

PA

POSITIVELY AWARE

HIV TREATMENT, PREVENTION, AND SUPPORT FROM TPN
JANUARY+FEBRUARY 2018

**IDWEEK
HIGHLIGHTS**

HEART DISEASE,
HIV TREATMENT,
AND PrEP

A SENSUAL FILM
ABOUT LOVE
AND ACTIVISM

BPM

PRECEPTION

SERODIFFERENT
COUPLES WHO
WANT TO HAVE KIDS

HIV AND ADOPTION

A MOM ANSWERS
COMMON QUESTIONS

JADENNA MONAE
EVERETT, AUNSHA
HALL-EVERETT, AND
MICHAEL EVERETT

MODERN FAMILY

Redefining what a family is to create families of our own

WHAT IS DESCOVY[®]?

DESCOVY is a prescription medicine that is used together with other HIV-1 medicines to treat HIV-1 in people who weigh at least 77 lbs (35kg). DESCOVY is not for use to help reduce the risk of getting HIV-1 infection. DESCOVY combines 2 medicines into 1 pill taken once a day. Because DESCOVY by itself is not a complete treatment for HIV-1, it must be used together with other HIV-1 medicines.

DESCOVY does not cure HIV-1 infection or AIDS.

To control HIV-1 infection and decrease HIV-related illnesses, you must keep taking DESCOVY. Ask your healthcare provider if you have questions about how to reduce the risk of passing HIV-1 to others. Always practice safer sex and use condoms to lower the chance of sexual contact with body fluids. Never reuse or share needles or other items that have body fluids on them.

IMPORTANT SAFETY INFORMATION

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

DESCOVY may cause serious side effects:

- **Worsening of hepatitis B (HBV) infection.** DESCOVY is not approved to treat HBV. If you have both HIV-1 and HBV and stop taking DESCOVY, your HBV may suddenly get worse. Do not stop taking DESCOVY without first talking to your healthcare provider, as they will need to monitor your health.

What are the other possible side effects of DESCOVY?

Serious side effects of DESCOVY may also include:

- **Changes in your immune system.** Your immune system may get stronger and begin to fight infections. Tell your healthcare provider if you have any new symptoms after you start taking DESCOVY.
- **Kidney problems, including kidney failure.** Your healthcare provider should do blood and urine tests to check your kidneys. Your healthcare provider may tell you to stop taking DESCOVY if you develop new or worse kidney problems.
- **Too much lactic acid in your blood (lactic acidosis),** which is a serious but rare medical emergency that

can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.

- **Severe liver problems,** which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.

The most common side effect of DESCOVY is nausea. Tell your healthcare provider if you have any side effects that bother you or don't go away.

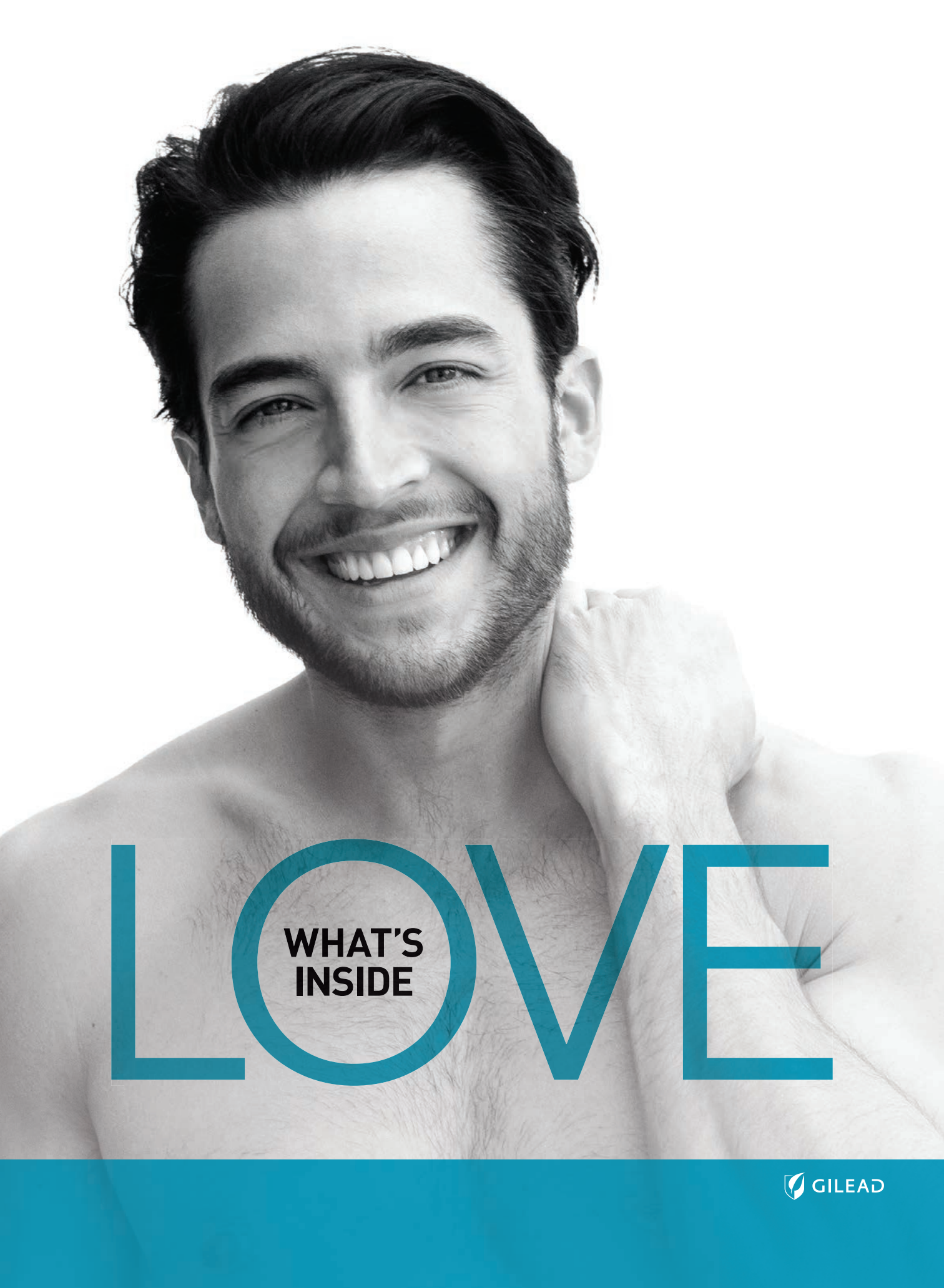
What should I tell my healthcare provider before taking DESCOVY?

- **All your health problems.** Be sure to tell your healthcare provider if you have or have had any kidney or liver problems, including hepatitis virus infection.
- **All the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. Other medicines may affect how DESCOVY works. Keep a list of all your medicines and show it to your healthcare provider and pharmacist. Ask your healthcare provider if it is safe to take DESCOVY with all of your other medicines.
- **If you are pregnant** or plan to become pregnant. It is not known if DESCOVY can harm your unborn baby. Tell your healthcare provider if you become pregnant while taking DESCOVY.
- **If you are breastfeeding** (nursing) or plan to breastfeed. Do not breastfeed. HIV-1 can be passed to the baby in breast milk.

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

Please see Important Facts about DESCOVY, including important warnings, on the following page.

Ask your healthcare provider if an HIV-1 treatment that contains DESCOVY[®] is right for you.



LOVE

**WHAT'S
INSIDE**

(des-KOH-vee)

MOST IMPORTANT INFORMATION ABOUT DESCOVY

DESCOVY may cause serious side effects, including:

- **Worsening of hepatitis B (HBV) infection.** DESCOVY is not approved to treat HBV. If you have both HIV-1 and HBV, your HBV may suddenly get worse if you stop taking DESCOVY. Do not stop taking DESCOVY without first talking to your healthcare provider, as they will need to check your health regularly for several months.

ABOUT DESCOVY

- DESCOVY is a prescription medicine that is used together with other HIV-1 medicines to treat HIV-1 in people who weigh at least 77 lbs (35kg). DESCOVY is **not** for use to help reduce the risk of getting HIV-1 infection.
- **DESCOVY does not cure HIV-1 or AIDS.** Ask your healthcare provider about how to prevent passing HIV-1 to others.

BEFORE TAKING DESCOVY

Tell your healthcare provider if you:

- Have or had any kidney or liver problems, including hepatitis infection.
- Have any other medical condition.
- Are pregnant or plan to become pregnant.
- Are breastfeeding (nursing) or plan to breastfeed. Do not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.

Tell your healthcare provider about all the medicines you take:

- Keep a list that includes all prescription and over-the-counter medicines, vitamins, and herbal supplements, and show it to your healthcare provider and pharmacist.
- Ask your healthcare provider or pharmacist about medicines that should not be taken with DESCOVY.

HOW TO TAKE DESCOVY

- DESCOVY is a one pill, once a day HIV-1 medicine that is taken with other HIV-1 medicines.
- Take DESCOVY with or without food.

IMPORTANT FACTS

This is only a brief summary of important information about **DESCOVY**[®] and does not replace talking to your healthcare provider about your condition and your treatment.

POSSIBLE SIDE EFFECTS OF DESCOVY

DESCOVY can cause serious side effects, including:

- Those in the “Most Important Information About DESCOVY” section.
- Changes in your immune system.
- New or worse kidney problems, including kidney failure.
- Too much lactic acid in your blood (lactic acidosis), which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- Severe liver problems, which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark “tea-colored” urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.

The most common side effect of DESCOVY is nausea.

These are not all the possible side effects of DESCOVY. Tell your healthcare provider right away if you have any new symptoms while taking DESCOVY.

Your healthcare provider will need to do tests to monitor your health before and during treatment with DESCOVY.

