



POSITIVELY AWARE
HIV Treatment and Health

MARCH / APRIL 2008
THE JOURNAL OF TEST POSITIVE AWARE NETWORK

Profiles
in **HIV**

**MO'NIQUE
AND OTHERS SHARE
HOW HIV AFFECTS US ALL**

Important Information

INDICATION: ATRIPLA™ (efavirenz 600 mg/emtricitabine 200 mg/tenofovir disoproxil fumarate [DF] 300 mg) is a prescription medication used alone as a complete regimen or with other medicines to treat HIV infection in adults.

ATRIPLA does not cure HIV and has not been shown to prevent passing HIV to others. See your healthcare provider regularly.

IMPORTANT SAFETY INFORMATION:

Contact your healthcare provider right away if you experience any of the following side effects or conditions associated with ATRIPLA:

- 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.
- If you have HIV and hepatitis B virus (HBV), your liver disease may suddenly get worse if you stop taking ATRIPLA. Do not stop taking ATRIPLA unless directed by your healthcare provider.

Do not take ATRIPLA if you are taking the following medicines because serious and life-threatening side effects may occur when taken together:

Hismanal® (astemizole), Vascor® (bepridil), Propulsid® (cisapride), Versed® (midazolam), Orap® (pimozide), Halcion® (triazolam), or ergot derivatives (for example, Wigraine® and Cafergot®).

In addition, ATRIPLA should not be taken with: Combivir® (lamivudine/zidovudine), EMTRIVA® (emtricitabine), Epivir® or Epivir-HBV® (lamivudine), Epzicom™ (abacavir sulfate/lamivudine), SUSTIVA® (efavirenz), Trizivir® (abacavir sulfate/lamivudine/zidovudine), TRUVADA® (emtricitabine/tenofovir DF), or VIREAD® (tenofovir DF), because they contain the same or similar active ingredients as ATRIPLA.

Vfend® (voriconazole) should not be taken with ATRIPLA since it may lose its effect or may increase the chance of having side effects from ATRIPLA. Fortovase®, Invirase® (saquinavir) should not be used as the only protease inhibitor in combination with ATRIPLA.

Taking ATRIPLA with St. John's wort (*Hypericum perforatum*) is not recommended as it may cause decreased levels of ATRIPLA, increased viral load, and possible resistance to ATRIPLA or cross-resistance to other anti-HIV drugs.

This list of medicines is not complete. Discuss with your healthcare provider all prescription and nonprescription medicines, vitamins, and herbal supplements you are taking or plan to take.

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

- Severe depression, strange thoughts, or angry behavior have been reported by a small number of patients. Some patients have had thoughts of suicide and a few have actually committed suicide. These problems may occur more often in patients who have had mental illness.
- Dizziness, trouble sleeping or concentrating, drowsiness, unusual dreams, and/or hallucinations are common, and tend to go away after taking ATRIPLA (efavirenz 600 mg/emtricitabine 200 mg/tenofovir DF 300 mg) for a few weeks. Symptoms were severe in a few patients and some patients discontinued therapy. These symptoms may become more severe with the use of alcohol and/or mood-altering (street) drugs. If you are dizzy, have trouble concentrating, and/or are drowsy, avoid activities that may be dangerous, such as driving or operating machinery.
- Kidney or liver problems. If you have had kidney or liver problems, including hepatitis infection or take other medicines that may cause kidney or liver problems, your healthcare provider should do regular blood tests.
- Pregnancy: Women should not become pregnant while taking ATRIPLA. Serious birth defects have been seen in children of women treated during pregnancy with one of the medicines in ATRIPLA. Women must use a reliable form of barrier contraception, such as a condom or diaphragm, even if they also use other methods of birth control.
- Breast-Feeding: Women with HIV should not breast-feed because they can pass HIV through their milk to the baby. Also, ATRIPLA may pass through breast milk and cause serious harm to the baby.
- Rash is a common side effect that usually goes away without treatment, but may be serious in a small number of patients.
- Seizures have occurred in patients taking a component of ATRIPLA, usually in those with a history of seizures. If you have ever had seizures, or take medicine for seizures, your healthcare provider may want to switch you to another medicine or monitor you.
- Bone changes. If you have had bone problems in the past, your healthcare provider may want to check your bones.
- If you have ever had mental illness or use illegal drugs or alcohol.

Changes in body fat have been seen in some people taking anti-HIV medicines. The cause and long-term health effects are not known.

Common side effects of ATRIPLA include tiredness, headache, upset stomach, vomiting, gas, and diarrhea. Skin discoloration (small spots or freckles) may also happen with ATRIPLA.

You should take ATRIPLA once daily on an empty stomach. Taking ATRIPLA at bedtime may make some side effects less bothersome.



If you or someone you know needs help paying for medicine, call 1-888-4PPA-NOW (1-888-477-2669). Or go to www.pparx.org



Partnership for Prescription Assistance

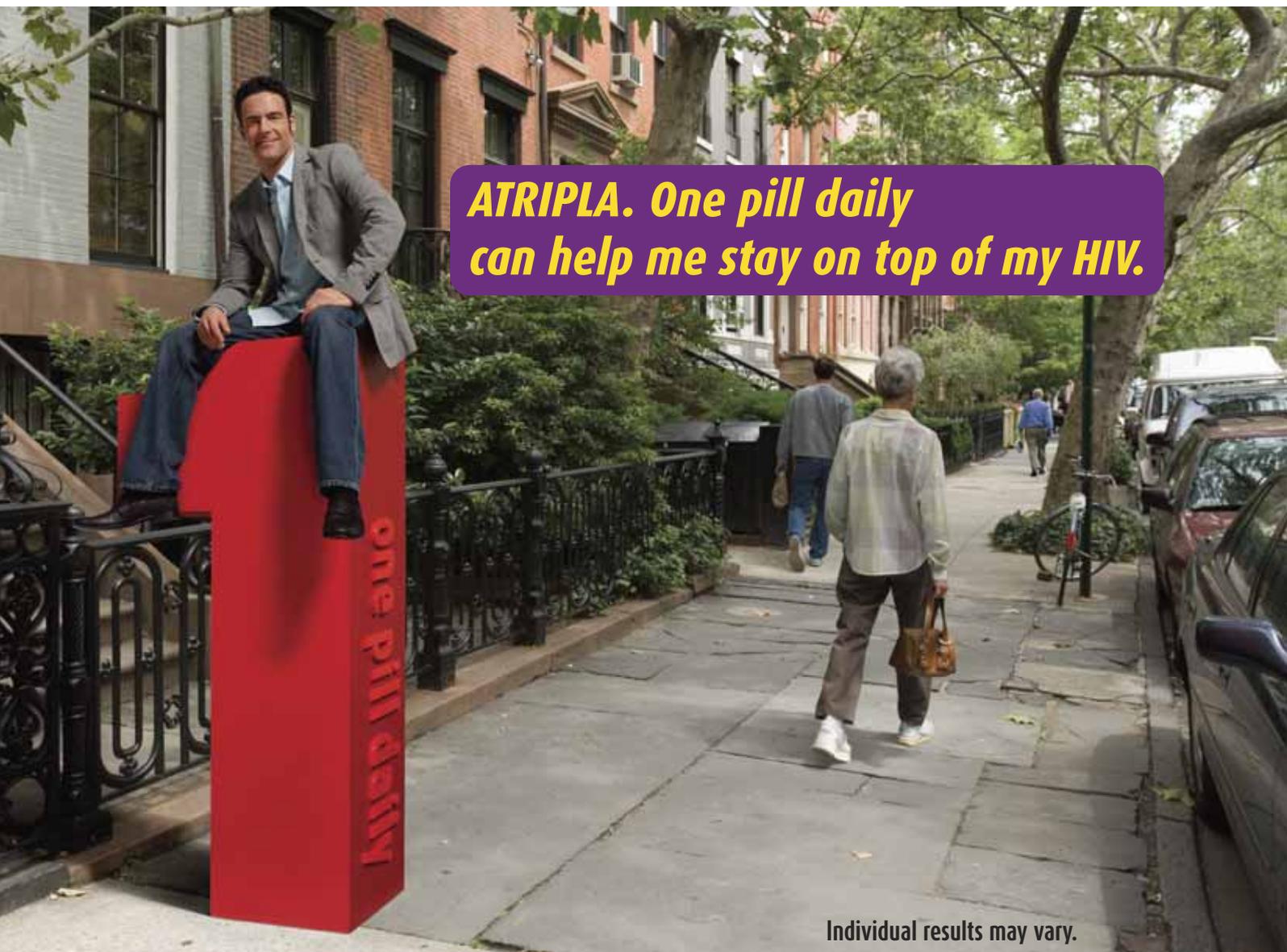


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**ATRIPLA. One pill daily
can help me stay on top of my HIV.**

Individual results may vary.

The first and only **complete HIV regimen** in one pill daily.
ATRIPLA may be taken alone or with other HIV medicines.

- **Effective:** Proven to lower viral load to undetectable[†] and help raise T-cell (CD4+) count through 48 weeks of a clinical study.
- **One Pill, Once a Day:** Take on an empty stomach, preferably at bedtime, and you're done with ATRIPLA for 24 hours. Taking ATRIPLA at bedtime may make some side effects less bothersome.
- **Tolerability:** Well-established patient experience in clinical studies with the three proven medicines in ATRIPLA.

[†] Undetectable was defined as a viral load of less than 400 copies/mL.

Ask your doctor if ATRIPLA is right for you.

visit www.ATRIPLA.com

* ATRIPLA is a combination of 3 HIV medicines – SUSTIVA® (efavirenz), EMTRIVA® (emtricitabine), and VIREAD® (tenofovir disoproxil fumarate).

Please see Patient Information including “What is the most important information I should know about ATRIPLA?” on the next page.

ATRIPLATM
(efavirenz 600 mg/emtricitabine 200 mg/
tenofovir disoproxil fumarate 300 mg) Tablets

It all adds up to one.^{TM *}

PATIENT INFORMATION

ATRIPLA™ (uh TRIP luh) Tablets

Rx ONLY

ALERT: Find out about medicines that should NOT be taken with ATRIPLA (efavirenz 600 mg/emtricitabine 200 mg/tenofovir disoproxil fumarate 300 mg).

Please also read the section **"MEDICINES YOU SHOULD NOT TAKE WITH ATRIPLA."**

Generic name: efavirenz, emtricitabine and tenofovir disoproxil fumarate (eh FAH vih renz, em tri SIT' uh bean and te NOE' lo veer dye soe PROX il FYOU mar ate)

Read the Patient Information that comes with ATRIPLA before you start taking it and each time you get a refill since 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 ATRIPLA. **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 ATRIPLA.

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

- **Some people who have taken medicine like ATRIPLA (which contains 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 ATRIPLA 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-containing medicines, like ATRIPLA, for a long time.
- **If you also have Hepatitis B Virus (HBV) infection and you stop taking ATRIPLA, you may get a "flare-up" of your hepatitis.** A "flare-up" is when the disease suddenly returns in a worse way than before. Patients with HBV who stop taking ATRIPLA need close medical follow-up for several months, including medical exams and blood tests to check for hepatitis that could be getting worse. ATRIPLA is not approved for the treatment of HBV, so you must discuss your HBV therapy with your healthcare provider.

What is ATRIPLA?

ATRIPLA contains 3 medicines, SUSTIVA® (efavirenz), EMTRIVA® (emtricitabine) and VIREAD® (tenofovir disoproxil fumarate also called tenofovir DF) combined in one pill. EMTRIVA and VIREAD are HIV (human immunodeficiency virus) nucleoside analog reverse transcriptase inhibitors (NRTIs) and SUSTIVA is an HIV non-nucleoside analog reverse transcriptase inhibitor (NNRTI). VIREAD and EMTRIVA are the components of TRUVADA®. ATRIPLA can be used alone as a complete regimen, or in combination with other anti-HIV medicines to treat people with HIV infection. ATRIPLA is for adults age 18 and over. ATRIPLA 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.

ATRIPLA helps block HIV reverse transcriptase, a viral chemical in your body (enzyme) that is needed for HIV to multiply. ATRIPLA lowers the amount of HIV in the blood (viral load). ATRIPLA may also help to increase the number of T cells (CD4 cells), allowing your immune system to improve. 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).

Does ATRIPLA cure HIV-1 or AIDS?

ATRIPLA does not cure HIV infection or AIDS. The long-term effects of ATRIPLA are not known at this time. People taking ATRIPLA 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 ATRIPLA.

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

ATRIPLA has not been shown to lower your chance of passing HIV to other people through sexual contact, sharing needles, or being exposed to your blood.

- 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.

Who should not take ATRIPLA?

Together with your healthcare provider, you need to decide whether ATRIPLA is right for you.

Do not take ATRIPLA if you are allergic to ATRIPLA or any of its ingredients. The active ingredients of ATRIPLA are efavirenz, emtricitabine, and tenofovir DF. See the end of this leaflet for a complete list of ingredients.

What should I tell my healthcare provider before taking ATRIPLA?

Tell your healthcare provider if you:

- Are pregnant or planning to become pregnant (see "What should I avoid while taking ATRIPLA?").
- Are breastfeeding (see "What should I avoid while taking ATRIPLA?").
- Have kidney problems or are undergoing kidney dialysis treatment.
- Have bone problems.
- Have liver problems, including Hepatitis B Virus infection. Your healthcare provider may want to do tests to check your liver while you take ATRIPLA.
- Have ever had mental illness or are using drugs or alcohol.
- Have ever had seizures or are taking medicine for seizures.

What important information should I know about taking other medicines with ATRIPLA?

ATRIPLA may change the effect of other medicines, including the ones for HIV, and may cause serious side effects. Your healthcare provider may change your other medicines or change their doses. Other medicines, including herbal products, may affect ATRIPLA. For this reason, it is very important to let all your healthcare providers and pharmacists know what medications, herbal supplements, or vitamins you are taking.

MEDICINES YOU SHOULD NOT TAKE WITH ATRIPLA

- The following medicines may cause serious and life-threatening side effects when taken with ATRIPLA. You should not take any of these medicines while taking ATRIPLA: Hismanal (astemizole), Vascor (bepridil), Propulsid (cisapride), Versed (midazolam), Orap (pimozide), Halcion (triazolam), ergot medications (for example, Wigraine and Cafergot).
 - ATRIPLA also should not be taken with Combivir (lamivudine/zidovudine), EMTRIVA, Efavir, Efavir-HBV (lamivudine), Epizcom (abacavir sulfate/lamivudine), Trizivir (abacavir sulfate/lamivudine/zidovudine), SUSTIVA, TRUVADA, or VIREAD.
 - Vmend (voriconazole) should not be taken with ATRIPLA since it may lose its effect or may increase the chance of having side effects from ATRIPLA.
- It is also important to tell your healthcare provider if you are taking any of the following:
- Fortovase, Inivase (saquinavir), Bixxin (clarithromycin); or Sporanox (itraconazole); **these medicines may need to be replaced with another medicine when taken with ATRIPLA.**
 - Calcium channel blockers such as Cardizem or Tiazac (diltiazem), Covera HS or Isoptin (verapamil) and others; Crivarin (indinavir); Methadone; Mycobutin (rifabutin); Rifampin; cholesterol-lowering medicines such as Lipitor (atorvastatin), Pravachol (pravastatin sodium), and Zocor (simvastatin); or Zolof (sertraline); **these medicines may need to have their dose changed when taken with ATRIPLA.**
 - Videx, Videx EC (didanosine); tenofovir DF (a component of ATRIPLA) may increase the amount of didanosine in your blood, which could result in more side effects. **You may need to be monitored more carefully** if you are taking ATRIPLA and didanosine together. Also, the dose of didanosine may need to be changed.
 - Reyataz (atazanavir sulfate) or Kaletra (lopinavir/ritonavir); these medicines may increase the amount of tenofovir DF (a component of ATRIPLA) in your blood, which could result in more side effects. **You may need to be monitored more carefully** if you are taking ATRIPLA and either Reyataz or Kaletra together. Also, the dose of Reyataz or Kaletra may need to be changed.
 - Medicine for seizures [for example, Dilantin (phenytoin), Tegretol (carbamazepine), or phenobarbital]; your healthcare provider may want to switch you to another medicine or check drug levels in your blood from time to time.
 - **Taking St. John's wort (*Hypericum perforatum*), or products containing St. John's wort with ATRIPLA is not recommended.** St. John's wort is a herbal product sold as a dietary supplement. Talk with your healthcare provider if you are taking or are planning to take St. John's wort. Taking St. John's wort may decrease ATRIPLA levels and lead to increased viral load and possible resistance to ATRIPLA or cross-resistance to other anti-HIV drugs.

These are not all the medicines that may cause problems if you take ATRIPLA (efavirenz 600 mg/emtricitabine 200 mg/tenofovir disoproxil fumarate 300 mg). Be sure to tell your healthcare provider about all medicines that you take.

Keep a complete list of all the prescription and nonprescription medicines as well as any herbal remedies that you are taking, how much you take, and how often you take them. Make a new list when medicines or herbal remedies are added or stopped, or if the dose changes. Give copies of this list to all of your healthcare providers and pharmacists every time you visit your healthcare provider or fill a prescription. This will give your healthcare provider a complete picture of the medicines you use. Then he or she can decide the best approach for your situation.

How should I take ATRIPLA?

- Take the exact amount of ATRIPLA your healthcare provider prescribes. Never change the dose on your own. Do not stop this medicine unless your healthcare provider tells you to stop.
- You should take ATRIPLA on an empty stomach.
- Swallow ATRIPLA with water.
- Taking ATRIPLA at bedtime may make some side effects less bothersome.
- Do not miss a dose of ATRIPLA. If you forget to take ATRIPLA, take the missed dose right away, unless it is almost time for your next dose. Do not double the next dose. Carry on with your regular dosing schedule. If you need help in planning the best times to take your medicine, ask your healthcare provider or pharmacist.
- If you believe you took more than the prescribed amount of ATRIPLA, contact your local poison control center or emergency room right away.
- Tell your healthcare provider if you start any new medicine or change how you take old ones. Your doses may need adjustment.
- When your ATRIPLA 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 ATRIPLA and become harder to treat.
- Your healthcare provider may want to do blood tests to check for certain side effects while you take ATRIPLA.

What should I avoid while taking ATRIPLA?

- **Women taking ATRIPLA should not become pregnant.** Serious birth defects have been seen in the babies of animals and women treated with efavirenz (a component of ATRIPLA) during pregnancy. It is not known whether efavirenz caused these defects. **Tell your healthcare provider right away if you are pregnant.** Also talk with your healthcare provider if you want to become pregnant.
- Women should not rely only on hormone-based birth control, such as pills, injections, or implants, because ATRIPLA may make these contraceptives ineffective. Women must use a reliable form of barrier contraception, such as a condom or diaphragm, even if they also use other methods of birth control.
- **Do not breast-feed if you are taking ATRIPLA.** The Centers for Disease Control and Prevention recommend that mothers with HIV not breast-feed because they can pass the HIV through their milk to the baby. Also, ATRIPLA may pass through breast milk and cause serious harm to the baby. Talk with your healthcare provider if you are breast-feeding. You should stop breast-feeding or may need to use a different medicine.
- Taking ATRIPLA with alcohol or other medicines causing similar side effects as ATRIPLA, such as drowsiness, may increase those side effects.
- Do not take any other medicines, including prescription and nonprescription medicines and herbal products, without checking with your healthcare provider.
- **Avoid doing things that can spread HIV infection** since ATRIPLA does not stop you from passing the HIV infection to others.

