTMs, can take the male hormone testosterone. Male-to-female transgender individuals, or MTFs, can take the female hormones estrogen and progesterone (progesterone is not recommended). Everyone is born with both male and female hormones in their body, but the levels depend on the sex of the person.

Testosterone is an androgen, one of a number of steroid hormones in the body that stimulate the development of male sex organs and male secondary characteristics, such as beard growth or a deep voice. MTFs will therefore usually take an anti-androgen drug in addition to their female hormones. Estrogens alone do not lower testosterone levels and anti-androgens alone lead to serious bone density loss. One advantage of taking an anti-androgen is being able to reduce the estrogen dose taken. If they undergo transsexual surgery, they can drop the anti-androgen.

Hormones are available in pills, injections, and transdermal preparations (delivered through the skin in the form of creams, gels, and patches). Anti-androgen therapy includes anti-androgen drugs, GnRH ago-

nists (gonadotropin-releasing hormone), and bilateral orchiectomy (removal of the testicles).

Medical providers warn that “more is not better.” Premarin is removed in the urine—there is a limit to what the body can absorb. The side effects of the other hormones can become intolerable.

Also, hormones should be avoided in people with breast cancer, a history of blood clots, or active substance abuse. In addition, patients should be assessed for suicidal tendencies, before and during therapy, but especially if taking testosterone.

Hormonal therapy is highly individualized. It depends on the levels of the hormones already in the person’s body and then the individual’s response to therapy, which is affected by such things as age, weight, and genetics. There are other interactions as well. For example, when faced with an anti-androgen, the body may respond by increasing its production of testosterone, although eventually the testosterone will stay suppressed as the anti-androgen wins the battle. These are among the reasons that monitoring takes place, to make sure everything gets into the correct balance over time.

“With estrogen we’re worried about clotting and cardiovascular effect while with testosterone, we’re worried about the liver effect,” says pharmacist Andrew Halbur of Walgreens specialty pharmacy in Chicago.

“Most of the antivirals [but not all—see chart on page 48] cause an increase in estrogen,” says nurse practitioner Bethsheba Johnson of the Luck Care Center, also in Chicago. “We try to use the lowest dose of estrogen and then look at testosterone levels [in male-to-female patients, or MTFs].” She says estrogen therapy generally costs from \$25 to \$80 a month, plus the cost of lab monitoring, which can be costly. She finds that insurance companies will pay for the measurement of male hormones in men and female hormones in women, but not for a measure of both hormones in one person. She likes prescribing the patch, because of its lower risk of adverse events along with its efficacy.

She says her clinic, which focuses on HIV, looks at the effects on patients as well as their blood levels. Body hair, she says, is a big problem. An androgen antagonist suppresses male hormones in the body, which helps control male characteristics such as hair all over the body, she said. But, she points out that, “You can’t change bone with hormones—the strong jaw, the big hands.” Surgery on the jawline is available.

TESTOSTERONE THERAPY

A. Injection of testosterone cypionate (Depo-testosterone) and testosterone enanthate—every two to four weeks, and testosterone propionate—once or twice a week.

- B. Androderm patch—one or two patches a day.
- C. Androgel, rub directly on skin. May rub off on partner.
- D. Testosterone ointment (cream), applied to the face and clitoral area. Requires large areas of skin for application.
- E. Methyl/testosterone and oxandrolone pills are generally avoided due to their side effect profile (potential liver complications).

Permanent effects of testosterone include atrophy of the uterus and ovaries (resulting in sterility), baldness and hair loss (especially at temples and crown of head), beard and mustache growth, deepening of the voice, enlargement of the clitoris, increased growth of body hair, and sterility. Temporary testosterone effects, reversible upon discontinuation, include behavioral developments associated with production during puberty (aggression and increased libido), development of acne, increased muscle mass and strength, increase in number of red blood cells, and redistribution of fat from breast, hips and thighs to abdominal area. Other potential side effects include weight gain; larger feet; peripheral edema (swelling in the hands and feet); liver enzyme increases (a sign of liver damage); decreases in HDL (the “good” cholesterol); increased risk of cardiovascular disease and breast or endometrial cancer; headache; and high blood pressure. Caution should be used when taken with other liver-toxic drugs.

In many patients, changes in voice pitch, muscle mass, and hair growth become apparent after just a few months.

ANTI-ANDROGEN THERAPY

- A. Pills include spironolactone and finasteride. Spironolactone (brand names Aldactone, Novo-Spiroton, Spiractin, Spiroton, Verospiron, and Berlactone) is the treatment of choice due to safety and availability. It is a potassium-sparing diuretic. Finasteride (Propecia 1 mg or Proscar 5 mg) may be used alone or in combination with spironolactone. It reduces the size of the prostate and improves male pattern baldness. There are debates about its value and expense. Other anti-androgen drugs include Androcur (cyproterone acetate) and Eulexin (flutamide). They are unfa-

vorable because of their toxicity profile and lack of availability.

- B. GnRH agonists (gonadotropin-releasing hormone) include nafarelin acetate, goserelin acetate, and leuprorelin acetate. They are generally fully reversible in adolescents and do not carry risk of thromboembolic disease (due to blood clots). They are available by pill, injection, or nasal spray.
- C. Bilateral orchiectomy is removal of the testicles. This eliminates 90% of testosterone production and helps reduce the estrogen dose used for therapy, but may shrink the amount of skin available to create a vagina, should that surgery be pursued.

ESTROGEN THERAPY

- A. Oral estrogens include the conjugated estrogen Premarin (purported to cause more mood swings); the synthetic, plant-based version of Premarin, Cenestin; and the estradiol valerate tablets Estradiol and Estrace. Oral estrogens stress the liver more than transdermal and injectable estrogens do. Sublingual forms of estrogen (dissolving under the tongue) absorb better and avoid passing through the liver, which reduces the risk of blood clots. Premarin is removed in urine and there is a limit to what can be absorbed, so taking more in one dose is not helpful.
- B. Transdermal estrogens include the skin patches Estroderm, Climara, Alora, and Vivelle, the creams Premarin and Estrace, and the gel Estrasorb. Patches may cause irritation and people could be allergic to the adhesion used. Creams require frequent use on large areas of skin.
- C. Estrogen injections include estradiol valerate (Delestrogen) and estradiol cypionate (Depo-Estradiol). One vial can last up to six months. The hormone preparation is thick and requires a 3 cc or 3 ml syringe, an 18 or 20 gauge needle to draw up, and a 21 or 22 gauge needle to inject. Length should be 1 to 1-½ inch. Because of the large sizes required, the puncture wound is bigger; watch for infection at the injection site. In Illinois, people over the age of 18 can buy up to 20 syringes without a prescription at a pharmacy (not always without a

hassle). Bulk purchases where available can save money; for example, a pack of 10 syringes may cost \$12 while 100 may cost \$25. Check also syringe exchanges, such as the one at TPAN, for free supplies.

Warning: Some medical providers believe only one form of estrogen should be used, not a combination of the different categories, although some doctors may disagree.

According to the Bantam Medical Dictionary, an estrogen is “one of a group of steroid hormones (including estriol, estrone, and estradiol) that control female sexual development, promoting the growth and function of the female sex organs (see menstrual cycle) and female secondary sexual characteristics (such as breast development).”

Permanent effects of estrogen include breast development, enlargement of the nipples, loss of ejaculation, loss of erection, shrinkage of the testicles, and sterility. Temporary effects reversible upon discontinuation include a decrease in acne, decrease in facial and body hair, decrease in muscle mass and strength, softening of the skin, slowing of balding pattern, decreased libido, suppression of testosterone production, and redistribution of fat from abdominal area to hips and buttocks.