GET MORE INFORMATION

- This is only a brief summary of important information about DESCOVY. Talk to your healthcare provider or pharmacist to learn more.
- Go to DESCOVY.com or call 1-800-GILEAD-5
- If you need help paying for your medicine, visit DESCOVY.com for program information.



A DAY WITH HIV

Share the everyday moments of extraordinary lives with an exciting new photo book from **A Day with HIV**

Every year in September, **A DAY WITH HIV** captures a single 24-hour period in the lives of those affected by HIV, as people across the country and around the globe capture a moment of their day and share their story on social media. A new 36-page book featuring select images from A Day with HIV 2017 is now available—as a downloadable digital edition and in a print edition.

DOWNLOAD the free digital edition,
ORDER your copy of the print edition:
www.tpan.com/adaywithhiv



adaywithhiv.com



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TPAN was founded in 1987 in Chicago as Test Positive Aware Network, when 17 individuals gathered in a living room to share information and support in response to the HIV/AIDS epidemic. POSITIVELY AWARE is the expression of TPAN's mission to share accurate, reliable, and timely treatment information with anyone affected by HIV.



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JADENNA MONAE EVERETT, AUNSHA HALL-EVERETT, AND MICHAEL EVERETT, PHOTOGRAPHED AT GRIFFITH PARK IN LOS ANGELES, CALIFORNIA BY LOUIS "KENGI" CARR



Time out... times change

I enjoyed this issue of POSITIVELY AWARE, (Winter 2017/2018, The Cure Issue). I was especially interested in the article "Time Out." It was a bit of *déjà vu* for me. Back in 1999, [then PA editor] Steve Whitson commissioned me to write an article regarding my experience with AIDS. I have been living with AIDS since 1990 and have, like many long-term survivors, gone through the wringer of drug trials, drug interactions, opportunistic infections, and the general challenge of living with a virus that entered not only our bodies but our psyches as well.



Back then, taking a break from treatment meant taking what was called a "drug holiday." Interestingly enough, my article was titled "Time Out/Time In: Suspending One's Drug Regimen" and was included in the September + October 1999 issue entitled "HIV—An Owner's Manual" [an issue devoted to HIV basics].

Taking a time out is not for the faint hearted. I am attaching a copy of my article. You might find it interesting to compare some of the information with that in the current article.

My time out lasted 11 weeks. That was in 1998. Over the next period of nearly two decades, I have taken other time outs. They have lasted anywhere from five to 16 weeks. During each one, my body kick starts itself and the emotional residual effects remain long after starting back on the drug regimen.

During those years I was a caregiver and "death coach" to many, burying more than 250 of my best friends. I continue that work even today as a certified hospital chaplain. The work that continues to draw me in is oncology, the ICU [intensive care unit], and full cardiac arrests in the ER. I know

the daunting feeling of facing a terminal diagnosis and am able to work with patients and their families in dealing with hard news.

I also know that when the human spirit refuses to give in and decides to fight, that miracles can and do happen. While chemo, radiation, and aggressive drug therapy can stabilize patients, the mental and spiritual attitude of the patient is paramount to any recovery. This is true of any approach to those living with HIV/AIDS when they consider a drug holiday.

For good or bad, my medical journey has been complex, challenging, and a compelling model for study, especially in the area of HPV [human papilloma virus], which is a conversation in itself. Here in Asheville, I have helped raise awareness of HPV in men who have sex with men. Now, instead of having to travel to New York to see my long-time surgeon, Steven Goldstone—who pretty much wrote the book on the subject—I can be tested and treated, if need be, here in Asheville. I am attaching an article that I wrote about that as well. It is a mix of humor and practical advice.

Having had 13 surgeries, humor is about the only way one can get through the experience. Goldstone would give copies to some of his patients to help them cope. Today, instead of incisions with sutures, ablation is the treatment of choice, but even that is not as easy to deal with as some doctors suggest.

I want to thank you and your staff for taking on some rather edgy topics. As I have told people over the years, "We long-term survivors survive because we aren't afraid to be on the cutting edge of change, but being there can sometimes give you a paper cut."

FRANKLIN L. COURSON, ED.D.
VIA THE INTERNET

Editor Jeff Berry responds: Thanks so much for your email. It's interesting how the titles were similar, but as you say, a lot of things have changed since 1999!

The article "Time Out" in our latest issue on HIV cure looks at treatment interruption only as a strategy for potential drug candidates for cure research, not for taking a drug holiday. As you are probably aware, studies have not borne out the utility of treatment interruptions as an effective strategy, and it should only be used in very specific situations such as drug toxicities, surgery, or in the setting of a clinical trial, and even then only under the close supervision of a licensed medical provider. The SMART study, which was designed to test the effectiveness of treatment interruptions, was supposed to have gone on for nine years, but was stopped after only 18 months due to an increase in morbidity and death in those interrupting their treatment.

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CONVERSATION



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We are family

One of the first disco albums I ever owned, “We Are Family” by Sister Sledge, I didn’t actually buy, but I won in a radio call-in contest in the spring of 1979. I was still living at home at the time, and remember driving down to the local Southwest Michigan radio station to pick it up, excited to be a winner. The enduring club anthem about having “all my sisters with me” has always been a part of my ethos for my entire adult life, and I still have the vinyl record in my possession. I can’t seem to part with it.

The people in our families can be a source of unconditional love, those who we can always rely on, and will support us no matter what, who share in our joys and accomplishments, and we in theirs. Families for many can also be a source of frustration, pain, suffering, despair, conflict, anger, resentment, and drama.

At one point in my life I thought I might make a good parent, but by the age of 30 I figured I wasn’t able to have a child because I was HIV-positive—the technology and methods that are available today were not around then, or were prohibitively expensive. I knew though that raising a child would have altered the course of my life for sure, judging by my reaction to my partner Stephen bringing home a puppy one October day in 2010, unannounced. (I believe my exact words were, “What have you done?”) I knew then and still today that there is a lot of work that goes into raising a puppy, let alone a child, but the rewards are immeasurable.

I guess I’ll never know whether I would have been a good parent, but luckily I have other children and people in my life through my extended family with my partner’s mom, sister, and nephews, who were always incredibly welcoming from the very first time I met them.

While the stories in this issue focus on families with children, there are also the families we choose, and sometimes it’s a combination of the two.

In Jourdan Barnes’ article “Modern Family” on page 12 we’re introduced to one couple that is redefining what it means to be a family. Aunsha and Michael, who are married and in a serodifferent relationship, are raising their young daughter Jadenna Monae, while learning how to navigate the world as same gender loving men of color.

We hear from Kathy, who adopted a child with HIV from China, in “Easiest Special Need Ever,” on page 19. Kathy, whose son David (not his real name) is “undetectable and thriving,” takes every opportunity to educate others who are considering adopting children with special needs on misconceptions about raising a child with HIV.

For those who may be considering conceiving a child in situations where the man is HIV-positive and

the woman is HIV-negative, the article “PrEPception,” by Emily S. Miller, MC, MPH, tells us how access to conception methods that protect the HIV-negative partner, such as PrEP and TasP, remain limited. Dr. Miller explains how recent activism spurred the CDC to change their outdated guidelines, but more provider education is still needed.

Speaking of activism, “The Erotic Militarism of AIDS Activist Art” by Rick Guasco on page 28 showcases a new book by long-time POSITIVELY AWARE contributor Dan Berger, MD, which focuses on the ACT UP affinity group ART+Positive and its political impact. In the film *BPM (Beats Per Minute)*, which I review on page 29, the story centers on the relationship of two young gay men who are members of ACT UP Paris during the early nineties at the height of the epidemic. But *BPM* is also about a “family” of activists that lean on each other for support, while seeking to effect change for the larger family of people living with HIV and AIDS, who were literally fighting for their lives.

Families come in all shapes and sizes—there are the families we are born into, and those we choose. I have my relatives, my extended family, my family of friends, and my work family, to name just a few. Families can sometimes drive you crazy. But if it weren’t for family, I would be lost. We cannot exist in isolation, as much as we think we’d like to sometimes. We need the social support, connection, and interaction with each other, to learn, to grow, to forgive, and to give back. I am grateful for my family and my families, and hope that all of us appreciate them in whatever form or shape they may take. One type of family is no better than the other, but each family is an opportunity for us to stay connected, and to ultimately understand the good qualities that we all share in common.

Take care of yourself, and each other.

Families can sometimes drive you crazy. But if it weren’t for family, I would be lost.



BRIEFLY

ENID VÁZQUEZ  @ENIDVAZQUEZPA

FDA approves new HIV drug, Juluca

New medication represents a shift in treatment as the first antiviral for use as maintenance therapy

The FDA has approved the first HIV medication to be used as a maintenance therapy, meaning that patients first need to have an undetectable viral load on other HIV treatment before they can be switched to Juluca to maintain that suppressed virus.

Switching over to two meds “is a very hot topic and is being heavily studied right now as a new ART [antiretroviral therapy] strategy and potentially a game-changer,” said Eric Farmer, PharmD, BCPS, AAHIVP, HIV Clinical Pharmacist at Indiana University Health LifeCare Clinic in Indianapolis. This is particularly true, he added, because there are other dual-drug regimens on the way, including dolutegravir/lamivudine and intramuscular cabotegravir/rilpivirine. Dr. Farmer worked on the upcoming POSITIVELY AWARE 2018 HIV Drug Guide (March + April).

In a press release from the FDA, Debra Birnkrant, MD, says, “Juluca provides a two-drug maintenance regimen for select individuals who are virologically suppressed. This group of select individuals will clearly benefit from this once-daily NRTI-sparing regimen... we are also aware that this approval represents a paradigm shift in the treatment of HIV-infected patients.” Dr. Birnkrant is director of the Division of Antiviral Products in the FDA’s Center for Drug Evaluation and Research.