What are the possible side effects of ATRIPLA?

ATRIPLA may cause the following serious side effects:

- **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 healthcare provider right away if you get signs of lactic acidosis.** (See "What is the most important information I should know about ATRIPLA?")
- **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 ATRIPLA?")
- **"Flare-ups" of Hepatitis B Virus (HBV) infection**, in which the disease suddenly returns in a worse way than before, can occur if you have HBV and you stop taking ATRIPLA. Your healthcare provider will monitor your condition for several months after stopping ATRIPLA if you have both HIV and HBV infection and may recommend treatment for your HBV.
- **Serious psychiatric problems.** A small number of patients may experience severe depression, strange thoughts, or angry behavior while taking ATRIPLA. Some patients have thoughts of suicide and a few have actually committed suicide. These problems may occur more often in patients who have had mental illness. Contact your healthcare provider right away if you think you are having these psychiatric symptoms, so your healthcare provider can decide if you should continue to take ATRIPLA.
- **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 ATRIPLA 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.

Common side effects:

Patients may have dizziness, headache, trouble sleeping, drowsiness, trouble concentrating, and/or unusual dreams during treatment with ATRIPLA. These side effects may be reduced if you take ATRIPLA at bedtime on an empty stomach. They also tend to go away after you have taken the medicine for a few weeks. If you have these common side effects, such as dizziness, it does not mean that you will also have serious psychiatric problems, such as severe depression, strange thoughts, or angry behavior. Tell your healthcare provider right away if any of these side effects continue or if they bother you. It is possible that these symptoms may be more severe if ATRIPLA is used with alcohol or mood altering (street) drugs.

If you are dizzy, have trouble concentrating, or are drowsy, avoid activities that may be dangerous, such as driving or operating machinery. Rash may be common. Rashes usually go away without any change in treatment. In a small number of patients, rash may be serious. If you develop a rash, call your healthcare provider right away.

Other common side effects include tiredness, upset stomach, vomiting, gas, and diarrhea.

Other possible side effects with ATRIPLA include:

- Changes in body fat. Changes in body fat develop in some patients taking anti-HIV medicine. These changes may include an increased amount of fat in the upper back and neck ("buffalo hump"), in the breasts, 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 fat changes are not known.
- Skin discoloration (small spots or freckles) may also happen with ATRIPLA.

Tell your healthcare provider or pharmacist if you notice any side effects while taking ATRIPLA.

Contact your healthcare provider before stopping ATRIPLA because of side effects or for any other reason.

This is not a complete list of side effects possible with ATRIPLA. Ask your healthcare provider or pharmacist for a more complete list of side effects of ATRIPLA and all the medicines you will take.

How do I store ATRIPLA?

- **Keep ATRIPLA and all other medicines out of reach of children.**
- Store ATRIPLA at room temperature 77 °F (25 °C).
- Keep ATRIPLA 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 ATRIPLA:

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

This leaflet summarizes the most important information about ATRIPLA. If you would like more information, talk with your healthcare provider. You can ask your healthcare provider or pharmacist for information about ATRIPLA that is written for health professionals.

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

What are the ingredients of ATRIPLA?

Active ingredients: efavirenz, emtricitabine, and tenofovir disoproxil fumarate

Inactive ingredients: croscarmellose sodium, hydroxypropyl cellulose, microcrystalline cellulose, magnesium stearate, sodium lauryl sulfate. The film coating contains black iron oxide, polyethylene glycol, polyvinyl alcohol, red iron oxide, talc, and titanium dioxide.

Rx ONLY

May 2007

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Monique; photo by Kevin McIntyre. Appearing in "Welcome Home Roscoe Jenkins" in theaters February 2008. See story on page 37

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A model, photograph, 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

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
- TRADE (Teachin', Reachin', Advocatin', Demonstratin', Empowerin')— 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

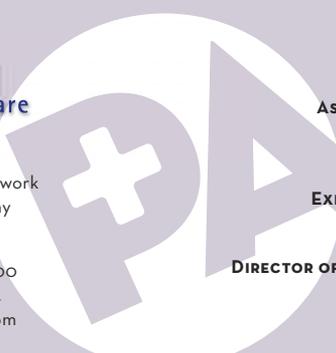
- Jackets Required
Sunday, March 9th, 2008
visit www.tpan.com
- Ride for AIDS
June 7-8, 2008
visit www.rideforAIDS.org
- Aware Affair Gala
Saturday, September, 13th, 2008
visit www.tpan.com
- Other Special Events

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



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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.

EDITOR'S NOTE



Why We Care

This issue has been one of the most enjoyable issues of *Positively Aware* that I have had the privilege to be a part of during my last four and a half years as editor. Throughout the process, I learned a great deal about how HIV has affected and drawn together people from very diverse walks of life. Some who are living with the virus in their bodies, and others for whom HIV has infected and ravaged their communities, their family members, and their friends. These individuals have decided to try to make a difference, in whatever way they can. HIV has stirred them to action, and no action is too small, or too trivial, to be counted.

On these pages you'll find just a small sampling, a minute cross-section if you will, of the countless, untold stories that unfold in the deadly wake of HIV. It's so vitally important to tell these stories, each and every one of them. No one, specific story is more or less important than another, and each one differs radically from the next. Some are inspiring. Others are bittersweet. And many, far too many, have ended in tragedy, loss, and heartache. But together they weave a tapestry of hope and light.

I'd also invite our readers to share with us your stories, or the story of someone you know, or knew, who has overcome adversity in the face of HIV. Someone whose strength, and courage, inspires you to carry on, and to have hope. Shoot us an e-mail at publications@tpan.com, or send us a link to your video on YouTube. We want to hear from you!

While putting the "finishing touches" on this issue I felt compelled to re-read some of the articles and musings in *TPANews*, the forerunner of *Positively Aware*. *TPANews* was the monthly newsletter of Test Positive Aware Network (TPAN), and one of the few sources of information for people living with HIV in Chicago in the late 1980's. This was before the advent of the Internet and the information superhighway (do they even call it that anymore?), and people depended on the newsletter to improve their health and survival, and to hear about how others overcame their own struggles.

It's always interesting to read some of these stories; I'm continually struck by how appropriate they are, even to this day. If you change some of the names, dates, and therapies being used, you wouldn't know that they were written 20 years ago.

So in keeping with the theme of this issue, I'd like to share with you an edited version of the following, which originally appeared in the December 1989 issue of *TPANews*.

Take care of yourself, and each other.

Jeff Berry
Editor
publications@tpan.com

IT WAS YOUR LOVE THAT GOT ME BY

Thom Hudson helped begin TPAN in the summer of 1987 and served on our first Board of Directors. In September of [1989], he spoke at TPAN during our program on "HIV and AIDS Anniversaries." That was four years after he learned he was HIV positive and 16 months after his first bout of pneumonia. After an autumn of mixed health, Thom died on October 19th [1989], surrounded by those he loved and who loved him. Here is a transcript of portions of his comments just five weeks earlier.

I was hospitalized this year from the 22nd of May to the 8th of June, with Cryptococcal pneumonia. At first, we thought it was Cryptococcal meningitis, which can be very bad if it gets into your spinal fluid and goes into your brain; but I guess when it got to my brain it starved and decided to retreat to my lungs. So everything turned out just fine even though I was very, very sick.

When I was in the hospital the drug that got me by was those of you here at TPAN. You know who you are. The cards and the letters and the visitations. It was your love that got me by; it wasn't

Photo © Russell McGonagle

any drug that they could give me; it wasn't any shot, any IV. It was love that got me by. And I sincerely mean that from the bottom of my heart.

During that time in the hospital, I was thinking; 'My AIDS diagnosis anniversary is June 1st 1988, when I first had PCP.' And it gave me some strength and made me think about different things. And it helped me make some decisions in my life that I needed to make and I changed a few things.

It seemed like a lot longer than a year. It seems at times I've been through a lot more than I have. And I really don't think I've been through that much. Others have been through some episodes that make us look perfectly healthy.

That was an anniversary time for me and I'm very glad that came about.

MY HIV TEST RESULTS

It was the beginning of '85 when my lover Dale was diagnosed with AIDS. I knew, then and there, that I was positive also. I previously had some symptoms, neuroplasia in my extremities and sheer exhaustion; many of us know what that's like. The NIH accepted Dale as part of the program and they asked me if I wanted to test. I did. Sure enough, I was positive in '85.

Lots of people have asked, "Is it like sitting around, waiting for something to happen?" Well, yes, but I never really dwell on it. And I didn't. I just kept going and doing everything I wanted to do. I travelled more. That's why so many folks don't see me and think I'm a millionaire because I'm always out of town. Don't talk about it, *do it*. Just get up, get on a plane, train, bus and *go*; you won't regret it. Any of you can do it.

It was this summer that slowed me down with the Cryptococcal pneumonia. In fact, while I was in the hospital Eastern Airlines went under. I knew that when I was in the hospital that this was going to be a little tougher than my first infection with PCP; and it was. It took a little more out of me than the PCP.

Many times I didn't attend meetings because I just didn't have the energy. You come home after trying to do different errands during the day and you're huffin' and puffin' after trying to get up the stairs. But these things you have to expect; you can't let them hold you back. Don't use them as excuses. There's no such thing as a good excuse.

TOUGH MEDICINE

I'm doing some chemotherapy for some KS lesions they found in my mouth. The hospital people said "Oh, you're not going to get sick with this." Sure. The first time, for a couple of days, they were right. The third day it hit and I was sick with nausea for a week. The second time I didn't have any nausea but I was just drawn out; I couldn't get out of bed for three days. I saw the nurses at the hospital today and they still looked at me and said, "You didn't get sick because of the chemo." So I said, "Then *you* take it next time."

Still, they mean well, and you learn that this is going to last 3 or 4 days and afterwards your energy picks up again and you're off and out and doing your errands, running round, doing whatever you can do.

You have to plan on these things. I know I can't take chemo and run off on a plane and visit because I just wouldn't enjoy myself. So, it's brought some organization into my life.

DRUG ADMINISTRATION

I have a port installed in my chest to make the administration of drugs a lot easier. There are different ones. Mine is a sub-clavian under the skin that we use for administering medications. When I got out of the hospital, I had to hook myself up every night to a very strong drug that would run through the night. Then I would unplug in the morning. But it's not as bad as it sounds.

I take vitamins and I've been part of the Megace study at Northwestern. It's a hormone that's allowed me to look a lot better because I was very drawn from loss of weight. It definitely stimulates your appetite and gives you the power and the will to eat. And believe me, it does work. Sometimes at 11:00 at night it just hits you and you want a pizza, *plus*, cookies plus this plus that. It's amazing.

I'M A BETTER PERSON

When I was HIV-positive, I did not live in dread. I figured, "Whenever it happens, it will happen." I think it helped me, it encouraged me. I still remember the day we knew Dale was diagnosed with AIDS, I turned to him and said, "For some reason I'm gonna be a better person by the time this is all through." And every once in a while he used to throw that back to me; "What do you mean by that?" And I'd say, "I don't know; I just feel that in my heart."

Dale only lived 18 months after his diagnosis. But I still believe that, because I know that's the way it is in my life. I mean, look at this! Look at all of us sitting here tonight. That's bad? No, that's good. Think of all the good, all the love here.

Everything that has happened to me in the past three or four years has made me a better person and it continues daily.

NUMBERS AREN'T EVERYTHING

I always like to mention this because deep down I'm really proud of it. There's quite a few of you here, in fact, whose mouths used to drop wide open when we talked about this: A couple years ago when I did orientation my T-cells were about 150. And some of you would come with your T-cells at 450 or 500 and you'd be frantic: "I'm gonna die next week!"

Get over it. Numbers aren't everything. I've had three T-cells for the last six months. I've named them after the Three Stooges: Mo, Larry and Shemp. (I always liked Shemp better than Curley.) It's what's up here in your head, and here in your heart that really counts. ✚

READERS FORUM



planning. They provide great case management and housing assistance, and substance abuse and other services to ex-offenders and their families. Addresses to contact for assistance:

Argus Community, Inc, 760 East 160th St., Bronx, NY 10456

Center for Community Alternatives, 115 East Jefferson St., Suite 300 Syracuse, NY 13202

William Lopez, 06A4146, Program Coordinator, PACE Program, Box 3600, Marcy, NY 13403-3600

NYC INMATE RESOURCES

The Prisoners for AIDS Counseling & Education (PACE) program here at Marcy Correctional Facility had another success with our yearly World AIDS Day event, held December 6, 2007. About 250 inmates participated in the event this year. We had some wonderful speakers join us. We didn't think they would be able to attend because of the weather, but a representative of one program from New York City, Argus Community, Inc., traveled five hours to get here and didn't let the conditions stop her from their commitment to help us. We were lucky to have deputy director Mrs. Dianna Diaz join us. They provide some unique services to those being discharged in New York City. Also, representatives of the Center for Community Alternatives were available to speak on the importance of HIV testing. Anyone being paroled to the NYC area should contact Argus Community for discharge

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

Fax: (773) 989-9494

E-mail: readersforum@tpan.com

WE ALSO INVITE YOU TO JOIN US ON MySPACE AT WWW.MYSPACE.COM/POSITIVELYAWARE ADD US AS YOUR FRIEND AND CHECK OUT SOME OF OUR OTHER COMMUNITY FRIENDS.

DON'T MISS OUT!



PA E-MAIL UPDATES

Sign-up today for our *Positively Aware* e-mail newsletter and receive timely updates on HIV treatment news and information.

Visit www.tpan.com and click on Subscribe to TPAN E-mail Updates, enter your e-mail address and click submit. Once you receive a confirmation e-mail, you can update your TPAN profile to include "*Positively Aware* Updates."

GET POSITIVELY AWARE!



M/A 2008

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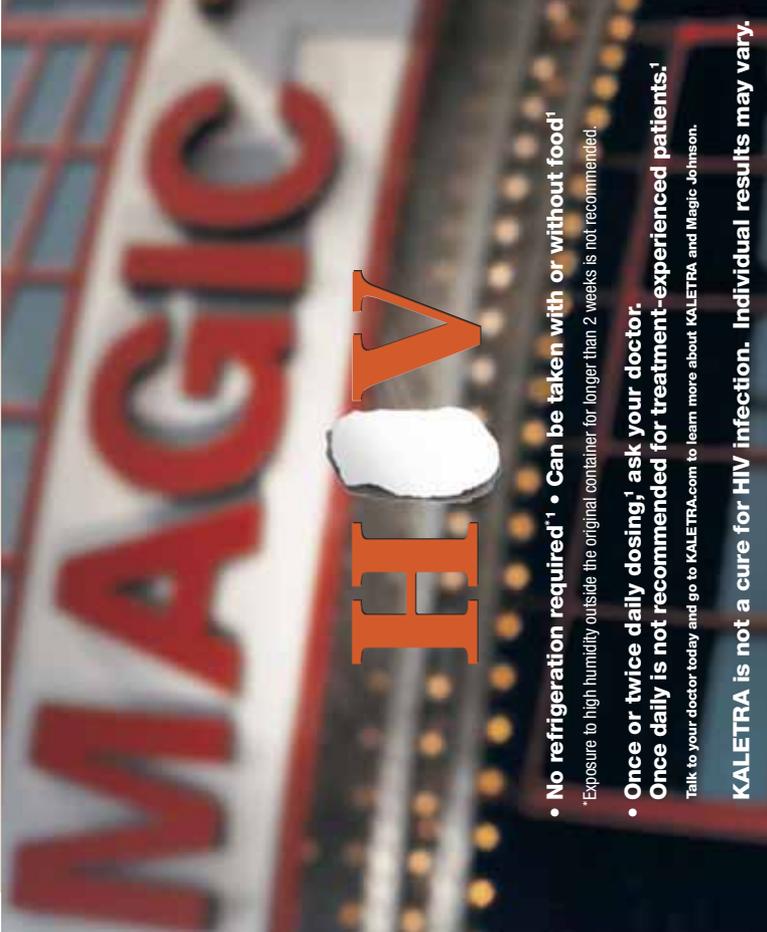
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Test Positive Aware Network (TPAN) is a not-for-profit organization dedicated to providing support and information to all people impacted by HIV.



- **No refrigeration required*** • Can be taken with or without food¹
 - **Once or twice daily dosing**¹ • **ask your doctor.**
 - **Once daily is not recommended for treatment-experienced patients.**¹
- Talk to your doctor today, and go to KALETRA.com to learn more about KALETRA and Magic Johnson.
- KALETRA is not a cure for HIV infection. Individual results may vary.**

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

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 Information

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 Verso® (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 Mavacor® (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® (nevirapine), Agenerase® (amprenavir), fosamprenavir, Viracept® (nelfinavir), phenobarbital, phenytoin (Dilantin® and others), Vireamune® (nevirapine), Agenerase® (amprenavir), 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®.

**I am still me
I take KALETRA
as part of my regimen.**



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.

*KALETRA Prescribing Information

Please see important patient information on adjacent page.
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.
1-866-KALETRA (525-3872)

**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 methylergonovine 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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NEWS BRIEFS

by Enid Vázquez



FDA GRANTS APPROVAL FOR INTELENCE

The U.S. Food and Drug Administration (FDA) in January granted accelerated approval to Intence (etravirine), or TMC-125, the first non-nucleoside reverse transcriptase inhibitor (NNRTI) proven to be effective in people who have developed resistance to the other drugs in that class (Sustiva and Viramune).



"NNRTIs have been used in HIV combination therapy for more than a decade, but their use has been limited by cross-resistance within the class. Resistance to one NNRTI generally meant resistance to all NNRTIs," said Richard Haubrich, M.D., Professor of Medicine in the Division of Infectious Diseases at the University of California, San Diego. Haubrich was also an investigator in the Phase III DUET studies of the drug. "Etravirine breaks new ground in the NNRTI class, and provides a new option to thousands of treatment-experienced patients with NNRTI-resistant HIV."

Intence was studied in clinically advanced, treatment experienced adults and is approved for people within this group who have a detectable viral load and virus that is resistant to an NNRTI and other HIV drugs. The most common side effects of any intensity in the studies of the drug were rash and nausea.—Keith R. Green

RAPID TESTING IN THE COMMUNITY

A third of the almost 24,000 individuals being tested for HIV in a community outreach project were taking the test for the first time in their lives. The project was part of the efforts of the U.S. Centers for Disease Control and Prevention (CDC) to decrease the number of positive people who are unaware of their infection, estimated by the CDC to be 25% of all people living with HIV in this country. Findings of the project were published in the November 30, 2007 issue of the CDC's *Morbidity and Mortality Weekly Report*.

