POSITIVELY AW
THE HIV TREATMENT JOURNAL OF TEST POSITIVE
JANUARY + FEBRUARY 2016

KATE BURTON CARRIES ON A LEGACY

LONG-TERM THRIVERS

MY JOURNEY BACK TO TREATMENT

WOMEN AND HIV

Finding the strength they need
—from outside and from within

THE WOMEN OF
CHRISTIE'S PLACE, SAN DIEGO

ISENTRESS®
raltegravir film-coated tablets 400 mg

HIV Positive Model

Hey Birthday! It's always great to see you.

I wanted to know more about my HIV treatment options. So I spoke with my doctor and we chose ISENTRESS as part of my HIV regimen. My doctor told me it could fight my HIV and may fit my needs and lifestyle.

I have so many plans for what's next.

ISENTRESS® (raltegravir) has been available to help people manage their HIV since 2007 and has been tested in long-term clinical trials.

- ISENTRESS has been available for previously treated patients since 2007 and for first-time patients since 2009
- A long-term clinical study lasting more than 4 years (240 weeks) of patients being treated with HIV medicine for the first time showed that ISENTRESS plus *Truvada* may help:
  - Lower viral load to undetectable
  - Raise CD4 cell counts

ISENTRESS may not have these effects in all patients.

INDICATION

ISENTRESS is a prescription HIV-1 medicine used with other antiretroviral medicines to treat human immunodeficiency virus (HIV-1) infection in people 4 weeks of age and older. HIV is the virus that causes AIDS (Acquired Immune Deficiency Syndrome).

It is not known if ISENTRESS is safe and effective in babies under 4 weeks of age.

The use of other medicines active against HIV-1 in combination with ISENTRESS may increase your ability to fight HIV.

ISENTRESS does not cure HIV-1 infection or AIDS.

You must stay on continuous HIV therapy to control HIV-1 infection and decrease HIV-related illnesses.

IMPORTANT RISK INFORMATION

Some people who take ISENTRESS develop serious skin reactions and allergic reactions that can be severe, and may be life-threatening or lead to death. If you develop a rash with any of the following symptoms, stop using ISENTRESS and call your doctor right away: fever, generally ill feeling, extreme tiredness, muscle or joint aches, blisters or sores in mouth, blisters or peeling of skin, redness or swelling of the eyes, swelling of the mouth or face, problems breathing.

Sometimes allergic reactions can affect body organs, such as your liver. Call your doctor right away if you have any of the following signs or symptoms of liver problems: yellowing of your skin or whites of your eyes, dark or tea-colored urine, pale-colored stools (bowel movements), nausea or vomiting, loss of appetite, pain, aching or tenderness on the right side of your stomach area.

Changes in your immune system (Immune Reconstitution Syndrome) can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your doctor right away if you start having new symptoms after starting your HIV-1 medicine.

People taking ISENTRESS may still develop infections or other conditions associated with HIV infections.

The most common side effects of ISENTRESS include: trouble sleeping, headache, dizziness, nausea, and tiredness. Less common side effects include: depression, hepatitis, genital herpes, herpes zoster including shingles, kidney failure, kidney stones, indigestion or stomach area pain, vomiting, suicidal thoughts and actions, and weakness.

Tell your doctor before you take ISENTRESS if you have a history of a muscle disorder called rhabdomyolysis or myopathy or increased levels of creatine kinase in your blood.

Tell your doctor right away if you get unexplained muscle pain, tenderness, or weakness while taking ISENTRESS. These may be signs of a rare serious muscle problem that can lead to kidney problems.

These are not all the possible side effects of ISENTRESS. For more information, ask your doctor or pharmacists. Tell your doctor if you have any side effect that bothers you or that does not go away.

Tell your doctor about all your medical conditions, including if you have any allergies, are pregnant or plan to become pregnant, or are breastfeeding or plan to breastfeed. ISENTRESS is not recommended for use during pregnancy. **Do not breastfeed if you take ISENTRESS.** Women with HIV should not breastfeed because their babies could be infected with HIV through their breast milk.

Tell your doctor about all the medicines you take, including, prescription and over-the-counter medicines, vitamins, and herbal supplements. Some medicines interact with ISENTRESS. Do not start taking a new medicine without telling your healthcare provider. Your healthcare provider can tell you if it is safe to take ISENTRESS with those other medicines.

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

Please read the adjacent Patient Information for ISENTRESS and discuss it with your doctor.

Merck Helps™ | Having trouble paying for your Merck medicine?
Merck may be able to help. www.merckhelps.com

Talk to your healthcare professional about ISENTRESS and visit isentress.com.

MERCK

Patient Information
ISENTRESS® (eye **sen** tris) (raltegravir) film-coated tablets

Read this Patient Information before you start taking ISENTRESS and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is ISENTRESS?

ISENTRESS is a prescription HIV medicine used with other antiretroviral medicines to treat Human Immunodeficiency Virus (HIV-1) infection in people 4 weeks of age and older. HIV is the virus that causes AIDS (Acquired Immune Deficiency Syndrome).

It is not known if ISENTRESS is safe and effective in babies under 4 weeks of age.

When used with other HIV medicines to treat HIV-1 infection, ISENTRESS may help:

- reduce the amount of HIV in your blood. This is called " viral load".
- increase the number of white blood cells called CD4+ (T) cells in your blood, which help fight off other infections.
- reduce the amount of HIV-1 and increase the CD4+ (T) cells in your blood, which may help improve your immune system. This may reduce your risk of death or getting infections that can happen when your immune system is weak (opportunistic infections).

ISENTRESS does not cure HIV-1 infection or AIDS.

You must stay on continuous HIV therapy to control HIV-1 infection and decrease HIV-related illnesses.

Avoid doing things that can spread HIV-1 infection to others:

- Do not share needles or re-use needles or other injection equipment.
- Do not share personal items that can have blood or body fluids on them, like toothbrushes and razor blades.
- Do not have any kind of sex without protection. Always practice safe sex by using a latex or polyurethane condom to lower the chance of sexual contact with any body fluids such as semen, vaginal secretions, or blood.

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

What should I tell my doctor before taking ISENTRESS?
Before taking ISENTRESS, tell your doctor if you:

- have liver problems
- have a history of a muscle disorder called rhabdomyolysis or myopathy
- have increased levels of creatine kinase in your blood
- have phenylketonuria (PKU). ISENTRESS chewable tablets contain phenylalanine as part of the artificial sweetener, aspartame. The artificial sweetener may be harmful to people with PKU.
- have any other medical conditions
- are pregnant or plan to become pregnant. It is not known if ISENTRESS can harm your unborn baby.
  Pregnancy Registry: There is a pregnancy registry for women who take antiviral medicines during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Talk to your doctor about how you can take part in this registry.
- are breastfeeding or plan to breastfeed. **Do not breastfeed if you take ISENTRESS.**
    - You should not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.
    - Talk with your doctor about the best way to feed your baby.

Tell your doctor about all the medicines you take, including, prescription and over-the-counter medicines, vitamins, and herbal supplements. Some medicines interact with ISENTRESS. Keep a list of your medicines to show your doctor and pharmacist.

- You can ask your doctor or pharmacist for a list of medicines that interact with ISENTRESS.
- Do not start taking a new medicine without telling your healthcare provider. Your healthcare provider can tell you if it is safe to take ISENTRESS with other medicines.

How should I take ISENTRESS?

- Take ISENTRESS exactly as prescribed by your doctor.
- **Do not** change your dose of ISENTRESS or stop your treatment without talking with your doctor first.
- Stay under the care of your doctor while taking ISENTRESS.
- ISENTRESS film-coated tablets must be swallowed whole.
- ISENTRESS chewable tablets may be chewed or swallowed whole.
- ISENTRESS for oral suspension should be given to your child within 30 minutes of mixing. **See the detailed Instructions for Use that comes with ISENTRESS for oral suspension**, for information about the correct way to mix and give a dose of ISENTRESS for oral suspension. If you have questions about how to mix or give ISENTRESS for oral suspension, talk to your doctor or pharmacist.
- **Do not switch between the film-coated tablet, the chewable tablet, or the oral suspension without talking with your doctor first.**
- **Do not** run out of ISENTRESS. Get a refill of your ISENTRESS from your doctor or pharmacy before you run out.
- If you miss a dose, take it as soon as you remember. If you do not remember until it is time for your next dose, skip the missed dose and go back to your regular schedule. Do not double your next dose or take more ISENTRESS than prescribed.
- If you take too much ISENTRESS, call your doctor or go to the nearest hospital emergency room right away.

What are the possible side effects of ISENTRESS?

ISENTRESS can cause serious side effects including:

- **Serious skin reactions and allergic reactions.** Some people who take ISENTRESS develop serious skin reactions and allergic reactions that can be severe, and may be life-threatening or lead to death. If you develop a rash with any of the following symptoms, stop using ISENTRESS and contact your doctor right away:
    - fever
    - generally ill feeling
    - extreme tiredness
    - muscle or joint aches
    - blisters or sores in mouth
    - blisters or peeling of the skin
    - redness or swelling of the eyes
    - swelling of the mouth or face
    - problems breathing

  Sometimes allergic reactions can affect body organs, such as your liver. Call your doctor right away if you have any of the following signs or symptoms of liver problems:
    - yellowing of the skin or whites of your eyes
    - dark or tea colored urine
    - pale colored stools (bowel movements)
    - nausea or vomiting
    - loss of appetite
    - pain, aching, or tenderness on the right side of your stomach area
- **Changes in your immune system (Immune Reconstitution Syndrome)** can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your doctor right away if you start having new symptoms after starting your HIV-1 medicine.