Estrogen risks include benign (non-cancerous) pituitary tumors (see below for potential complications with this condition), gallbladder disease, high blood pressure (hypertension), hypothyroidism, liver disease, migraine headache, weight gain, worsening of depression (if present) and increased sensitivity to stress, melasma (skin darkening), acne, lipid abnormalities, nausea and vomiting, and tendency for blood to clot (which can be fatal)—aneurysm, deep vein thrombosis (DVT), and pulmonary embolism. Blood clots usually begin in the calf. If they break off and travel to an organ such as the heart, brain, or the lungs, they can cut off necessary blood flow carrying oxygen to vital organs, and so the organs can die. Oral estrogen has greater risk than transdermal formulations. Age over 40 also increases risk of clotting. Maintain weight control and watch for high blood sugar.

A prolactinoma is a benign (non-cancerous) tumor in the pituitary gland, located at the base of the brain, that may lead to excess levels of the hormone prolactin and

pressure on surrounding tissues, causing headaches and visual problems, including loss of vision, and may require surgical removal.

An aneurysm is a swelling in the wall of an artery. DVT is a blood clot, usually occurring in the lower legs. It may break off and travel to an organ. This can be fatal. Symptoms include swelling and a sharp, localized pain, often with redness. Lack of mobility, as with a hospital stay or a trans-

continental flight, increases the risk of DVT. There are other risk factors as well, such as obesity and varicose veins, and the biggie—smoking. Hormones should be stopped if experiencing trauma that leads to immobilization and weeks before undergoing surgery. If you suspect DVT or any other blood clot, go immediately to the emergency room, where an IV-drip medication can slowly work on dissolving the clot. If it's broken up quickly, it can burst, and be fatal. A pulmo-

nary embolism is a blood clot that traveled to the lungs. Again, this is often fatal.

People with a history or a family history of heart attack, coronary artery disease, or stroke should be supervised with a stress test and be treated with blood thinners as well as treated for high blood pressure and high lipid levels. To reduce the odds of a cardiac complication, estradiol (Estrace 1 or 2 mg), a naturally occurring estrogen, is preferred to Premarin. Cigarette smokers and people who are over 40 years old, obese, or have cardiac risk factors may take a daily aspirin to help reduce risks. Others may also consider taking aspirin. Also, try to control other conditions that may increase the risk of adverse events, such as cigarette smoking, diabetes, hepatitis, and alcoholic liver disease.

PROGESTERONE THERAPY

A. Provera (medroxyprogesterone) is usually avoided. There is no clinical evidence suggesting that it helps feminization, and it may cause a higher incidence of breast cancer, cardiovascular disease, high blood pressure, cholesterol increase, weight gain, depression, and varicose veins. Natural progesterone (Prometrium) does not have the adverse effects of Provera on blood cholesterol or blood pressure. ☞

Sources of information: the Tom Waddell Health Center Protocols for Hormonal Reassignment of Gender (www.dph.sf.ca.us/chn/HlthCtrs/transgender.htm); The Harry Benjamin International Gender Dysphoria Association's Standards Of Care For Gender Identity Disorders, Sixth Version February, 2001 (www.wpath.org/Documents2/socv6.pdf); Hormone Replacement Therapy for Transgenders: Do's and Don'ts, a PowerPoint presentation by Dr. Steven M. Brown, M.D., step-by-step information from "what is a hormone?" on up (from Trans-Health.com, <http://www.trans-health.com/displayarticle.php?aid=127>); and Transgender Pharmacopoeia, a PowerPoint presentation by Drew Halbur, BSPHarm, Walgreens Specialty Pharmacy at Howard Brown Health Center in Chicago.

DRUG INTERACTION CHART

Note: this is not a comprehensive list.

Hormones used for transgender therapy have not been tested in the lab for interactions with other drugs. Instead, the much lower dose of ethinyl estradiol (a form of estrogen) in birth control pills is used as a guide. Transgender therapy requires a much higher dose of estrogen than that used in the Pill. An increase in blood levels of a drug generally increases the risk of a side effect or adverse event. A decrease in blood levels generally decreases the efficacy of a drug.

	HIV DRUGS	OTHERS
Levels of estradiol, ethinyl estradiol, and testosterone are increased by	Sustiva (efavirenz) Crixivan (indinavir) Invirase (saquinavir) Reyataz (atazanavir) Intelence (etravirine)	Tagamet (cimetidine) Biaxin (clarithromycin) diltiazem erythromycin Diflucan (fluconazole) grapefruit isoniazid Sporonox (itraconazole) Nizoral (ketoconazole) verpamil vitamin C
Levels of estradiol, ethinyl estradiol, and testosterone are decreased by	Kaletra (lopinavir/ ritonavir) Norvir (ritonavir) Aptivus (tipranavir) Prezista (darunavir) Viracept (nelfinavir) Viramune (nevirapine)	Tegretol (carbamazepine) dexamethasone phenobarbital Dilantin (phenytoin) rifampin Topamax (topiramate)

1. According to the Tom Waddell Health Center in San Francisco, Lexiva (fosamprenavir) is the only HIV medication whose concentration decreases in the presence of ethinyl estradiol. The clinic recommends caution when using Lexiva.
2. In diabetic patients on testosterone, blood sugar decreases, requiring adjustments in dose of their diabetic medication.
3. Testosterone may also potentiate (increase blood levels of) the blood thinner warfarin (Coumadin).

Special thanks to Drew Halbur, BSPHarm, of Walgreens Specialty Pharmacy, for reviewing this drug chart.

While she admits that transitioning from male to female wasn't as difficult for her as it is for many other transpersons, Lois Bates is certain that the transition from "advocate to victim," as she says, has been the hardest pill she's ever had to swallow.

She knew early on that she was different, more than just gay. She was unable to put a finger on exactly what it was at the time, seeing that there was no official "language" available to help steer her in the right direction. And, had she shared what she felt with the wrong person in those days, she could have easily found herself institutionalized among the severely mentally unstable.

Being different didn't bother her, though. She takes pride in having always possessed the unique ability to celebrate difference in herself as well as in others. It helps that she's got thick skin as well, so she's never been concerned about what anyone else thinks or says about her. She is who she is, period—a characteristic of her personality that she believes may have developed as a result of having the unconditional love and support of her parents.

Lois Bates

The essence of strength,
courage, and wisdom

by Keith R. Green

Though they were also unable to articulate exactly what was going on with their youngest child, their primary concern was for her self-preservation. They wanted her to be able to support herself, regardless of the discordance that she felt relating to her gender orientation. With that in mind, Lois made a conscious choice to delay her physical transformation until such a time when she could be the person who she knew in her heart and mind she was born to be, and live a normal, productive life in that form.

Meanwhile, and with the ultimate goal of creating a space within which she could comfortably begin this transition, Lois enlisted in the U.S. Navy as a young man.

This was before the Clinton administration's policy of "Don't ask, don't tell." She was forthcoming with the recruiter about her sexual and gender orientation, though she is sure that he was more interested in meeting his quota than assessing what her experience would be like in such an environment. Thus, she found herself in route to the Persian Gulf in service of her country.

Ironically, despite an isolated incident where she punched an officer for calling her a faggot, Lois lists her tenure in the military as one of the most memorable periods of her life. And, for the record, she admits that finding others who were like her—gay, transgender, or otherwise—was not as difficult of a task as she imagined it would be.