Rapid testing and referral to medical care was conducted in eight community-based organizations (CBOs) in seven cities—Boston, Chicago, Detroit, Kansas City, Missouri, Los Angeles, San Francisco, and Washington, D.C. (Here in Chicago, testing was done through a mobile unit of the Night Ministry.) Sites used for testing in either mobile units or inside were deemed used by high-risk people, including parks, shelters, and syringe exchanges. Of the 267 individuals testing positive for HIV (1%, same as other CDC testing sites), 200 returned for a confirmatory test result. The most common reason given for not providing a confirmatory test to the other 67 persons is that they could not be found.

"These results suggest that rapid HIV testing in outreach and other community settings can

effectively target substantial numbers of persons at high risk for HIV infection," editorial comments to the report noted. The commentary also suggested that people with a preliminary positive test result for HIV can be immediately referred to medical care without waiting for confirmatory results.

NEW DRUG TARGETS

Harvard researchers reported finding more than 200 proteins that HIV uses to infect people. That's 200+ targets for new HIV medications. One media report quoted one of the researchers as saying that medications already existing which affect these proteins may be able to fight the virus. Whether medications that can hit these targets exist or not, it will take a long time to see any effective drugs for HIV. At any rate, progress is good. The report was published in the February 8 edition of *Science*.

PHYSICIAN ASSISTANCE

The outstanding *AIDS Clinical Care* newsletter, written by and for HIV medical providers, now offers a free daily e-mail alert reviewing medical news affecting HIV care. Providers can go to jwatch.org to sign up. The newsletter is from the publishers of *Journal Watch* and the *New England Journal of Medicine*.

ABSTINENCE AND CONDOMS

Speaking of *AIDS Clinical Care*, kudos to Associate Editor Carlos del Rio, MD, of Atlanta's Grady Hospital, for a witty turn of phrase in his editorial comments. Looking at study results showing that abstinence programs do not effectively prevent risks from sexual contacts here in the U.S., he noted that, "In the end, abstinence vows break more than condoms do!"

100 QUESTIONS & ANSWERS ABOUT HIV AND AIDS

This new book by *Positively Aware* contributor and internationally recognized HIV expert Joel Gallant, MD, MPH, of Johns Hopkins University, provides answers to many of the most common questions asked by people living with HIV/AIDS, their partners, and family members. Written in easy to understand lay language, this is an invaluable resource for those living with HIV as well as those who care for them. Also included is commentary by two HIV-positive individuals, as well as information on testing and prevention. Available at most bookstores and online booksellers; or call (800) 832-0034. Visit www.jbpub.com. —Jeff Berry

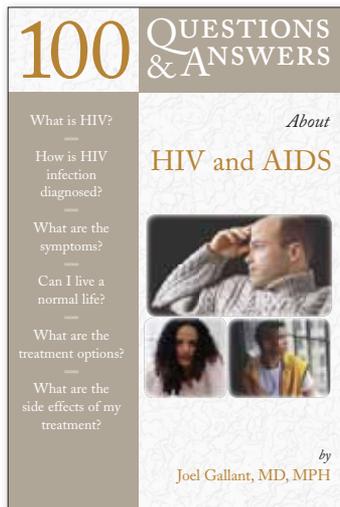


Photo © Russell McGonagle

ASK THE
AAHIVM
HIV
SPECIALIST™



Tonia Poteat, AAHIVS

IT'S A FAMILY AFFAIR

My late husband developed AIDS and died five months after being diagnosed with HIV. We have one four year-old child, and my child and I tested negative for HIV after my husband was diagnosed, and I have not had sex with my husband or anyone since that time. The last time I was tested was six months after my exposure, and I tested negative with both the ELISA and Western Blot tests. My doctor says I am most likely negative but advised me to check again after six months, a year after my exposure.

Is there any chance of becoming HIV-positive after the sixth-month window period?

Is there any chance of ELISA or Western Blot tests falsely indicating no HIV infection because of certain body conditions?

Are there other HIV tests that could confirm my HIV status?

I have not had my child tested since I was testing negative. Should I? How safe is my child now from HIV?

Are there other couples where one party is HIV-infected and the other is not? Is there a medical reason why I am not infected?

Dear Family:

As your doctor mentioned, 99% of people who have been infected with HIV will test positive within three months after their most recent exposure. In very rare cases, a few health workers did not test positive until 6–12 months after exposure. If you have had

repeatedly negative HIV antibody test results for one year after your most recent exposure, then no additional tests are needed. However, this negative test result does not prevent you from becoming infected by another partner at a future date! Your four year-old child does not need additional HIV testing unless he has been exposed to HIV-infected fluids such as blood, semen, or vaginal secretions within 3–6 months before his last test or any time afterwards.

In order to receive a positive HIV test result, one has to test positive on both ELISA and Western Blot. The ELISA may have a false positive result if a person has other medical conditions. There are no known medical conditions that cause false negative ELISA results. However, HIV antibody tests done using oral swabs may give false negative results if not administered properly. Once someone tests positive on the ELISA, a Western Blot is done to confirm the results.

There are many couples in which one person has HIV and the other does not. One famous example is former NBA basketball star Magic Johnson and his wife Cookie, who remains HIV negative after many years of marriage. The average risk of transmitting HIV during one episode of vaginal sex is much less than 1%. Therefore, while any exposure can lead to infection, every exposure does not lead to infection.

Tonia Poteat, MMSC, PA-C, MPH, AAHIVS, has been providing medical care to people with HIV since 1996. She currently works as a physician assistant at the Grady Infectious Disease Program in Atlanta, Georgia.

Photo courtesy of Tonia Poteat

Ask The HIV Specialist

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

HELPFUL ONLINE RESOURCES INCLUDE:

- **HIV Insite testing information:**
<http://hivinsite.ucsf.edu/hiv?page=basics-00-18>
- **San Francisco AIDS Foundation:**
Testing and transmission links
http://www.sfaf.org/aids101/hiv_testing.html
<http://www.sfaf.org/aids101/transmission.html>
- **The Body—Caring for the Caregiver:**
<http://www.thebody.com/content/art32361.html>

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LOOK FOR THE LETTERS

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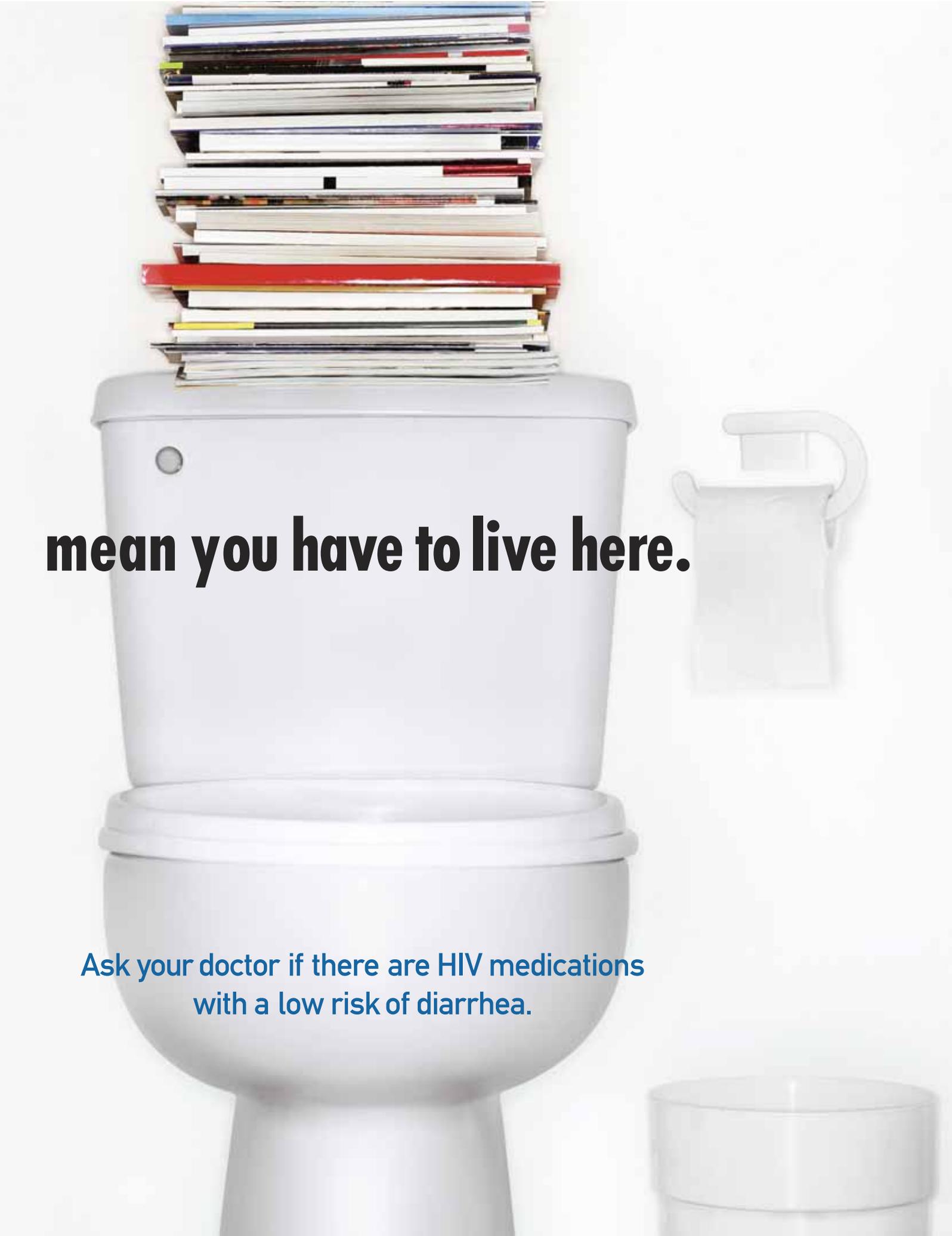
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Due to the space limitations, all submitted questions cannot be answered in this column but we are making every effort to ensure you receive the information you have requested from the HIV Specialist™. For more information about AAHIVM, call 202-659-0699

Living with HIV doesn't



mean you have to live here.

Ask your doctor if there are HIV medications
with a low risk of diarrhea.



MATTHEW CUSICK

—PERFORMANCE EXTRAORDINAIRE

Patrick Dempsey, in the feature film *Enchanted*. He currently performs for the New York Metropolitan Opera as a supernumerary, appearing in scenes which require an acrobatic element or other non-singing roles.

“I love the feeling of being onstage, performing in front of an audience,” says Cusick. “I never get nervous, or have to go backstage and throw up or anything.” Thousands looked on as he gave a powerful, four-act *tour de force* during the opening ceremonies of the Gay Games in Chicago in 2006. The theme of the exquisitely choreographed numbers dealt with overcoming adversity, which closely mirrored his life up to that point.

Born in Alexandria, Virginia, Cusick, 36, was the youngest of four children, with two brothers and one sister. His father was a U.S. Park Service policeman, his mother a homemaker, and the family moved around quite a bit during his childhood. Cusick began studying gymnastics when he was only five years old, but stopped at the age of 18, mainly because he was too tall to compete—over six feet—but also because by then he needed a break. “I was basically pushed out by my coach, who was really tough on me, and expected me to live up to his own standards, not just the USA Gymnastics standards,” says Cusick. After that he went on to coach and train other gymnasts for several years. Although he was a tough coach himself, he says his girls loved him, and he still keeps in touch with some of them to this day.

Cusick learned he was positive at the age of 22, prior to the advent of protease inhibitors, so he really didn’t think he’d be around this long. He began HIV therapy about five years later, and

By now you’ve probably heard the familiar story of gay gymnast Matthew Cusick, fired by Cirque du Soleil in 2003 because he was HIV-positive. Cusick, at the time training for the Las Vegas show *Mystere*, had disclosed to Cirque his status eight months earlier, when it came up in discussion during a routine checkup. He continued training until one day he was called into the office and abruptly fired, solely on the basis of being HIV-positive. Cirque officials informed him that he was considered a health risk to fellow employees, performers, stagehands, and even the audience. Cusick enlisted the help of LAMBDA Legal, sued and subsequently won a landmark federal antidiscrimination lawsuit, based on the American with Disabilities Act (ADA), which prohibits discrimination by employers against people with disabilities.

What you may *not* know is that Cusick recently appeared alongside gay icon Susan Sarandon and big and small screen heartthrob

Photo © Bob Olayas, courtesy Gay Games VII



A victory for all

by Jeff Berry

is now doing quite well. Currently single, he lives and works in New York City. When he's not at the Met, you'll find Cusick and his performance partner Ken Berkely, a National Sports Aerobics Champion, touring in their handbalancing act, KENiMATTix.

Following the Cirque lawsuit, fearing he'd been blacklisted, Cusick was unsure whether he'd ever work again. However, in 2004 Cusick was once again able to show his true colors, and much more, at Broadway Bares, a one-night event produced by Broadway Cares/Equity Fights AIDS, which has raised millions for HIV/AIDS organizations nationwide. Appearing in Broadway Bares, two years in a row, was a very self-affirming experience for Cusick. Contrary to being blacklisted, he now found himself embraced by the very community for which he had gone to bat.

Steve Villano, director of Cable Positive, the AIDS action organization of the cable industry, describes Matthew as a very inspiring person. "He is so upfront, and doesn't exaggerate things. He's a courageous example of what one person can do to change how a company responds to HIV-positive individuals." Cable Positive recently produced a short video documentary on Matthew's plight which aired on the Sundance Channel. "He won an enormous victory," continues Villano, "not only for himself, but for a lot of people around the world."

As part of the settlement, Cirque was required to change their policy, and to implement one of the largest, annual company-wide education programs in the country. Cusick continues to travel around the country, speaking to audiences about his experience, in hopes that something like this never happens again.

When asked why he ultimately chose to fight back, Cusick replies, "I just didn't want anyone else to go through what I went through." ✚

To learn more, visit www.kenimattix.com, www.cablepositive.org, and www.lambdalegal.org.

CHICAGO TAKES OFF

Keith Elliott and Todd Kiech are producers of this year's Chicago Takes Off: *Under A Big Top*, a circus-themed event with fun burlesque performances. The event, which took place on Saturday, February 9th at the Park West Auditorium in Chicago, this year added a second show, and highlighted the finest assets of Chicago's professional dance and theater communities.

"We're excited to be producing a successful fundraising event for TPAN," said Keith Elliott prior to the evening's two sold-out shows. "The performers are ready to strut their stuff again this year for *Under A Big Top*. It will definitely be a circus-themed event like you've never seen before."

"The producers and committee are working hard to raise HIV awareness and support for TPAN," said TPAN's executive director Rick Bejlovec. "This event provides funding to continue offering innovative programs and services to our clients."

For more information on Chicago Takes Off visit www.tpan.com.

Dazon Dixon Diallo

—Sisterly Love at its Best



Helping those in need

by Keith R. Green

Dazon Dixon Diallo was working towards a B.A. in English and Communications at Spellman College when she was drawn into the work of HIV/AIDS.

The year was 1985. True to the nature of students who attend Spellman and other historically Black colleges and universities, her commitment to community service occupied most of her free time. She was actively involved in the women's reproductive health movement, volunteering regularly at a local clinic in Atlanta.

Shortly after Rock Hudson announced to the world that he had AIDS, the clinic where she worked received a disturbing call from a local AIDS service organization (ASO), a call that would change her life forever.

Because AIDS had been labeled "the gay plague," most, if not all, of the services and information regarding the disease was geared towards gay men. The people at the local ASO, then, found themselves clueless as to how to handle the flood of phone calls that they were receiving from newly-

diagnosed Black women. As a result, they called upon women in the community who were already working with women's health issues, in some capacity or another, to help them to figure out this emerging crisis. That was Dazon's introduction to what became her life's work. At the time, however, she was clueless as to just how politically driven that work would become.

Long story short, the women's organization she was volunteering for teamed up with that AIDS service organization to create and implement HIV/AIDS prevention and support programming for women. Then one day, as a result of what she calls "CBO (community based organization) political upheaval," all of the female volunteers and staff at the ASO simply walked out, at the same time.

In an effort to salvage what they had helped to establish (the first and only HIV/AIDS program for women in Atlanta or anywhere in the southeast at that time), Dazon and her colleagues from the women's clinic decided to take on the program themselves.

Relocating it was a challenge that, like so many others, they overcame. She would soon learn, though, that the politics involved in the work would be inescapable.

HARD WORK

Although the numbers clearly demonstrated the need, funding for HIV/AIDS services for women was tough to come by in the late 1980's. And, with Ronald Reagan as president, funding for anything that had to do with abortions, including the clinics that provided them, was even more scarce.

The clinic that Dazon worked for was organized by mostly white, middle-class, pro-choice feminists. Their primary focus was reproductive health rights and not necessarily the increasing number of Black women living with HIV/AIDS. Therefore, when funding really became an issue, the HIV/AIDS program that they offered (the only one like it in the entire region at that time) was the first of their programs to get the ax.

Understanding the need, Dazon remained steadfast in her desire to be of



Photos courtesy of Dazon Dixon Diallo

service to women with HIV, Black women in particular. With the support of some of the others who had also been involved, she opened up her home to provide space for the program. From there, SisterLove, Inc., was born.

Realizing that the program was lacking in the area of cultural sensitivity, the collective of women began to incorporate Black feminist theory and the “self-help” model created by the National Black Women’s Health Project into the program. Their primary objective was to empower Black women to take charge of their own lives, in order to stop the spread of HIV. SisterLove became one of the few places in Atlanta where HIV-positive Black women could go for support and comfort and, oftentimes the only place they could go for love.

In time, though, the program grew too large for the bedroom in Dazon’s house that it once comfortably occupied. Eventually, and somewhat to her dismay, SisterLove made the transition from a grassroots collective to a more sophisticated operation,

offering a wide array of services for women and children.

“I didn’t realize that I would have to literally build a business from the ground up,” she says. “All I wanted to do was provide services to my community. I got in this to bring some solutions to some serious problems, not to worry about grants and funding or whether or not I’m going to be able to make my payroll.”

But she does what she has to do, and she does it well. She even found time, somehow in the midst of all that she does, to return to school to obtain a masters degree in public health (MPH).

Realizing the interconnectedness of women’s reproductive health issues and HIV/AIDS, services at SisterLove now extend beyond HIV prevention and care to more fully address the entire Black female experience—regardless of HIV status, age, sexual identity, or country of birth.

Today, SisterLove operates two locations in Atlanta and one in South Africa, doing capacity building work with small, grassroots organizations that were already

doing tremendous work in that country, but lacked the infrastructure and/or the resources necessary to sustain it.

SOUTH AFRICA

Their most recent project is called the Thembuhlelo Trust Cooperative. Thembuhlelo is Swahili for “trust your own program.”

Essentially, SisterLove organized a formal trust of three non-government organizations (NGO’s) in a region about 90 miles east of Johannesburg, who were doing either home-based care, orphan care, or youth prevention work. Those three organization identified 60 individuals, who are either volunteers or recipients of services, to work collectively in a cooperative.