The most common side effects of ISENTRESS include:

- trouble sleeping
- headache
- dizziness
- nausea
- tiredness

Less common side effects include:

- depression
- hepatitis
- genital herpes
- herpes zoster including shingles
- kidney failure
- kidney stones
- indigestion or stomach area pain
- vomiting
- suicidal thoughts and actions
- weakness

Tell your doctor right away if you get unexplained muscle pain, tenderness, or weakness while taking ISENTRESS. These may be signs of a rare serious muscle problem that can lead to kidney problems.

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of ISENTRESS. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store ISENTRESS?

Film-Coated Tablets:

- Store ISENTRESS Film-Coated Tablets at room temperature between 68°F to 77°F (20°C to 25°C).

Keep ISENTRESS and all medicines out of the reach of children.

General information about ISENTRESS

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information Leaflet. Do not use ISENTRESS for a condition for which it was not prescribed. Do not give ISENTRESS to other people, even if they have the same symptoms you have. It may harm them.

You can ask your doctor or pharmacist for information about ISENTRESS that is written for health professionals.

For more information go to www.ISENTRESS.com or call 1-800-622-4477.

What are the ingredients in ISENTRESS?

ISENTRESS film-coated tablets:

Active ingredient: raltegravir
Inactive ingredients: calcium phosphate dibasic anhydrous, hypromellose 2208, lactose monohydrate, magnesium stearate, microcrystalline cellulose, poloxamer 407 (contains 0.01% butylated hydroxytoluene as antioxidant), sodium stearyl fumarate.
The film coating contains: black iron oxide, polyethylene glycol 3350, polyvinyl alcohol, red iron oxide, talc and titanium dioxide.

This Patient Information has been approved by the U.S. Food and Drug Administration.

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VOLUME 28 NUMBER 1

FEATURES

HEALING THROUGH BARRIERS: LOUIS “KENGI” CARR LONG-TERM THRIVERS: JEFF BERRY

IN EVERY ISSUE

ALSO INSIDE

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HCV UPDATES FROM THE LIVER MEETING 2015
BY ANDREW REYNOLDS

POSITIVELY AWARE

JOURNALISM. INTEGRITY. HOPE.

EDITOR-IN-CHIEF
JEFF BERRY
@PAeditor
“My hope for everyone is that 2016 will be a year of happy coincidences and synchronicity.”

ASSOCIATE EDITOR
ENID VÁZQUEZ
@enidvazquezpa
“I have always loved POSITIVELY AWARE, and for me it’s a great privilege to do this work.”

CREATIVE DIRECTOR
RICK GUASCO
@rickguasco
“Treatment is only part of the story. Making the decision to get into care, finding the resources you need, and facing the challenges of treatment, are also aspects of life with HIV.”

PROOFREADER
JASON LANCASTER

CONTRIBUTING WRITERS
DAVID DURÁN
JIM PICKETT
ANDREW REYNOLDS

PHOTOGRAPHERS
LOUIS “KENGI” CARR
JOHN GRESS
CHRIS KNIGHT

ADVERTISING
LORRAINE HAYES
L.Hayes@tpan.com

DISTRIBUTION AND
SUBSCRIPTION SERVICES
DENISE CROUCH
distribution@tpan.com

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TPAN
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5050 N. BROADWAY ST.
CHICAGO, IL 60640-3016
PHONE: (773) 989-9400
FAX: (773) 989-9494
EMAIL: inbox@tpan.com
positivelyaware.com
@PosAware

FRONT COVER BACKSTORY

FRONT: JAY R. BLOUNT; THEN, LEFT TO RIGHT, SILVIA CRYSTAL GAONA VILLEGAS, MARTHA ZARATE, ERIN FALVEY, ELIZABETH JOHNSON, AND PRISCILLA MAHANNAH.

Living with HIV often means dealing with a number of barriers to care. Issues surrounding race, ethnicity, and socioeconomic status can affect the ability to get—and stay—on treatment. HIV-positive women often face their own unique challenges, including a disproportionate rate of gender-based violence.

Christie’s Place is one of several organizations featured in this issue that provide support and services to women. Their stories, however, serve as inspiration to everyone living with HIV.

Los Angeles-based photographer Louis “Kengi” Carr drove down to San Diego for the cover photo shoot at Christie’s Place, and felt a connection almost as soon as he arrived.

“As a photographer I’m always on the hunt for the next image or project to inspire people, but this time it’s me who’s inspired,” Carr said. “In the middle of this shoot, I thought about how far I’ve come since my own diagnosis in 2008. This experience has reminded me that I’m in full control, and HIV is just along for the ride.”

ON THE COVER: (FRONT ROW) HEATHER ARCULEO, JAY R. BLOUNT, MARTHA ZARATE, JOHNEISHA JONES; (BACK ROW) CHARNEA HARRIS-ROBINSON AND PRISCILLA MAHANNAH.

PHOTO: LOUIS “KENGI” CARR

PHOTO: CHRIS KNIGHT

EDITOR'S NOTE

JEFF BERRY

Synchronicity

With one breath, with one flow
You will know
Synchronicity

A sleep trance, a dream dance,
A shared romance,
Synchronicity

A connecting principle,
Linked to the invisible
Almost imperceptible
Something inexpressible.
Science insusceptible
Logic so inflexible
Causally connectible
Yet nothing is invincible
—The Police

Last September during the United States Conference on AIDS in Washington D.C., I was waiting for the elevator on the top floor of the hotel when I realized I had forgotten my conference badge, and had to rush back to my room. When I called for the elevator again, a few moments later the door opened, and two gentlemen stood there looking somewhat perplexed as they glanced at the buttons—it seems they had missed their floor. I said something witty and hilarious (maybe not, but it seemed so at the time), and we all had a good chuckle. I introduced myself, and that's when I met Joel Goldman and Zakk Marquez of the Elizabeth Taylor AIDS Foundation. The events that followed eventually led to an article in this issue about actress Kate Burton and her work for the foundation.

They say nothing happens by coincidence and when things like that happen, it's kind of hard not to believe it. I like to recall the story my mother told of when she saw my dad for the first time across the room in a bar, while engaged to another guy, and she experienced *déjà vu*. She knew at that moment that my dad was the one. I had a similar sense of *déjà vu* when I saw my (future) partner Stephen across the crowd at Folsom Street Fair, some years ago (I choose not to dwell on exactly how many years ago, let's just say "some"). It was not by chance, and I'll never forget that moment.

This issue has synchronicity woven throughout its pages. Our feature story on women and HIV by Olivia Ford was sparked during another meeting, which immediately preceded USCA, the NLGJA gay journalists association 25th anniversary conference. Olivia and I sat together on a panel about HIV/AIDS and the media, along with *POZ* editor Oriol Gutierrez and Diane Anderson-Minshall, editor of *Plus* magazine. I caught up with Olivia in the hallway afterwards and we chatted briefly, and I knew then that she was the one to write this article.

When PA's creative director Rick Guasco recently posted a heartfelt message on Facebook about starting treatment again after a three-year self-imposed hiatus, activist Tim Horn's comment was, "Give this man a word count." And so, I did. The result is a realistic portrayal of why we may make the choices we make, and ultimately how initiating treatment is a very personal decision—one that can only be made when a person is ready.

In my editor's note in the last issue ("What can I say?" November+December 2015) I write about experiencing a writer's block "of sorts," and how when I hear from someone that my writing has moved them, it's incredibly meaningful.

Yesterday, I was handed a packet sent to me from an inmate at the Louisiana State Penitentiary in Angola, Louisiana. In it was a cover letter from a peer educator along with 11 handwritten letters from some of his fellow inmates, all dated August of 2013. It seems that only now was he able to get these letters to me, partially due to not having enough money for postage. For his HIV/AIDS awareness class, which was made up of all HIV-negative guys, he had them read my editor's note from the July+August 2013 issue of POSITIVELY AWARE titled, "The Struggle to be Authentic." Afterward he gave each an assignment to compose a letter to the editor in response, written as if they were HIV-positive.

As I read through each letter I was deeply moved, and one by one my worries about writer's block, what I write, or whether I was having any impact melted away. I realized that it's not up to me to worry about it, that we are all exactly where we need to be, doing what we need to do—and that we are all both teachers and students at the same time.

So I believe in synchronicity, serendipity, happy coincidences, whatever you want to call it. I believe that each of us has a story to tell, a unique take on the world we live in, and one with value that deserves to be heard. I believe that in sharing our stories with one another, we begin to see more of that which we have in common, rather than what sets us apart. I believe that listening is half of the conversation, and that we need only to open ourselves up to the possibility of miracles, for them to begin to happen.

My hope for everyone is that 2016 will be a year of happy coincidences and synchronicity. Step aside, move out of the way, and let them begin to happen.

Take care of yourself, and each other.

I believe that each of us has a story to tell, a unique take on the world we live in, and one with value that deserves to be heard. I believe that in sharing our stories with one another, we begin to see more of that which we have in common, rather than what sets us apart.

@PAEDITOR

INBOX@TPAN.COM

LET'S CONNECT

All communications (letters, email, online posts, etc.) are treated as letters to the editor unless otherwise instructed. We reserve the right to edit for length, style, or clarity. Let us know if you prefer we not use your name and city.

WRITE TO:
POSITIVELY AWARE
5050 N. Broadway St.,
Suite 300,
Chicago, IL
60640-3016

EMAIL:
inbox@tpan.com

TWEET:
@PosAware

WHAT CAN I SAY?

Beautifully said [Editor's Note, November+December]. How remarkable that HIV and its impact on our lives become smaller as we age and open ourselves up to everything else life has to offer.