It is hoped that this treatment simplification strategy will decrease the risk of side effects, as well as increase some other benefits, through the elimination of an entire class of HIV drugs currently used, the nucleoside analogs. (This drug class is also called nucleoside reverse transcriptase inhibitors, or NRTIs, “nukes” for short.)

Juluca contains only two medications, and all other HIV regimens contain at least three, including nucleosides.

Juluca is a single-tablet regimen (STR), a complete therapy in one pill. All current

HIV regimens consist of at least three medications, even if they’re only taken as a single pill. As such, Juluca is the first STR containing only a dual-drug combo.

Moreover, all the other STRs contain a pair of nukes, however tolerable.

Juluca consists of medications currently on the market, dolutegravir (DTG, brand name Tivicay) and rilpivirine (RPV, brand name Edurant). It is the smallest pill among the STRs. The dose is one pill a day, with a meal. Patients must be undetectable for six months with no history of treatment failure and no drug resistance to the medications in Juluca before they can take it. The most common adverse events in patients taking Juluca were diarrhea (2%) and headache (2%).

Dolutegravir is an integrase inhibitor (or integrase strand transfer inhibitor—“INSTI” for short), while rilpivirine is a non-nucleoside analog (or non-nucleoside reverse transcriptase inhibitor—NNRTI, “non-nuke” for short). All of the INSTI drugs on the market (Tivicay, Isentress/Isentress HD, and elvitegravir, which is not available separately but found in the STRs Genvoya and Stribild) are recommended for first-time HIV therapy for most people under the U.S. Department of Health and Human Services (DHHS) HIV treatment

guidelines. INSTIs are currently the only drug class to hold this distinction.

Dolutegravir, or Tivicay, is found in the STR Triumeq, in which it’s combined with the nukes abacavir (brand name Ziagen) and lamivudine (or 3TC, brand name Epivir).

In keeping with Juluca’s approval, the FDA also updated Tivicay’s drug label to note that it can be used “in combination with rilpivirine [brand name Edurant] as a complete regimen to replace the current antiretroviral regimen in those who are virologically suppressed (HIV-1 RNA less than 50 copies per mL) on a stable antiretroviral regimen for at least 6 months with no history of treatment failure” or drug resistance to either medication.

In last year’s POSITIVELY AWARE 2017 HIV Drug Guide, David J. Malebranche, MD, MPH, wrote, “Dolutegravir (DTG) has emerged as a clinician’s dream, primarily due to its higher genetic barrier to resistance than [INSTI competitors elvitegravir and Isentress], once-a-day dosing, and ability to be taken with or without food.

[Juluca, however, must be taken with a meal because it contains rilpivirine.] It is incredibly well tolerated with a favorable side effect profile, and has proven in several randomized clinical trials to be non-inferior to comparator INSTI, NNRTI, and PI-based regimens in maintaining an HIV RNA equal to or less than 50 copies/mL.”

Edurant is found in the STRs Complera and Odefsey.

Cabotegravir is a still-investigational, long-acting (LA) injectable INSTI medication. The combination of cabotegravir LA plus rilpivirine LA is being studied at doses of once every four or eight weeks.



TAKING AIM AT HIV IN THE DEEP SOUTH

Two new ventures have been announced which target what continues to be **the region of the U.S. hardest hit by HIV/AIDS**—the Deep South.

A \$2.65 million partnership among the Elton John Foundation, the Ford Foundation, Gilead Sciences, Johnson & Johnson, and ViiV Healthcare seeks to increase and expand HIV care and prevention services in nine states by collaborating with area HIV community organizations and social justice movements. The year-long effort is organized by Funders Concerned About AIDS and is administered by AIDS United. Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Texas are the focus of this partnership. The program runs through Nov. 30, 2018.

At the second annual Biomedical HIV prevention Summit in New Orleans last December, Gilead announced a 10-year, \$100 million commitment to support community-based, underfunded organizations in the southeast. The Gilead COMPASS Initiative will work with three regional coordinating centers—the Southern AIDS Coalition, the University of Houston Graduate College of Social Work, and Emory University Rollins Schools of Public Health—to expand access to treatment, aid prevention efforts, and support education and anti-stigma campaigns.

According to the CDC, eight of the ten states with the highest rates of new HIV diagnoses are in the South.

—RICK GUASCO

UPDATE ROUNDUP: Drug labels

RECENT FDA CHANGES

Tivicay and Triumeq updates

The FDA in November updated the Tivicay (dolutegravir) and Triumeq (dolutegravir/abacavir/lamivudine) drug labels. It added a new indication (prescribed usage) to Tivicay; see previous page.

Triumeq can now be taken by patients weighing at least 40 kg (88 pounds).

The liver toxicity section (found in most drug labels) in Triumeq was also updated. The section now notes that, “Drug-induced liver injury leading to liver transplant has been reported with Triumeq (abacavir, dolutegravir, and lamivudine). Monitoring for hepatotoxicity [liver toxicity] is recommended.” Most HIV treatments already include monitoring of kidney and liver function.

The FDA also reported that clinicians should be aware of drug interactions that may lead to adverse reactions or the development of drug resistance.

Go to tivicay.com and triumeq.com for more information.



Isentress now for neonates

The FDA in November approved the use of HIV drug Isentress (raltegravir) for use in full-term neonates (birth to four weeks of age and weighing at least

2 kg, or 4.4 pounds). An oral suspension formula is available to give infants. Neonates of moms who took Isentress or Isentress HD should be given their first Isentress dose within 24 to 48 hours after birth.



Reyataz label updated

The Reyataz (atazanavir) drug label was updated by the FDA late last year. All patients should have kidney lab tests done before going on the medication (including Evotaz). This testing should include serum creatinine, estimated creatinine clearance, and urinalysis with microscopic examination. People should be informed that taking atazanavir may lead to chronic kidney damage and be reminded to insure adequate hydration while taking therapy that includes the HIV medication. Go to reyataz.com.



Drug labels updated for hep C meds Viekira Pak, Viekira XR, and Technivie

The following updates were made to the drug labels of the hepatitis C virus (HCV) medications Viekira Pak, Viekira XR, and Technivie:

Section 6: Adverse Reactions. The following statement was deleted:

“There were no serious events or severe cutaneous reactions, such as Stevens Johnson Syndrome (SJS), toxic epidermal necrolysis (TEN), erythema multiforme (EM) or drug rash with eosinophilia and systemic symptoms (DRESS).”

Section 6.2 Post-Marketing Experience.

The following information was added to Skin and Subcutaneous Tissue Disorders: Erythema multiforme (EM).

Section 7: Drug Interactions was updated to state that fluctuations in INR values may occur in patients receiving warfarin concomitant with HCV treatment. If coadministered with warfarin, close monitoring of INR values is recommended during treatment and post-treatment follow-up.



UPDATE ROUNDUP: HIV treatment guidelines

A SUMMARY OF RECENT CHANGES

HIV treatment guidelines updated

The U.S. Health and Human Services (HHS) panel on HIV treatment guidelines issued an update of their recommendations on October 17. No longer are HIV regimens labeled as “preferred,” “alternate,” and “other.” Instead, there are two categories of regimens:

1. Recommended initial regimens for most people with HIV.
2. Recommended initial regimens in certain clinical situations.

The panel also added a table on guidance for treatment options in the Virologic Failure section.

Other changes discussed in the updated guidelines:

Several studies have shown that persons with HIV who have sustained viral suppression with no drug resistance may be maintained on regimens with only two active drugs. Results from clinical trials using two-drug maintenance therapy are discussed in the Regimen Switching in the Setting of Viral Suppression section.

Both the Hepatitis B Virus (HBV)/HIV Coinfection and Hepatitis C Virus (HCV)/HIV Coinfections sections have been updated to discuss reactivation of HBV infection in persons with HBV/HCV coinfection starting interferon-free HCV therapy.

In the drug interaction tables found in the Drug Interaction section, a number of drug classes have been

added or expanded, including oral anticoagulants, new oral hypoglycemic agonists, and hormonal therapy for menopausal management and for gender affirmation.

In addition, the guidelines now use People-First Language, which is a way of reducing stigma and showing respect for individuals who are living with HIV by focusing on the person instead of the disease. [For example, saying “people living with HIV” rather than “HIV-positive people.”]

Perinatal guidelines updated

Several updates were also made in October by the panel of the HHS perinatal guidelines:

After review of available study findings, the Panel continues to recommend tenofovir [Viread] as a component of first-line therapy and zidovudine [Retrovir, AZT] as a second-line agent for use in antiretroviral-naïve pregnant women living with HIV in the United States.

Based on limited but increasing experience with use in pregnancy, dolutegravir [Tivicay] is now classified as an Alternative agent for antiretroviral-naïve pregnant women.

The Panel has changed its classification of elvitegravir/cobicistat [found in Genvoya and Stribild] to Not Recommended for Initial Use in Pregnancy based on data showing inadequate levels of both drugs during the 2nd and 3rd trimester as well as viral breakthroughs.

When a pregnant woman presents on elvitegravir/cobicistat regimens, providers should consider switching to a more effective regimen. If elvitegravir/cobicistat regimens are continued, viral load should be monitored frequently and therapeutic drug monitoring may be useful.

Maraviroc [Selzentry] and enfuvirtide [Fuzeon] are not recommended for use in antiretroviral-naïve pregnant women, in accordance with guidelines for non-pregnant adults and due to lack of pharmacokinetic and safety data in pregnancy.

OI guidelines updated

The HIV opportunistic infections guidelines were changed in October to add isavuconazole as a treatment option for patients with uncomplicated esophageal candidiasis (thrush). Information on complications from fluconazole during pregnancy was added. Also added was information on infections by non-*albicans* *Candida* strains; drug-drug interactions and absorption issues with posaconazole; and the importance of HIV treatment and immune restoration in preventing mucosal candidiasis.