SisterLove worked with the South African government, on behalf of that cooperative, to purchase a 700-acre dairy farm. They then transferred it into the trust and trained those individuals to work it—from the chickens and cows to the management and marketing.



from whom they bought the farm initially tried to sabotage it, telling people in the community that it was being run by “those AIDS people.” The people in the community, however, are very poor. And because there is such a demand for necessities as basic as milk and eggs, they could care less about who’s running the farm. They come to purchase these goods there for nearly half the price that they would pay for them at any of the nearby stores and, at the same time, learn how HIV is and is not transmitted, as well as how to access services.

BACK HOME

While she is fully invested in the work that SisterLove is doing in South Africa, Dazon is always thinking of ways to transfer what she’s learning and doing there to assist with curbing the epidemic here in the U.S.

“The problems are not that different,” she says. “[In both locations,] you have women who are vulnerable or who are not able to get the treatment and care that they need because they are economically dependent or depressed.”

At press time for this issue, SisterLove was in the process of establishing a women’s focused cyber center for low-income women and their families in Atlanta.

“How do people get their information these days?” Dazon asks, and then answers herself. “Through e-mail. And so what happens if you don’t have e-mail? Or if you can’t read, for that matter? You miss out.”

With the cyber center, she hopes to eliminate the “digital divide” barrier, while continuing to create safe spaces for women to learn and grow and to take charge of their own lives, always staying true to her original purpose for becoming involved.

In her spare time, she teaches in the MPH program at Morehouse School of Medicine. She is also a member of the adjunct faculty at Spellman College in the Women’s Studies Program. As if she doesn’t have enough to keep her busy, Dazon is also the producer and host of a weekly Black women’s radio program known as *Sista’s Time*, which she affectionately calls an “audio magazine featuring the life, health and cultural issues of women of African descent and those who love us.”

With so much sistalove exuding from this woman and others like her, who in their right mind couldn’t love them. ☒

“It is an HIV/AIDS project,” Dazon says, “but it involves land ownership, income generation, economic empowerment for women, and making sure that the people, in this community at least, have access to all the care and treatment that they need.”

The project has ignited a spark for the Department of Land Affairs there, as they are trying to figure out how their efforts at land redistribution might have a lasting effect on alleviating HIV/AIDS and poverty as well. The Thembuhlelo Trust Coopera-

tive has been named a pilot project for them, with SisterLove helping to re-create it in different areas throughout the country.

“This is really important stuff,” Dazon says with great excitement. “It’s returning the land back to the people from whom it was taken illegally. And it’s about being innovative with how you approach HIV/AIDS beyond healthcare.”

Thembuhlelo has also been successful at helping to diminish the stigma that is associated with the disease. The farmer



Photos courtesy of Dazon Dixon Diallo

Evelyn Hernandez Valentino

-No Longer Alone in the Desert

One woman's quest to raise awareness

by Enid Vázquez



She has a kind voice with gentle words. She is honest and open. The image that comes to mind is “*sincera*”—sincere, which along with “*humilde*” (humble) is a highly valued trait among Latinos.

Evelyn Hernandez Valentino is humble enough to pick up the phone herself rather than let it go into voicemail, even though she founded and directs the non-profit agency Working Wonders in the desert land of Southern California. Besides, the agency's staff of three is down to two, plus volunteer speakers and educators.

“Working Wonders” alludes to her strong faith in God. She turned to that faith and prayed for guidance, and Working Wonders was born. She loves the fact that her agency is located in Cathedral City. “This is my purpose in life,” she said.

That's a blessing for a woman who came to California not knowing if she was going to live or die.

Evelyn Hernandez grew up in an impoverished Puerto Rican community on New York City's Lower East Side, raised by her mom and alcoholic father, who “managed to get well,” she says in her bio. “[My] family struggled financially but always managed to make ends meet,” she wrote.

Later, as a young adult, she developed a passion for advocating for those who are less fortunate. Her advocacy career led her to a position on the staff of New York State Assembly Speaker Sheldon Silver.

Two years into her state advocacy job she married her longtime boyfriend in 1993 and two weeks later, he learned he was HIV-positive. Hernandez Valentino expected her own test results to be just fine, but they weren't. She also tested positive. Worse, her husband quickly became ill and died later that year. She was a bride and a widow in the same year, at the age of 29.

She continued to hold down her job, but her experience helps her to understand the needs of the positive women she serves today. Like herself, she said, women often don't recognize the HIV risks in their lives. (After her husband's diagnosis, he realized he was at risk by sharing needles for steroid use in his gym.)

She came to Los Angeles in 1998 when her health was poor, and where she had family members who could help take care of her. Two brothers already there had urged her to move from New York. She spent a couple of years doing legal advocacy for Crystal Stairs,

a non-profit child care resource and referral agency, but that time included a medical leave. After moving to the nearby Palm Springs area in 2000, she joined several committees where she could advocate on behalf of people living with HIV, but came to feel that there wasn't enough work being done on behalf of women, children, and families. It is also where she met the man she is still with today, in a “very loving relationship,” she wrote, after expecting the worst when she disclosed her HIV status.

A pharmaceutical representative in the area, a gay man, said that at first the gay community felt threatened by Hernandez Valentino and her quest to establish her own agency, which would compete for funding with existing work being done in the GLBT community, but came to accept her, including recognizing her by giving her a seat of honor in the local Pride parade. He urged *Positively Aware* to tell her story.

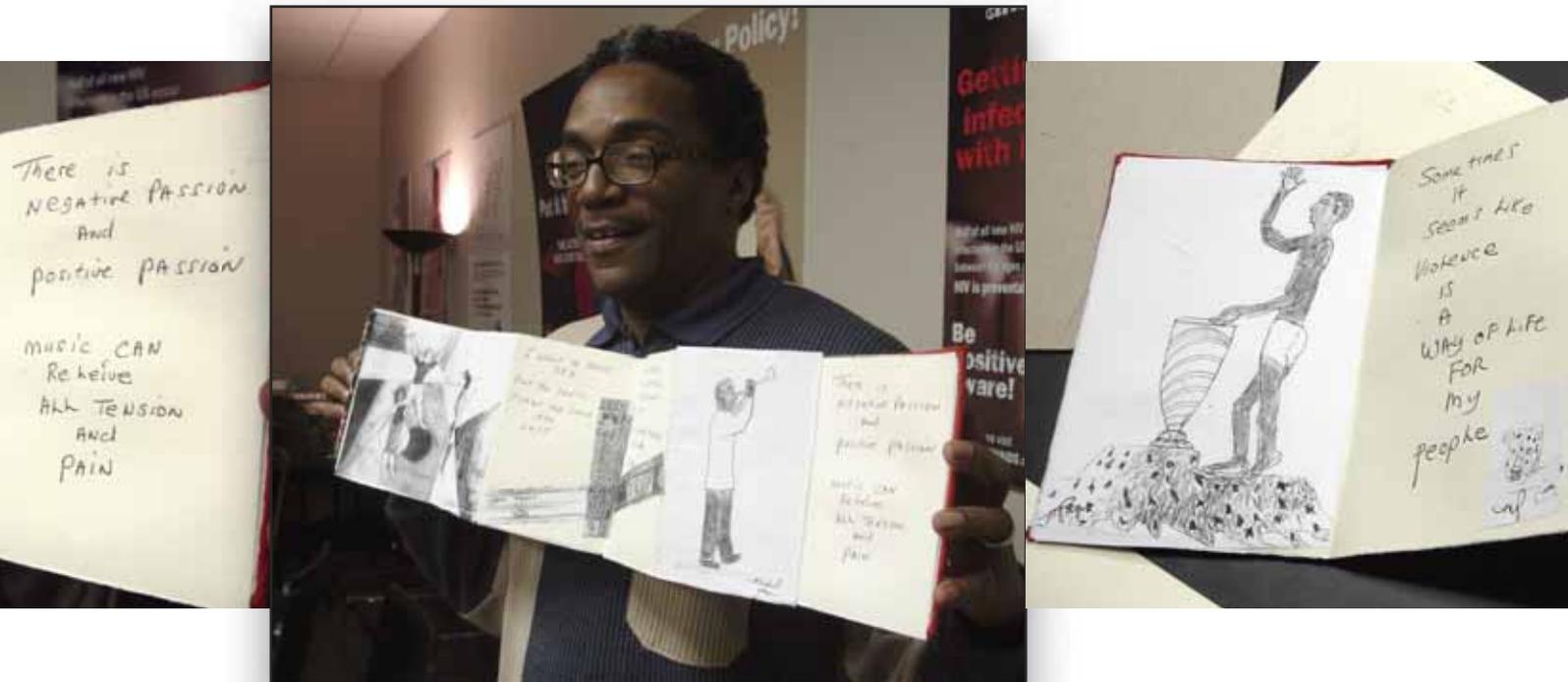
Through Working Wonders, women and youth hear about HIV and risk. Speakers go out to schools and community forums and tell their story about living with HIV. If attending a forum or workshop at Working Wonders, women can leave their children in the agency's play room. Recently, the agency received the green light to talk to 7th graders in the public schools, kids who are 13. This is the first time that adolescents this young in this region have been allowed to hear a presentation on HIV, said Valentino Hernandez. She estimates that they have reached 3,500 individuals in the past 24 months.

“We address issues that affect women: domestic violence, dating violence, survival sex,” she said. “We see everyone as potentially at risk. We have an open discussion about forced sex, economic dependence, negotiating safer sex and other things women need to know.” ☒

Photo courtesy of Evelyn Hernandez Valentino

MICHAEL PAYNE

- SAVED BY THE ART



When I heard about the bookbinding workshop here at TPAN, I thought it was about writing mini-diaries, but it ended up being much more.

I suffered from lipoatrophy [facial wasting] for years. We gay men are very concerned about our appearance and I was very depressed. I was seeing a shrink when we did the bookbinding workshop.

When I did the book, I didn't expect people to react to my art the way they did. It was more than a therapeutic stress reliever. The whole experience for me was divine intervention. It was like God saying, "Look, you have talents you could be using. Stop focusing on that [problem] and focus on your gifts and everything else that you're blessed with."

It got me thinking about art and doing something with it.

Jesús [Macarena-Avila, the instructor] had asked us to collect photography or pictures from magazines that reflected something about who we are. Then we were to merge pictures into this little book that we made.

I have hundreds of sketches and paintings just sitting in my closet collecting dust. I also keep a diary of what I call profound thoughts, constructed while daydreaming. I pulled some thoughts

from my diary that seemed to connect as a caption to my drawings, then I incorporated them together. The question was how to do this without destroying the original artwork.

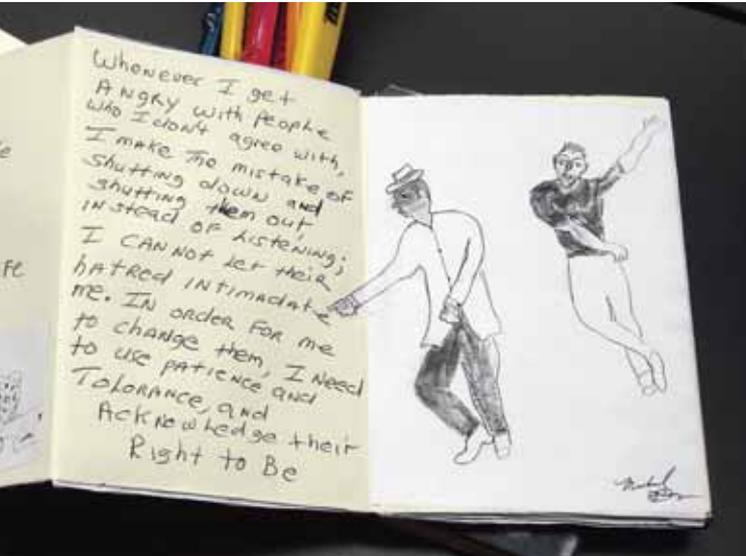
Jesús came up with a great idea. Why not Xerox the artwork, then condense the copies so they could fit into the small books? The results even amazed me.

I don't have time to focus on the lipoatrophy any more. I've been pulling out my art little by little and as I can afford it, I've been framing it. I'm on a fixed income and it may take a year, it may take a couple of years, but my goal is to get all of it framed. It's become like a child to me. Maybe a hundred years from now, it can be a part of me that survives.

I realize, wow—I really like what I did; it's really good. I just didn't have the self-confidence to pursue it more. This has made me re-evaluate my whole life. It's like when I was first diagnosed, in 1995, and I thought it was the end of the world. I was told I had three years to live, and was very depressed.

I have an upcoming consultation on surgery for my lipoatrophy, but I don't care what I look like any more. I don't want to focus on that. I'm too busy trying to accomplish things now. ☕

A REDISCOVERED
TALENT CHANGES
ONE MAN'S LIFE
BY MICHAEL PAYNE



ART FEEDS THE SOUL: BOOKMAKING WITH TPAN

by Jesús Macarena-Avila

Last October of 2007, I had the pleasure of working with Brothers United in Support (BUS) at Test Positive Aware Network (TPAN). It is often believed that creativity feeds the soul, but I believe it builds community as well.

I led four art workshops with BUS. I had entitled this project "Let Us Talk: Pictures and Stories" to explore personal histories of BUS members through making their own "one-of-a-kind" books. We learned professional bookmaking skills and discovered what an "artist book" is. It looks like a book, but we use a codex or accordion-like book format; each book had an original idea by a BUS member using drawn images and pictures to tell their stories. We were able to exhibit several copies at a branch of the Chicago Public Library.

In each session BUS learned and used different art techniques such as beadwork, collage, drawing, and of course, creating their very own book. During the workshops, we discussed how art or the human expression can sometimes give us strength, or at least an outlet to relieve stress. We also had some "show and tell" sessions for budding artistic inspiration.

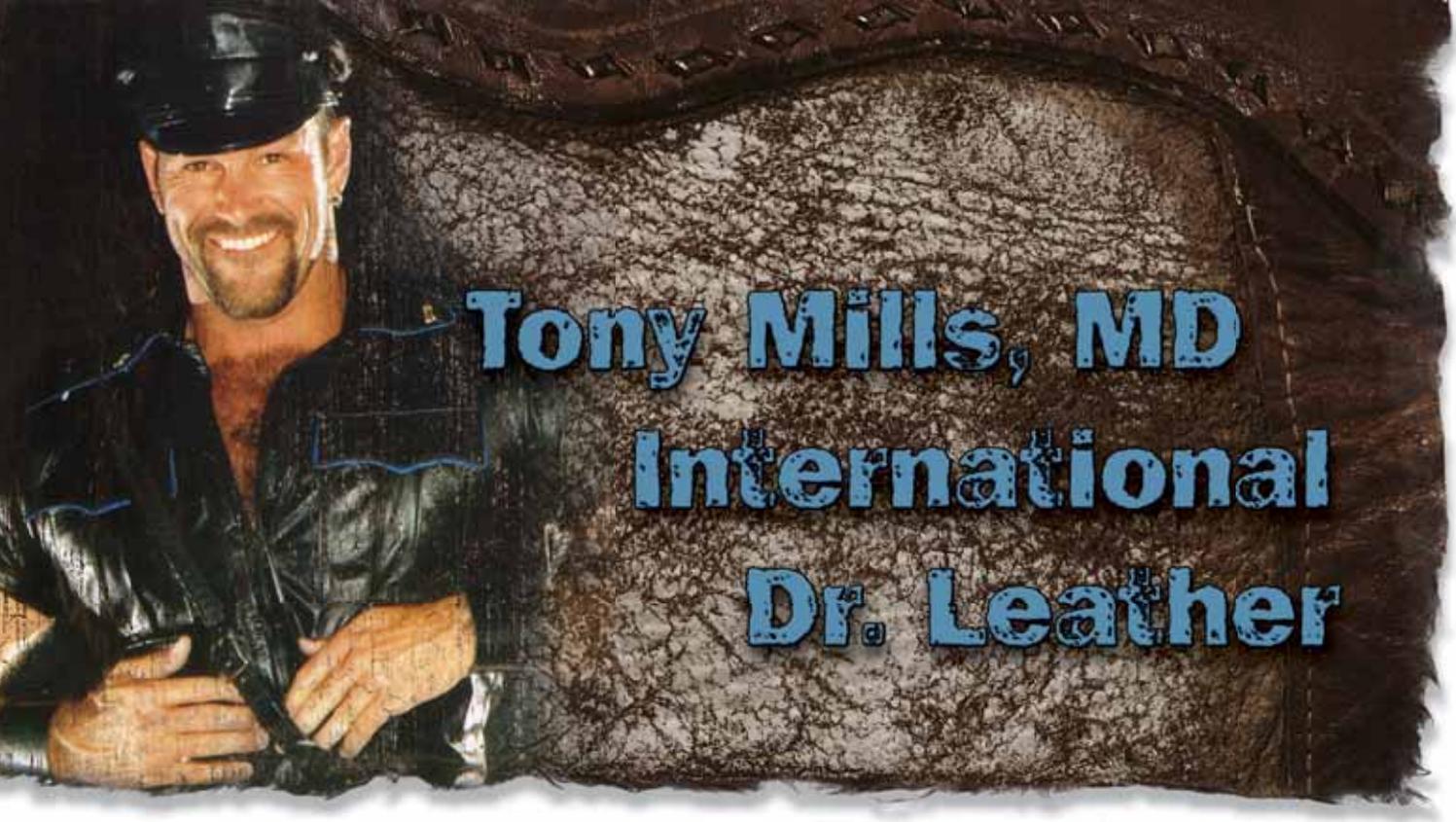
At the last session, BUS members held their monthly social event and shared completed books talking about their life. Memory played a big role in their stories. Some used actual pictures of their family and friends and others used original poetry. Maya Angelou once wrote, "There is no greater agony than bearing an untold story inside of you."

Jesús Macarena-Avila is an arts educator working with Chicago's communities since the early 1990's. He is a faculty member with Columbia College Chicago's Liberal Education Department and exhibits his community-based and studio artwork in the city of Chicago and abroad.

BUS is a TPAN support group for HIV-positive gay and bisexual men of African descent. BUS meets every Thursday at 7:30 p.m.

Special thanks to the Critical Encounters program of the Center for Teaching Excellence at Columbia College Chicago for funding the "Let Us Talk: Pictures and Stories" workshop at TPAN.

Photos by Enid Vázquez



Tony Mills, MD

International

Dr. Leather

In 1999, Tony Mills opened his practice in Los Angeles specializing in HIV care. Mills says the trends in care today are probably 90 degrees opposite from what he saw then, and 180 degrees from 1985, when he began his first practice in San Francisco.

“Going to work, in that clinic in 1985, was so hard because everyone I diagnosed got sick, and I didn’t have anything to offer anybody. I was just starting off my career in medicine, and I had gone into medicine because I wanted to help people,” says Mills. “There I was, at the beginning of the whole HIV thing, and I thought ‘God, I really need to do HIV work.’ But then when I started doing it, it was so difficult, because I would look at these people who were my peers, and give them the diagnosis, and see them die within a year.”