—**MARK S. KING**
FACEBOOK

I totally get it. I intentionally did not center my life around HIV, trying to avoid my diagnosis for 16 years and then using acceptance of it as impetus for rising from a professional slump over 17 years ago. The last year, though, as I have focused my research towards an MPH on HIV long-term survivors, I have had to give the disease more time and space, and being intellectually engaged without becoming emotionally overwhelmed has been a huge challenge.

—**DAVID PHILLIPS**
FACEBOOK

ON THE COVER OF A MAGAZINE

Readers responded with pride in discovering that their loved ones had been selected for one of four covers of the November+December issue, which featured pictures submitted for A Day with HIV, PA's anti-stigma campaign.

My son has come a long way. So suprised to see his picture on the cover. So very proud of him.

—**JUDY BURGESS**
FACEBOOK

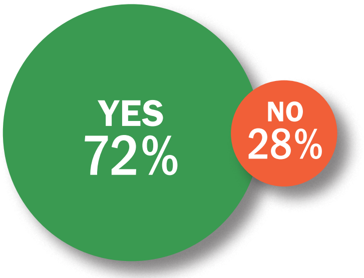
Congratulations, Dee, on making the cover. You are an inspiration.

—**DARLENE KING**
TWITTER

READERS POLL

IN THE NOVEMBER+DECEMBER ISSUE WE ASKED

Did you know that half of the people living with HIV around the world are women?



YES. I first learned this as an HIV volunteer in Kenya. I knew it wasn't only gay men, but I had no idea how large the percentage of women infected was until then. To me, that's a failure of our secondary health education in the U.S.

THIS ISSUE'S QUESTION

Have you stopped HIV medications and not gone back on therapy?

MAKE YOUR VOICE HEARD
POSITIVELYAWARE.COM

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Briefly

ENID VÁZQUEZ @ENIDVAZQUEZPA

GENVOYA, SON OF STRIBILD, IS BORN

The new version of Stribild is now available. The FDA approved Genvoya (jen-VOY-uh) on November 5. It includes the medications contained in Stribild, but has tenofovir alafenamide (TAF) instead of tenofovir DF (TDF). As a result, the new version of the single tablet regimen has been shown to have **less toxicity to the bones and kidneys.** Genvoya also received a switch indication for people with undetectable viral load for more than six months, as long as they have no previous treatment failure and don't have drug resistance to the medications in Genvoya. For more information, read the press release from Gilead Sciences at bit.ly/1GOqtt8.

GENVOYA IMAGE COURTESY OF GILEAD SCIENCES

LIVER WARNING FOR VIEKIRA PAK AND TECHNIVIE

In October, the drug labels for the hepatitis C medications Viekira Pak and Technivie were updated to state that the treatments are contraindicated (not to be taken) by patients who have Child-Pugh B cirrhosis. Previously, the drugs were "not recommended" for these patients. "Patients taking these medications should contact their health care professional immediately if they develop fatigue, weakness, loss of appetite, nausea and vomiting, yellow eyes or skin, or light-colored stools, as these may be signs of liver injury," reported the FDA in a press release. For more information, read the statement at fda.gov/Safety/MedWatch/SafetyInformation/SafetyAlertsforHumanMedicalProducts/ucm468757.htm.

LONG-ACTING INJECTABLE EFFECTIVE

A long-acting injectable HIV treatment given every four or eight weeks was shown to be as effective as a daily triple-drug oral regimen. More than 90% of the people given the medications achieved undetectable viral loads (less than 50). The LATTE 2 study results are from 32 weeks of research combining two long-acting injectable HIV drugs, rilpivirine (already on the market as the oral medication Edurant and found in Complera) and cabotegravir, an integrase inhibitor similar in structure to dolutegravir. The regimen was compared to oral therapy with cabotegravir plus two other drugs. For more information, read the press release at prnewswire.com/news-releases/first-investigational-all-injectable-long-acting-hiv-combination-regimen-study-results-at-32-weeks-announced-539776031.html.

NEW HEP C COMBO DRUG SUBMITTED FOR APPROVAL

On October 28, a new medication for hepatitis C virus (HCV) was submitted to the FDA for approval. The fixed-dose drug combination of sofosbuvir and velpatasvir (SOF/VEL) is all-oral and pan-genotypic (meaning that it can treat all genotypes of HCV, genotypes 1–6). "As the first fixed-dose combination of two pan-genotypic, direct-acting antivirals, SOF/VEL represents an important step forward in the treatment of patients with hepatitis C," said Gilead Sciences' Chief Scientific Officer, Norbert Bischofberger, PhD, in a press release. "Genotype 1 is the most prevalent form of HCV in the United States, but worldwide, more than half of people living with HCV are infected with other genotypes. SOF/VEL complements our current HCV portfolio of Sovaldi and Harvoni, offering high cure rates and the potential to simplify treatment and eliminate the need for HCV genotype testing." The combination is also being considered for approval by the European Medicines Agency. The company's filings are based on the studies ASTRAL-1, 2, 3, and 4.

RESOURCE FOR HIV CARE PROVIDERS

The HIV Medicine Association (HIVMA) has launched a new website to help medical providers, including information on health-care financing. "HIVClinican.org is geared more toward actual problems of navigating through patients' coverage issues, billing and coding, and adapting to healthcare reform," as well as the latest treatment information, said HIVMA board member Alan Taege, MD.

NARCAN NASAL SPRAY APPROVED

In November, the FDA approved a nasal spray version of the opioid overdose reversal drug Narcan (naloxone). While Narcan was already available as an injectable, that formulation needs to be assembled (drawn up into a syringe) and runs the risk of contaminated needle stick injury. "We cannot stand by while Americans are dying," FDA acting commissioner Stephen Ostroff, MD, said in a press release. The agency noted that drug overdose deaths result primarily from prescription medications and are the leading cause of death by injury in the U.S., surpassing car crashes. Opioids include heroin and the prescription medications oxycodone, hydrocodone, and morphine. Narcan can stop an overdose in progress as well as reverse one. Read the press release at atforum.com/2015/12/fda-moves-quickly-approve-easy-use-nasal-spray-treat-opioid-overdose/.

Briefly

FRANCE SAYS *‘OUI’* TO PrEP...

At the end of 2015, Truvada for PrEP was approved in France. “It will enable everyone involved—health professionals, nonprofit organizations, municipal authorities, researchers—to work together towards a new goal: Eradication of HIV,” and open the way to PrEP for other European countries, said the executive director of the French HIV research agency ANRS, Professor Jean-François Delfraissy, in a press release. Read the online statement at anrs.fr.

...AS SOUTH AFRICA SAYS ‘YES’ TO PrEP, TOO

After France approved Truvada for PrEP, so did South Africa. It is hoped that other countries will soon follow their lead.

CDC ISSUES PrEP REPORTS

On November 24, the CDC published two PrEP reports in its MMWR (*Morbidity and Mortality Weekly Report*). The first estimated that of people who are HIV-negative, one in four MSM (men who have sex with men) and one in five injection drug users meet the criteria for PrEP use. “Increasing delivery of PrEP and other highly effective HIV prevention services could lower the number of new HIV infections occurring in the United States each year,” the CDC noted. An easy-to-read chart shows what constitutes risk.

A separate report that looks at New York state Medicaid prescriptions for PrEP shows that they increased from 259 in 2012–2013 to 1,330 in 2014–2015. “Other state and local jurisdictions can use New York state’s implementation strategies as a model to adopt or adapt to increase PrEP use among their own populations,” said CDC. Get links to the reports at cdc.gov/vitalsigns/hivprep/index.html.

LAMBDA LEGAL HELP FOR PrEP

Lambda Legal is collecting information about denials to PrEP access. If your doctor said no to your request for PrEP, contact Lambda Legal at (866) 542-8336 or online at lambdalegal.org/help.

PrEP LAWSUIT

GLAD (Gay and Lesbian Advocates and Defenders), in Boston, has filed a lawsuit against the Mutual of Omaha Insurance Company for discriminating against a gay man taking the HIV prevention pill Truvada. The 61-year-old man was denied long-term care insurance because of his PrEP use. In a press release, GLAD reported that, “This is the first lawsuit in the country challenging discrimination against a person on PrEP.” Read GLAD’s statement at glad.org/work/cases/doe-v-mutual-of-omaha.

STUDIES FOR TREATMENT-EXPERIENCED PEOPLE

Clinical studies looking at two experimental HIV medications in people who are treatment-experienced are being conducted by Bristol-Myers Squibb (the maker of Atripla, Reyataz, Evotaz, and Sustiva). Study AI438-047 looks at the attachment inhibitor medication BMS-663068 in people with drug resistance, intolerability, and/or contraindications to several classes of HIV drugs, and whose current treatment regimen is failing. Study AI468-048 looks at the maturation inhibitor drug BMS-955176 in people whose current therapy is no longer effective. For more information on these studies, go to HIVTrialFinder.com.

DON’T TAKE VAT

The makers of Egrifta, a medication for the treatment of excess belly fat that often resulted from early HIV medications, has launched a new website to raise awareness about the dangers of excessive abdominal adipose tissue. As with some of the other physical changes that were seen with early HIV therapy, the changes can come with real dangers. Go to DontTakeVAT.com.

BLUE RIBBON BOYS

The Global Forum on MSM & HIV (MSMGF), the largest global advocacy network focused on HIV among men who have sex with men (MSM), has partnered with the gay app Hornet to launch “the largest targeted, global HIV viral suppression campaign to date,” including petitions for access to PrEP and to HIV treatment. Read the press release at msmgf.org/current-projects/blue-ribbon-boys.