Upon returning home from the Navy she enrolled in school to become a licensed cosmetologist, still identifying as a male but now freer to give a more feminine appearance. She also held positions at the United States Post Office and as an armed security guard, in preparation for life as a full-time, no-nonsense, independent woman.

Growing up in a household where both of her parents had more than one career, Lois later decided to return to school for business administration. It was there that she learned that her ability to do a job and do it well could outshine any distractions that her gender discordance might create. This lesson, she says with certainty, has carried her through to this point in her life, opening doors that she never imagined possible for transgender persons.



Just as she thought the "right" time to fully transition was approaching, life threw a wrench into Lois' plans. At the tender age of 26 she was diagnosed with end stage renal failure. She was told by several healthcare professionals that she would be denied access to a kidney transplant if she revealed her intent to someday transition from male to female. The apprehension was that she'd begin hormone therapy upon receiving a donated kidney, which could cause her body to reject it.

With her parents' emphasis on self-preservation reverberating through her heart and mind, Lois toyed with the idea of keeping her true gender identity a secret until after her transplant was complete, delaying her transition yet again. Not willing to give up her dreams

of transitioning, but also not wanting to jeopardize her health in any way, she began to consider and research the use of natural hormones. She learned that they would be far less toxic and taxing on her body. So, with great caution and under the strict supervision of her healthcare team, Lois took the initial steps toward her transition while still in the process of waiting on a new kidney.

Following a successful transplant, the time had finally come for Lois to live the life that she'd always believed she should. And, for the very first time, she went to find work as a woman.

She obtained a position in the human resources department of a not-for-profit organization that provided specialized training for industrial corporations, while also working part-time as a salon assistant. It was in the salon that she met local Chicago trans-advocate Raven Bonté. She recruited Lois to conduct a workshop on résumé writing at a support group for transwomen that she was facilitating. Lois agreed, marking her segue into transgender social support services. Feeling good about having a platform to assist other people who were like her, Lois soon made the transition from volunteer to full-time employee, eventually landing the position of Program Director for the Minority Outreach Intervention Project (MOIP), then the premier black LGBT organization in Chicago.

During her work with MOIP, however, Lois was forced to face the fact that while she was finally able to live in the truth of her gender orientation, there was a part of herself that she was not quite ready to grapple with. Shortly after her transplant, she learned that she was diabetic, a condition that she was managing well, for the most part. However, even though she frequently encouraged and supported others to be tested for HIV and be treated if found to be positive, Lois herself was unaware of her own status.

There was a part of her, she says, that didn't want to know. And another part that already did. With support from some of the same transwomen she had once provided support to, Lois agreed to take the test. The result was as she expected it to be.

Testing positive didn't stop her, though, but actually propelled her even further into the work of advocating for greater access to quality social and medical services for transpersons. Following her diagnosis, Lois became involved with numerous community advocacy groups, including the HIV Prevention Planning Group and the Chicago Area Ryan White Services Planning Council. Then, in an effort to expand her reach to transpersons and to further her development as a helping professional, Lois accepted a position as Manager of Transgender Services at Howard Brown Health Center. She was also appointed Secretary of the Windy City Black Pride committee (Chicago's black LGBT pride organization), making her the first transperson to hold office on a black LGBT pride committee anywhere in the country.

It was during this incredibly progressive period of her life, however, that her roles unexpectedly began to shift.

One sunny afternoon last summer, she was talking on her cell phone while waiting to have her oil changed at a gas station on Chicago's impoverished West Side. A man walking past mistakenly thought that her conversation was directed at him. While assuring him that it was not, Lois believes that the guy suspected that she was not a physically born female. As a result, he attacked her.

He was much bigger than she, and she was wearing high heels. She fell hard to the ground when he hit her, bruising her knee pretty badly. In spite of her fall, she was able to reach for the blade that she kept in her purse in case a situation arrived where she would happen to need it. She never really expected to use it.

He hit her again and then she cut him. At that point he ran away, leaving her with a deep cut on her face and a twisted wrist. In shock, she drove herself to the hospital.

It wasn't the first time she'd ever been in an altercation as a result of transphobia. It was, however, the first time it had happened while she was alone. Aside from the physical scars, the incident has left her with a bruised spirit that, still to this day, she is working hard to mend.

And as if that wasn't enough, approximately a week after the incident, Lois received news that her donated kidney had failed and that she would need to begin dialysis soon. In retrospect she admits that she slipped into a severe state of depression at that time. On top of the stress associated with her involvement with Windy City Pride (which was extremely chaotic at the time, to say the least) and being the victim of a brutal hate crime, learning that her kidney had failed was the final straw.

Despite overwhelming support and encouragement from her mother and from the LGBT community, Lois opted not to pursue charges against her assailant. Not only did she feel that she just didn't have the energy to go through with the process, considering her current health challenges, she also wasn't sure if she wanted to live in the spotlight that would come with being a poster child for violence against transpersons. After all, her HIV status, kidney trouble, and diagnosis as diabetic were not public knowledge. Therefore, coming out as a victim of assault could potentially open the door to out her about many things that, until this point, she was dealing with in private.

While in preparation to be added to the list to receive another kidney transplant, however, Lois had what she describes as a wonderful epiphany. She realizes now that the self-preservation her parents spoke of is bigger than just being able to support oneself so that you can live your life as you please. Self-preservation also involves having all of the elements of your life—physical, mental, spiritual, professional, etc.—work together to create a more cohesive and fulfilling life experience. Lois admits that for the greater part of her life things have been working, thank God, but they have not been working together.

Today, she is in a different place. Her health is stable, though not perfect. She's never had to take medication for HIV and, ironically, the challenges she was having relating to her diabetes have subsided. Agreeing to be a part of this very special issue of *Positively Aware* is her first major step at bringing all of the elements of her life together. It's the first time that she's publicly spoken out about the assault, or having renal failure, or diabetes, or about being HIV-positive. She has also begun to more aggressively incorporate a more holistic approach to her work with transgender people.

She wants it to be clear that she doesn't regret any of her life experiences or choices that she's made until now, because they've all helped to make her the proud transwoman she is today. What she hopes that people will get from her story, especially other transwomen, is that all of the components of your life must work together in order for you to live your very best life.

The other thing that she wants people to understand is that transition is a lifelong journey and that, for transpersons, the physical part of it is just one piece to the puzzle. Life is filled with transition. Therefore, approaching it holistically and with self-preservation in mind is the best advice that Lois can offer to anyone. ✚

SAFER SEX POST-SRS:

A BRAVE NEW WORLD, INDEED

Answers to
questions about
sexual safety after
sex reassignment
surgery

by Laura Jones

This article is written to address questions about sexual safety after sex reassignment/realignment surgery (SRS). This is not because we assume everyone has or wants SRS, or that surgery is required in order to be fully female or male. When doing research, we discovered that there's not much information available on post-surgical sexual health, so we figured we should try to put some out there. We encourage readers with first-hand experience (whether that's your own hand or someone else's) to let us know what's been working for you with regard to safe post-op sex, or what you know works well for clients—this article is only a start, and we look to the experts (you!) to share more information.

A word also about language used in this article: We deliberately avoided pronouns and “FTM/MTF” designations as much as possible, so as to better focus on body parts and sexual activities. This is because tissues heal more or less the same way in everyone, and viruses and bacteria don't care about

gender identity, sexual orientation, or how a person calls themselves before or after SRS. They only care about setting up shop in the human body, and whether what we're doing with our bodies helps or hinders them in that goal. With that in mind, let's take a cruise down SRS Lane.