GO TO aidsinfo.nih.gov TO REVIEW ALL HIV TREATMENT GUIDELINES, INCLUDING THOSE FOR PERINATAL AND PEDIATRICS.

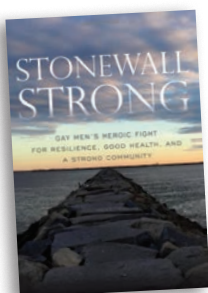


A call for racial and social justice

A collaborative of 20 HIV movement leaders of color has developed a framework calling for “radical leadership” to overcome racial, social and economic injustice in the HIV community. Working for several months to craft the document, the group hopes the framework will be adopted and used by organizations involved in HIV care, prevention, research and advocacy to analyze and adjust their practices, and also inspire leaders of color working in the HIV movement to join forces and demand a racial justice audit of their organizations. The document, *A Declaration of Liberation: Building a Racially Just and Strategic HIV Movement*, is available at hivracialjustice.wixsite.com/framework.

New book, Stonewall Strong

Journalist and author John-Manuel Andriote has written a new book, *Stonewall Strong: Gay Men’s Heroic Fight for Resilience, Good Health, and a Strong Community*. “I describe it as **the ‘bookend’ for my earlier book, Victory Deferred,**” wrote Andriote. “Where *Victory Deferred* documented the impact of HIV/AIDS on individuals, institutions, and the LGBT equality movement, *Stonewall Strong* celebrates the courage, resilience, and



strength of gay men that became so evident in the epidemic.” Andriote interviewed more than 100

individuals nationwide for the book. He covers leading-edge research on gay men as well as personal experiences. Go to stonewallstrong.com.

A Day with HIV

The HIV.gov blog has highlighted POSITIVELY AWARE’s A Day with HIV anti-stigma campaign as **an example of effective use of Instagram in combating stigma**. “Every month, 700 million people around the world sign in to Instagram and 80% of them follow at least one business or organization,” the blog noted on October 10. “These data make Instagram one more reason our mobile phones have become an incredibly powerful tool for reaching, informing, and motivating people with HIV messages.”

The blog said, “A Day with HIV, observed annually on

September 22, mobilizes people around the country to combat stigma through their social media posts.... The content uses clear, close-up pictures of people’s faces to create an immediate emotional connection with the audience.”

In December the health information website “Healthline” recognized inspirational leaders in HIV advocacy and awareness in its fifth annual HIV Influencer Honors, naming A Day with HIV “Best ongoing HIV awareness campaign.” Go to healthline.com.

A new book featuring a selection of photos from A Day with HIV 2017 is now available as a free digital edition download; the print edition is also available for order at tpan.com/adaywithhiv.



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MODERN FAMILY

Two same gender loving men in a serodifferent marriage start a family of their own

BY JOURDAN BARNES

PHOTOGRAPHY BY LOUIS "KENGI" CARR

What was the last fairy tale you've read or watched? Were you able to see yourself in it? Could you see yourself being one of the characters or in situations they portrayed? Growing up, did TV shows like *The Cosby Show*, *Full House*, *The Brady Bunch*, and *Fresh Prince of Bel Air* give you visions of the family life you wanted one day?

If your answer is no, then you are probably dealing with the same emotions Aunsha Hall-Everett has been dealing with. Aunsha is a superman: In addition to being Senior Development Manager for Black AIDS Institute, he's co-owner, along with his husband Michael Everett, of the consulting firm Intimacy & Colour, and most importantly a father to their daughter, Jadenna Monae Elizabeth Everett. As with any fairytale Aunsha's life with his family is always full of excitement, mystery, and challenges.

Unfortunately in every fairytale there's a hitch, and for Aunsha and his family the problem is that there's no guidance for how to exist as a queer family. When there's an issue, or advice is needed for a family of two same gender loving black fathers raising a daughter, there's just not a lot of support to be found. Imagine yourself having to fulfill multiple roles and responsibilities on top of living in a society where you aren't the norm. Even before fears and prejudice become factors, the truth is, you aren't in a world quite designed for the life you desire to live. Aunsha and his husband Michael live this reality every day and they strive to create a blueprint, their own fairytale, to ensure they provide the best life they can for their daughter. They also give



A WALK IN THE PARK:

(FROM LEFT) MICHAEL EVERETT, JADENNA MONAE EVERETT, AND AUNSHA HALL-EVERETT.





guidance to other same gender loving black, married, fathering men so that they can achieve their own happily ever afters.

It's only natural to wonder what brought Aunsha and Michael together to begin their magical journey. It all began at the HIV Prevention Leadership Summit in Washington, D.C in 2011. Introduced to each other by Michael's boss to explore capacity-building opportunities for New Jersey's HIV workforce, Aunsha and Michael's relationship flourished into a romantic connection where they became "baes." Aunsha, who's HIV-positive, is in a serodifferent relationship with Michael, who is HIV-negative. After two years of dating they decided to take their relationship to the next level, and in June of 2013, they exchanged their vows to one another in Puerto Rico. Since being married they've created Intimacy & Colour, a consulting business that uses African principles to promote physical and mental well-being for organizational wellness and to "build emotional communication tools among same gender loving men, whether it's for their relationships, for themselves and their self-esteem, or for their family," said Michael in a 2015 interview with the Human Rights Campaign (HRC). "It's about giving people the emotional language to talk about how they feel and what they need."

Aunsha and Michael noticed that there were no tools for same gender loving men to use for guidance in communication with one another. Not being able to convey what you truly feel can be really toxic to the foundation of any sort of relationship. Their goal was, and still is, to provide the necessary tools to individuals so that they might be able to build a foundation to be understood by their partner. Especially for those who were raised in the South, where there is an unspoken rule that expressing and conveying emotions and feelings is forbidden. This also goes for trauma in the black family, it's something that isn't to be shared, but instead kept hidden, particularly if it goes against religion, family, or social status. Internalizing these unspoken rules sets the playing field for a toxic relationship. Thinking about these barriers, it's no surprise that this is no setup for a happily ever after, especially in the black same gender loving male community, and both Aunsha and Michael were aware of this. To make their goal even more personal, Aunsha began to realize he was reacting to present life situations based on his past

experiences growing up with his family, and was still not able to accept and learn from his past.

Aunsha and Michael believe that what helps people build family, whether in a romantic relationship, the workplace, or even with friends, is focusing on communication skills. “A lot of our work is trying to counter all of the shame and stigma surrounding HIV,” Aunsha explained in the 2015 interview with HRC. “It’s not just about HIV prevention. It’s about talking about the situations in our daily lives. Conversations around HIV risk and acquisition can trigger deep feelings of shame, because many of us navigate the world already in fear of disappointing people. Having permission to discuss the wholeness of our lives—meaning who we loved, how we loved, what made us feel pleasure, desired, and safe—tells the most important part of our stories. When we can talk about the love in the life of the people we serve, then we can talk about HIV.” Intimacy & Colour has brought together many people, created healthy communication practices, and ultimately, successful families.

A family isn't quite a family without a couple of things: a ring, a pet, a child, and of course sharing the bills. With Aunsha and Michael the journey didn't stop with their work. In July 2016, Aunsha and Michael welcomed two-month-old Jadenna Monae into their home. She was adopted through a kinship adoption—her mom is Michael's first cousin.

“Having Jadenna Monae is a constant reminder of selfless and unconditional love, as it really does take a village to raise a child,” says Aunsha in a blog post for Black AIDS Institute. Starting a family has broadened his worldview. “Being a dad has allowed me to begin forgiving my own childhood pain, as I have come to learn we all come into this world with good intentions, but with limited capacities. It’s amazing to watch a young being grow, figure life out, and learn so much.”

Michael and Jadenna inspire Aunsha to be a better person. “Now when I’m walking anywhere I make it a point to speak to people, greet them, or at least share a smile, because I would want other people to share that same courtesy to my family.”

Constant improvement in any relationship is important and Aunsha and Michael know this. So, they've decided to start practicing meditation, which has rubbed off on their 18-month-old

daughter. Aunsha explains that he and Michael needed to find a solution for Jadenna, because she would throw tantrums if she didn't get what she wanted, as many children do. Their solution was meditation. Now, when she attempts to throw a tantrum they encourage her to chant, and they do this simply by chanting with her as she's fired up. After months of showing Jadenna how to chant and calm down, Aunsha says Jadenna is even beginning to meditate on her own. Starting a family has created positive magic that's inspired Aunsha and Michael to push their boundaries and to keep an open mind to new experiences, perspectives, and possibilities.

Even though both Aunsha and Michael strive to be better for their family, unlike TV families, most of their problems can't be resolved in a 30-minute episode. While we might expect perfection from our family due to the pressures of society, life is not a fairytale, and Aunsha is not afraid to confront reality. We've all had moments where we listened to someone's argument, while planning to make a counterargument—it's human. Aunsha has concerns about communicating effectively with his husband, and recognizes the power in actively listening for understanding, versus listening to respond defensively.

“Communication is hard because it doesn't feel good to express unfavorable emotions and then [receive] feedback you don't want to hear,” says Aunsha. He longs for a community that he can run to for support and advice, a group of people who understand his challenges, but it's hard to find a same gender loving black, male married couple with a child who would understand or at least be able to empathize with Aunsha's concerns. He also recognizes that Michael needs his own outlet, but neither have that luxury of meeting other couples in their situation. Aunsha feels not having that social support is probably the biggest challenge in building a family. He and Michael can pull bits of advice from other people, but it's never from someone who has lived or is living their story.