U.S. SENATE COMMITTEE EXAMINES GILEAD PRICING

According to a press release from the Fair Pricing Coalition (FPC), which focuses primarily on HIV drug pricing, “The U.S. Senate Finance Committee ranking member Ron Wyden (D-OR) and senior committee member Chuck Grassley (R-IA) issued a scathing bipartisan investigative report on December 1, 2015, revealing a Gilead Sciences, Inc. pricing strategy showing little concern for patient access to its lifesaving drugs Sovaldi (sofosbuvir) and Harvoni (ledipasvir/sofosbuvir).” The release went on to say that, “Sovaldi was approved by the FDA on December 6, 2013—a first-in-class hepatitis C drug that helped usher in a new era of short-course, all-oral, well-tolerated, and highly curative treatment. Unfortunately, Gilead turned this long-awaited treatment option into a perfect storm of near-impossible drug access, marked by public and private insurance roadblocks in the form of prior approval, fibrosis, and strict sobriety requirements.” Read the release at fairpricingcoalition.org.

LATEST U.S. HIV STATISTICS

In one decade, the number of new HIV diagnoses in the United States went down by 19%. But in the same time, new HIV diagnoses almost doubled for young (ages 13 to 24) black and Latino men who have sex with other men (MSM). Both groups saw an increase of 87% in new HIV diagnoses.

"More than three decades after the first cases of AIDS were diagnosed in the United States, HIV continues to pose a substantial threat to the health and well-being of Americans," the CDC reported in December. The agency released its latest HIV statistics for the U.S., covering the decade of 2005–2014. The CDC reported that "progress has been uneven and certain groups, particularly gay and bisexual men and African Americans, continue to be the most affected."

The 87% increase represents an increase from 866 to 1,617 young Latino MSM and from 2,094 to 3,923 young black MSM.

Other increases and declines are listed below. Read the CDC report, which includes state-by-state statistics, at cdc.gov/nchhstp/newsroom/docs/factsheets/hiv-data-trends-fact-sheet-508.pdf.

DECREASES IN NEW HIV DIAGNOSES

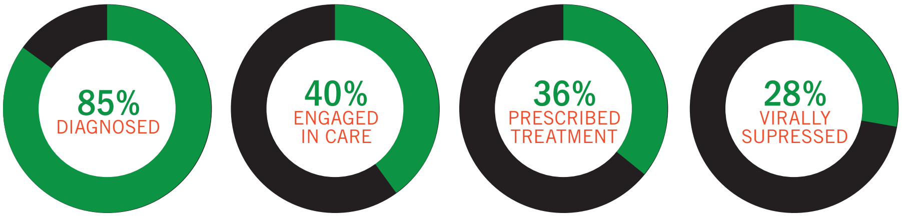
Women (overall) **40%**
African American women **42%**
Latinas **35%**
White women **30%**
Men (overall) **11%**
White MSM **18%**

INCREASES IN NEW HIV DIAGNOSES

MSM (overall) **6%**
Black MSM **22%**
Latino MSM **24%**
American Indian/Alaskan Native MSM **63%** (from 81 to 132)
Black and Latino MSM, ages 13-24 **87%** (from 2,960 to 5,540)
Asian MSM **101%** (from 357 to 717)

PHOTO COURTESY OF BRANT MILLER

IN 2011, 490,000 AFRICAN AMERICANS WERE LIVING WITH HIV...



SOURCE: CENTERS FOR DISEASE CONTROL AND PREVENTION

BLACK HIV/AIDS AWARENESS DAY

There are an estimated 490,000 African Americans are living with HIV, according to the Centers for Disease Control and Prevention; nearly 15 percent of them are unaware of their HIV status. February 7 is National Black HIV/AIDS Awareness Day. Begun in 1999, the campaign's theme this year is "I am my Brother/Sister's Keeper: Fight HIV/AIDS." It's an opportunity to go get tested, get into treatment, and to educate others about HIV. For information about how to take part in the day, or to locate a testing facility or treatment resources near you, go to NationalBlackAIDSDay.org.

INFECTIOUS READING. Five HIV activists performed a reading of *The Infection Monologues*, a thought-provoking play about modern life with the virus. The one-night only event was held at the Washington, D.C. headquarters of the Human Rights Campaign (HRC) for World AIDS Day to mark the play's 10th anniversary. HRC, The DC Center, and the National Minority AIDS Council sponsored the performance by (above, from left) Mark S. King, Brant Miller, Shawn Jain, Alex Garner, and Cedric Gum.

COMPLERA is a prescription medicine for adults who have never taken HIV-1 medicines before and who have no more than 100,000 copies/mL of virus in their blood. COMPLERA can also replace current HIV-1 medicines for some adults who have an undetectable viral load (less than 50 copies/mL) and whose healthcare provider determines that they meet certain other requirements. COMPLERA combines 3 medicines into 1 pill to be taken once a day with food. COMPLERA should not be used with other HIV-1 medicines.

Just the **one** for me

COMPLERA is a complete HIV-1 treatment that combines the medicines in TRUVADA + EDURANT in only **1 pill a day.***

Ask your healthcare provider if COMPLERA may be the one for you.

*COMPLERA is a combination of the medicines in TRUVADA (emtricitabine and tenofovir disoproxil fumarate) and EDURANT (rilpivirine).

Pill shown is not actual size.

COMPLERA does not cure HIV-1 infection or AIDS.

To control HIV-1 infection and decrease HIV-related illnesses you must keep taking COMPLERA. 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.

It is not known if COMPLERA is safe and effective in children under 18 years old.

IMPORTANT SAFETY INFORMATION

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

COMPLERA can cause serious side effects:

- **Build-up of an acid in your blood (lactic acidosis),** which is a serious medical emergency. Symptoms of lactic acidosis include feeling very weak or tired, unusual (not normal) muscle pain, trouble breathing, stomach pain with nausea or vomiting, feeling cold especially in your arms and legs, feeling dizzy or lightheaded, and/or a fast or irregular heartbeat.
- **Serious liver problems.** The liver may become large (hepatomegaly) and fatty (steatosis). Symptoms of liver problems include your skin or the white part of your eyes turns yellow (jaundice), dark "tea-colored" urine, light-colored bowel movements (stools), loss of appetite for several days or longer, nausea, and/or stomach pain.
- **You may be more likely to get lactic acidosis or serious liver problems** if you are female, very overweight (obese), or have been taking COMPLERA for a long time. In some cases, these serious conditions have led to death. Call your healthcare provider right away if you have any symptoms of these conditions.
- **Worsening of hepatitis B (HBV) infection.** If you also have HBV and stop taking COMPLERA, your hepatitis may suddenly get worse. Do not stop taking COMPLERA without first talking to your healthcare provider, as they will need to monitor your health. COMPLERA is not approved for the treatment of HBV.

Who should not take COMPLERA?

Do not take COMPLERA if you:

- **Take a medicine that contains:** adefovir (Hepsera), lamivudine (Epivir-HBV), carbamazepine (Carbatrol, Equetro, Tegretol, Tegretol-XR, Teril, Epitol), oxcarbazepine (Trileptal), phenobarbital (Luminal), phenytoin (Dilantin, Dilantin-125, Phenytek), rifampin (Rifater, Rifamate, Rimactane, Rifadin), rifapentine (Priftin), dexlansoprazole (Dexilant), esomeprazole (Nexium, Vimovo), lansoprazole (Prevacid), omeprazole (Prilosec, Zegerid), pantoprazole sodium (Protonix), rabeprazole (Aciphex), more than 1 dose of the steroid medicine dexamethasone or dexamethasone sodium phosphate, or the herbal supplement St. John's wort.
- **Take any other medicines to treat HIV-1 infection,** unless recommended by your healthcare provider.

What are the other possible side effects of COMPLERA?

Serious side effects of COMPLERA may also include:

- **Severe skin rash and allergic reactions.** Call your doctor right away if you get a rash. Some rashes and allergic reactions may need to be treated in a hospital. Stop taking COMPLERA and get medical help right away if you get a rash with any of the following symptoms: severe allergic reactions causing a swollen face, lips, mouth, tongue or throat which may lead to difficulty swallowing or breathing; mouth sores or blisters on your body; inflamed eye (conjunctivitis); fever, dark urine or pain on the right side of the stomach-area (abdominal pain).
- **New or worse kidney problems, including kidney failure.** Your healthcare provider should do blood tests to check your kidneys before starting treatment with COMPLERA. If you have had kidney problems, or take other medicines that may cause kidney problems, your healthcare provider may also check your kidneys during treatment with COMPLERA.
- **Depression or mood changes.** Tell your healthcare provider right away if you have any of the following symptoms: feeling sad or hopeless, feeling anxious or restless, have thoughts of hurting yourself (suicide) or have tried to hurt yourself.
- **Changes in liver enzymes:** People who have had hepatitis B or C, or who have had changes in their liver function tests in the past may have an increased risk for liver problems while taking COMPLERA. Some people without prior liver disease may also be at risk. Your healthcare provider may do tests to check your liver enzymes before and during treatment with COMPLERA.
- **Bone problems,** including bone pain or bones getting soft or thin, which may lead to fractures. Your healthcare provider may do tests to check your bones.
- **Changes in body fat** can happen in people taking HIV-1 medicines.
- **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 COMPLERA.

The most common side effects of COMPLERA include trouble sleeping (insomnia), abnormal dreams, headache, dizziness, diarrhea, nausea, rash, tiredness, and depression. Other common side effects include vomiting, stomach pain or discomfort, skin discoloration (small spots or freckles), and pain. Tell your healthcare provider if you have any side effects that bother you or do not go away.

What should I tell my healthcare provider before taking COMPLERA?