SURGICAL STUFF

In order to discuss post-op sexual activities and risk factors, we need an understanding of what sexual reassignment/realignment surgery (SRS) entails. SRS comes in many packages—some people opt for the full range of “top” and “bottom” procedures, while others pick and choose according to their priorities and needs. Below is a chart providing very basic information on SRS procedures, including

healing times and post-op concerns.^{1, 2, 3, 4} For more detailed information, check the Resource List on page 57.

Since healing from SRS can be a slow process, you need to keep your new parts safe while they're getting used to the world. Risk of infection is a major concern for all who undergo SRS, but even more so for those living with HIV. SRS involves major surgeries performed on delicate parts of the body, and healing requires your body to re-wire nerve responses and recover from blood loss in addition to repairing tissues. Take care of yourself after surgery! Do not push yourself past your limits, work-wise or sex-wise! You're going to have your genitals for the rest of your life, so no need to jump on the horse before your body says it's ready to ride (if you know what I mean).

Ask your medical team when it's safe to experiment with sexual penetration, and listen to your body when you start out. If you are living with HIV and/or Hep B and C, it's especially important that you wait until your post-op bleeding and wound drainage is over before resuming sexual activity, both for your own health and that of your partner. This includes anal sex as well as genital sex, since the muscles and tissues of the entire anal-genital area are involved in SRS and must be allowed to heal too. Follow your medical team's post-op instructions carefully for optimal healing, take it slow, and use lube when you start having sex again. Traditional or Reality condoms are good protection against blood and wound fluids that might not be easily visible. For those who use sex toys, clean

	PROCEDURE	HEALING TIME	POST-OP CARE	MAIN POST-OP CONCERNS
Feminizing				
Breast Augmentation (augmentation mammoplasty)	Saline-filled implant surgically inserted under chest muscle	1-2 weeks for normal activity; strenuous activity after 3-4 weeks	Keep surgical site clean; start implant displacement massage 3-5 days after surgery	Infection—check for redness, tenderness, heat, and/or discharges at incisions
Vaginoplasty	Surgical creation of female genitals—includes creation of a “neo-vagina” through penile inversion or with lining from the colon, plus one or more of the below	Variable	Keep surgical site clean; use Betadine douches as recommended; daily dilation exercises as recommended; follow-up exams to monitor healing	Infection; loss of neo-vaginal depth/length if dilation isn't done; skin tears and pain with rough dilation or sexual penetration
Orchiectomy	Removal of the testes	See above	See above	Infection
Penectomy (“nullification”)	Removal of penile tissue + urethral shortening. Can be done solo if you don't want a penis or a neo-vagina.	See above	See above	See above
Clitoroplasty	Creation of a clitoris out of glans penis tissue	See above	See above	See above
Labiaplasty	Creation of labia majora and minora out of scrotal and penile skin	See above	See above	See above

your toys properly before and after penetrative sex, and change condoms if alternating between anal and vaginal penetration.

VAGINAL STUFF

Contrary to myth, neo-vaginas are not more resistant to infections than natal vaginas. Whether your neo-vagina is constructed out of your former penile and scrotal skin or from a section of your colon, your genitals are delicate and limited in their stretch capacity—your dilation exercises will give

you a good sense of what's comfortable and what is too much. While women have been known to experience some natural lubrication from urethral tissue or Cowper's and prostate gland secretions, most neo-vaginas are not self-lubricating. Therefore, lube is an even better friend than it was before SRS! The more lube used, the more comfort and the less risk of tearing.

All vaginas can end up playing host to vaginal and bacterial infections, sexually transmitted or naturally occurring. Vagi-

nas are among yeast and bacteria's favorite places to live—the dark, warm, enclosed environment is perfect for their breeding needs. Close proximity to the anal area also increases the odds of bacterial vaginal infections, so get used to wiping front to back now if you aren't already. Your partner/s should also use condoms on their penises or on sex toys to help further reduce your risk of neo-vaginal infection.

Herpes simplex virus (HSV I or HSV II) can be transmitted to your new genitals

	PROCEDURE	HEALING TIME	POST-OP CARE	MAIN POST-OP CONCERNS
Masculinizing				
Chest surgery—subcutaneous mastectomy or breast reduction surgery	Removal of breast tissue and inframammary folds	1-2 weeks for normal activity; 3-4 weeks for strenuous activity	Keep surgical site clean; tensor bandage around chest for 1 month	Infection—check for redness, tenderness, heat, and/or discharges at incisions
Hysterectomy	Removal of part or all of the uterus (full hysterectomy = no cervix)	Same as for natal women—about 6 weeks	Keep surgical site clean; follow-up at six weeks to check healing and remove staples	See above
Oophorectomy	Removal of the ovaries	See above	See above	See above
Vaginectomy	Removal of vaginal tissue, repositioning of muscles, and vaginal closure	Variable	Keep surgical sites clean; follow-up to check healing and function of genitals and donation sites (forearm, leg, etc.)	See above
Urethral Lengthening	Uses vaginal or bladder mucosa to lengthen urethra and allow urine to empty through the neophallus	Variable	See above	Inability to urinate; infection
Phalloplasty	Creation of a “neophallus” out of vaginal mucosa and forearm skin	About 1 year before penile prosthesis can be implanted.	See above	See above
Metaidoioplasty	Hormonally-enlarged clitoris, labia minora skin, and lengthened urethra create small “microphallus”	Variable—follow-up to check healing and function	See above	See above
Scrotoplasty	Creation of scrotal sac from labia majora and minora tissue and skin	About 1 year before scrotal implants can be placed	See above	Infection

via oral or genital sex, or an old HSV infection may flare up as your immune system prioritizes healing from surgery. Keep an eye out for discharges, odors, tissue irritation, small sores, and/or itching or pain—skin irritations and sores can bleed, as well as leave open pathways for HIV and bacterial infections. Douches will be prescribed to help speed your surgical-site healing, but douching can't be counted on to clear up a yeast or bacterial infection, and it won't help with herpes. If your vagina was constructed out of penile skin, you may also experience itching and discharge related to hair growth in your neo-vagina. Given all the possibilities, it's worth a visit to your doc or clinic if you notice anything unusual.

PHALLIC STUFF

Condoms are an important part of sexual safety for all men, including those who don't produce semen (ejaculate, jizz, spoo, cum, etc.). Neo-phallus skin needs protection from HSV and HPV, as well as yeast infections of the skin and bacterial urinary tract infections. If you have a penile prosthesis implanted as part of your SRS, condoms will also help reduce the risk of infected micro-tears as you learn how your new penis skin stretches during erection and penetrative sex (put the condom on after inflation, just like you would with any other erection). Men with "tranny-cocks" resulting from metoidioplasty may find traditional condoms too large for fun or safety. A suggestion from James Cullen's "Safer Sex for Transguys" pamphlet is to "... cut a (latex or polyurethane) glove along the thumb side from the wrist down to about where your first thumb knuckle would be. The thumb of the glove becomes your condom, and the rest of the glove hangs free to cover all the other important stuff from your cock to your ass."⁵ Another option is to cover your own or your partner's genital or anal area with a dental dam, and then enjoy yourselves.

EVERYONE'S STUFF

Anal sex can be enjoyed safely post-SRS healing with a few precautions. Lubricants and condoms are the easiest way to keep skin happy and body fluids contained—water-based lubricants must be used with

latex condoms, but oil- and silicone-based lubes are safe for use with polyurethane traditional or Reality condoms. Bottoms of any gender can use Reality condoms to protect their butts and their partner's penis. Tops can protect their natal- and neo-phalluses—as well as their partner's vagina or ass—with traditional condoms. Also use fresh condoms if alternating between anal and vaginal penetration, to reduce the risk of vaginal infections caused by butt bacteria and STIs in any area.