When he found out that he himself was positive in 1987, it was like looking at his own mortality every day, and psychologically he just couldn’t do it, it became more than he could handle. So he went back and trained and practiced in anesthesiology for about 10 years. “And I loved doing it, but I always felt like I had failed, that I wasn’t strong enough to be an HIV doctor, and that was really what I was supposed to do. In ’99 I finally made the decision that this was what my life was supposed to be about and I wanted to give this a shot, and so I moved out to L.A. and opened a practice out here.”

Mills is open about his own status with his patients, and has been since the mid-nineties. In 1998, he won the International Mr. Leather (IML) contest in Chicago. “When I did the IML stuff,” says Mills, “for me that was really emotionally about the fact that I had just gotten on a triple drug combination in 1996. My virus had been suppressed to undetectable levels, and my T-cells, which had been at 35, began moving up from there. I started feeling better, and gaining weight, and exercising more, and thinking about going back to work, and I wanted to carry that message to other people—that there was hope.”

When asked if he feels being positive gives him any special insight, whether his patients can perhaps trust him more, Mills replies, “I think they do trust me more—I have patients who come and see me from all over the world. I always tell them, ‘Look, I have a lot of friends out there, that are really good HIV specialists in your city.’ But they come to me for a variety of reasons. They come to me because they want to see a gay man, and they can’t find a physician in their city who’s gay and can understand them. Or they may come to me because I’m positive. Or they may come to me because of my experience in the leather community, and that’s an aspect of their life that they think is important, or they don’t feel comfortable talking to their doctor about it, and they need to be able to talk about their behaviors

and the risks that are involved there, and what precautions they need to take.

“So all of those things that I had fear about in the past that might keep people from coming to see me are now the things that actually bring them to my office, and make them feel comfortable there, and make them feel like I understand, and they can really open up and talk to me about who they are.”

Mills believes in order to provide the best possible care it’s as important to understand his patients’ psychological health as it is their physical health. And he firmly believes that providers need to be comfortable having frank and open dialogue with their clients about risk behaviors and recreational drug use. He says that sometimes it’s easier for providers to not delve beneath the surface and talk about what’s really going on with their patients.

“One of the most exciting groups that we have meeting in L.A. is the HIV-positive over 50 group. There’s a waiting list because there are all these guys out there who find it’s hard to connect with people, for whom disclosure is still an issue, and some of them have been on medications that have long-term side effects. And aging is compounding the lipodystrophy effects that we got from the medications, and it’s a difficult situation to face.”

While he sees a lot less lipodystrophy in his practice today, and doesn’t even consider

The journey of an HIV-positive provider

by Jeff Berry

it a real problem, Mills admits that's probably because he lives in L.A., where they've been on the cutting edge of cosmetic treatments over the years. Southern California was also very early to jump on the bandwagon of getting people off of the offending agents, such as Zerit, and making changes in people's regimens. "When I travel to talk to people in locations in the middle of the country or in more rural areas, I'm always shocked when I walk into a room full of HIV-positive men in Kansas, and I see the ravages of lipodystrophy. But in L.A., and I think in New York and Chicago, and the big areas where physicians are more keyed into the issues, I think it's becoming less of an issue. I think the new drugs are definitely less toxic, we understand which ones tend to cause the lipodystrophy, and which ones are safer. I really believe when I start patients on a new regimen, certainly my naïve patients, I can start them on a regimen that has a low incidence of side effects."

In New York City in the 1990's, Mills regularly attended a group for HIV-positive physicians who came together for support. Today, they all kind of know who each other are, but he's continually surprised by those who he may have known for years, who come in to see him and are HIV-positive. "It's really a burden, to have to carry that around by yourself for so long."

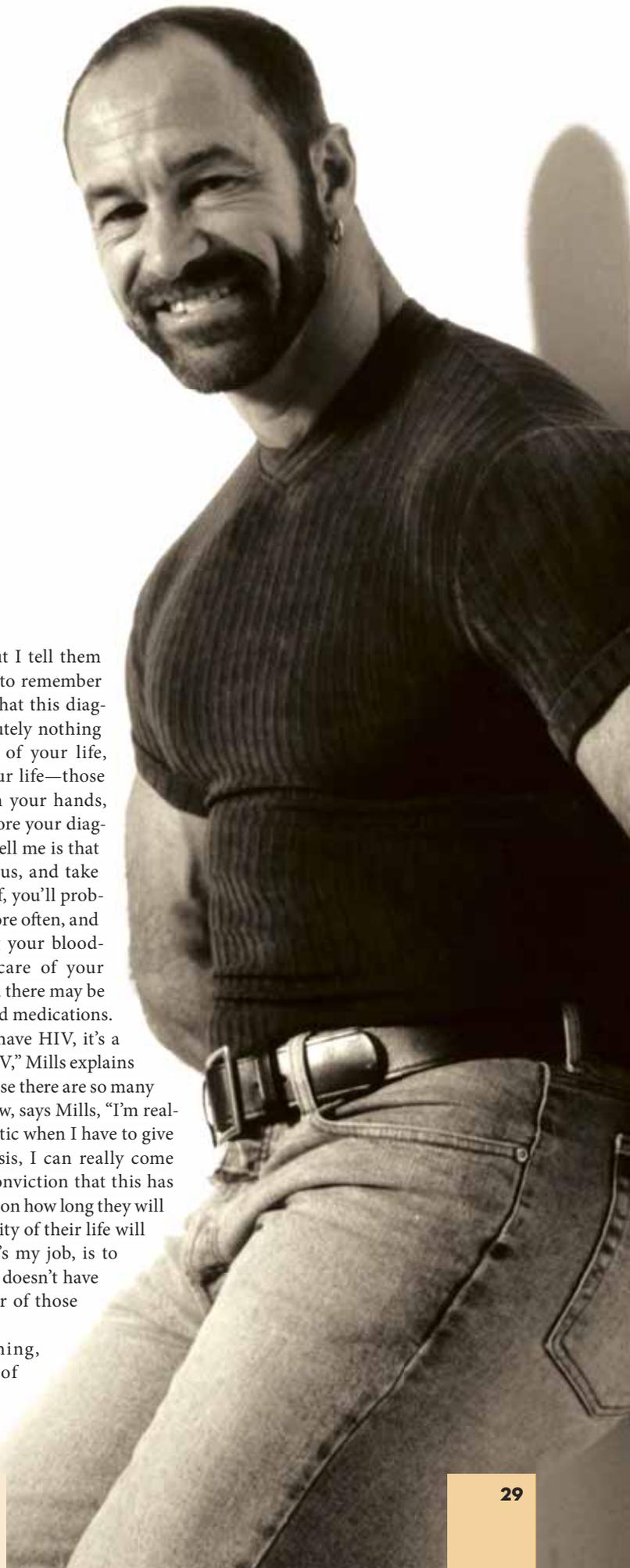
Says Mills, "When someone first tests positive, I give them a lot of information

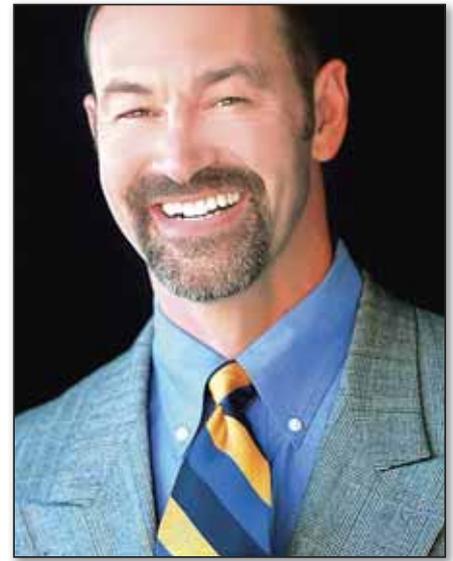
on the first visit. But I tell them I don't expect them to remember everything, except that this diagnosis tells me absolutely nothing about the duration of your life, or the quality of your life—those things are totally in your hands, just as they were before your diagnosis. What it does tell me is that if you're conscientious, and take good care of yourself, you'll probably be seeing me more often, and we'll be monitoring your bloodwork, and taking care of your immune system, and there may be a time when you need medications.

"If you've *gotta* have HIV, it's a *great* time to have HIV," Mills explains to his patients. Because there are so many possibilities right now, says Mills, "I'm really extremely optimistic when I have to give somebody a diagnosis, I can really come to them with this conviction that this has absolutely no impact on how long they will live or what the quality of their life will be. I tell them, that's my job, is to make sure that HIV doesn't have any impact on either of those things for them."

Charles Farthing, former director of AIDS Healthcare Foundation, taught Mills something

Photos courtesy of Tony Mills





that he says has been really beneficial when talking to patients about their therapy.

“What he does with his new patients, when he’s starting therapy, is tell them, ‘We’re going to start this therapy. And you may come to me and say, I want to change therapy, and I’m going to listen to you, and I’m going to consider that, and we may make some changes. I may come to *you* and say, I want to change therapies, and I’ll have *my* reasons, and we can discuss that as well.’”

It establishes the relationship at the beginning of therapy, says Mills—that this is an evolving science, and fortunately, it’s evolving in the right direction.

Mills, who served on the national board of the American Academy of HIV Medicine (AAHIVM) for about five years, stepped down about a year ago in order to devote more time to his practice and research. But he’s still an active member and supporter of the organization. “It’s really important that people with HIV be taken care of by HIV specialists. I’ve heard some horror stories of people who have been mismanaged, and the thing is, you can do some real damage to people with HIV. You can take somebody with wild-type virus, who is placed on an inferior regimen, and suddenly they have two- or three-class drug resistance, and now you’re talking about Fuzeon.

“I think that credentialing is very important. Even if you’re working in Boystown in Chicago, and only treating gay, white men, you still need to know about the differential effects of the drugs on racial groups or gender differences. The credentialing process emphasizes the fact that providers need to be taking

care of a significant number of patients, and staying current—there is a big emphasis on continuing education.”

Mills sometimes lies in bed awake at night, thinking about what can be done to stem the tide of the epidemic.

“How can we really stop the spread of HIV?” asks Mills. “I give more HIV diagnoses now than I did 20 years ago. Maybe people have less fear of it, maybe they have safe sex fatigue, maybe they’re longing for a more intimate connection with other people and they feel that having safe sex prevents that from happening. But how are we going to stop more and more people in our community from becoming positive?”

One of the ways, suggests Mills, is if the medications that we have now are truly better and better, and turn out to be, as we

hope, less and less toxic, maybe we should put more people on medications. “We certainly know that the likelihood of transmitting HIV is less if people’s viral loads are undetectable, and maybe putting more people on medications might be beneficial for stemming the spread of the epidemic, I don’t know. But I just think that we really have to start looking within our community, because I’m really tired of giving HIV-positive diagnoses to highly intelligent men in their forties, who have been able to negotiate the path of safe sex for so many years, who have just given it up. I don’t know how to convince them that it is something that’s important—it seems to have lost its weight.”

Mills loves the clinical research and care that he is able to provide, and expects he’ll still be practicing medicine 10 years from now, provided he himself remains healthy—and there’s no reason to think that he won’t. And with the second- and third-generation drugs now available or in development—some that may even only have to be taken once a week—and looking at the synergy between these new agents, and how they can best be used together, Mills says that the next 10 years will continue to bring increased optimism and hope.

“I feel so fortunate,” says Mills. “I get up every morning and I can’t wait to go to work. I love my life, and I love my practice—I can’t see myself doing anything different.” ☞

E-mail Dr. Mills at tmills@tony-millsmd.com.



River Huston —I Feel Good!

Attaining
survival
through
illness

by River Huston

She's still alive!" James laughs. He was telling me how when he told his psych professor he was going to this lecture and the teacher asked what it was about, James said someone living with AIDS is going to talk. His professor asked, "What's their name?" James said, "I think it's River something." The professor laughed, "River Huston, she's still alive! Oh, my God, I heard her 18 years ago at Rutgers University!"

The kid told me this story with such glee I had to laugh. I had just finished my 55th lecture in three months, but this one was different. It had been a long time since I spoke about living with AIDS. "AIDS is out. Can you speak on anything else?" my agent asked almost 14 years ago.

Since then I developed a whole series of lectures from body image to sex. But a student at Providence College was doing an independent study on HIV/AIDS and had gotten ahold of my long remaindered book, *A Positive Life: Portraits of Women Living With HIV*. It was not exactly a best seller—it's a coffee table book on women and AIDS. Somehow it came into his life, he tracked me down and asked me to come speak. He also asked, "Since we're a Catholic college, please don't even mention condoms or anything, you know, too racy."

If the kid had not been so earnest, I would have skipped it. But it all worked out fine. As I walk up to the podium, he said, "Fuck it, I am going to graduate, go for it." So I did.

I start right in with the part about thinking I met the man of my dream in my last year of school at Hunter College in 1990. It's just one of my set-up/punch lines that I had been using for years to gauge the humor quotient in an audience. "So, I met this guy, you know what I mean that kind of guy, gal, species, whatever, the one that makes your heart go pitter patter. When you walk into the same room as him you have to excuse yourself and go to the ladies room... and put your panties under the blow dryer."

They roar. It's not that it's that funny a line, it's just they realize this is going to be a whole lot different than they thought. I hear a collective sigh, they relax and I'm off.

An hour and a half later I walk out into an end of April, Rhode Island evening. It's dusk but I can still see the tiny buds on all the trees. It's my favorite time of year, a time of rebirth, or maybe just the hope that things will be different. I laugh to myself, "I'm still alive." Christ, maybe that is why I don't get a lot of callbacks. They all think I'm dead.



For the first time in 18 years I feel all right

Here I am, 22 years later surviving not only AIDS, but an unruly bone marrow disease that nearly killed me more than once. After eating some Japanese food with my new Catholic buddies, I head over to my friend Rick's house where I am going to stay the night.

Margaret, his wife, answers the door. "Oh, my God! You look great, you got so skinny!" She holds me by the shoulders and looks at my newly svelte bod. Then all serious, "You're all right, aren't you?" Oh yeah! For the first time in 18 years I feel all right. I explain how the AIDS cured my other terminal illness. All I have to do is take a handful of pills every day and I don't have to do the weekly chemo-like treatment that I have been doing along with steroids and Procrit for the last 13 years.

Read that again. Every fucking week for 13 years.

Each Friday my nurse, Sue, same one for nine years, would come over and stick an IV in my arm. Often she would laugh and say, "You know, I can barely tie my shoes but I never miss *your* vein!" I have probably spent more time with my nurse than anyone I know. She is the only right wing, born-again Christian I have ever known so intimately. We have the most amazing conversations,

After my third request he says, "Honey, you need to go look in the mirror"

though I steer clear of anything political while she is sticking the needle in. The great thing is I can always run by any Bible references I might need to use when I am invited to some of the more conservative conferences or colleges. I don't know why they invite me. I have a reputation for being notorious but on paper I look good: author, poet, Ph.D. I often think someone in the organization wants to be naughty so they invite me to shake things up. No matter how much I edit, I still seem to offend someone.

I'd taken a Vicodin to numb the side effects, but still feel like I'm crumbling. After about an hour she's done. Then the super shot of Procrit. I sing at this stage of the game or make some loud noise because it burns so much. After she packs up and leaves, my husband, who has been with me for seven years and has never missed a Friday, runs me a bath and helps me in. He holds me while I shake and shudder. Finally I crawl into bed, and curl up in a fetal position with Lola, Bear and Buddy, our three terriers who position themselves around me. Their furry needs distract me as I drift off with the help of another Vicodin.

When I wake up I feel like someone beat me, put me in the trunk of a car and drove down a bumpy road. I drag my butt out of bed and try my best to get on with the day. Sometimes I even have to get on a plane and fly somewhere, or finish a piece on deadline. If I am lucky I can just sit on the deck and drink tea. The next day is a little better, I only feel like I slept in the trunk. By Sunday, just slapped around, Monday unplugged, Tuesday is like that day right before the cold is gone. Wednesday, a little weak. Thursday I feel good, all right! Then it's Friday. Again. 13 years.

When I was infected with HIV, my immune system went into high gear and kicked HIV's ass. It did a shock and awe campaign. Essentially my own immune system destroys my bone marrow on a daily basis.

Idiopathic thrombocytopenia purpura. Some people do respond to treatment and it goes into remission, but because of the HIV or some other unknown element, it progressed to the point I was in critical condition every week.

I rapidly go from HIV-positive to AIDS when my immune system finally gives up. Uncontrollable infections coupled with the inability to find effective treatments put me in bed unable to work for the first time. But hey, my immune system can't save me from infection, but it also can't kill my marrow! No more IVs. I have to laugh when I realize AIDS cured idiopathic thrombocytopenia purpura. I wonder if I could market it?

Now I must battle AIDS. Two years drag by filled with every side effect known to the drugs that treat the disease. When I read the inserts for the meds, they list things like, "headache, nausea, fatigue, metallic taste in your mouth, kidney failure, liver damage, death. If any of these things happen, please contact your

doctor immediately." I guess I would need a Ouija board for the last "side effect." I always get the thing right before death.

One time I'm flying to San Diego and I'm feeling warm. I ask the flight attendant to turn up the air, but I keep getting hotter. After my third request he says, "Honey, you need to go look in the mirror." I go in the bathroom and I'm startled to see my face and neck flushed red. When I pull down my pants, I'm shocked to see my whole torso covered in flaming red bumps. The rest of the flight doesn't go so well for the guy sitting next to me, who probably paid for his first class seat (I'm usually upgraded for all the miles I fly) as I break down in a crying jag, "I have AIDS. WHAAAA."

I go to the emergency room when I arrive in San Diego. They tell me I have Stevens-Johnson Syndrome and I am shot up with steroids. Insane, miserable, and scared, I still do the gig. Not my best performance.

I finally find a drug combination that does not try to kill me and here I am at Rick's door feeling like I can do just about anything. Sometimes I want to shake total strangers and just tell them, "I feel good! You feel good? I feel good!" I didn't know how sick I was until I stopped being sick.

For the last 17 years I have been dragging myself around the country doing lectures and performances and writing books on an empty tank. Now I am filled with premium unleaded ready for anything. Recently I re-did my website and I put my book *A Positive Life* up in slide show format. It took me days and when I finished it was beautiful (you can see it www.riverhuston.com under "A Positive Life" lecture). I cried every time I played it. So many of the women in the book have died. For some reason I was spared. I am in the bonus rounds of my life. With the advent of new medication I might actually live until old age unless, of course, I get hit by a bus. The challenge is to still live my life each day as if it is the last. ☘

River Huston is an award-winning poet, author, and performer. She gives lectures around the world to universities, conferences, and celebrations of all sorts. River is currently performing her one woman show, "Sex, Cellulite and Large Farm Equipment: One Girl's Guide to Living and Dying" in theaters nationwide.