- **All your health problems.** Be sure to tell your healthcare provider if you have or had any kidney, mental health, bone, or liver problems, including hepatitis virus infection.
- **All the medicines you take,** including prescription and nonprescription medicines, vitamins, and herbal supplements. COMPLERA may affect the way other medicines work, and other medicines may affect how COMPLERA works. Keep a list of all your medicines and show it to your healthcare provider and pharmacist. Do not start any new medicines while taking COMPLERA without first talking with your healthcare provider.
- **If you take rifabutin (Mycobutin).** Talk to your healthcare provider about the right amount of rilpivirine (Edurant) you should take.
- **If you take antacids.** Take antacids at least 2 hours before or at least 4 hours after you take COMPLERA.
- **If you take stomach acid blockers.** Take acid blockers at least 12 hours before or at least 4 hours after you take COMPLERA. Ask your healthcare provider if your acid blocker is okay to take, as some acid blockers should never be taken with COMPLERA.
- **If you are pregnant** or plan to become pregnant. It is not known if COMPLERA can harm your unborn baby. Tell your healthcare provider if you become pregnant while taking COMPLERA.
- **If you are breastfeeding** (nursing) or plan to breastfeed. Do not breastfeed. HIV-1 can be passed to the baby in breast milk. Also, some medicines in COMPLERA can pass into breast milk, and it is not known if this can harm the baby.

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 Brief Summary of full Prescribing Information with **important warnings** on the following pages.

COMPLERA®
emtricitabine 200mg/rilpivirine 25mg/
tenofovir disoproxil fumarate 300mg tablets

GILEAD

Brief Summary of full Prescribing Information

COMPLERA® (kom-PLEH-rah)

(emtricitabine 200 mg, rilpivirine 25 mg, tenofovir disoproxil fumarate 300 mg) tablets

Brief summary of full Prescribing Information. For more information, please see the full Prescribing Information, including Patient Information.

What is COMPLERA?

- **COMPLERA is a prescription medicine** used as a complete HIV-1 treatment in one pill a day. COMPLERA is for adults who have never taken HIV-1 medicines before and who have no more than 100,000 copies/mL of virus in their blood (this is called 'viral load'). Complera can also replace current HIV-1 medicines for some adults who have an undetectable viral load (less than 50 copies/mL) and whose healthcare provider determines that they meet certain other requirements.
- **COMPLERA is a complete HIV-1 medicine** and should not be used with any other HIV-1 medicines.
- **COMPLERA should always be taken with food.** A protein drink does not replace food.
- **COMPLERA does not cure HIV-1 or AIDS.** You must stay on continuous HIV-1 therapy to control HIV-1 infection and decrease HIV-related illnesses.
- **Ask your healthcare provider about how to prevent passing HIV-1 to others.** Do not share or reuse needles, injection equipment, or personal items that can have blood or body fluids on them. Do not have sex without protection. Always practice safer sex by using a latex or polyurethane condom to lower the chance of sexual contact with semen, vaginal secretions, or blood.

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

COMPLERA can cause serious side effects, including:

- **Build-up of an acid in your blood (lactic acidosis).** Lactic acidosis can happen in some people who take COMPLERA or similar (nucleoside analogs) medicines. Lactic acidosis is a serious medical emergency that can lead to death. Lactic acidosis can be hard to identify early, because the symptoms could seem like symptoms of other health problems. **Call your healthcare provider right away if you get any of the following symptoms which could be signs of lactic acidosis:**
  - – feel very weak or tired
  - – have unusual (not normal) muscle pain
  - – have trouble breathing
  - – having stomach pain with nausea or vomiting
  - – feel cold, especially in your arms and legs
  - – feel dizzy or lightheaded
  - – have a fast or irregular heartbeat
- **Severe liver problems.** Severe liver problems can happen in people who take COMPLERA. In some cases, these liver problems can lead to death. Your liver may become large (hepatomegaly) and you may develop fat in your liver (steatosis). **Call your healthcare provider right away if you get any of the following symptoms of liver problems:**
  - – your skin or the white part of your eyes turns yellow (jaundice)
  - – dark "tea-colored" urine
  - – light-colored bowel movements (stools)
  - – loss of appetite for several days or longer
  - – nausea
  - – stomach pain
- **You may be more likely to get lactic acidosis or severe liver problems if you are female, very overweight (obese), or have been taking COMPLERA for a long time.**
- **Worsening of Hepatitis B infection.** If you have hepatitis B virus (HBV) infection and take COMPLERA, your HBV may get worse (flare-up) if you stop taking COMPLERA. A "flare-up" is when your HBV infection suddenly returns in a worse way than before. COMPLERA is not approved for the treatment of HBV, so you must discuss your HBV with your healthcare provider.
  - – Do not run out of COMPLERA. Refill your prescription or talk to your healthcare provider before your COMPLERA is all gone.
  - – Do not stop taking COMPLERA without first talking to your healthcare provider.
  - – If you stop taking COMPLERA, your healthcare provider will need to check your health often and do blood tests regularly to check your HBV infection. Tell your healthcare provider about any new or unusual symptoms you may have after you stop taking COMPLERA.

Who should not take COMPLERA?

Do not take COMPLERA if you also take any of the following medicines:

- **Medicines used for seizures:** carbamazepine (Carbatrol, Equetro, Tegretol, Tegretol-XR, Teril, Epitol); oxcarbazepine (Trileptal); phenobarbital (Luminal); phenytoin (Dilantin, Dilantin-125, Phenytek)
- **Medicines used for tuberculosis:** rifampin (Rifater, Rifamate, Rimactane, Rifadin); rifapentine (Priftin)
- **Certain medicines used to block stomach acid called proton pump inhibitors (PPIs):** dexlansoprazole (Dexilant); esomeprazole (Nexium, Vimovo); lansoprazole (Prevacid); omeprazole (Prilosec, Zegerid); pantoprazole sodium (Protonix); rabeprazole (Aciphex)
- **Certain steroid medicines:** More than 1 dose of dexamethasone or dexamethasone sodium phosphate
- **Certain herbal supplements:** St. John's wort
- **Certain hepatitis medicines:** adefovir (Hepsera), lamivudine (Epivir-HBV)

Do not take COMPLERA if you also take any other HIV-1 medicines, including:

- Other medicines that contain emtricitabine or tenofovir (ATRIPLA, EMTRIVA, STRIBILD, TRUVADA, VIREAD)
- Other medicines that contain lamivudine (Combivir, Epivir, Epzicom, Triumeq, Trizivir)
- rilpivirine (Edurant), unless you are also taking rifabutin (Mycobutin)

COMPLERA is not for use in people who are less than 18 years old.

What are the possible side effects of COMPLERA?

COMPLERA may cause the following serious side effects:

- **See "What is the most important information I should know about COMPLERA?"**
- **Severe skin rash and allergic reactions.** Skin rash is a common side effect of COMPLERA but it can also be serious. Call your doctor right away if you get a rash. In some cases, rash and allergic reaction may need to be treated in a hospital. Stop taking COMPLERA and call your doctor or get medical help right away if you get a rash with any of the following symptoms:
  - – severe allergic reactions causing a swollen face, lips, mouth, tongue or throat, which may cause difficulty swallowing or breathing
  - – mouth sores or blisters on your body
  - – inflamed eye (conjunctivitis)
  - – fever, dark urine or pain on the right side of the stomach-area (abdominal pain)
- **New or worse kidney problems, including kidney failure.** Your healthcare provider should do blood and urine tests to check your kidneys before you start and while you are taking COMPLERA. If you have had kidney problems in the past or need to take another medicine that can cause kidney problems, your healthcare provider may need to do blood tests to check your kidneys during your treatment with COMPLERA.

- **Depression or mood changes. Tell your healthcare provider right away if you have any of the following symptoms:**
  - feeling sad or hopeless
  - feeling anxious or restless
  - have thoughts of hurting yourself (suicide) or have tried to hurt yourself
- **Change in liver enzymes.** People with a history of hepatitis B or C virus infection or who have certain liver enzyme changes may have an increased risk of developing new or worsening liver problems during treatment with COMPLERA. Liver problems can also happen during treatment with COMPLERA in people without a history of liver disease. Your healthcare provider may need to do tests to check your liver enzymes before and during treatment with COMPLERA.
- **Bone problems** can happen in some people who take COMPLERA. Bone problems include bone pain, softening or thinning (which may lead to fractures). Your healthcare provider may need to do tests to check your bones.
- **Changes in body fat** can happen in people taking HIV-1 medicine. These changes may include increased amount of fat in the upper back and neck ("buffalo hump"), breast, and around the main part of your body (trunk). Loss of fat from the legs, arms and face may also happen. The cause and long term health effect of these conditions are not known.
- **Changes in your immune system (Immune Reconstitution Syndrome)** can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your healthcare provider if you start having any new symptoms after starting your HIV-1 medicine.

The most common side effects of COMPLERA include:

- Trouble sleeping (insomnia), abnormal dreams, headache, dizziness, diarrhea, nausea, rash, tiredness, depression

Additional common side effects include:

- Vomiting, stomach pain or discomfort, skin discoloration (small spots or freckles), pain

Tell your healthcare provider if you have any side effect that bothers you or that does not go away.

- These are not all the possible side effects of COMPLERA. For more information, ask your healthcare provider.
- Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

What should I tell my healthcare provider before taking COMPLERA?