Sharing hormone syringes and other injection equipment carries the same risks as sharing equipment for recreational drug use, even though hormones are injected into muscle instead of a vein. Hepatitis C is of particular concern, since this virus is much more durable and easily transmitted than HIV. Please don't share equipment! Many syringe exchange programs can provide hormone-grade syringes if you run out or don't have a prescription. Please also consider the risks of using street hormones, even if you have an ongoing relationship with your supplier and bring your own injection equipment or see the equipment packages being opened. As with recreational drugs, you never know for sure what you're going to get on the street. Injected silicone can cause severe health problems, along with injection-related scarring and infections. Regardless of where you get your therapies, please keep up with regular clinical monitoring so any health complications can be addressed quickly.

EXTRA STUFF

Another note: Some of what you're born with, you keep. If you were born with a male body, you have a prostate gland up there in your rectum. Your prostate remains even if you have SRS, so remember to get that checked once a year and anytime you notice rectal pain, frequent urination, or any other sign of prostate trouble. If you were born with a female body and have not had a full hysterectomy, you have a cervix that needs to be screened for cervical cancer. If you are HIV-positive, follow the guidelines for prostate exams and Pap smears that are suggested for your natal gender: once a year for prostates over age 40, and once a year for cervixes (more often if you have a his-

tory of abnormal Paps). If you have no cervix, natal or neo, an annual pelvic exam is recommended, though the value of vaginal Pap screening is unclear at this time.⁶

Speaking of Pap smears, anyone who has receptive anal sex is now encouraged to get an anal Pap to screen for HPV-related anal cell changes and cancers. HIV-positive people are at especially high risk for developing anal cancer, due to the immune system's compromised ability to keep HPV under control. Butts are butts are butts no matter what your gender, so don't shy away from the anal probe! Once-a-year screening is recommended for everyone with a history of receptive anal sex, regardless of HIV status.⁷

Just as everyone has a butt, everyone has breast tissue. This means everyone needs to think about breast cancer. Even if you've had chest/top surgery to remove breasts, you need to do monthly breast self-exams and get a checkup if you notice unusual lumps or growths, especially if the lump sticks to your chest wall and can't be wiggled around. If your breasts are created via hormone therapy or "boob job" augmentation surgery, you too need to do a monthly breast self-exam. Neither testosterone nor estrogen therapy appears to increase the risk of breast cancer, but breast cancer is becoming increasingly common in general—can't hurt to check yourself out, even if you consider your risk to be low.

That's it for now, friends. Send us some feedback from your own experience, and take care of your parts! 🍆

For a directory of surgical groups in the country and abroad that specialize in transgender work, contact the Tom Waddell Health Center in San Francisco at (415) 554-2727.

Laura Jones is a harm reduction activist based in Chicago, with a Masters in Human Sexuality pending from the University of Sydney in Australia. You can contact her at brannock@hotmail.com.

References available online at www.positivelyaware.com.

Joy Morris-Hightower

SURVIVAL AND
TRANSCENDENCE, BLESSED
AND NOT DAMNED

by Enid Vázquez

"I am 45 years old, I've been living with HIV 27 years, and I'm undetectable," says Chicagoan Joy Morris-Hightower. "I've been through every complication of HIV/AIDS in the '90s. I'm a recovering addict and a recovering prostitute—I really do believe it was an addiction. I was addicted to the money and the drugs that came along with it. I'm grateful that I survived."

Joy told her mother when she was five that she was going to be a girl. "She gave me a whupping and told me I was a boy. But I was still feminine and got beat up by the boys. I suppressed my feelings because of my family's morals, but at 18 I became transgender when I went to the streets. There were no jobs for transgenders, although it's better today. We all wound up in the sex trade."

She says she suffered from depression and fear. "I was in a lot of pain. It wasn't easy to stop drugs. I've relapsed and relapsed since I've been in my recovery, but it was nothing like when I was in my addiction. I was on a suicide mission."

She was diagnosed with HIV in 1986, but believes she contracted it in 1981 from a lover who died in 1984. "The doctor told me I had six months to two years to live. This was when there were no medications, no medical nothing. I went directly into my drug addiction and stayed there for the next 16 years. And when I realized I wasn't going to die and that God had a plan for my life, I changed."

She entered drug treatment at the Haymarket Center in Chicago.

"I had wasting syndrome and was in a nursing home. I was still in my addiction. They gave me hope in Haymarket. They gave me encouragement, they gave me faith. They gave me my life back. I'm truly in debt to them. I left the nursing home and made it to the city in March 2002 and I haven't looked back."

What she found at Haymarket was a loving support she had not expected. "[Counselor and Associate Program Director] Kenis Williams at Haymarket was so understanding and open-minded, not discriminatory. She made me feel that I could do this, that I could recover from my addiction."

It was in recovery that she says she discovered someone else who wasn't discriminatory.



“I WASN’T IN DENIAL ABOUT MY HIV,
BUT IT WAS HARD TO TALK ABOUT IT.
I DIDN’T HAVE ANYONE TO TALK TO.”

“I didn’t realize it until I started working the steps [of Narcotics Anonymous], the whole process is getting back in touch with God. Some people say Higher Power.”

An important part of her recovery was releasing the condemnation she’s felt from religious leaders. She believes the eunuchs of the Bible, including Daniel from the Book of Daniel, would be considered transgender today, and that they were glorified, not damned.

“They were considered noble, honorable wise men of that era, but today we have been demonized, ostracized, and outcast. We’re

told we’re going straight to hell. They demonize gay people and say we’re an abomination. Meshach, Shadrach, Abednego, and Daniel—the eunuchs are the ones who will be singing hallelujah to Jesus. They had the favor of God on them and I know God favors me.”

She says she uses the term “gay men” because “that’s how they put us, all in the same chart.”

“[Ministers] Farwell, Farrakhan—they say HIV is a curse for gays. I know that was a lie because I’m still here. And ministers are still lying. I had believed all those things those preachers said all those years. Being gay meant being HIV-positive. If you’re gay, you’re already an outcast. Then if you’re positive, you’re a leper. That’s how everyone treated you. But just looking at the evidence, I know that God loves me.”

Ironically, joining the recovery support group that Haymarket runs with TPAN helped her greatly, ironically because TPAN was unable to help her 15 years ago.

“It wasn’t TPAN necessarily that was uncomfortable as it was the group. I felt out of place in a room full of MSM (men who have sex with men). They talked around me as if I wasn’t there. I didn’t feel like I could relate to what they were talking about, and there was nobody there like me. I wasn’t in denial about my HIV, but it was hard to talk about it. I didn’t have anyone to talk to. It wasn’t a welcoming feeling and I was discouraged. I didn’t feel accepted, I didn’t feel welcome. Now [when she returned to TPAN] I didn’t feel ostracized, I didn’t feel rejected.

Although the support group she attends here today has only a few transgender individuals, Joy feels at home.

“My purpose is to help people. I try to encourage them. I try to show that by me living with this disease, they know they can live,” she says. “I tell people, hold on to your dreams.

“You don’t have to be ashamed or afraid to talk about this disease, because it’s not a curse from God.”

The pain she felt before, she says, had come not only from not being accepted for being transgender and for being HIV-positive, but for not having an education. “Basically, I felt like a failure. Today I have my high school diploma and a little bit of college, and I’m gainfully employed. I’m an outreach consultant. My whole philosophy is to prevent this disease.”