MARTELL RANDOLPH



RARE VIRUS, RARE STRENGTH

If an HIV diagnosis is considered to be a “tough pill to swallow,” then imagine that a diagnosis of HIV-2 would be like trying to swallow the whole bottle at once. Well, maybe it’s not that bad, but for Martell Randolph it has been *the* toughest obstacle that she’s ever had to overcome.

The diagnosis came in 2000, and was as unexpected as it was ironic. Martell was working in the development department at the Gay Men’s Health Crisis in New York City. She’d always wanted to be involved in HIV, and happened upon the job by way of reference from a friend.

When she suddenly became very ill, without any explanation as to the cause, HIV was the last thing that she expected. When her doctor suggested that she be tested for it, just to be able to “rule it out,” Martell agreed. She sincerely believed that she didn’t have anything to worry about. Little did she know, she had every reason to be concerned.

The original test came back inconclusive. The follow-up test came back the

same. At that point in time, the test that was used to detect HIV-1 was not able to detect HIV-2. It would be some time before she would come into contact with a doctor who had experience working with people in Africa who were infected with HIV-2, who was eventually able to officially diagnose her.

She believes that she contracted it in the early 90’s, while living in Europe. She’d dated a man there who was originally from West Africa. Though it is rare in comparison to HIV-1, it is the dominant type in West Africa and other developing regions of the world. At that time, she was told that there were no more than 30 known cases of HIV-2 in the U.S.

Because it is so rare, many healthcare providers were clueless about how to treat it, and about how it differs from HIV-1. Even today, many still are. Martell knew immediately that if she was to have any chance at

survival, it was imperative that she educate herself extensively about the virus.

She learned that though the differences between the two types are slight, and still not fully understood, they are terribly significant.

HIV-2 is thought to develop at a slower pace than HIV-1, but to be more virulent in its later stages. It is also believed to be more easily transmissible from women to men. Lastly, and probably most important to Martell at the time of her diagnosis, all of the existing non-nucleoside reverse transcriptase inhibitors (Sustiva and Viramune) are completely ineffective against it.

Another pertinent difference has to do with viral load testing. The standard method of diagnostic testing used for managing HIV includes regular viral load and CD4 measurements. The viral load assay, or test, used to measure HIV-2, however, is different from the one that is used to detect HIV-1, and it is not commonly available in the U.S. Therefore, for the first four years after being diagnosed, Martell received

Photo: Paul Rutter

A STRUGGLE AGAINST THE LESSER- KNOWN HIV-2

BY KEITH R. GREEN



treatment based solely on her CD4 count, which was determined to be only 27 at the time.

As odd as it may sound, she was started on Kaletra monotherapy. Not surprisingly, she developed all of the mutations associated with resistance to Kaletra, knocking out a majority of the protease inhibitors (PIs) as options for a sustainable treatment regimen.

Martell connected with a researcher in the Netherlands who happened to be treating lots of people who had migrated there from regions in Africa where HIV-2 is most prevalent. He agreed to conduct a viral load assay for her at no cost, if she could have a sample of her blood shipped to him. To this day, that's still the only way that she knows of to have the test done.

Thankfully, she was able to recover from her initial illness and, with the help of second-generation protease inhibitors and a couple of nucleoside reverse transcriptase

inhibitors, her health has stabilized. Unfortunately though, possibly due to the early mistakes made regarding treatment with monotherapy, she is currently not able to increase her CD4 count above 270, at 11%. Her viral load, however, remains steady at 1,100, and she says that she feels as healthy as she did before she was diagnosed.

Martell has dedicated her life to learning as much as she can about HIV-1 and HIV-2, and to sharing that information with others. She left New York City in 2003 for warmer days in Los Angeles. There, she works with several organizations and is on the community advisory boards of a couple of different pharmaceutical companies. She is also registered with various speakers bureaus, helping others to understand that their lives are not defined by their HIV status.

Practicing what she preaches, Martell has allowed her love for writing, and for the English

language in particular, to redefine her own life. She is currently pursuing a degree in English literature, and happily engaged to an Australian man who she describes as her soul mate. They plan to marry and live in the U.S., but immigration laws regarding people who are living with HIV are extremely tough.

Martell, however, is no stranger to adversity. She refuses to see the glass as anything but half full, and is determined not to allow this minor bump in the road to get her down. "[Living with this virus] has built character in me," she says. "Life is full of challenges, and this has given me the assertiveness to ask questions, to get involved, and to seek out the information that can help myself and others to live long and healthy lives." 🏥

Photo: Paul Rutter

BECAUSE IT IS SO RARE, MANY HEALTHCARE PROVIDERS WERE CLUELESS ABOUT HOW TO TREAT IT, AND ABOUT HOW IT DIFFERS FROM HIV-1

Brett Grodeck

—Infinite Possibilities

A former editor catches up

by Brett Grodeck



On a recent trip to Chicago, my hometown, I was transported back to a time 20 years ago when I believed that anything was possible. At 18, I was smart-alecky kid with a punk haircut, taking college classes by day, and by night clubbing at Smart Bar and the Metro. Only two years later, I was standing between the swinging doors at the Jewel on a pay phone when I learned that I had the virus that causes AIDS. At that moment, my life took an unexpected turn.

In the 1980s, the outlook for AIDS was grim and the gloom wasn't just a statistic. I watched my friends die. In time, my own health weakened as well. Starting with rashes and skin problems and then giving way to a host of blood disorders and unrelenting fatigue—not a place you want to be at the age of 25.

But what I lacked in health, I made up for in youth. I was spunky, idealistic, and believed that we—patients, doctors, scientists, and researchers—if we truly had the intention, we could cure AIDS. I know that sounds idealistic, but we needed inspiration at the time. Like my ACT-UP comrades, idealism is what kept me going when there was little hope.

I had always wanted to write. After my diagnosis, I knew *exactly* what I would be writing about and dove into the topic. I scraped together enough non-profit money to launch a magazine called *Plus Voice*. My vision was a lifestyle magazine for people with the virus, the first of its kind. This was long before there were any pharmaceutical drugs and without advertising dollars to keep it alive, *Plus Voice* was forced to close shop.

In 1994, people were still hysterical about AIDS and I was publicly open about my status. I felt blacklisted both socially and

professionally until *Positively Aware* hired me as an associate editor. Covering HIV treatment during its infancy, I often took what I learned on the job and applied it to my own life. I wrote about AZT and took it every day, back when it was offered as a single drug at toxic doses.

Two years later, I was the editor of *Positively Aware* when the undeniable success of the combination therapy AIDS cocktail made headlines. At the highly publicized 1996 World AIDS Conference in Vancouver, Dr. David Ho predicted that the eradication of AIDS was near. The war seemed to be over. Only years later would we learn that this conquest was akin to knocking down a statue of Saddam Hussein and proclaiming victory over Iraq.

With these new advances in HIV therapy, the drug companies flourished. A top pharmaceutical public relations agency was able to woo me away from *Positively Aware*. I'm only human and the money was irresistible. Suddenly, I found myself giving Power-Point presentations to pharmaceutical executives, counseling them on how to make the most money from the HIV market. Honestly, the work was dirty, never felt right, and eventually I quit that job wanting to get out completely.

So when I moved to Los Angeles and was hired by the RAND Corporation, I was thrilled to make an honest wage writing about terrorist attacks and smallpox vaccines. During my off hours, I pursued my own pet projects, like consulting with the FDA about the slippery marketing practices of Big Pharma. My way of making amends.

It was during this time that a publishing company contacted me about writing a book, part of a larger series of health books

called *The First Year*. My background and personal history made me the ideal “patient/expert” they needed to author: *The First Year: HIV—An Essential Guide for the Newly Diagnosed*. I had wanted to stay away from the topic, but the opportunity to write a book—even if it was about HIV—was a dream come true. For a whole year of my life, I did nothing but work. I would come home from my day job and write about HIV every night.

After the book was published and it got a good review in *The New York Times*, I was professionally confident but personally a mess. Once the high of writing the book ended, I was left craving something more. I had always struggled with being overweight, but I now had become technically obese. I was in my late 30s and getting older. I headed in the wrong direction and sank into substance abuse and addiction.

Although I lived in sunny Los Angeles, my days of using illicit drugs were dark. It began as a misguided attempt to lose weight. Of course I lost weight, at one point 30 pounds in three months. But soon my thinking became distorted and I found myself surrounded by a posse of losers, all of us fooling ourselves into believing that our substance use was recreational.

The first step in leaving that lifestyle, for me, was understanding that any sense of well-being or thrill from drugs is a lie. Each time I used, the lie got hardwired deeper into my brain, drawing me further away from true happiness. The damage I was doing to myself—willingly—presented a greater challenge than any virus in my body. Luckily, by seeking counseling, upgrading my “friends,” and staying rigorously honest with myself, I managed to survive that dark chapter as well.

Last year, my publisher called me to write a second edition. This time I approached the subject from a larger perspective, where HIV is just one of many concerns. For anyone who hasn’t taken

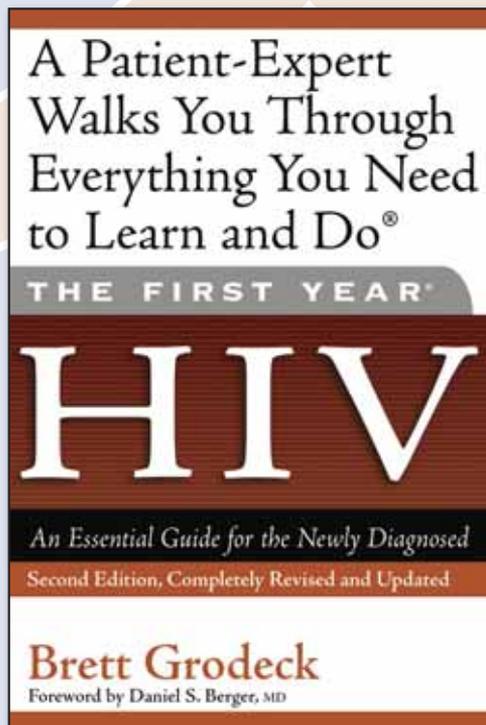
HIV medicine, the outlook is incredibly bright. Living a perfectly normal life span is entirely possible. But as we live, it’s the everyday things—like depression, drugs, smoking, drinking, unsafe sex, and overeating—these are the real issues that will hurt us.

I’ve been HIV-positive my entire adult life. Of course, we still don’t have a cure for AIDS. But in 2008, we have excellent medicine to keep the virus at bay indefinitely. And it’s getting better every year. But this new medicine doesn’t give you a free pass to be unhealthy in other ways. Wear your seatbelt. Don’t smoke. Drink moderately. Avoid white-powder drugs (they’re especially bad). Get mental help when you need it. Exercise. And be rigorously honest with yourself not just about your own sexual behaviors or bad habits, but with every aspect of your life.

This year, I will be 42 years old. My HIV has been undetectable since 1996. My T-cells are in the 500s. I feel strong and healthy. I own a condo in Los Angeles and have a decent-paying job that doesn’t stress me too much. My partner just moved in and we’re remodeling. Sure, I struggle with my weight, blood pressure, and cholesterol. And although I love smoking cigarettes, I know I must quit.

My first thought, when I think about how HIV has altered my life, is of course that it sucked. To the core. But when I take the time to appreciate the health and happiness I have at the moment, I reconsider. Today, my life is pretty good. And life can be good for you, too. After all, anything is possible. ☕

Brett Grodeck is the author of The First Year—HIV: An Essential Guide for the Newly Diagnosed, with a foreword by Daniel S. Berger, M.D. (see sidebar). Published by Marlowe & Company; Revised edition June 1, 2007. For films on HIV prevention, transmission, testing and treatment, visit www.videojug.com/tag/hiv.



THE FIRST YEAR: HIV

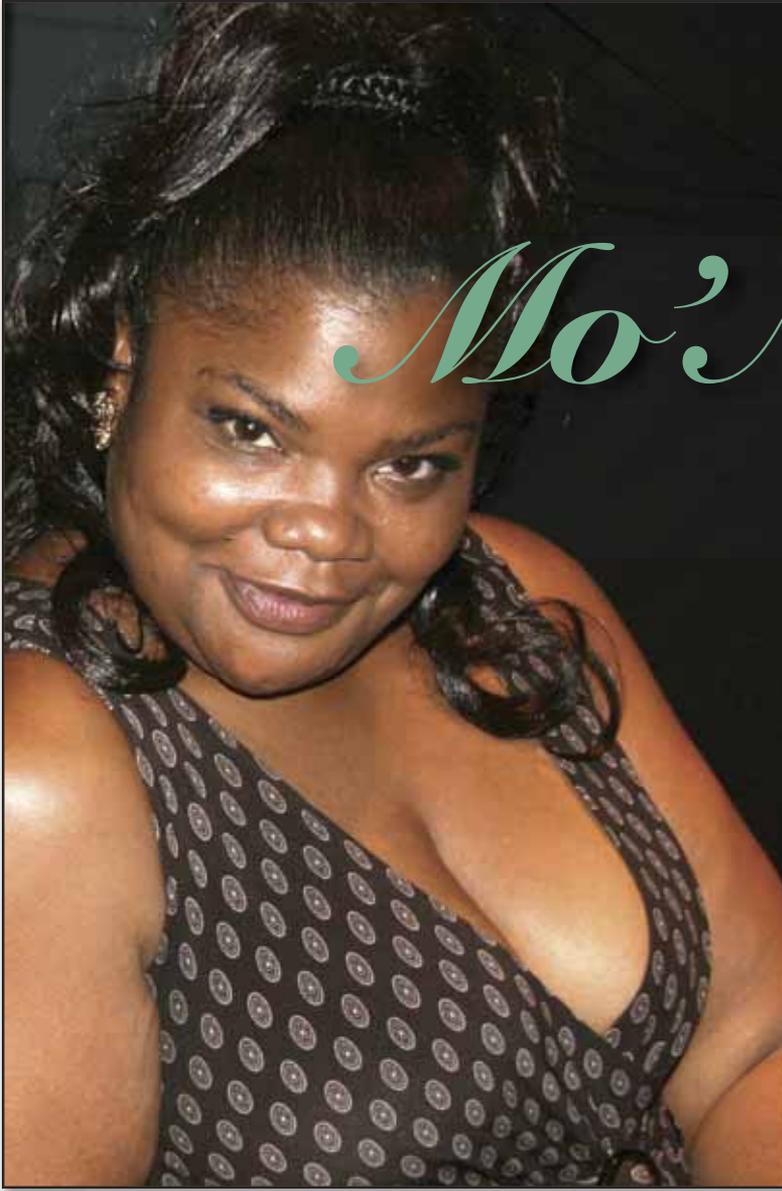
The First Year—HIV is unique because it is written by someone who knows your struggle: a regular person who’s lived with the virus for over 20 years.

A review by *The New York Times* called the book “optimistic” and “level-headed.” Combining the human element with essential information about treatment options, choosing the right doctors, the importance of diet and exercise, holistic alternatives and sex, the book transforms a complex disease into one that can be understood and managed.

This newly revised second edition offers new insight into the next generation of HIV medicine, new ideas about AIDS, alternative health, crystal meth, sex addiction, and getting health insurance.

This new book is a supportive and educational resource for patients, counselors, case managers, health professionals, friends and family members who want to take an active role in the management of HIV.

Available at *Amazon.com*, *Borders*, *Barnes & Noble*, and your local bookstore or library. Discounted bulk rates available by calling (800) 788-3123.



Mo'Nique

Celeb with a Cause

Using her
power for good

by Keith R. Green

After stalking her for weeks, when Mo'Nique's assistant told me that the best time she had available for an interview would be at 8 o'clock in the morning, I nearly backed out.

In my mind, for some reason, the combination of celebrity and self-admitted "phat girl" don't make for an easy morning. And I've seen her stand-up act. She's ruthless. I just knew I was preparing myself to be the butt of her next "skinny bitches are evil" series of jokes. Only it would be more along the lines of, "Those AIDS-reporting bitches should be shot!"

I was prepared for the worst.

When she called, however, I realized instantly that I couldn't have been more off base. She greeted me with the warmest "good morning" that I'd heard in weeks and, immediately, my anxiety subsided.

To be clear, she was still the same crazy and boisterous Mo'Nique whom the world

has come to know and love. She's funny as hell, without even really trying to be. And though her mouth is unapologetically *foul*, she's probably the most down to earth and sincere person I've ever met. So before long, we were chatting it up like old college roommates—about life, love, and why she is committed to the fight against HIV/AIDS.

"I knew a lot of people who had died from AIDS," she tells me, sentimentally. "And then it struck home."

"I lost an uncle to AIDS. I lost a best girlfriend to AIDS. So, because I do have a platform, thank God, I asked myself, 'What can I do to help stop this disease from running so rampant in our communities?'"

The answer came when she met John Fleming at a comedy club in downtown Chicago. John is an entrepreneur and long-time HIV/AIDS services advocate. He approached her and asked if she would be willing to perform at a fundraiser that he

was hosting to benefit African American HIV/AIDS service organizations throughout the Windy City. Without hesitation, she agreed.

"I think I got paid like \$350 the first time, and if I'm wrong, tell John please don't hurt me," she says, half-jokingly.

"But every year after that I said, you know what, brother, don't pay me any money. Whatever you were going to pay me, give it to the cause, because we're in a situation where it is affecting our community and there is no help."

And so every year, for the past seven years, that's what has happened. From a small, 150-seat venue to a massive theater that seats over 800, John's annual Pride Comedy Showcase (which also includes spoken word artists as well now) has taken on a life of its own.

"We do very little promotion for it now," John says in a separate conversation. "Last



year, through word-of-mouth alone, we were practically sold out from reservations before tickets actually even went on sale! And people started asking me about this coming years show before the dust could settle from the last one. We have to start looking for a bigger venue.”

Mo’Nique’s routine for this particular show is as inspirational as it is funny, and there is no subject that is off limits. She speaks out about everything from safe sex to homophobia to the “down low phenomenon.”

“I understand it,” she says about Black men who have sex with other men but opt out of telling their girlfriends and wives. “I can’t judge it.”

“We as Black people still have a hard time with a Black gay man. So you have some Black gay men who are boxers, football players, basketball players, singers,

accountants, doctors...but they aren’t free enough to say, ‘this is who I am.’”

“We live in a society, especially our [African American] society where people are like, ‘Oh my God, can you believe he’s gay?’ Well, bitch, can you believe you’re not?! Like...so what! Who are we to turn anybody away? Black people know all too well what it feels like to be turned away from some shit! We should be ashamed of ourselves.”

“We have an agreement that we’ll be honest, and if sex happens with another person, that’s not a deal breaker for us.” They are both knowledgeable about the risk that is associated with extra-marital activities, and have vowed to protect themselves and each other no matter what.

When asked why she believes that HIV is such an issue among people of color in particular, a side of Mo’Nique that most of the world does not get to experience evolves.

“We have to start having real dialogue and real conversations”

Her position on this topic is not a popular stance among other Black people, especially as women of color continue to become one of the fastest growing populations of people living with HIV. She’s clear, though, that in order to turn things around, we have to start saying “the real shit.”