Tell your healthcare provider about all your medical conditions, including:

- If you have or had any kidney, mental health, bone, or liver problems, including hepatitis B or C infection.
- If you are pregnant or plan to become pregnant. It is not known if COMPLERA can harm your unborn child.
  - There is a pregnancy registry for women who take antiviral medicines during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Talk to your healthcare provider about how you can take part in this registry.
- If you are breastfeeding (nursing) or plan to breastfeed. Do not breastfeed if you take COMPLERA.
  - You should not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.
  - Two of the medicines in COMPLERA can pass to your baby in your breast milk. It is not known if this could harm your baby.
  - Talk to your healthcare provider about the best way to feed your baby.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements:

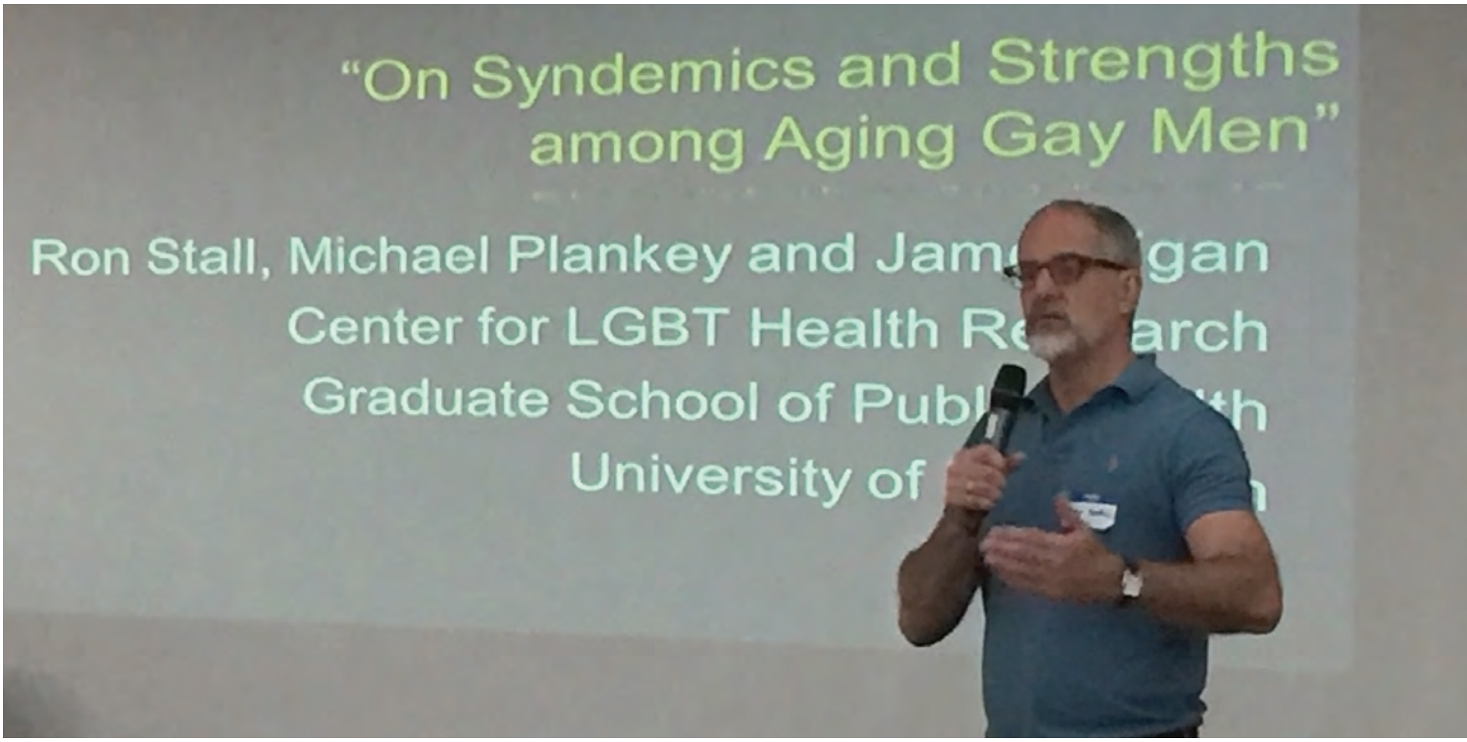
- COMPLERA may affect the way other medicines work, and other medicines may affect how COMPLERA works.
- If you take certain medicines with COMPLERA, the amount of COMPLERA in your body may be too low and it may not work to help control your HIV-1 infection. The HIV-1 virus in your body may become resistant to COMPLERA or other HIV-1 medicines that are like it.
- Be sure to tell your healthcare provider if you take any of the following medicines:
  - Rifabutin (Mycobutin), a medicine to treat some bacterial infections. Talk to your healthcare provider about the right amount of rilpivirine (Edurant) you should take.
  - Antacid medicines that contain aluminum, magnesium hydroxide, or calcium carbonate. Take antacids **at least 2 hours before or at least 4 hours after** you take COMPLERA.
  - Certain medicines to block the acid in your stomach, including cimetidine (Tagamet), famotidine (Pepcid), nizatidine (Axid), or ranitidine hydrochloride (Zantac). Take the acid blocker **at least 12 hours before or at least 4 hours after** you take COMPLERA. Some acid blocking medicines should never be taken with COMPLERA (see "Who should not take COMPLERA?" for a list of these medicines).
  - Medicines that can affect how your kidneys work, including acyclovir (Zovirax), cidofovir (Vistide), ganciclovir (Cytovene IV, Vitrasert), valacyclovir (Valtrex), and valganciclovir (Valcyte).
  - clarithromycin (Biaxin)
  - erythromycin (E-Mycin, Eryc, Ery-Tab, PCE, Pediazole, Ilosone)
  - fluconazole (Diflucan)
  - itraconazole (Sporanox)
  - ketoconazole (Nizoral)
  - methadone (Dolophine)
  - posaconazole (Noxafil)
  - telithromycin (Ketek)
  - voriconazole (Vfend)

Know the medicines you take. Keep a list of all your medicines and show it to your healthcare provider and pharmacist when you get a new medicine. Do not start any new medicines while you are taking COMPLERA without first talking with your healthcare provider.

Keep COMPLERA and all medicines out of reach of children.

This Brief Summary summarizes the most important information about COMPLERA. If you would like more information, talk with your healthcare provider. You can also ask your healthcare provider or pharmacist for information about COMPLERA that is written for health professionals, or call 1-800-445-3235 or go to www.COMPLERA.com.

Revised: May 2015



CLOCKWISE, STARTING FROM THIS PAGE: Ron Stall explains how many gay men survived twin epidemics, both HIV/AIDS and a culture of violence and victimization while growing up; Joshua Tree National Park; the cast of College of the Desert's production of *Rent* performs; Eric Jannke (left) and *Desert Migration* director Daniel Cardone (right).

PHOTO: MATT SHARP

LONG-TERM THRIVERS

THE REUNION PROJECT IN PALM SPRINGS EXAMINES THE ISSUES FACED BY LONG-TERM SURVIVORS

BY **JEFF TAYLOR**

More than 75 long-term HIV survivors met in Rancho Mirage, California on November 3 for The Reunion Project, a daylong summit on living well with HIV as we get older. The Palm Springs area has become a magnet for long-term survivors who moved to the desert resort city for its warm weather, affordable housing compared to the rest of California, excellent healthcare and HIV services, and a more relaxed lifestyle. This has made it unique in having the largest concentration of older HIV positives anywhere in the country. As such, it is a bellwether for the graying of the HIV epidemic. Currently more than half of all people living with HIV in the U.S. are over 50, and by 2020 research projects it to be 70 percent.

The day began with a panel discussion about long-term survivorship with organizers Matt Sharp and Gregg Cassin from San Francisco, POSITIVELY AWARE Editor-in-Chief Jeff Berry, David Richwine of Bristol-Myers Squibb (BMS), and Jeff Taylor, from Positive Life/Palm Springs. Richwine, who was a nurse when the epidemic began, reminded the group that as an HIV-negative gay man who cared for the dying in his community, the emotional impact was—and continues to be—as devastating for him as it was for everyone who lived through the worst days of the epidemic. Scenes were shown from the documentary *Desert Migration*, which chronicles the experiences of several HIV-positive men who moved to the desert—some because they thought they were going to die, and others to start life over. Director Daniel Cardone and Eric Jannke, who was one of the men featured in the film, shared their experiences of living through the epidemic, and the day-to-day challenges experienced by survivors. The film is now being shown throughout the country, and clips can be viewed on their Facebook page: facebook.com/DesertMigration.

Throughout the day, Gregg

PHOTOS: JEFF BERRY

Cassin from the Honoring Our Experience program in San Francisco checked in with the group, inviting participants to share their experiences, and helping them process the emotions that arose [see sidebar, next page].

One of the most touching moments of the day was when a young man and woman, who were two of the approximately 20,000 of those in the U.S. who were born prematurely and infected with HIV via blood transfusions in the early 80s, before the supply was being screened, shared their stories. Being among the only 50 or so of their HIV-positive peers who survived into adulthood, they reminded the group that long-term survivors are of all ages and backgrounds.

Other presentations covered the policy issues facing people living with HIV as we grow older, with Phil Curtis from AIDS Project Los Angeles (APLA), Chris Brown from the LA Gay & Lesbian Center, and Octavio Vallejo from BMS; UCSD neurobehavioral researchers Drs. Ron Ellis and David Moore on the memory loss and other neurocognitive problems often seen in HIV; and psychologist Dr. Jill Gover of the Palm Springs Gay & Lesbian Center who described the AIDS survivor syndrome she sees in many of the older HIV-positive clients she counsels. Local physician Rick Loftus spoke about a new research collaboration between area HIV doctors and the Palm Springs HIV community called GRACIE that will compare aging between HIV survivors and their HIV-negative counterparts, as well as innovative treatments to improve their quality of life (hivstory.org). Long-term survivor Nick Nicholas spoke about how he has overcome some of his HIV-associated neurocognitive problems by developing an innovative system of memory aids and using various phone apps that have allowed him to complete his master's degree. And University of Pittsburgh researcher Ron Stall talked about his encouraging research into the "resiliency factors" that allow the majority of HIV survivors to thrive in spite of their challenges.