Aunsha and Michael are not set on the idea of a “perfect family;” what keeps

When we can talk about the love in the life of the people we serve, then we can talk about HIV.

them moving forward is their commitment and respect for one another, and creating their own story their way. They understand that there will always be a challenge in making sure they are communicating effectively with one another, but they are up for the test. It won't always be easy, due to their busy traveling schedules, lack of social support from people like them, and being two fathers, which adds even more complexity. All of this demands more growth within their communication with one another.

Life's hurdles require more than just true love's kiss or the flick of a magic wand. After dating for two years, being married for four, and having their precious daughter for 18 months, Aunsha and Michael understand the value of commitment, investment, and social support. Yes, they expect difficult times within the family, but they understand ultimately it's about respecting the commitment made to each other. Aunsha explains that it's also about holding oneself accountable for their role in the relationship. He remembers when he tested positive for HIV seven years ago, and how he was quick to blame others, but after much reflection he had to hold himself accountable and reflect on his own actions to truly be at peace with himself. Aunsha started antiretroviral therapy within three months after his diagnosis and is undetectable, and now uses his life experience as a source of empowerment to help others.

Working on a family means having the willingness to learn more about yourself, understanding your past and your future, so that a healthy foundation can be built. In no way do Aunsha and Michael think their family is perfect, but they feel family is worth fighting for and staying committed to. No matter what boundaries society may set, they will continue to work and create their happily ever after, so that other people wanting to start a family of their own can be inspired to create their own happiness. **PA**

JOURDAN BARNES is a community engagement specialist with the Louisiana Office of Public Health and STD/HIV Program.

For more information go to intimacyandcolour.com.

WHAT IS GENVOYA®?

GENVOYA is a 1-pill, once-a-day prescription medicine used to treat HIV-1 in people 12 years and older who weigh at least 77 pounds. It can either be used in people who are starting HIV-1 treatment and have never taken HIV-1 medicines before, or people who are replacing their current HIV-1 medicines and whose healthcare provider determines they meet certain requirements. These include having an undetectable viral load (less than 50 copies/mL) for 6 months or more on their current HIV-1 treatment. GENVOYA combines 4 medicines into 1 pill taken once a day with food. GENVOYA is a complete HIV-1 treatment and should not be used with other HIV-1 medicines.

GENVOYA does not cure HIV-1 infection or AIDS.

To control HIV-1 infection and decrease HIV-related illnesses, you must keep taking GENVOYA. Ask your healthcare provider if you have questions about how to reduce the risk of passing HIV-1 to others. Always practice safer sex and use condoms to lower the chance of sexual contact with body fluids. Never reuse or share needles or other items that have body fluids on them.

IMPORTANT SAFETY INFORMATION

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

GENVOYA may cause serious side effects:

- **Worsening of hepatitis B (HBV) infection.** GENVOYA is not approved to treat HBV. If you have both HIV-1 and HBV and stop taking GENVOYA, your HBV may suddenly get worse. Do not stop taking GENVOYA without first talking to your healthcare provider, as they will need to monitor your health.

Who should not take GENVOYA?

Do not take GENVOYA if you take:

- **Certain prescription medicines for other conditions.** It is important to ask your healthcare provider or pharmacist about medicines that should not be taken with GENVOYA. Do not start a new medicine without telling your healthcare provider.
- **The herbal supplement St. John's wort.**
- **Any other medicines to treat HIV-1 infection.**

What are the other possible side effects of GENVOYA?

Serious side effects of GENVOYA may also include:

- **Changes in your immune system.** Your immune system may get stronger and begin to fight infections. Tell your healthcare provider if you have any new symptoms after you start taking GENVOYA.

- **Kidney problems, including kidney failure.** Your healthcare provider should do blood and urine tests to check your kidneys. If you develop new or worse kidney problems, they may tell you to stop taking GENVOYA.
- **Too much lactic acid in your blood (lactic acidosis),** which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- **Severe liver problems,** which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.

The most common side effect of GENVOYA is nausea. Tell your healthcare provider if you have any side effects that bother you or don't go away.

What should I tell my healthcare provider before taking GENVOYA?

- **All your health problems.** Be sure to tell your healthcare provider if you have or have had any kidney or liver problems, including hepatitis virus infection.
- **All the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. Other medicines may affect how GENVOYA works. Keep a list of all your medicines and show it to your healthcare provider and pharmacist. Ask your healthcare provider if it is safe to take GENVOYA with all of your other medicines.
- **If you take antacids.** Take antacids at least 2 hours before or after you take GENVOYA.
- **If you are pregnant** or plan to become pregnant. It is not known if GENVOYA can harm your unborn baby. Tell your healthcare provider if you become pregnant while taking GENVOYA.
- **If you are breastfeeding** (nursing) or plan to breastfeed. Do not breastfeed. HIV-1 can be passed to the baby in breast milk.

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

Please see Important Facts about GENVOYA, including important warnings, on the following page.

Ask your healthcare provider if GENVOYA is right for you.

GENVOYA does not
cure HIV-1 or AIDS.

SHOW YOUR POWER

Take care of what matters most—you. GENVOYA is a **1-pill, once-a-day complete HIV-1 treatment** for people who are either new to treatment or people whose healthcare provider determines they can replace their current HIV-1 medicines with GENVOYA.

Genvoya 
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200mg/tenofovir alafenamide 10mg tablets

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MOST IMPORTANT INFORMATION ABOUT GENVOYA

GENVOYA may cause serious side effects, including:

- **Worsening of hepatitis B (HBV) infection.** GENVOYA is not approved to treat HBV. If you have both HIV-1 and HBV, your HBV may suddenly get worse if you stop taking GENVOYA. Do not stop taking GENVOYA without first talking to your healthcare provider, as they will need to check your health regularly for several months.

ABOUT GENVOYA

- GENVOYA is a prescription medicine used to treat HIV-1 in people 12 years of age and older who weigh at least 77 pounds and have never taken HIV-1 medicines before. GENVOYA can also be used to replace current HIV-1 medicines for some people who have an undetectable viral load (less than 50 copies/mL of virus in their blood), and have been on the same HIV-1 medicines for at least 6 months and have never failed HIV-1 treatment, and whose healthcare provider determines that they meet certain other requirements.
- **GENVOYA does not cure HIV-1 or AIDS.** Ask your healthcare provider about how to prevent passing HIV-1 to others.

Do NOT take GENVOYA if you:

- Take a medicine that contains: alfuzosin (Uroxatral[®]), carbamazepine (Carbatrol[®], Carnexiv[®], Epitol[®], Equetro[®], Tegretol[®], Tegretol-XR[®], Teril[®]), cisapride (Propulsid[®], Propulsid Quicksolv[®]), dihydroergotamine (D.H.E. 45[®], Migranal[®]), ergotamine (Cafergot[®], Migergot[®], Ergostat[®], Medihaler Ergotamine[®], Wigraine[®], Wigrettes[®]), lovastatin (Altoprev[®], Mevacor[®]), lurasidone (Latuda[®]), methylergonovine (Methergine[®]), midazolam (when taken by mouth), phenobarbital (Luminal[®]), phenytoin (Dilantin[®], Dilantin-125[®], Phenytek[®]), pimozide (Orap[®]), rifampin (Rifadin[®], Rifamate[®], Rifater[®], Rimactane[®]), sildenafil when used for lung problems (Revatio[®]), simvastatin (Vytorin[®], Zocor[®]), or triazolam (Halcion[®]).
- Take the herbal supplement St. John's wort.
- Take any other HIV-1 medicines at the same time.

GET MORE INFORMATION

- This is only a brief summary of important information about GENVOYA. Talk to your healthcare provider or pharmacist to learn more.
- Go to GENVOYA.com or call 1-800-GILEAD-5
- If you need help paying for your medicine, visit GENVOYA.com for program information.



IMPORTANT FACTS

This is only a brief summary of important information about GENVOYA[®] and does not replace talking to your healthcare provider about your condition and your treatment.

POSSIBLE SIDE EFFECTS OF GENVOYA

GENVOYA can cause serious side effects, including:

- Those in the "Most Important Information About GENVOYA" section.
- Changes in your immune system.
- New or worse kidney problems, including kidney failure.
- Too much lactic acid in your blood (lactic acidosis), which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing, stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.
- Severe liver problems, which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms: skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.

The most common side effect of GENVOYA is nausea.

These are not all the possible side effects of GENVOYA. Tell your healthcare provider right away if you have any new symptoms while taking GENVOYA.

Your healthcare provider will need to do tests to monitor your health before and during treatment with GENVOYA.

BEFORE TAKING GENVOYA

Tell your healthcare provider if you:

- Have or have had any kidney or liver problems, including hepatitis infection.
- Have any other medical condition.
- Are pregnant or plan to become pregnant.
- Are breastfeeding (nursing) or plan to breastfeed. Do not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.

Tell your healthcare provider about all the medicines you take:

- Keep a list that includes all prescription and over-the-counter medicines, vitamins, and herbal supplements, and show it to your healthcare provider and pharmacist.
- Ask your healthcare provider or pharmacist about medicines that should not be taken with GENVOYA.

HOW TO TAKE GENVOYA

- GENVOYA is a complete one pill, once a day HIV-1 medicine.
- Take GENVOYA with food.

'EASIEST SPECIAL NEED EVER'

A mom describes her journey adopting a child living with HIV—and the most common questions she gets asked

BY KATHY*

THE FIRST TIME I REMEMBER hearing about HIV, I was reading an article about Ryan White. In it, his mom was interviewed and talked about how she was not scared of catching HIV. That she hugged him and kissed him and shared his soda. I remember wondering why anyone would be scared to catch it from hugging or kissing or sharing soda. I was in middle school probably, but knew it could not be spread by casual contact.