“We have to start having real dialogue and real conversations,” she says. “And we gotta stop sugarcoating it.”

“I admit that when my husband walks into a room, I still get butterflies,” she tells me. “And keep in mind that we have been best friends since we were 14 years old.” While she admits to willingly taking the submissive role in her marriage, she also has no problem with having “real” conversations with him. In fact, she shared with *The New York Times* recently that they have an open relationship, and that they would never end up in divorce court for being unfaithful because they don’t have to cheat.

The jokester who brought us to tears laughing at her pursuit of Professor Oglevee in the hit sitcom *The Parkers*, transforms into a serious-minded intellectual, leaving all jokes aside.

“There are so many problems in our community,” she sighs. “AIDS is just one of them.”

“We have poverty. There is illiteracy. There are drugs. There is domestic...wait...not domestic violence. We fight. Because you not just gon’ smack a bitch in her face and the fight be over. We’re gonna be on the corner fighting.” I laughed.

“So, we fight. We are single parents. We have a lot of forces coming at us, and it’s very easy to gravitate towards negativity. It’s like you have to make a conscious effort to do right, which is sad!”

She’s clear that these issues, combined with ignorance as it relates to the virus itself and a communal lack of self love (which

may be the result of such issues), are at the root of the problem. More than anything, though, she recognizes that until people of color take the lead on such issues for themselves, things are going to get a whole lot worse before they get any better.

“When has the government *ever* said that ‘we’re gonna help Black people?’” she asks. “So now, because we have *this* disease, did we really think the cavalry was going to come in?” asking more for effect than in anticipation of an answer that she already knows.

“I’m at a place where it gets frustrating because I’ll say to my brothers and sisters, ‘Okay, we know the cavalry ain’t coming. Why do we keep putting ourselves in that place?’

“I know he’s fine. Godammit, I know he’s fine! I know she’s cute. But can you tell

“And you know how I know that works?” she asks. “Because I changed my mind, and I’m nothing special. When they told me that I had high blood pressure, I said, ‘No no. I’m not going to take medication for the rest of my life.’ So I get my fat ass out there every day and I work out. I want to see my grandchildren; God-willing, my great, great-grandchildren. So I had to change my mind. If we are to turn this thing around, we simply have to change our minds.”

Strong in her convictions about what must be done to curb the epidemic, Mo’Nique is by no means insensitive to how the laundry lists of issues facing Black people oftentimes makes changing one’s mind a far more difficult task than it has to be.

“We have to think about the generations that will come behind us who will have to wear the same uniform that we are wearing

“When has the government ever said that ‘we’re gonna help Black people?’”

him to just cover up? Can you tell her that she’s gotta cover it up? As simple as that sounds, we are making it really difficult.”

The solution she offers for turning things around is as unpretentious as she is. “We have to simply change our minds,” she says.

right now; the uniform that our ancestors wore before us. I know it’s hard, but every morning when you wake up you gotta say, ‘I will not let anything steal my joy, *nothing!* And you gotta mean it.’

I couldn’t help but question how she manages to stay so grounded, working in the cut-throat business of Hollywood.



“Hollywood cares about the numbers,” she tells me. “Not integrity, not morals, and when did they ever give a damn about us. But the way I see it is that I am in a position to change peoples’ minds and get paid for it.”

And whether she’s at the *BET Awards* showing R&B sensation Beyonce that big girls can move too (which actually prompted the superstar to incorporate big girls into her 2007 *Beyonce Experience* world tour), or encouraging the inmates at a women’s prison in Ohio to keep their heads up in the special that she did with Showtime called *I Coulda Been Your Cellmate*, it is obvious that this Queen of Comedy takes her position very seriously. ✚



MICHAEL

—THE TRUTH MAY NOT SET YOU FREE

I'm here because my doctor referred me to you," Michael* said quietly, haltingly, and with his eyes on the floor. "He said I should be in your group." Since I facilitated a number of groups, I asked Michael which of the groups he was thinking of joining. After listening to them for him, he finally nodded when I talked about the group for married and formerly married gay and bisexual men.

As we continued to talk, I learned that Michael was 45 years old and had been married for the past 25 years to his wife, Virginia. They had three children: Allison who was 21 and in college, Sam who was 16, and Casey who was 9. The family lived in a neighborhood on the far southwest side of Chicago in what Michael described as modest, middle class, and mostly Catholic. His two younger children attended Catholic school and his oldest was in college in central Illinois.

Michael worked as a graphic designer and his wife was a manager at a downtown department store. "Everything looks completely 'normal' on the outside, but I feel like I can barely function," he said. "I feel trapped. Scared. Alone. I told my doctor all of this and he said I should see you and be in your group."

I didn't need to do much prompting as Michael shared more of his story. He said he knew he was most likely gay from the time he was a little boy. But growing up when he did and where he did (also on Chicago's southwest side), he believed he could not share with anyone that he had these feelings. He met his wife when they were both in college and they became best friends. He shared with her that he thought he might be gay, but Virginia came to love Michael and believed if they loved each other enough, his past feelings for men would pass. And so they married and, according to Michael, had never spoken of his disclosure since.

Michael's sexual attraction to other men did not end, however, with the marriage. For several years he reported he was monogamous. But after Allison's birth, his desire to be sexual with men increased and he began to search out anonymous sexual encounters at bookstores and in forest preserves. This behavior continued sporadically until the birth of his youngest child.

After Casey was born, Michael and Virginia stopped being sexual with one another and Michael's sexual behavior with men increased dramatically. "I started using the Internet to find sex, going to other men's homes, meeting in hotels, and I still used

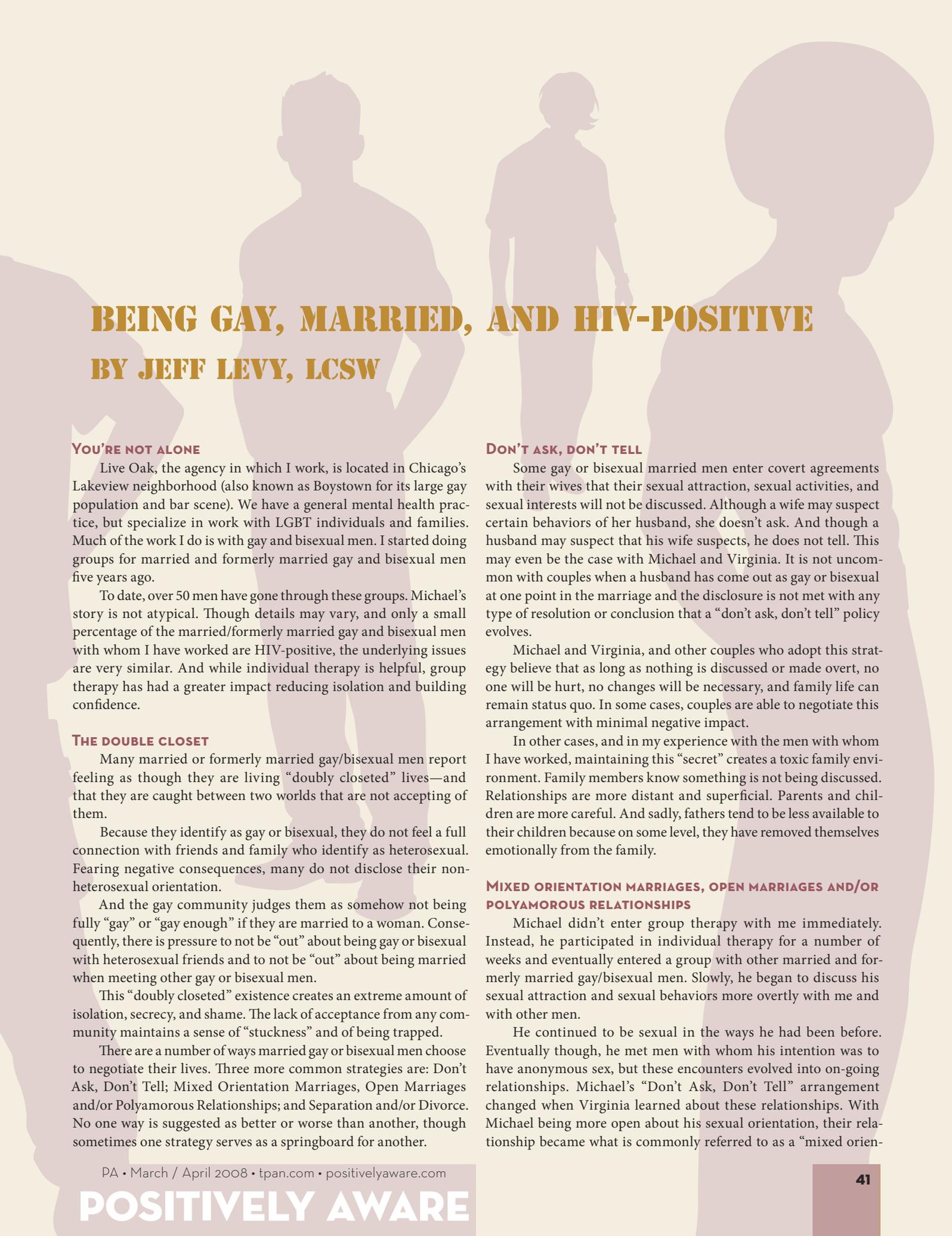
bookstores and forest preserves," he said. "I also started leaving work in the middle of the day to hook up with strangers. Over those years I contracted STD's five or six times. I know Virginia knew about it, but she never said anything and I never explained. Sometimes I'd come home late at night and she'd never ask why." He stopped briefly and then continued. "I felt worse and worse about myself and, the worse I felt, the more I had sex with men. It was a horrible cycle."

Because of his children, worries about finances, and his concern for Virginia, Michael didn't feel as though he could leave his marriage—and he wasn't even sure he wanted to. He knew he didn't want to hurt the people he loved, yet he also felt as though he couldn't keep living with such secrecy and deception. He felt trapped and didn't know how he could ever extricate himself.

He added: "I knew I was putting myself at risk for more STD's and possibly HIV, but that didn't stop me. I used to think that if I got HIV, I would feel relieved because then I would *have* to tell Virginia everything and finally, she would know the truth and I would be 'free.'" He didn't *want* to seroconvert, but a part of him thought this would necessitate conversation with Virginia and they would be required to address what he had been hiding for so many years.

And then it happened. Michael wasn't feeling well and he went to his doctor for what he thought was a cold or the flu. He shared he had been having unprotected sex and had been engaging in fairly high-risk sexual behaviors. His doctor suggested an HIV test. Michael agreed and learned that he was HIV-positive. He panicked and drove around aimlessly for hours. He eventually returned home and remained silent. Despite his previous thoughts about telling Virginia everything, he said nothing and tried to continue with his life as usual.

The pressure built and when Virginia asked about his most recent medical appointments, he disclosed everything to her. Everything. She cried, screamed, accused, and then returned to silence. Nothing changed. Michael did not pursue communication with Virginia or she with him. He was in the same position he was in prior to seroconverting. His doctor referred him to my group.



BEING GAY, MARRIED, AND HIV-POSITIVE

BY JEFF LEVY, LCSW

YOU'RE NOT ALONE

Live Oak, the agency in which I work, is located in Chicago's Lakeview neighborhood (also known as Boystown for its large gay population and bar scene). We have a general mental health practice, but specialize in work with LGBT individuals and families. Much of the work I do is with gay and bisexual men. I started doing groups for married and formerly married gay and bisexual men five years ago.

To date, over 50 men have gone through these groups. Michael's story is not atypical. Though details may vary, and only a small percentage of the married/formerly married gay and bisexual men with whom I have worked are HIV-positive, the underlying issues are very similar. And while individual therapy is helpful, group therapy has had a greater impact reducing isolation and building confidence.

THE DOUBLE CLOSET

Many married or formerly married gay/bisexual men report feeling as though they are living "doubly closeted" lives—and that they are caught between two worlds that are not accepting of them.

Because they identify as gay or bisexual, they do not feel a full connection with friends and family who identify as heterosexual. Fearing negative consequences, many do not disclose their non-heterosexual orientation.

And the gay community judges them as somehow not being fully "gay" or "gay enough" if they are married to a woman. Consequently, there is pressure to not be "out" about being gay or bisexual with heterosexual friends and to not be "out" about being married when meeting other gay or bisexual men.

This "doubly closeted" existence creates an extreme amount of isolation, secrecy, and shame. The lack of acceptance from any community maintains a sense of "stuckness" and of being trapped.

There are a number of ways married gay or bisexual men choose to negotiate their lives. Three more common strategies are: Don't Ask, Don't Tell; Mixed Orientation Marriages, Open Marriages and/or Polyamorous Relationships; and Separation and/or Divorce. No one way is suggested as better or worse than another, though sometimes one strategy serves as a springboard for another.

DON'T ASK, DON'T TELL

Some gay or bisexual married men enter covert agreements with their wives that their sexual attraction, sexual activities, and sexual interests will not be discussed. Although a wife may suspect certain behaviors of her husband, she doesn't ask. And though a husband may suspect that his wife suspects, he does not tell. This may even be the case with Michael and Virginia. It is not uncommon with couples when a husband has come out as gay or bisexual at one point in the marriage and the disclosure is not met with any type of resolution or conclusion that a "don't ask, don't tell" policy evolves.

Michael and Virginia, and other couples who adopt this strategy believe that as long as nothing is discussed or made overt, no one will be hurt, no changes will be necessary, and family life can remain status quo. In some cases, couples are able to negotiate this arrangement with minimal negative impact.

In other cases, and in my experience with the men with whom I have worked, maintaining this "secret" creates a toxic family environment. Family members know something is not being discussed. Relationships are more distant and superficial. Parents and children are more careful. And sadly, fathers tend to be less available to their children because on some level, they have removed themselves emotionally from the family.

MIXED ORIENTATION MARRIAGES, OPEN MARRIAGES AND/OR POLYAMOROUS RELATIONSHIPS

Michael didn't enter group therapy with me immediately. Instead, he participated in individual therapy for a number of weeks and eventually entered a group with other married and formerly married gay/bisexual men. Slowly, he began to discuss his sexual attraction and sexual behaviors more overtly with me and with other men.

He continued to be sexual in the ways he had been before. Eventually though, he met men with whom his intention was to have anonymous sex, but these encounters evolved into on-going relationships. Michael's "Don't Ask, Don't Tell" arrangement changed when Virginia learned about these relationships. With Michael being more open about his sexual orientation, their relationship became what is commonly referred to as a "mixed orien-

tation marriage”—loosely defined as a marriage comprised of individuals with different sexual orientations—Michael identified as gay, and Virginia as straight.

Michael told Virginia he had no intention of divorcing her, but wanted to stay married *and* continue to have sexual/romantic relationships with men. Not all mixed orientation marriages are open. Some men and women acknowledge the difference in their orientations and continue to have sex only with each other. Others in mixed orientation marriages choose celibacy. While Virginia didn't like the idea of an open marriage, for her it was better than losing Michael and the family they had created together so she agreed to open the relationship. In this case, however, "open" meant only that Michael could see other men. There was no discussion of Virginia having relationships outside their marriage.

Other couples have defined an open marriage differently, with both spouses having the ability to date and/or develop a secondary relationship outside of their primary marriage. Still other couples have addressed a husband's disclosure of being gay or bisexual by inviting other partners into the primary relationship (polyamory). In my experience, some wives are initially receptive to polyamory in an effort to "save" the marriage. Over time for some couples, this arrangement becomes limiting as either the husband or wife meets someone with whom they would like to have a primary relationship. At times such as this, an open or polyamorous relationship may lead to separation and/or divorce.

SEPARATION OR DIVORCE

Other couples determine that it is not in either spouse's best interest, or in the best interest of the children, for them to remain married. These couples may separate indefinitely, they may separate knowing that eventually they will divorce, or they may separate and file for divorce simultaneously.

For many men with whom I have worked, this is the most feared arrangement. Such a decision requires some explanation to children, extended family, friends and, in some instances, co-workers. There are also significant financial implications for couples that choose this strategy.

Many times, it is the fear of disclosure (of judgment, shame, and ostracism) in combination with the financial fear (of maintaining two households) that impedes gay and bisexual married men from moving toward this arrangement. In some instances, husband and wife share resources that if they divorced, would cause hardship for one member of the couple.

In Michael's case, for example, he was receiving health insurance through his wife's employer. As a self-employed graphic designer, if they were to divorce and he tried to acquire a policy



WHAT I HAVE LEARNED FROM THESE MEN IS THAT THERE IS NO ONE UNIVERSAL JOURNEY GAY AND BISEXUAL, MARRIED, AND HIV-POSITIVE MEN SHOULD PURSUE

for individual health insurance, he would most certainly be rejected due to his HIV status. And though he may be eligible for subsidized programs through the state (CHIP in Illinois, for example), the cost to him both for his premium and then for his medications would be prohibitive.

In addition to the more practical or logistical concerns of separation or divorce, the emotional journey, even in the best of circumstances, is difficult and challenging. Both spouses are in a position to "start over" and, for some, this is a formidable task. For gay or bisexual men, the challenge is to move into a community they have previously denied themselves. They struggle with trying to attach old rules to new partners/circumstances, while learning new rules at the same time.

For Michael and other HIV-positive married and formerly married gay or bisexual men, there are "double or triple-disclosure" decisions: when to share about being gay or bisexual, when to share about being married, and when to share about being HIV-positive. For some men, these challenges foster the status quo of marriage. Others see these as difficult but surmountable.

CHOICES

What I have learned from these men is that there is no one universal journey gay and bisexual, married, and HIV-positive men should pursue. I have been surprised when men share frustrating experiences with psychotherapists—many of whom adopt a dichotomous strategy for conceptualizing intervention: *either* help gay or bisexual married men stay married to their wives *or* help gay or bisexual married men separate and divorce.

Men who have had such experiences are typically wary of me when we first meet. What is *my* agenda—they wonder. Am I invested in helping them remain married despite their sexual attraction to men, or am I invested in helping them divorce despite their desire to stay married at all costs?

I have had gay and bisexual men begin therapy with me insisting they will never divorce who ultimately decide to divorce. I have also, however, worked with gay and bisexual men who came to me seeking to divorce but then decided to remain married. I have found that the one agenda I do support is the agenda of increased authenticity, though this may manifest differently for each man—and may even manifest differently for the same man at different periods of time in his life.

TOWARDS HEALING

Michael's shame, secrecy, and isolation were the result of judgment, prejudice, and oppression. For Michael, gay, married, and HIV-positive, "full disclosure" in all circumstances, all relationships, and all contexts felt, and actually was, dangerous, fraught

with both real and imagined negative consequences. Our work together involved an exploration of possibilities and experimentation with authenticity. And Michael evidenced great courage as he tackled these challenges.

Initially, Michael experimented by being more authentic in his relationship with me. He shared more about himself, his history and his feelings. Having an opportunity to share parts of himself he had never shared was scary but empowering at the same time. If he could fully be himself in the presence of another person and have that person accept him, he could move closer to accepting himself. As long as he kept “secrets”—as long as he was inauthentic—he could continue to believe that if people found out who he “really” was (gay, HIV-positive, someone who had anonymous sex, etc.), they would reject him. As Michael shared more, and as he experienced acceptance, he became more confident to further experiment with authenticity.