She has volunteered with the HIV program planning councils for the city of Chicago and the state of Illinois, and several other organizations.

“Today I work with Men and Women in Prison Ministry. I’m on the board of directors developing an orphanage in Africa (www.thefutureofbenin.com).”

Her family has changed with her.

“I talk to my mother all the time, and my father too. Today they are my best friends. They’re older and mature, and now understand. Back then they thought it was a phase.” ✚



Photo courtesy of Joy Morris—Hightower

where to
go for more
information on
transgender
and HIV

compiled by Jeff Berry

Resources

Information for the transgender community is increasingly becoming integrated into many of the mainstream gay, lesbian, and bisexual resources that currently exist. Below are some additional resources you may find helpful. There are also numerous online websites and forums for the transgender community, as well as organizations which have local support group chapters around the country. Visit www.positivelyaware.com for an expanded list of resources, including personal stories.

ORGANIZATIONS AND WEBSITES

ADVOCATES FOR YOUTH

Resources for GLBTQ youth. 2000 M Street NW, Suite 750, Washington, D.C. 20036; Tel: (202) 419-3420; visit www.advocatesforyouth.org, click on search function and enter "Transgender"

AMERICAN MEDICAL STUDENT ASSOCIATION (AMSA)

Website with Transgender Health Resources section; visit www.amsa.org/lgbt/transgender.cfm

WWW.ANNELAWRENCE.COM

Website for trans women with text from published studies and books.

CENTER FOR AIDS PREVENTION STUDIES (CAPS)

MTF fact sheet; CAPS, 50 Beale Street, Suite 1300, San Francisco, CA 94105; Tel: (415) 597-9100; visit www.caps.ucsf.edu/pubs/FS/MTF.php

CHRYSALIS

Website which offers support for transgender teens and their families; lists therapists by state. Visit www.tgchrysalis.com/therapists.htm

FTM INTERNATIONAL

Serving the female-to-male community. FTMI, 601 Van Ness Ave., Suite E327, San Francisco, CA 94102; Tel: (877) 267-1440; visit www.ftmi.org

HUMAN RIGHTS CAMPAIGN

Tips on coming out (comingout@hrc.org), resources for employees (workplace@hrc.org), legal/advocacy issues (legal@hrc.org); personal stories. HRC, 1640 Rhode Island Ave., NW, Washington, DC 20036-3278; Tel: (202) 628-4160; TTY: (202) 216-1572; Toll-free: (800) 777-4723; e-mail: hrc@hrc.org; visit www.hrc.org/issues/transgender.asp

INTERNATIONAL FOUNDATION FOR GENDER EDUCATION

Organization advocating for freedom of gender expression. PO Box 540229, Waltham, MA 02454; Tel: (781) 899-2212; e-mail: info@ifge.org; visit www.ifge.org

PARENTS, FAMILIES AND FRIENDS OF LESBIANS AND GAYS (PFLAG)

National non-profit organization with over 200,000 members and supporters and over 500 affiliates in the U.S.; website has comprehensive section for transgender individuals and their families. PFLAG, 1726 M Street NW, Suite 400, Washington, DC 20036; Tel: (202) 467-818; e-mail: info@pflag.org; visit www.pflag.org

TRANSGENDER LAW AND POLICY INSTITUTE

Non-profit organization dedicated to advocacy for transgender people. Great source of news stories and other documents. E-mail: info@transgenderlaw.org; visit www.transgenderlaw.org

U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Transgender fact sheets. Tel: 1-800-CDC-INFO (232-4636); 1-888-232-6348 (TTY). Visit www.cdc.gov/lgbthealth/transgender.htm

VANCOUVER COASTAL HEALTH

Canadian health services agency with Transgender Health Program. VCH, 11th Floor, 601 West Broadway, Vancouver, BC, V5Z 4C2, Canada; call Vancouver Coastal Health Information Line (604) 736-2033; (866) 884-0888 (toll free for residents outside the Lower Mainland); visit www.vch.ca/transhealth/resources/

WORLD PROFESSIONAL ASSOCIATION FOR TRANSGENDER HEALTH (WPATH)

Formerly the Harry Benjamin International Gender Dysphoria Association (HBI/GDA), professional organization devoted to the understanding and treatment of gender identity disorders. Contact: Tara L. Tieso, MSW, Executive Administrator, 1300 South Second Street, Suite 180, Minneapolis, MN 55343; e-mail: wpath@wpath.org; visit www.wpath.org ☒

THE BUZZ



HAART 2.0

Some future hope, a current nightmare

by Daniel S. Berger, M.D.

Antiretroviral therapy has undergone a renaissance of sorts, seeing an outpouring of newer and, more importantly, truly unique agents during the last two years. This has had a major impact on treatment, and has advanced our goals for patients who are HIV-positive, almost without regard to their treatment history. The purpose of this article is not really to describe these newer agents individually while affixing a rubber stamp, but instead to provide some different perspectives on where we can improve as we embark into the future. A recent experience I had while seeing a new patient had a saddening effect on me. I had the displeasure of observing his previously prescribed cocktail, which showed me that inferior treatments are still being offered despite all the progress in HIV therapy. Overall, however, I was so glad to be able to assume his care and eventually remedy his situation. This example is the vehicle for my message.

ONE PILL A DAY MAKES ME HAPPIER AND GAY

Atripla, the one pill, once-daily drug cocktail is a reality for a small subset of HIV-positive individuals. But nevertheless, one can't overemphasize its milestone in development. Patients who are starting treatment for the first time (antiviral naïve), and those that have never been exposed to any of Atripla's components are candidates for this landmark in HIV therapy.

Patients experienced or resistant to one or more of Atripla's components must rely on other treatment, often many more pills and often administered twice daily. These patients are the majority in care and cannot take advantage of a drug like Atripla. Thus, there is an unmet need for more co-formulations using newly developing agents that could be utilized for a wider-based audience. Therefore, as an early preview of what should be coming, the new non-nuke, TMC 278 (rilpivirine), currently in phase III development at Northstar in Chicago, as well as a new nucleotide developed for resistant virus which should be going into phase I, can be pictured as candidates for other co-formulations and more simplified regimens. These, in contrast to Atripla, may become useful for patients with antiviral resistance, but it will take several years before this becomes a reality.

ANTIVIRAL GOULASH

A smorgasbord of new antivirals has become part of our armamentarium within record time. These include a new protease inhibitor, Prezista (darunavir), and the first in the integrase inhibitor class, Isentress (raltegravir). These agents are approved for patients that harbor resistance to conventional treatment and have helped allow us to achieve undetectable virus for highly treatment-experienced patients. In addition, early and ongoing studies have shown excellent safety and effect for use in patients starting their first treatment regimen. Thus you can bet that we'll see these drugs being used also in this naïve patient population.

While Atripla's formulation of being one pill, once daily is tough to beat, patients who may have the propensity for side effects to Sustiva (a component of Atripla) have other alternatives in some of the newer antivirals. Additionally, there are several unique properties of these newer antivirals that set them apart from other drugs, thus making for an attractive consideration for specific situations. Isentress, for example, showed an unprecedented decline in viral load compared to Sustiva. I'll not go into details about their unique properties here but wait for another and future article of The Buzz.

Other new antiviral agents also include a second-generation non-nuke, Intelence (etravirine), and a first-in-class chemokine co-receptor (CCR5) inhibitor, Selzentry (maraviroc). These agents are also currently used for treatment-experienced patients.