The next time HIV blipped my radar, I was in nursing school. We went around the room introducing ourselves and said what area of nursing we were interested in. My answer was pediatric nurse practitioner (I got that half right!). One of my classmates said emphatically, "HIV/AIDS—that is what I want to work with." I remember thinking that would be an intriguing population to work with.

The first child I met who was HIV-positive was during my hospice clinical rotation. The girl was 6 or 7, her braided pigtails flying behind her as she played. I asked her hospice nurse how in the world she qualified for hospice (in order to qualify, a physician must say they do not expect you to live longer than six months). The nurse said that she will most likely live to be an adult (this was the mid-1990's and the new medications were just beginning to be available), but no one knew for sure. That little girl was so full of life, and so adorable, I could not fathom her life may be cut short because of a virus.

Fast-forward over 15 years (how did that happen so fast?). We are beginning the adoption process for our daughter. It was time to fill out that medical checklist. Which medical needs would we



HE SLID INTO OUR FAMILY SEAMLESSLY. He is the happiest, most easygoing boy. He is learning what it means to be in a family. The HIV affects us daily, but it doesn't.

PHOTOS COURTESY OF THE AUTHOR

* LAST NAME WITHHELD BY REQUEST.

be ok with? Many needs made that list, including hepatitis and HIV. I think that was the point where I knew that adopting a kiddo with HIV was in our future. We knew that HIV was considered a treatable, chronic condition. It no longer was a death sentence. HIV is easier to manage and has fewer complications than diabetes.

We did pounds and pounds of adoption paperwork. We completed our parent training. We excitedly told our families who were overall supportive. Then the day came that we got *The Call*. It was our 15th wedding anniversary. The agency rep said they had the file of a girl younger than we'd requested, but otherwise fit our medical checklist. She had cleft lip and palate, hepatitis B, and some hearing loss. Did I want her to email the file to us? Well, I thought that was a silly question.

We both knew when we opened

the file she was ours. We raced through more paperwork, and finally traveled to China and arrived home in February 2013. She had several medical appointments, including the cleft team and a GI specialist who would manage her hepatitis B. Her labs came back and she was hepatitis negative. The doc called the lab and spoke to them to be sure. We have no idea why the labs in her file said she was hep B positive. We settled into our new life of parents of three kids.

In April (yes about two months after arriving home) I saw the face of a little boy in a waiting child group. He was 5 1/2. He was HIV positive. He was the cutest boy in all of China. I loved him. We just got home though. We were broke. We were trying to find our new normal. So I advocated for him. Surely I could find this sweetheart a family. Time passed. His sixth birthday came in July and I grieved.



A NEW HOME: AT THE CHINA CENTER FOR CHILDREN'S WELFARE AND ADOPTION OFFICE IN NANNING, FINALIZING DAVID'S ADOPTION.

THE MOST COMMON QUESTIONS

1. What about boo-boos and blood? Do your kids know what to do when they bleed? Are there any risks if my kid plays with a child who is HIV-positive?

HIV HAS NEVER been spread through casual contact. Bleeding boo-boos are not scary. HIV is killed quickly by contact with air. Any spilled body fluid has to get into the bloodstream to infect someone—which is hard to do. Putting on a Band-Aid happens the same way it does at your house. Intact skin is the best defense against any virus. We teach all of our kids not to touch other people's blood. That is the medical part of me though—it has nothing to do with HIV. I don't want my kids touching anyone's body fluids – that is just gross and unnecessary. They know to come get a grown-up if they see blood. There are no risks for children playing together. They can pass on the flu or colds—but not HIV.

2. If I adopt an HIV-positive child—what if she gets sick? Will she end up in the hospital from a cold? Do I need to worry about her immune system?

ALL KIDS GET SICK. It is part of life. Yes—you would watch a bit more

closely, but it really depends on what her immune system is up to. A cold does not mean a hospitalization. The medications used to combat HIV also help normalize the immune system. Most of the time the body will fight it off just like it would for anyone else. Of course there are exceptions, and sometimes kids living with HIV do get sicker. Just like cardiac kids, or diabetic kids, or any kid that deals with a chronic medical condition. There are things you can do to help your kid's immune system. The most important thing is frequent hand washing. In our family we use vitamin C and D as immune boosters (especially in the winter). We also avoid gatherings when others are sick. That also has more to do with my not wanting the kids to get sick than the HIV. Sick kids are not fun!

3. How often are doctor visits? How much do the meds cost? How often is lab work?

DOCTOR VISITS WITH the pediatric infectious disease (or PID) doc are every 3–4 months for most kids with HIV. Labs are the same frequency. The medications are usually covered well under insurance, and if not there are medication programs to help reduce

I am much more aware of the perception of HIV in the general public.

I GET ASKED

the cost if needed. The families I polled pay about \$35–80 per month for all the meds. We fall in the middle of that.

4. What if the meds don't work? What if the child becomes resistant to the meds? What about medication side effects?

DRUG RESISTANCE

usually occurs when the medications are not given consistently. Missed doses or frequent medication changes can lead to drug resistance. There are now very sophisticated tests that help the PID if this situation arises. There are two different types of HIV (HIV-1, which is the most common, both in the U.S. and globally, and HIV-2, which is relatively uncommon and found mostly in West Africa), and each responds better to different meds. There are five categories of HIV meds, and around 30 different meds total. Research is being done to increase the medication options. If resistance occurs, there are tests for that too. The resistance tests (all of which are blood tests) help determine what the next step will be. Thankfully this is rare, and PIDs are usually more than willing to collaborate with each other.

There is still a great deal of research in HIV.

I talked with several people who have kids who are drug resistant and none of them regret choosing this medical need. So far all have found treatment options—different combinations of medications or even research trials. My advice would be to call your local PID and ask them how they would handle this. The meds can have side effects, and like any med it really is dependent on the individual. We have been through one med change because of side effects. There are many medication options out there and finding the treatment regimen that has the least amount of side effects may take time. Part of the quarterly lab work is monitoring liver function and such to keep an eye out for early indicators of side effects.

5. What is the long-term prognosis? Can a person living with HIV marry an HIV-negative person and not infect them?

PEOPLE WITH HIV have normal life expectancy. Dying from AIDS is pretty rare. A person with HIV can marry and have kids (even the old fashioned way!), without infecting their partner (or baby if they are the woman). Magic Johnson and his wife have been married many years, and she is still HIV negative.

After much prayer, we decided that we were his family. One small issue. His file was assigned to another agency. We wanted to reuse our dossier paperwork to save time and money (a family can reuse much of their adoption paperwork required by China if they submit a LOI [letter of intent] before the one-year adoption date of the child who just arrived home). I called the other agency. They wanted to keep his file one more week, and then they would transfer it. That was one of the longest weeks of my life. I called back exactly a week later. The agency rep said they requested the transfer the day before. Our agency emailed very soon after saying they had his file.

We did more paperwork. It was near our anniversary again (16 years!), so we announced to family that our sweet David (not his real name) was our gift that year. We did more paperwork. We moved to a different state. That required more paperwork. We scrimped and saved and went into debt to pay fees and travel. In April 2014, David joined our family, about a year after I first saw his picture.

He slid into our family seamlessly. He is the happiest, most easygoing boy. He is learning what it means to be in a family. The HIV affects us daily, but it doesn't. He takes meds (3 different antivirals) twice a day. He needs labs every 3–4 months. His viral load has always been undetectable, so technically he cannot pass it to anyone. Other than David getting tired more easily than our other kids, HIV does not affect his health very much. He is a normal healthy kid. He loves swimming and dragons. He loves ice cream but still does not like cheese. He fights with his siblings.

I am much more aware of the perception of HIV in the general public. My heart breaks when I hear stories of a mom losing custody of her kids because her new fiancée is HIV-positive. My heart soars when families with one HIV-positive parent posts pictures of his HIV-negative family—including his kids.

I feel heartbroken when I hear of a housekeeper in China whose husband wants a divorce and custody of their children because she simply worked for a family who was fostering a child exposed to HIV at birth.

The truth is in China the stigma is much worse when compared to the U.S. People living with HIV are routinely denied jobs, housing, and medical care. This breaks my heart. I have willingly become an educator and advocate. I make it well known that I am always willing to answer HIV questions, without judgment, no need to be embarrassed. Asking questions is how we learn.

I have a confession. When I traveled to get our David, my good friend went with me. She is also a nurse, and we both have seen a lot of different medical needs. We both had adopted from China's Waiting Child program before, and had experienced several needs in our own families. Twice a day, when it was time for David to take his meds (which he did by swallowing the pills all at once), we would gleefully look at each other and one of us would say, "Easiest special need ever!" We felt like we had a secret. David was so healthy, such a normal 6-year-old boy, it felt like he had no special need. And we still feel that way. **PA**

UPDATE: David has now been part of our family for over three years. He is undetectable and thriving. We have had a few incidences where we have run into people who are not very educated about HIV, but overall we have few issues (we currently selectively disclose). We see David not as "an HIV kid" but as a typical 10-year-old who is an integral part of our family. HIV would be at the top of our medical conditions checklist if we were to adopt again.

*Reprinted with permission by the author, who wishes to remain anonymous, and No Hands But Ours, a website that provides resources and information on adopting children from China with special needs. Go to nohandsbutours.com.



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PrEPception

CDC guidelines for serodifferent couples trying to conceive have been updated, but provider education is still needed

BY EMILY S. MILLER, MD, MPH

Research shows a strong desire to have a child among HIV serodifferent heterosexual couples (where one is HIV-positive and the other is not). Unfortunately, however, access to conception methods that protect the HIV-negative partner are limited.