In group therapy, Michael continued to risk sharing more of himself. And, he was rewarded with others sharing more of themselves. In fact, others shared feelings, behaviors, and histories that were so similar to Michael’s that he felt validated and, for perhaps the first time in his life, he felt connected to other people fully. His self-confidence grew and he became willing to share more honestly—even when he feared negative consequences.

Finally Michael took more risks with Virginia. He shared more about his love for her, his desire not to hurt her, and his desire to pursue his feelings for men. Though Virginia felt betrayed and uncertain about her own future, they actually became closer to one another than they had been in years. Surprised by his renewed friendship with Virginia, Michael felt less shame, more pride, and an even lesser need to keep secrets.

While Michael experienced primarily positive consequences as a result of being more honest and authentic, this is not the case for all men in his circumstances. Many gay and bisexual married men have had greater conflict with their wives/ex-wives, children, extended family, and friends as they become more truthful. For some, their fears of rejection have been confirmed as loved ones cut off contact or limit contact considerably. There are instances when these initial reactions soften and over time, relationships are restored and strengthened.

There are also instances when prior relationships cannot be maintained. In cases of divorce, the relationship between husband and ex-wife may be extremely strained and acrimonious. Even in these instances, however, most married and formerly married gay and bisexual men report that honesty brings some sense of relief, improved self-confidence, and a sense of hopefulness for what may come.

Michael continues to face daily decisions about how to live his life. While Virginia knows almost everything, his children know only that he is gay and not that he is HIV-positive. And, he remains ambivalent about his desire to divorce—still dealing with a sense of being trapped. Even with an ambiguous future, however, Michael feels less shame and a greater sense of pride. He recently shared: “Being more truthful has been my strongest antidote.” ☞

**Michael’s story is a composite of the stories of married, gay or bisexual, and HIV-positive men with whom I have worked. His name and the names of his family members are not actual client*

names. His situation has been constructed from the common challenges faced by these men and their families.

Jeff Levy, LCSW is a psychotherapist and the Chief Executive Officer of Live Oak, Inc. in Chicago’s Lakeview neighborhood. Live Oak provides psychotherapy, consultation, and professional training. To learn more, visit www.liveoakchicago.com.

Internet Resources and Meetings

For Gay and/or Bisexual Married Men

- Men’s Refuge: MensRefugeHelpinMakingtheToughestTransition@groups.msn.com (Go to MSN groups to subscribe)
- Chicago Married Men’s Group: ChiMMG-subscribe@yahoogroups.com
- Gay and Struggling: GayAndStruggling-subscribe@yahoogroups.com
- HOW (Husbands Out to Wives): how@groups.queer-net.org
- MMOMW (Making Mixed Orientation Marriages Work): MMOMW-subscribe@yahoogroups.com
- M-Group Chicago: TheMen@MGroupChicago.org
- Gay Dad’s List: gaydads@rdrop.com
- CLR List (Closed Loop Relationships): Closed-Loop-subscribe@yahoogroups.com

For Straight Spouses

- Straight Spouse’s Network: www.straightspouse.org
- Alternate Paths...a yahoogroups listserve for wives of bi/gay married men
- Alternate Futures...for wives of bi/gay men facing separation and divorce (has a yahoogroup listserve)
- Straight Lounge...a listserve for wives and husbands of gay spouses

Chicago-area Meetings for Gay or Bisexual Married Men

- Psychotherapy and Support Group for Married and Formerly Married Gay or Bisexual Men, 8-week cycles, Live Oak, Inc. Contact Jeff Levy at (773) 880-1473.
- The M Group, meets 2nd Thursday and 4th Tuesday of every month at the Gale House (behind the Unitarian Church) on Kenilworth in Oak Park.
- Chicago Married Men’s Group, meets the 2nd Wednesday of every month at Live Oak, 1300 W. Belmont, Suite 402, 7:30–9:30 p.m.
- DuPage Married Men’s Support Group, meets the 4th Monday of each month at the DuPage Unitarian Universalist Church (Naperville), 4 South 535, Old Naperville Road, Naperville, 60563. Call (630) 505-9408.



Dating Positively

When should we disclose our status while dating?

by Matthew Carter

Dating can be exciting as well as exhausting, and being HIV-positive can add a whole new layer. I have been positive for almost three years and have been on many dates—before and after my diagnosis. In fact, if your dates have been anything like mine, they can be likened to a job interview that ends with a root canal instead of a goodnight kiss. Yet I endure them in the hopes that the next one will be the last one and I will find my soul mate. Dates are all about selling ourselves and trying to find out if the person across the table from us is a good match. We laugh, flirt, and tell them our good qualities, while keeping our snoring and other bad habits out of the picture until the move-in date—surprise! In those first few meetings we leave out the big stuff, our political and religious differences, our incomes as well as our views on Paris Hilton. But, when should we disclose our status?

Dating when you are HIV-positive is an entirely separate ballgame. There is the inevitable, difficult and possibly awkward conversation when you have to tell them your status. Being positive is nothing to be ashamed about, but there is a very real possibility that the person with the perfect laugh and similar interests as your own might reject you. I made a promise to myself that I would tell them by the third date—or earlier if it looks like he's making a break to steal third base. Sounds like a good plan, right? Maybe. The third date rule worked in the past, twice. Then recently after a third

dinner with someone I was really beginning to care about, I disclosed my status and was rejected. Not for being positive, but for not being honest and upfront about my status.

So what do we do? Only date positive people? I know there are thousands of serodiscordant couples (couples where one is positive and the other negative) who are living happily ever after. Should we tell them on the first date, the second or the third? There is no easy answer, if there even is one. It is a highly personal and touchy decision to make. But it must be made.

If you decide to go the route of meeting people in a similar position, one alternative is a dating website for HIV-positive individuals. Gay or straight you can register, log in and find that perfect someone, complete with a hundred great qualities and about the same number of T-cells. This can take the guesswork out of when to reveal your status. With everything we know about how HIV is transmitted, there should be little fear when having sex. Positive or negative, everyone should keep themselves and their partners protected. I once heard some great advice—always assume the person you are having sex with is HIV-positive, even if they say they otherwise.

In the past I have dated HIV-negative people, who after some time were just too afraid to let go of their fear (or ignorance) to have a normal sex life. I have also dated negative people who understand the reality and risks and were okay to have a great, and creative, sex life. In my opinion, I think dat-

ing would be easier if our status was on the table from moment one. If nothing else we already have something in common—and could possibly learn something new.

I now tell potential partners before or on date number one. Being HIV-positive has taught me more about myself than I cared to know at first, but I now relish in all the new knowledge. I used to be afraid of things that I now face head-on. Rejection still hurts, of course, but I find I am rejected less when I keep my head held high and speak the truth—proud of who I am and how far I have come.

Living with HIV means we have to make some changes and that our lives will inevitably become different from before. I see my diagnosis date as a new birthday, and I've been lucky enough to have been able to celebrate my continued health every year with a ski trip—although if you've ever seen me ski, the phrase "continued health" could be a thing of the past. But yes, dating can be hard and I don't see it becoming easier for anyone in the near future. We can only take care of ourselves, be proud of who we are and what we can do, and hope that the next root canal—or date—will be the last one. ☒

Matthew Carter is a freelance writer originally from Cambridge, Massachusetts, now living in Chicago. He has been HIV-positive for three years.



The Real Heroes

Profiles of courage

by Sue Saltmarsh

In considering how this column could fit in with the theme of the issue, I took a few moments to think about the people I've known and admired in my 15 years of working in the HIV/AIDS community. There are so many that should be mentioned that I'm sure Enid would tear her hair out at the 15-page article I could submit! However, I will stick with the ones who I believe stick with me.

My first connection with this community came in 1993 at the AIDS Alternative Health Project (AAHP). Freshly graduated from the Southwest School of Botanical Medicine, I'd come back to Chicago to "corner the Midwest market," as most herbalists in the U.S. are on either coast. A client whose son was HIV-positive suggested I contact AAHP to see if there was a place for me there. Little did I know it, but that suggestion would lead me to meet Sal, with whom I would share one of the deepest friendships of my life; it would urge me to practice my modality in a constant state of learning and growth; it would begin the weaving of one of my strongest heartstrings and it would change my life forever.

I will never forget that first day or the three first clients I met—Catherine, Scott and Chris. I was almost literally shaking as I listened to Catherine tell me about her son who had been born with HIV soon after she was diagnosed. Here was a woman who was looking to me to help her and her son stay alive! I believe she must've known how nervous I was, because by the end of the hour, as she put her bottle of sleep herbs in her purse, she patted me on the shoulder, assuring me that she was sure they would work.

Scott appeared next, his face covered with molluscum and a huge smile. He was so enthused and so optimistic that I found myself forgetting about the huge responsibility I had in trying to help him with digestive difficulties (some of the trickiest things to handle since most of the herbs that would be greatly beneficial were contraindicated by the meds he was taking) and just

enjoying talking to him. I gave him a bag of organic peppermint tea and promised to have some capsules made up for him by the next week.

And then there was Chris. Toweringly tall, painfully thin, obviously a victim of acne (teenage and beyond), KS legions, hair loss from chemo, pasty grey complexion, dark circles under his beautiful brown eyes. He had just been released from the hospi-

tal after a bout of PCP and teetered a bit as he sat down. Oh, man, I thought to myself, how am I ever going to find a way to help this poor guy? I expected him to start in on a litany of complaints—he certainly would have been justified! But, instead, he cheerfully told me that he was so glad to be back at home where he could have his favorite breakfast—yogurt and fruit—instead of the dreary hospital food. When I asked him, as part of his intake, what his main health complaint was, he laughed and said, "You mean my favorite? That would have to be nausea at the moment, but it's just like the weather—wait a few minutes and I'm sure it will change!" Nausea? NAUSEA?? The one thing that I could actually do something about!

OH, MAN, I THOUGHT TO MYSELF, HOW AM I EVER GOING TO FIND A WAY TO HELP THIS POOR GUY?

Over the next nine months, I met more and more people who were courageous and scared; open-minded and stubborn; believers and skeptics; frustrating and inspirational. Catherine slept better and eventually moved downstate so her family could help her raise her son. Scott struggled with kidney failure. Chris hung on. My own life went through changes, and my time

was now split between AAHP and Project Vida. At Project Vida I found more people who wove their way into the tapestry of my heart. Those first years were amazing and helped me, more than anything previously, to understand who I was and who I wanted to be. Unfortunately, also by the end of the first year, all these precious people had died. Twelve of my original group of clients were

gone. I was faced, for the first time in my life, with grief and loss. And I learned about "pressing the bruise" (March/April 2006). At Chris' memorial, I thought about how, with all the horrible things he had to deal with, he would always, sincerely, ask how I was and not let me get away with "Oh, I'm fine." At Project Vida, we did a ceremony, releasing a balloon for each person we'd lost, and I thought about the example of gentle dignity that Claudia set; the ever-resilient Saybert; the love between Mark and Bob.

There have been, and will continue to be, people I meet through the vehicle of this disease who will enrich my life beyond any treasure—Leroy, Adelfio, Mary, Mark, Patrice, Jim, Rick and my TPAN family, Gary, Robert, Reynaldo, and Una, just to name a few. And while we, as humans, will always need those "bigger than life" heroes like Magic Johnson and Greg Louganis, for me it is these unknown, personal heroes who will always mean the most to me. Thank you all for gracing, guiding, and inspiring my life. Breathe deep and live long. ✚



Dying in Silence

An ode to Black gay men

by Keith R. Green

Vincent died in silence.

Always the life of the party, when he had life, his final departure was ironically absent of any form of the high-fashioned faggot frolicking or fanfare that is his legacy. In that moment, Vincent's final moment, there was only silence.

No Chicago-style house music that he so adored. No smoke-filled rooms overflowing with down-low b-boys searching for

know the real reason he lay there dying. In silence. With a lifelong sense of loneliness.

But just as he did, they also knew. Maybe not as concretely, but innately, they knew. Choosing to remain comfortable in their respective worlds of denial. Allowing him to be silently swept away to a cross not necessary for him or anyone else like him to bear in this day and age, alone or otherwise. Paying the price for already forgiven

Silence of our pain. Silence of our struggle. Silence of our feelings for one another. And silence of our disease.

But just as a man who conceals his disease cannot expect to be cured, a man who hides himself behind fear cannot expect to be affirmed for who he is. For he will always be perceived as weak. And the weak in our profit-driven society are considered of no value and, therefore, disposable.

So, my brothers, to whom I am writing, never seek to be validated in this world. For I am inclined to believe that the day in which that happens may never, ever come. At least not in this lifetime.

Instead, be fierce enough to validate the world by your existence. Understand that there exists no other creature like you. And that in the absence of all of the fabulousness that you are, the rest of this measly old universe would simply be just a bland old ball of confusion. Because that's all it's been made out to be.

You, however, are the spice of this life, challenging the status quo to the extent that it makes others uncomfortable. That's okay. They should be uncomfortable.

Be who you are and be it well.

Respect yourself and others will have no choice but to respect you. Love who you are and others will do the same. And even if the ones who you most desperately want to love you do not, your light will shine so bright that others who don't even know you will want to love you. Allow them to. Allow yourself to experience love and all of the joy it can bring to your life. Trust that if you are honest about who you are and what you feel, you will attract the same thing.

Understand that there is no other creature in the world like you. And never allow yourself to be convinced of the notion that you are disposable.

Death is inevitable. So choose to live your life out loud and, when it's time, to die in that very same spirit, free of that lifelong weight of loneliness. ✚

I WRITE FOR EVERY VINCENT WHOM I HAVE EVER ENCOUNTERED

their rhythm while ditching their blues.

No Phyllis. No Patti. No Aretha. No Sylvester. No Janet. No Destiny's Child. No high-fashioned faggot frolicking or fanfare. In that moment, Vincent's final moment, there was only silence.

And the lifelong weight of loneliness.

Drowning in the dingy blue sea of hospital walls. Surrounded by marvels of medical technology that, when it really mattered the most, were of no value to him. Loved ones grieving at his bedside, yet far enough away that in his mind they might as well have been some place else, doing some other thing besides watching him lay there dying. In silence. And with the lifelong weight of loneliness.

From renal failure, they believed. Or congestive heart disease, possibly. But more from a fragile heart shattered by decades of rejection from even some of them beside him in that moment, who had claimed to really love him.

But if the truth be told, they never even knew him. And they most certainly did not

sin. Or sin discovered perhaps to not be sin after all.

A lie perpetuated by high-minded persons of significant influence, their personal way of grappling with their own homoerotic impulses. Hypocrites.

I digress, however, for I write not to give energy to their madness or to waste time convincing those who could care less about Vincent or the thousands, perhaps millions, of other men who walk in his shoes.

I write for every Vincent whom I have ever encountered. And for those who have yet to cross my path. For the Vincent's whom I will never know, but who are at risk of suffering the same unfortunate fate that he did, the same fate that I miraculously escaped.

I write so that others may understand the reason why some of us choose that road, rather than to walk with the mark of the beast. The "big disease with the little name" that curses men into corners of silence.



Snake Oil for Meth Addiction—Only 15k

We need good science, not shady marketing

by Jim Pickett

The controversial and unproven treatment protocol for alcohol, cocaine, and methamphetamine addiction—called Prometa and being heavily marketed by the Hythiam company—is something you should have on your radar, folks. Since gay men, including those living with HIV, are disproportionately dealing with crystal meth problems—we are smack dab in the middle of Hythiam’s unscrupulous sights.

Don’t be a sucker. We all need to be good consumers of substance abuse treatment, and need to be wary of swamp land, snake oil, and anything that comes across as magical or miraculous. If it’s too good to be true, it probably is. Would you respond to that e-mail from the wealthy Nigerian widow who wants to give you a percentage of her \$15 million inheritance in exchange for a little help with international banking?

So what’s the skinny on Prometa?

Recently, MSNBC reported Prometa, the drug “cocktail” designed to combat addiction to cocaine and methamphetamine, got another nail in the cross when authorities in Pierce County, Washington froze the funding for an \$800,000 pilot program, citing “irregularities” in testing after a damaging audit.

Basically this drug protocol, using three already FDA approved drugs off-label, has yet to be proven safe and effective. That’s a big deal. It means that data from randomized, double-blind, placebo-controlled studies have yet to be published, though there is such a trial currently underway at UCLA now and we might see some results in the next quarter.

Sure, Hythiam has touted a number of studies, that don’t meet the above criteria, but as we know, when you don’t have a placebo control (where neither the patients nor the investigators know who is taking the active agent and who is essentially getting a sugar pill) or randomization, we can’t really know whether the drug treatment being tested actually works or not.

The treatment, which costs \$15,000 for crystal and cocaine treatment, and a few grand less for alcohol treatment, involves intravenous infusions of Flumazinil, a reversal agent for benzodiazepines like Valium and Klonopin. The second drug, hydroxyzine, is an antihistamine, and the third, sold as Neurontin, is an anti-seizure medication frequently used “off prescription” as a treatment for a number of ailments, including alcoholism and hearing loss.

Hythiam doesn’t need FDA approval for their scheme, because it is only selling a “protocol” and is not the maker, nor the seller of these drugs. So, no approval needed, and Hythiam, by clearly putting

ment that hasn’t been proven to be safe or effective?

We all deserve substance abuse treatment that has met the rigorous demands of science and has been proven to work.

Prometa is not the first, and won’t be the last, shady marketing scheme to prey on vulnerable people, like gay men and their friends and lovers in the throes of a tina meltdown. It behooves us all to be smart, savvy, and critical.

By the way, if a placebo-controlled, randomized, double-blind clinical trial proves that Prometa is effective at treating crystal meth addiction, I will be in the front of the line doing high kicks and twirling my tassles. But not a second before. ☚

BUT LOOK CLOSELY AND YOU WILL SEE THAT THE MAJORITY OF FOLKS IN THE STUDY CONTINUED TO USE CRYSTAL! CRAVINGS BE DAMNED

profits before proof, doesn’t seem to care a rat’s patoot about science, though they do pretend. Buyer beware—the Prometa study recently concluded in Dallas (and conducted by a Prometa practioner) showed some diminishment of “cravings” for crystal, trumpeted far and wide, especially to the financial community. But look closely and you will see that the majority of folks in the study continued to use crystal! Cravings be damned.

Would you spend \$15,000 for an appetite suppressant that doesn’t diminish your hunger? Would you spend \$15,000 for the pleasure of testing a novel HIV treat-

In addition to being advocacy director at the AIDS Foundation of Chicago and being obsessed with rectal microbicide research and development, Jim Pickett runs the Life-Lube blog and is co-chair of Chicago’s LGBT Task Force on Substance Use and Abuse (formerly the Chicago Crystal Meth Task Force.) Read more recent press in the online version at www.tpan.com.

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