HIV therapy has indeed become complicated for physicians not immersed in clinical HIV development and antiviral research; more than 20 antiviral agents have become developed providing an ever-increasing number of combinations. While posing a challenge for physicians to keep up with one of the fastest growing fields in medicine, there are ample sources for medical practitioners, as well as patients, to become more educated about their use. It is my hope that medical providers treating more than a few patients take the time to read and become knowledgeable, without relying on advertising or marketing tricks.

THE STORY OF J

This brings me to the story and focus of this article. In my wildest dreams, I never expected a wake-up call such as the recent experience I'm about to describe. While routinely providing lectures to physicians who are not yet proficient with some of the newer antiviral drugs, I've observed the natural desire by many to be further educated. This is a wonderful quality about the practice of medicine: a physician's way of life is a continuous cycle of further learning, self-development and growth through acquired knowledge and experience. However, sometimes a patient suffers when their doctor has not yet taken the time for valued thought, or acquired some basic principles of treatment and understanding of the current treatment for advanced disease.

It was thus recently fated that a young man in his mid-thirties would find me and become my patient. How that happened is another story for another article, but to get to the crux, Jay was being taken care of by two infectious disease (ID) specialists on the East Coast. He was being seen for many years by his ID physician and had several AIDS defining illnesses under the care of this physician. He was very resistant to most medications and was referred to another ID physician in the closest major city to gain access to one of the newer drugs. The new drug has been highly regarded as being effective for patients such as Jay. At the time, his T-cells had already spiraled downward to barely 50, and his viral load was in the hundreds of thousands.

The medication was Isentress (raltegravir), one of the first in a new class of drugs called integrase inhibitors, a very impressive drug providing hope for many HIV-positive patients.

Jay made the extended drives to the big city and was, for the most part, adherent to a regimen that this physician designed. However, Jay never had a chance. He was unfortunately placed on an easy, yet substandard regimen; one that would be used for naïve patients and not someone with highly resistant virus.

His background treatment involved two nukes—one that he was already resistant to, and the other he was also partially resistant to. As a result, he did not respond properly to the cocktail and thus failed treatment within two months. He was, in effect, on a mono-therapy regimen, or being administered Isentress without any protection. This also resulted in his becoming resistant to the entire integrase inhibitor class. His regular physician gave up on Jay and never offered further or proper treatment. This while his T-cells plummeted to 21 and viral load reaching 1 million. It is a wonder that he hasn't become even sicker.

You would think that in this day and age, with many new antivirals, Infectious Disease specialists taking care of HIV-infected patients, especially those who are participating in the early expanded access program for a new drug, should be familiar with its use. If not, you'd think Jay's other doctor, his primary physician who is also an ID specialist, would catch this grave but fundamental misjudgment by the other supposed experienced ID specialist/investigator who was allowed to participate in the Isentress expanded access program. Finally, you'd expect that the pharmaceutical company that allows physicians to become investigators using their new drug, of an entirely new class, would ensure that these doctors be able to have some treatment competency and be versed in its use.

Unfortunately for Jay, none of the above was true. Thus what should have been a promising option for a patient highly resistant to treatment, turned out to be a treatment disaster that reduced already minimal options left to him and narrowed his choices further and permanently for the future.

MESSAGE IN A BOTTLE

With all the new antiretrovirals that have become available, constructing a new regimen for a patient that is failing their current cocktail should be a no-brainer for the truly experienced and knowledgeable physician. Not only do we have agents in completely new classes, or antivirals that target a different aspect of the viral replicative process, we have true second-generation agents of older

classes that have very specific and unique qualities. However, bridging the educational gap to physicians should be paramount. Perhaps too many new agents have confounded some physicians as to their best use. This poses questions regarding the quality of care for patients seeing those physicians who do not make it their business to keep up or take the time, especially when confronted with a treatment-needy patient.

PHYSICIANS PRESCRIBING TREATMENT FOR EXPERIENCED PATIENTS SHOULD BECOME WELL EDUCATED AND INFORMED IN THE CONSTRUCTION OF EFFECTIVE REGIMENS.

Physicians prescribing treatment for experienced patients should become well educated and informed in the construction of effective regimens. If not, more patients will fail therapies, despite using newer agents, and we will witness a new era in resistance to these novel medications. This is compounded by the real-world reality that safe sex has virtually become extinct or non-existent within the gay community. Patients failing the newer agents can potentially open more floodgates for transmission of resistance to these newer antiviral classes. Patients should have the responsibility of taking their medications as prescribed without missing significant doses. This would help. Moreover, we need both competent construction of truly effective treatment regimens for treatment-experienced individuals, partnered with good adherence by patients. This combination should result in lower viral loads, better maintenance of effective treatment, and should help further reduce the emergence of resistance and the propensity for transmission of resistant virus to these novel classes. ☒

Dr. Daniel Berger is a leading HIV specialist in the U.S. and is assistant professor of medicine at the University of Illinois at Chicago and medical director and founder of NorthStar Medical Center, the largest private HIV treatment and research center in the Greater Chicago area. He has published extensively in such prestigious journals as The Lancet and The New England Journal of Medicine and serves on the Medical Issues Committee for the Illinois AIDS Drug Assistance Program and board of the AIDS Foundation of Chicago. Dr. Berger has been honored by Test Positive Aware Network with the Charles E. Clifton Leadership Award.

WHOLISTIC PICTURE



Balancing Male and Female

We all carry both genders within

by Sue Saltmarsh

In various indigenous cultures, including the Navajo, the traditional attitude towards homosexuality is that of respect for those who are “two-spirits,” often regarding them as having mystical powers that made them good healers, medicine people, and tribal counselors. Two spirits have the ability to embody both genders in one body and therefore can experience the work of balancing male and female within themselves in ways that others cannot, affording them unique perspectives and wisdom. While homosexuality is more common than being transgender, the concept still seems to fit.

whatever the criteria used for assessing ourselves and others and sorting by categories, as humans are wont to do.

And then there are the people who have the challenge of living inside bodies that don't feel like their own. I can't begin to imagine what that must be like. I think every person at some point or other has to deal with not liking, not wanting, not loving the body they were born with, but most of those are cosmetic conflicts, sometimes more than superficial, but nothing like what it must be to know you're female as you look at a male body in the mirror or vice versa. And yet, having been dealt that particularly

was not the case and our work then became focused on how this new body felt, how to know it and feel it was her “real” body.

I have known and worked with several transgender women since I knew her and most seemed to have the same struggle—even though they'd mastered the “look,” they very rarely seemed at home being girls. They were free to act female and to feel like they weren't aliens living in their own bodies, which of course was better than forcing themselves to look and act in ways that weren't true for them. But, as one joked to me, they don't have to worry about menstrual leaks, PMS, unwanted pregnancies, or menopausal hot flashes. But if medical science someday discovers ways to make those things also part of their new reality, is that the true measure of being female? It seems there are always going to be obstacles, even if it's just where to find size 15 high heels. Maybe females becoming male have it easier—even though they might not ever experience wet dreams, spontaneous erections, or the need for Flomax, at least they would have an easier time with their clothing!

I have always believed that at our most evolved human state, we all carry both genders within, just as we carry heart and head, physical and spiritual, youth and old age—in short, we have a wide range of spectrums to experience if we allow ourselves the possibilities. Perhaps transgender people are a step ahead of the rest of us in that they live each day confronted with the spectrum of gender and many find that precious balance point where they can feel with a woman's heart and think with a man's head while deciding which body is the one they truly live in. It can't be easy, but oh, what lessons it must bring, what wisdom it must convey. Now if only the rest of the world could find a way to revere them the way those indigenous cultures have, we might all make some significant progress.