Back in 1990, the U.S. Centers for Disease Control and Prevention (CDC) published a *Morbidity and Mortality Weekly Report* (MMWR) explicitly advising against insemination of semen from HIV-positive men. In the 27 years since then, multiple studies have been published demonstrating the efficacy of three methods that could help these couples: treatment as prevention (TasP); semen processing with the use of assisted reproductive technologies (either intrauterine insemination or in vitro fertilization); and pre-exposure prophylaxis (PrEP). And yet decades passed without any policy changes.

Ongoing stigma and fear surrounding safer conception options led to this stagnation and it was only in the summer of 2017 that the MMWR was finally updated. However, even this advancement wasn't far enough, as the guidance incorrectly suggested the need for the concomitant use of multiple prevention strategies, and further suggested that assisted reproductive technologies was the best approach to safer conception.

Community activists quickly leveraged a change to this information, concerned that this guidance may continue to limit access for decades to come. They pointed to the existing science showing that all of those extra efforts were unnecessary. And, in response, the CDC published an erratum and updated guidance that reflects a more

patient-centered approach and, instead, highlighted the effectiveness of TasP, assisted reproductive technologies, and PrEP—either individually or in combination. (See “How to Make a Baby” in the *Briefly* section of the November + December issue.)

At the center of debates about safer conception is U=U, an awareness effort created by the Prevention Access Campaign to promote the science showing that an undetectable viral load translates to untransmittable virus. While the scientific data to support this claim are undeniable, there remain two rationales for the scientific foot-dragging surrounding safer conception recommendations.

The first is the risk associated with seroconversion around the time of conception; women who acquire HIV while trying to conceive or in early pregnancy have a 2–3-fold increase in the risk of mother-to-child HIV transmission compared to women with HIV diagnosed prior to conception. The acceptance of this method thus changes for some people when considering the increased risk of infection for the mother and her developing fetus.

Furthermore, while TasP is certainly effective when viral suppression is achieved, we know that even for people engaged in HIV care, missed doses can happen and viral blips occur.

Therefore, the combination of TasP and PrEP may offer

an affordable and accessible option for safer conception that provide added protection during these aberrations.

In addition to supporting a wider spectrum of safer conception options in this most recent MMWR, the CDC states, “it is important that health care providers regularly assess mixed HIV-status couples’ plans for conception. Considering factors such as risk tolerance, personal health, costs, and access to health care services, providers can help couples make the best decision for their personal circumstances,” thereby recommending that health care providers bring this to the forefront of their counseling.

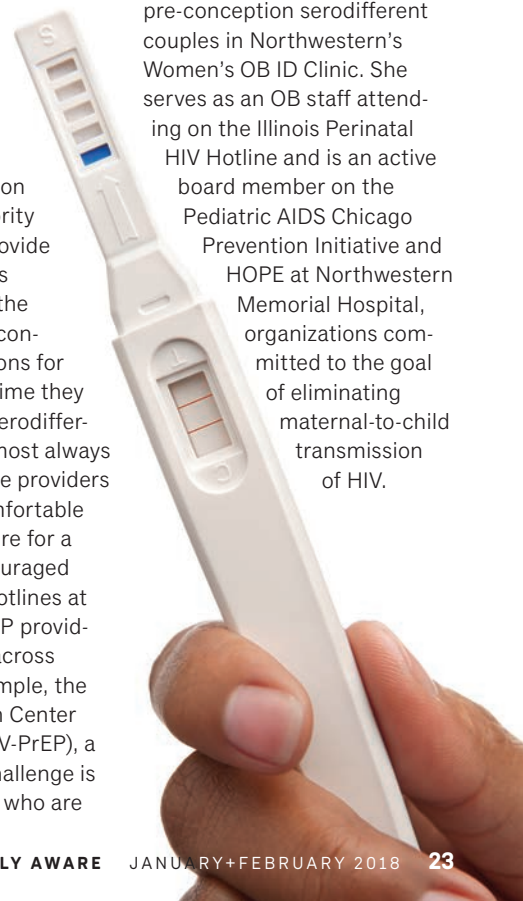
This health systems response remains a tall task as access to knowledgeable providers remains an issue. A recent study of family planning providers demonstrated that while they wanted education on PrEP, only a minority felt competent to provide PrEP services. This is compounded when the discussion requires consideration of all options for conception. By the time they arrive in my office, serodifferent couples have almost always encountered multiple providers who have felt uncomfortable discussing their desire for a child and even discouraged conception. While hotlines at and registries of PrEP providers are popping up across the country (for example, the Clinical Consultation Center PrEPline at 1-855-HIV-PrEP), a unique remaining challenge is to identify providers who are

comfortable and competent discussing all reproductive options.

We've come a long way since the 1990 MMWR, but meeting the CDC's charge to provide patient-centered guidance on family building for serodifferent couples will require an investment in education and health care access. The time for this is now!

REFERENCES AVAILABLE AT positivelyaware.com.

DR. EMILY MILLER is an Assistant Professor in the Department of Obstetrics and Gynecology, Division of Maternal Fetal Medicine at Northwestern University. She is a physician-scientist with clinical interests that include perinatal HIV. She cares for pregnant women living with HIV along with pre-conception serodifferent couples in Northwestern's Women's OB ID Clinic. She serves as an OB staff attending on the Illinois Perinatal HIV Hotline and is an active board member on the Pediatric AIDS Chicago Prevention Initiative and HOPE at Northwestern Memorial Hospital, organizations committed to the goal of eliminating maternal-to-child transmission of HIV.







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Highlights from IDWeek 2017

Heart disease, HIV treatment success, and PrEP news

BY WARREN TONG



PAUL SALCUNI, MPH

THE FOLLOWING REPORTS were among the most attention-grabbing at IDWeek 2017, held October 4–8 in San Diego, California. Go to idsociety.org for more conference news.

Prescriptions of PrEP increase almost 1,000% in New York City, but disparities remain

PrEP (pre-exposure prophylaxis) prescriptions in New York City increased by 974% between 2014 and 2016, though mostly in younger white males, according to a study presented by Paul Salcuni, MPH, at IDWeek 2017.

New York City has one of the highest rates of new HIV transmissions, with nearly 2,500 new diagnoses in 2015.

These new cases were disproportionately occurring in specific communities, including men who have sex with men (58%), Black and Latina women (16%), and individuals living in high-poverty neighborhoods (53%).

Research has already shown that oral PrEP when taken consistently reduces the risk of sexual HIV transmission by 92%. Therefore, **New York City has been making a concerted effort to scale up PrEP prescription and use,** with a particular focus on the

priority populations mentioned above.

The study looked at PrEP prescribing data among a sample of 602 New York City ambulatory care practices. PrEP prescription rate per 100,000 patients seen in these practices increased from 38.9 in 2014 to 418.5 in 2016, an increase of almost 1,000%.

Looking at some of the subgroups, male PrEP prescription rate per 100,000 patients increased from 89.5 to 1,036.4, while female PrEP prescription rate per 100,000 patients increased from 7.4 to 32.4, both statistically significant increases. However, Salcuni noted the overall gap between male and female prescriptions got wider. In 2014, men were 4.6 times more likely to be prescribed PrEP than women, and in 2016 that number increased to 13.5 times, highlighting the need to reach and prescribe PrEP to more women who may need it.

Among males, young males were more likely to be prescribed PrEP than older males. In 2014, for males between the ages of 18 and 29, PrEP prescription rate per 100,000 was 131.4 and in 2016 that rate increased to 2,297.1. For males over 30, the rate was 82.1 in 2014 and increased to 805.1 in 2016. By 2016, young males were 2.8 times more likely to be prescribed PrEP than their older counterparts.

Looking at race and ethnicity for males, all races (including white, black, Latino, Asian, and others) saw an increase in PrEP prescription rates from 2014 to 2016. However, the increase was much higher in white males. By 2016, men of color were about half as likely to be prescribed PrEP as white males.

Overall, by 2016, men made up 95% of PrEP prescriptions. Among males, PrEP prescription was associated with: younger age, white race, Manhattan practice location, community health centers vs. independent practices, onsite infectious disease specialist, and lower proportion of patient population from high-poverty neighborhoods.

The study results suggest that campaigns that promote PrEP for patients and PrEP prescribing by providers may be successful at increasing PrEP uptake. However, the disparity seen between male and female prescriptions suggest that the focus needs to shift to women and their primary care providers, including OB/GYNs, Salcuni said.

Moreover, Salcuni noted that the low prescribing rates seen in men of color compared to white men, despite men of color being disproportionately affected, needs to be addressed.

Additionally, continued outreach is needed for practices outside of Manhattan, independent practices, non-ID specialists, and practices seeing patients from high-poverty neighborhoods.

“These results show that educating healthcare providers can really help improve the rate of PrEP prescribing, but it’s apparent we need

additional programs to ensure equitable access,” Salcuni concluded in the study press release.

Missed opportunities for preventing cardiovascular disease among patients living with HIV

Cardiovascular disease risk factors need to be addressed among people living with HIV, even those doing well on treatment with undetectable viral loads, according to a study presented by the Ryan White-funded Palmetto Health clinic at the University of South Carolina in Columbia.

The retrospective study, which was led by Michael Kacka, MD, MPH, analyzed clinic data and found that there were missed opportunities for screening and preventing cardiovascular disease among some patients living with HIV—despite the fact that people living with HIV have a high prevalence of atherosclerotic cardiovascular disease (ASCVD) risk factors, including hypertension (high blood pressure), dyslipidemia (high cholesterol or fats), diabetes, high body mass index (BMI), smoking, physical inactivity, and poor diet, the study authors noted.

The researchers randomly selected 100 complete charts from patients living with HIV who were over 40 years old, did not have a previous diagnosis of cardiovascular disease, had three or more visits in the past three years, with at least one visit in the last year. Forty percent were between 40–49 years old, 44% were between 50–59 years old, 15% between 60–69 years old, and less than 5% were over

70. Thirty-one percent were female and 69% were male, while 36% were black and 64% were white. About 85% had an undetectable viral load.