There was vigorous discussion after each presentation, where attendees shared information on local resources, including the local Let's Kick ASS (AIDS Survivor Syndrome) chapter that formed last year after a visit by LKA founders Tez Anderson and Matt Sharp on World AIDS

Day 2014. Let's Kick ASS has also partnered with staff at The Center to provide closed therapy groups specifically geared toward long-term survivors and issues such as isolation and depression. One man proudly declared that he considered himself "not a survivor, but a thriver," an apt description of the theme of the summit.

The Reunion Project-Palm Springs was a collaboration between Test Positive Aware Network in Chicago and the Positive Life HIV Education Series in Palm Springs, and sponsored by an unrestricted educational grant from Bristol-Myers Squibb. The first event was held in Chicago in June 2015. More Reunion Project events are planned in other U.S. cities for 2016. PA

JEFF TAYLOR is a 30-plus year HIV long-term survivor who lives in Palm Springs, California. He has been active in HIV research advocacy for 20 years—currently focusing on anal cancer prevention, cure research, and HIV and aging.


LEFT TO RIGHT: PHIL CURTIS, OCTAVIO VALLEJO, AND CHRISTOPHER BROWN.

PHOTO: JEFF BERRY

THE BEGINNING OF THE EPIDEMIC

EDITOR'S NOTE: Gregg Cassin, a long-time activist from San Francisco and one of The Reunion Project organizers, spoke these powerful words at the beginning of both 2015 summits, and in doing so set the tone for each day's discussion.

There was a crisis, a horrible time when we were left to fight on our own. The government had left us to fend for ourselves, even our families and religious communities turned their backs on us. We reached out and reached out and finally learned "it was just us"—we had to rely on one another.

And we soon learned that we—COMMUNITY—was all that we had, and in some ways all that we needed. We joined together… We utilized every talent and every skill, each one of us was ESSENTIAL. We needed the caregivers, we needed the emotional support people, we needed the practical ones, we needed the thinkers and the strategists, we needed the healers, the hope givers—and we needed the fighters!

We joined forces and weathered a horrible storm, and as we did we realized our power, we saw who we were and who we were BECOMING. This community, which had been discarded, shamed, maligned, hated, outcast, and ignored came together in the most beautiful and powerful way. It is a story that is so heroic, noble and beautiful that it is now the stuff of films, books, plays, and anthems…Not only as history but as a testament to the power of the human spirit. In the middle of the war we were selfless angels when needed, brilliant strategists when needed, and ferocious attack dogs when needed. We do that all—EVERY talent was needed to respond to this war, and we did.

We, the marginalized and forgotten ones who the world said 'No!' to—realized we only had one another. Because we only have one another we brought our passion and commitment, our deep loyalty and integrity and this unbelievable resilience and love. It was ALL called up. This community not only took care of its own, but we changed the world. And in this turning to one another we saw the truth of who we were. We really saw one another and ourselves for the first time. And we were in awe of our power and humbled by our noble, profoundly resilient hearts. (Look around this room—and see these resilient hearts… See who we are.)

Some of us now feel like (and can look like) the war-torn heroes that we are. We went through hell and we survived!

And now we're realizing that the greatness of the time was in COMING TOGETHER. The coming together for one another, and for ourselves. But the magic stuff that held us together at the time was our deep sense of community. We cannot think back to those times without the memory of a profound sense of connectedness and purpose.

—GREGG CASSIN

HEALING THROUGH BARRIERS

THE CONNECTION BETWEEN TRAUMA AND BARRIERS TO CARE FOR WOMEN LIVING WITH HIV

BY **OLIVIA FORD**

> *"If we are really serious about retention in care for women living with HIV, we have to do the underlying work. You are bringing everything with you to the clinic, not just HIV."*
>
> —**VANESSA JOHNSON**,
> CO-OWNER, RIBBON CONSULTING GROUP;
> CO-FOUNDER, POSITIVE WOMEN'S NETWORK-USA;
> FOUNDER, COMMON THREADS

Women living with HIV experience multiple barriers to HIV care—both accessing care and experiencing the full benefits of care once connected.

Decades of research and clinical experience both within and outside the HIV community have shown a stark link, across races, ethnicities, genders, and socioeconomic backgrounds, between past and recent trauma and a wide range of chronic conditions and poor health outcomes. These statistics are especially troubling among people of color, particularly African Americans.

Successful treatment for chronic health conditions such as diabetes, depression, obesity, heart, lung, and liver diseases, substance use, and sexually transmitted infections including HIV, is often disturbingly elusive—in part because clinicians and care environments fail to address the trauma and post-traumatic stress disorder (PTSD) that underpin them.

A parallel body of evidence shows the overwhelmingly high burden of violence (including institutional violence, racism, and other forms of systemic injustice), abuse, and PTSD among women living with HIV—about 80 percent of whom are women of color, and most of whom are living in poverty—including the reality that three in four women living with HIV report a history of gender-based violence.

Meanwhile, there is a crater in the HIV care continuum for women living with HIV, by last gender-stratified count: 70 percent of women connect to care, but fewer than half of them remain in care.

Transgender women, historically, have some of the worst HIV health outcomes by many measures: very low rates of engagement and retention in care, high rates of loss to follow

CHRISTIE'S PLACE, SAN DIEGO
'Clients love it becuse it's a home-like environment; it's not all about HIV.'

PHOTO: LOUIS "KENGI" CARR

up, and in some studies, lower rates of HIV medication use than among injection drug users. The HIV rate among transgender women is disproportionately high: 2.6 percent among transgender people as a whole, and up to 4.4 percent for African American transgender women.

What's the connection between trauma and barriers to care for women living with HIV?

Women may have specific experiences, compounded by gender, that create unique barriers to their accessing HIV care. Wraparound services like peer-based, gender-responsive programming; transportation, housing and childcare assistance; nutritional support; and mental health and substance use treatment are essential for many women to be able to receive consistent and high-quality care. If these services are absent, a woman's ability to stay connected to HIV care becomes even more tenuous.

But even in a landscape of supportive services, trauma and violence continue to erode the health outcomes of women living with HIV in what Positive Women's Network-USA (PWN-USA), a national membership body representing women with HIV, has called a "crisis of unaddressed trauma among women living with HIV"—which may be the missing ingredient to account for systemic failure to provide high-quality care for women with HIV.

If the National HIV/AIDS Strategy is to reach the stated commitment of its second goal—increasing access to care and improving health outcomes for people living with HIV, and to meet the challenges therein—providers must be supported in their efforts to think and practice outside the box, to adapt innovative models to meet the needs of women living with HIV in their communities.

MEDICAL UNIVERSITY OF SOUTH CAROLINA RYAN WHITE HIV/AIDS CLINIC :

STRUGGLING TO KEEP WOMEN CONNECTED TO CARE IN SOUTH CAROLINA

Part D of the Ryan White HIV/AIDS Program serves women, young people, and families living with HIV in the U.S., and contributes to Ryan White's relative success retaining women with HIV in care—in part due to the essential wraparound services Part D is able to fund.

The Medical University of South Carolina (MUSC)'s Ryan White HIV/AIDS Clinic is funded in part through Part D. According to Lauren Richey, MD, of MUSC, in addition to medical care, MUSC provides transportation assistance, social work services including counseling, dental care, medication assistance, case management, peer navigation, housing assistance, nutritional supplements, meal tickets, substance use treatment referrals, and emergency financial assistance. They also have a new, on-site psychiatry clinic, where clients can be seen, evaluated, and followed by a psychiatrist in the same clinic space; and a women's health clinic where sexual and reproductive health care are available to women with HIV at all parts of their lifespan, from PrEP and preconception counseling to post-menopausal care.

Last year, when MUSC staff identified roughly 19 percent of their clients that they defined as "not retained" in care (meaning they didn't meet MUSC's criteria of having had two visits separated by 90 days over a one-year period), they set out to find out what had happened to them, and to get them back into care. Fifty-five percent of those folks were discovered to have "fallen out of care" (others' absence was found to be due to transferring care, experiencing incarceration, or passing away). Those who "fell out of care" were more likely to be female, African American, and have lower CD4 counts and higher viral loads than those who transferred care.

"Linda [the clinic's licensed professional counselor] completed a step-wise series of outreach: phone, letter and home visits to try to reach and re-engage our patients who are lost to care," Dr. Richey explains—and that intervention has been effective in getting clients to come back for a visit. But barriers remain to reaching clients who may need interventions like substance use treatment the most.

Even this level of care is unheard of for most health conditions—and is sorely needed in order for tens of thousands of people living with HIV to remain connected to care. But a growing number of providers are taking yet another innovative step to increase the effectiveness of the care they provide—and their clients' capacity to access it.

The Ryan White HIV/AIDS Program's models of care made it a pioneer in community-responsive health services. Recently, advocates have called for trauma-informed approaches to be the next legacy of the Ryan White HIV/AIDS Program—to solidify a bold standard in HIV care prioritizing environments that contribute to healing.

70% OF WOMEN WITH HIV CONNECT TO CARE, BUT **FEWER THAN HALF OF THEM** REMAIN IN CARE.

CHRISTIE'S PLACE:

BUILDING FOUNDATIONS FOR A TRAUMA-INFORMED ENVIRONMENT FOR WOMEN IN SAN DIEGO

"I think it's just the empathy that is exhibited here," says Jay Blount of what sets Christie's Place, a support services center for women, children, and families impacted by HIV in San Diego, apart from other area providers. "Clients love it because it's a home-like environment; it's not all about HIV."