Breathe deep, live long. ✚

TWO SPIRITS HAVE THE ABILITY TO EMBODY BOTH GENDERS IN ONE BODY AND THEREFORE CAN EXPERIENCE THE WORK OF BALANCING MALE AND FEMALE WITHIN THEMSELVES IN WAYS THAT OTHERS CANNOT, AFFORDING THEM UNIQUE PERSPECTIVES AND WISDOM.

In today's society, unfortunately, this attitude is not common towards any variance in “normal” sexual or gender identification. And yet we live with the desperate need for balance in all areas of our lives and with the consequences for ignoring that need. Our society has become polarized, disconnected, and unbalanced as pendulums swing frantically from one end of the spectrum to the other, hardly ever finding a point of balance in the middle. Many women seem determined to prove they're really men without penises. Men frequently struggle to find socially acceptable ways to express their emotions. All of us fight an uphill battle for acceptance of our Truth,

difficult card, do you ever feel “real,” even after surgery and hormones? Early in my practice at Project Vida, I met and worked with an individual who, even to my inexperienced perception, seemed to truly be a female in a male body. Her physical body was small and delicate, her voice soft, her movement graceful and feminine, and her energy looked and felt to me as female as any biological woman I'd ever worked with. She went through the whole torturous path of hormones and surgery and I expected our first session after her recovery to be a joyous one, celebrating that she had finally “come home” and was living in the body she'd always felt was truly her own. Sadly, that

PICKETT FENCES



The Path to Lemonade

Traveling from bitter to sweet

by Jim Pickett

So many HIV writers, yours ever so truly included, have belched, vomited, shat, and otherwise expelled countless, limitless nouns, verbs, adjectives, pronouns, modifiers, dangling...um...participles, hyperbole and conjunctions, all in slavish service to the mantra—"HIV really sucks."

Yes, yes, we know, it really does. Who can argue? HIV sucks. Really. Mucho. AIDS sucks the bag big time and to the max. It totally doesn't rock, ya know what I'm sayin'? It's not the way anyone wants to roll. It stinks. It's lousy rotten. It's out, it's not the new black and ya know what? It ain't on my friends list.

Right?

Illness, suffering, death, disaster, silence, patents, stigma, shame, poverty, politics, pain, anger, despair, decline, discrimination, drugs, needles, sinful, side effects, denial, lies, ideology, criminalization, pathological, punishment, irresponsible, hedonistic, risk, racism, sexism, homophobia, homelessness, hunger, judgment, lack, lipo, vulnerability, disenfranchised, disproportionate, disparities, co-occurring, co-morbidity, co-opt, whore, slut, junkie, faggot, innocent, and deserving.

Is the only way to describe our HIV/AIDS narrative through a deficit lens? Is the hyperbole of crisis and destruction the only way we can explain, understand, and rally around the enormous needs, the extraordinary injustices, and the complexities of this nasty, brutish, and cunning epidemic?

Well, we also go the other direction, don't we? In the story of AIDS we not only talk of whores, but of heroes, and there are indeed many "asset" words we utilize, words like selfless, tireless, brave, courageous, brilliant, visionary, leadership, strength, fight, truth, power, responsible, and you get the idea.

So I want to discuss the lemonade I can trace directly to the years after the HIV virus entered my bloodstream, and my life. So much beauty, so much meaning, so much value—all because of HIV.

First, and quite concretely, the beast has led me to a career in which my voice and my talents were allowed to develop and shine. Before I entered college as a freshman in 1984, I took a test that was designed to survey my strengths and characteristics and point me in a career direction best suited to me. The results at the time horrified me—the computer spit out "social worker" and "minister"—and I could not have been more disgusted. I proceeded to major in business, mass communication, English, film, linguistics, and theatre before dropping out and heading to Chicago for a new life—that of a waitress. Long story short, that led to working in the

alternative press. After doing a seven-year stint at a sassy, "predictably unsavory" local gay magazine as editor, writer, and ad-sales 'ho, I hesitantly accepted a contract with the health department to write stories about real people living with and impacted by HIV ("The Faces of AIDS"). This would never have happened if I had not started writing about my own HIV experience in that sassy mag. Without HIV I could still be writing gossip and snarky commentary—not that there is anything wrong with that—but HIV helped me find my voice and vocation (not unlike a social worker or a minister, really) and for that, I am eternally, and at every moment, grateful.

HIV has opened my eyes to the world. I have had the opportunity to know a Native American grandma in Oklahoma who became infected with HIV through sharing needles. I also met a young African American woman serving time in a Topeka prison, and advocating from within for access to treatment and care. How would I have ever met such incredible, interesting people without HIV as a common denominator?

HIV HAS FORCED ME TO SEPARATE THE BULL FROM THE SHIT, MAKE PRIORITIES, GET REAL.

I've met so many smart, passionate, fascinating, infuriating, inspiring, delightful, devious, and hilarious people because of HIV being in my life—I simply can't imagine what my world would be like without them. Maybe a few less headaches, sure... but give me a migraine over milquetoast and Pabulum!

I have to wonder if I'd ever have gone to Laramie, Wyoming, or Kearney, Nebraska, without the viral impetus. Probably not. And that would have been too bad, really. I probably wouldn't have gone to Cape Town, South Africa, or New Delhi, India, either. Or Spain. My first trip outside of North America was to Spain and was given to me by a lovely man named Leon here in Chicago who takes folks on tours of Morocco, Portugal, and Spain. He attached no strings. He merely wanted to thank me for my work as an HIV advocate and invited me along on a tour—free, a gift. That two-week trip to Barcelona, San Sebastian, and Madrid in the fall of 2001 led me

PICKETT FENCES CONTINUED

to falling in love with not only that country, but a man in Madrid to whom I had a crazy year-long affair. It also ignited a passion for world travel—both by plane and by armchair. Thanks, Leon. Thanks, HIV.

HIV has forced me to separate the bull from the shit, make priorities, get real. It has made me political. It helped me comprehend how being jaded and cynical is a lazy, entitled, arrogant, elitist luxury that I didn't want to pay for any longer. HIV has allowed me to value every moment of every day. While I fail at all the above early and often—I no longer do so without *knowing*. The process of knowing is among the greatest of HIV's gifts.

The journey that HIV set me on now 13 years ago also led me to meeting a man who I truly believe is the *one* for me. Never before have I felt so deeply calm and in love at the same time. We met just last year, months after my 42nd birthday and weeks after what I guess can be called a nervous breakdown, complete with hospitalization in a Fairy Farm. Sure, there were lots of "loves of my life" before Kevin—but hindsight tells me those were all two's and three's—some of them devilish, some of them quite lovely—but none of them right, or the *one*. None who accepted me as I am, none who were capable of comforting and being comforted, none

who were honest and clear and ready. And none who wanted to play Scrabble all the time, adored maps and exploring new places. Might I have found him without HIV in my life? Probably not. The events that unfolded after my positive diagnosis would have been profoundly different if that diagnosis had been negative. Thanks HIV.

HIV-free I'd probably still be smoking. And running around dance clubs til all hours, dabbling in the letters of chemical entertainment, and acting crazy. Or not. I do know that without HIV, I wouldn't have trained for four marathons and completed three. I know I wouldn't have been in the delivery room of the International Rectal Microbicide Advocates. And I wouldn't have missed Hector, Eric, Paul, Larry, Gigi, Rocky, and Dan when they died. And so many more.

Yes, the day I found out I was positive was singularly the worst day of my life. And it continues to hold that dubious record. But without that day, where would I be?

Likely not thanking HIV for so much good that has come my way. ☺

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