Of the complete charts, 66% had a high enough BMI to be overweight or obese, but less than 30% received a diagnosis or received an intervention for diet, exercise, or weight loss.

Hypertension was diagnosed in 42% of the patients, but only 52% of those diagnosed had their hypertension adequately controlled. An additional 4% met the criteria for hypertension, but were never diagnosed.

Documented diagnosis of diabetes was less than 5%, which the authors noted was surprisingly low. For patients who were eligible to be prescribed a statin (a medication that lowers cholesterol and helps reduce cardiovascular disease risk), less than 25% were prescribed one. More alarmingly, none of the patients with very high cholesterol, which is a low-density lipoprotein (LDL) cholesterol level over 190 mg/dL, or with diabetes received a prescription for statin therapy.

Thirty-one percent of the patients were current smokers and the majority were receiving a smoking cessation intervention. However, nurses had assessed smoking in 100% of the patients.

Overall, **despite 85% of the patients having an undetectable viral load, there were multiple missed opportunities to identify risk factors and help prevent cardiovascular disease**, including identifying and controlling hypertension and diabetes, assessing and giving interventions to

promote healthy diet and exercise, and statin therapy for those who may need it under current guidelines.

While the study does call attention to the overlooked cardiovascular disease risk factors, it was limited by small sample size, incomplete records or documentation, and unavailable information on statin allergy or intolerance.

Integrase inhibitors lead to higher rates of undetectable viral loads after 6 months of treatment

For people living with HIV who are starting treatment, regimens containing an integrase inhibitor (INSTI) led to the highest rate of viral suppression after six months of treatment, and were the fastest in terms of days to viral suppression when compared to regimens containing other drug classes, according to a study which analyzed data from 155 treatment-naive patients (individuals who had never been on treatment before) who had started treatment between 2013–2016. About 29% were female and 71% male. The mean age was 41.3 years and mean viral load before starting treatment was 293,974.

About 46% started a regimen containing an integrase inhibitor, about 37% started a regimen containing a non-nucleoside reverse transcriptase inhibitor (NNRTI), and 17% started a regimen containing a protease inhibitor (PI).

Overall, about 52% of patients achieved an undetectable viral load, with the median time to viral suppression being 105 days. Patients

on INSTI-based regimens were more likely to achieve an undetectable viral load by six months (93.2%), compared with NNRTI-based regimens (69.7%) and PI-based regimens (30.8%). Patients on INSTI-based regimens also experienced a lower median time to viral suppression (62.6 days), compared with NNRTI-based regimens (140.5 days) and PI-based regimens (154.5 days). Both these findings were statistically significant.

The authors note that their data support previous studies that have highlighted faster time to viral suppression using INSTI-based regimens. And while current guidelines define virologic failure as having a viral load over 200 after 24 weeks of treatment, perhaps this definition should be changed for those starting INSTI-based regimens to as early as 12 weeks.

The study, led by Karen Jacobson, MD, MPH, also has **important implications for situations where individuals would benefit from shorter time to viral suppression, such as for pregnant women**, the authors noted.

The study was limited by incomplete patient records which led to a small sample size, non-uniform timing of viral load measurements after treatment initiation, and lack of CD4 count data.

REFERENCES AT positivelyaware.com

WARREN TONG is a freelance health and science journalist, with an extensive background writing about HIV and hepatitis C. Follow Warren on Twitter: [@warrentong](https://twitter.com/warrentong).

THE **EROTIC** MILITARISM OF AIDS ACTIVIST ART

DURING THE REAGAN ERA, the federal government was silent and seemed indifferent to the AIDS epidemic. While ACT UP protested for better access to HIV medications in the late 1980s and '90s, artists loosely affiliated with the activist organization were producing some of the most iconic—and controversial—images of their time. Like the protests, the artwork was often loud, angry, and urgent. Because, like the activists, the artists were watching their friends die of AIDS; many of them were HIV-positive themselves.

Several “affinity groups” of artists were associated with ACT UP. Gran Fury was mostly comprised of artists who employed a commercial and advertising aesthetic, whereas ART+Positive included artists from New York’s East Village, whose roots were in the punk movement.

“The quality of the artwork that emerged from ART+Positive had a very raw quality,” says Daniel S. Berger, MD, one of the first doctors to treat people with HIV in Chicago, who is also a noted art collector. “Their work was in your face, very expressive; it directly spoke to you.”

Some of ART+Positive’s most memorable images targeted then-U.S. Senator Jesse Helms, a Republican from North Carolina, whose homophobic and racist views also made him the subject of ACT UP protests. Author of the infamous Helms Amendment which cut federal money for art deemed “obscene or indecent,” the senator also fought against funds for AIDS research.

In addition to his HIV-focused medical practice, Northstar Medical, Berger operates his own gallery, Iceberg Projects. After acquiring the group’s archives in 2015, he collaborated with Chicago artist John Neff to curate at Iceberg the first public exhibition of the archive in *Militant Eroticism: The ART+Positive Archives*. A new book produced by Berger and Neff through Berlin publisher Sternberg Press combines images from the exhibit with additional material. (Berger is also a long-time writer for POSITIVELY AWARE.)

Named for the gallery show, *Militant Eroticism* is aimed at exposing the archives to a wider audience. In documenting the exhibition, Berger hopes the book will also preserve an art movement that was political for its time, yet still relevant today.

“When AIDS hit, people had to come together because every subculture was affected. We had to come together to fight for what we believed in—access to medications, and defeating homophobia, misogyny, racism.

“The lessons here are how people fought for their rights,” Berger adds. “We still have to fight, because the things that we have fought for can still be taken away.”

—RICK GUASCO

MILITANT EROTICISM: THE ART+POSITIVE ARCHIVES IS AVAILABLE NOW AT BOOKSTORES AND ON AMAZON.COM.



ABOVE: UNTITLED ORIGINAL ARTWORK BY HUNTER REYNOLDS. **BELOW:** POSTER MOCKING U.S. SENATOR JESSE HELMS FROM ART+POSITIVE’S 1989 DEMONSTRATION AT THE METROPOLITAN MUSEUM OF ART IN NEW YORK CITY.



PHOTOS COURTESY OF DANIEL S. BERGER, MD



Nathan (Arnaud Valois) at an ACT UP demonstration from a scene in *BPM*.

BPM (BEATS PER MINUTE)

The clock ticks during a story of young love set against a backdrop of activism

BY JEFF BERRY

RUN, DO NOT WALK, to see *BPM*, the 2017 Cannes Film Festival Grand Prix Winner. Worthy of an Oscar nomination for Best Foreign Language Film, it's a fascinating insight into the inner-workings of ACT UP and how it actually works. It's sexy, funny, intense, and heart-wrenching.

BPM follows two young gay men, Nathan (Arnaud Valois) and Sean (Nahuel Pérez Biscayart). Nathan (HIV-negative) is the young newbie, while Sean is one of the co-founders of ACT UP Paris. The film is centered around their relationship, is set in the early nineties against a backdrop of activism and urgency. I stopped noticing that the French film was subtitled about 30 minutes into it, because that's how mesmerized by the story I became.

This movie, a drama, essentially picks up where David France's 2012 documentary *How to Survive a Plague* leaves off. It opens with an ACT UP meeting, and cuts back and forth between the meeting and a demonstration. The rules of ACT UP are clearly outlined in the beginning, but rules were made to be broken. There is always plenty of conflict, both within the meetings and in the outside world. In one scene, frustrated by the powers that be and by the reluctance of schools to provide accurate information, activists take matters into their own hands by passing out flyers to students on how to protect themselves.

Visually *BPM* is a work of art. The film moves effortlessly from a scene of an ACT UP demonstration to activists dancing in the clubs, and ends with a visual representation of how HIV infects a cell, without any explanation or dialogue—and leaves you breathless. Director Robin Campillo uses the color red predominantly throughout the film, weaving it skillfully into a river of blood in a memorable dream sequence.

The graphic sex scenes are erotic without being gratuitous, and you come to understand more about the characters during them. In one scene while Nathan and Sean are talking during sex (yes, people actually do that!), the camera flashes back to sex with another man (to portray the time Sean was probably infected), but you don't realize it at first.

Music becomes its own character in this film, and Bronski Beat's *Smalltown Boy*, an '80s gay anthem, taking center stage. The film's title, *BPM*, takes from the phrase *beats per minute*, which is a term used to signify songs that are in the same tempo, and is a categorizing system used by club DJs to mix songs together. It also comes to represent the beating of the heart and the

passing of time that our characters don't have the luxury of—the sound of the beating heart builds continuously throughout the film's score, accentuating the sense of urgency in the lives of these young activists.

There is a vivid reenactment of a demonstration at Melton Pharmaceuticals in which activists are trying to obtain the results of a pivotal protease inhibitor trial, splashing fake blood all over the carpeted office. The

bloody handprint on the transparency for the overhead projector left quite an impression on me.

Afterward they board a train, and Sean turns to his comrades and says, "There are times when I see how AIDS has changed my life. It's as if I lived things more intensely, as if I saw the world differently. As if it had more colors, more noise, more life."

The activism of these young men and women runs in parallel to their own lives affected by AIDS. Many brilliant young lives were extinguished at the height of the epidemic in the '80s and '90s, and this story is no exception. The courage of early activists paved the way for a better life eventually for all of us living with HIV, but this film humanizes them, with all their fearlessness and their flaws.

'There are times when I see how AIDS has changed my life. It's as if I lived things more intensely, as if I saw the world differently.'

I am a friend, a dreamer, and an activist.
And I am living with HIV.

Let's stop HIV together.™

—Hydeia



Hydeia (left) has lived with HIV since 1984.



Get the facts. Get tested. Get involved.

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