Blount is a family case worker at Christie's Place, as well as a peer navigator through its CHANGE (Coordinated HIV Assistance and Navigation for Growth and Empowerment) for Women program, helping women living with HIV like herself to engage with and stay in care. Christie's Place is literally based in a house, in a residential neighborhood. "Women can come and relax, get on the computer, just hang out, cook if they need to," says Blount. "It's not appointment based; we interact with clients all day long. Other places are very clinical, sterile."

And as the staff at Christie's Place is well aware, for women with trauma histories, a clinical medical environment can be re-traumatizing and become, in itself, a barrier to accessing care.

"One of the hallmarks of a PTSD diagnosis is avoidance of reminders of a traumatic event," Erin Falvey, Christie's Place's clinical director, explains. A medical or social-service environment can be a reminder of traumatic events for myriad potential reasons: invasiveness of procedures; unanticipated shifts in providers that can assault an already fragile sense of trust; or, for those who have experienced male violence, a clinic waiting room that may often be filled with men.

> **‘*All* of our staff—those who do administration, bookkeeping, outreach—everybody had to become competent, aware, and savvy about the principles and practices of trauma-informed service provision.’**
> —**ERIN FALVEY**, EXECUTIVE DIRECTOR, CHRISTIE’S PLACE

CHRISTIE’S PLACE STAFF AND CLIENTS.

PHOTO: LOUIS “KENGI” CARR

Falvey and Blount were both part of Christie’s Place’s process of becoming a fully actualized trauma-informed agency. The Substance Abuse and Mental Health Services Administration (SAMHSA) promotes a trauma-informed approach that shifts from the traditional medical view of “What’s wrong with this person?” to a more holistic framing—“What happened to this person?”—as a foundation for healing and recovery. According to SAMHSA, a trauma-informed environment

- realizes the widespread impact of trauma on the population;
- recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system;
- responds with full integration of trauma knowledge into policies, procedures, and practices; and
- resists re-traumatization in the care setting.

(**READ MORE ABOUT** SAMHSA’s principles of a trauma-informed approach: samhsa.gov/trauma-violence/samhsas-efforts.)

“Recognizing trauma is likely part of the client’s history, that may be playing out in how she’s showing up, helps us to see her resiliency—and to have a different level of compassion in our work,” Falvey says.

The year 2012 saw the publication of two key studies led by Edward Machtinger, MD, director of the Women’s HIV Program (WHP) at the University of California, San Francisco (UCSF): one showing, for the first time, a significant link between recent trauma and HIV-related health challenges for women living with HIV; the other a review of 29 studies revealing that women with HIV were two to six times more likely to have experienced traumatic events and PTSD than women in the general population—and that 60 percent of women with HIV reported lifetime sexual abuse, more than 5 times the percentage among women who reported the same in a general sample of women. (Read an interview with Dr. Machtinger at thebodypro.com/content/74768/unraveling-the-impact-of-trauma-on-people-with-hiv.html.)

This was around the time Falvey arrived at Christie’s Place. A licensed marriage and family therapist, she brought with her a history of working with trauma, and saw an immediate need for Christie’s Place to become more trauma focused. “[Dr. Machtinger’s research] really helped us to substantiate the data backing the link between trauma, PTSD, and women’s health outcomes,” Falvey says. Machtinger has since teamed with UCSF providers, in partnership with PWN-USA, to develop and publish an adaptable model for trauma-informed primary care.

(**GET MORE** practical information about this trauma-informed care model: whijournal.com/article/S1049-3867(15)00033-X/fulltext.)

The CHANGE for Women program already worked to deliver crucial support services that address women’s barriers to staying in care, in a safe space. In addition to counseling and outreach, Christie’s Place supports women who may be balancing multiple, competing survival priorities. The agency provides assistance to meet basic needs—hygiene products and food, baby diapers and formula—as well as onsite childcare and transportation support, a resource whose value cannot be overestimated in sprawling San Diego County, where travel for a clinic visit can run up to three hours one way. Christie’s Place also partners with a local public-interest law firm that can help with immigration relief—of tremendous concern to many clients in this border city—and employs many bilingual staff members, to make all Christie’s Place services available in English and Spanish. Since Christie’s Place implemented CHANGE for Women, women’s engagement in HIV care in San Diego County has increased by 14 percent.

“We were actually doing [trauma-informed] work already,” Blount says. “Now we have the language to go with it—we know what it is.” Equipped with a Retention in Care grant from AIDS United and the MAC AIDS Fund, Christie’s Place solidified its foundation as a trauma-informed agency. “*All* of our staff—those who do administration, bookkeeping, outreach—everybody had to become competent, aware, and savvy about the principles and practices of trauma-informed service provision,” Falvey says.

The staff is predominantly

female—of 18 current members of the team, two are men. Statistics of violence experienced among women in the general population already suggested a high likelihood that Christie's Place staff would have gone through similar experiences to the ones they learned about through the Office on Women's Health (OWH)'s trauma-informed trainings. “And we saw that,” says Falvey, “really, really quickly.”

Peer counselors in trauma work are considered “two-hatters,” wearing the “hats” of trauma survivors as well as service providers. “Our peer navigators are three-, four-, and five-hatters”—often bringing a combination of substance use and violence histories and mental health diagnoses, in addition to living with HIV and surviving trauma. Many of the staff who were not living with HIV also had violence histories.

Built into Christie's Place's model are strong commitments to supervision and peer support, as well as self-care, for all staff, supported by policies and practices like a wellness committee and time off for staff members' own therapy appointments. Though it can bring up painful experiences, Falvey believes the trauma-informed training and commitment help staff to feel far more prepared—and to see their own resiliency as well as that of their clients.

A key tenet of OWH's and SAMHSA's trauma-informed principles is that healing happens in relationships. “One of the most powerful things we can do is recognize that we all have the ability to help facilitate trauma recovery by how we are in relationship with people that we serve,” Falvey concludes. “Everybody has that potential, not just providers. It's all about the relationships and the environment that you're facilitating.”

TRANSACCESS:
CONNECTING WOMEN TO CARE IN THE MIDST OF COMPLEX LIVES

“I think we've been setting people up to fail,” states Royce Lin, MD, of conventional medical models of health care. “The more intersections of disparities that populations face, the higher a level of care is required to address them.”

Dr. Lin's main job is at the Tom Waddell Urban Health Clinic—among the first publicly-funded clinics providing services and care specifically for transgender clients, which recently celebrated its 25th anniversary in the Tenderloin community of San Francisco. There, the environment is more of a traditional, large clinic. But for the past several years, thanks to a grant from the Health Resources and Services Administration (HRSA)'s Special Projects of National Significance (SPNS), Dr. Lin has been able to bring trauma-informed principles to bear in serving clients with extraordinarily chaotic lives.

The demonstration project, called TransAccess, endeavors to improve access and retention to care, and often abysmal health outcomes, for transgender women of color living with HIV. “The clients we work with have not done well within existing conventional systems of care,” says Lin. Of about 50 patients who have received primary care through the program, about one-third started the program with advanced HIV, 80 percent or more are homeless at time of entry, and about 70 percent have serious mental health challenges including psychosis, often related to meth use as a coping mechanism for survival on the streets. Many women rely on survival sex work to get by.

“For folks who are the most vulnerable and the most in need, conventional medical structures oftentimes aren't able to meet the level of need,” Lin says.

National data reflect that all manner of social structures have historically done a terrible job meeting the needs of transgender women—particularly looking at the intersectionality of the incredibly high preponderance of poverty and trauma in the population, and coping mechanisms to trauma that cause more harm. High rates of family rejection, employment discrimination and limited educational opportunities, all underpinned by systemic bias, combine to create dire survival circumstances, and correlated HIV vulnerability, for many transgender women of color.

Further, a recent Transgender Law Center survey found that 48 percent of transgender respondents feel it is reasonable to avoid treatment. “It's not that trans people don't care about their health,” says Lin. “Those who stay away from care do so because of experiences they've had”—including a high likelihood of past negative experiences in a health care setting.

For example, for transgender individuals, being misgendered by clinic staff can be not only personally distressing, but physically unsafe. “Calling out ‘Mr. Jones’ in a crowded waiting room, and the person who stands up is feminine in her presentation: Right then she has been outed—and may be victimized or targeted for violence when walking out of the clinic,” Lin explains. “There may be no malice behind it from the staff, but the result is still that it ruins a client's whole day”—and makes it less likely for the client to return.

These concerns in health care settings can be addressed with greater transgender sensitivity and cultural competency, appropriate training and tweaks to the clinic environment to signal a culture of welcome and safety for trans people living with HIV. Posters and visual cues featuring trans subjects, as well as gender-neutral bathrooms, are a good start. Transgender professional organizations also recommend that medical forms adopt the “two-step ask” regarding gender—”What is the gender you were assigned at birth?” and “What gender do you identify as currently?”—to combat harmful misgendering experiences.

The TransAccess program is not based at the main, large, more anonymous clinic. Instead, for that half-day per week, the medical team is out-based at the Asian-Pacific Islander Wellness

'For folks who are the most vulnerable and the most in need, conventional medical structures oftentimes aren't able to meet the level of need.'
—**ROYCE LIN, MD,** SAN FRANCISCO DEPARTMENT OF PUBLIC HEALTH


DR. LIN WITH JOHANNA BROWN, A CLIENT IN API WELLNESS CENTER'S TRANSACCESS PROGRAM.

PHOTO COURTESY OF ASIAN & PACIFIC ISLANDER WELLNESS CENTER

Center (API Wellness)—home of TRANS:THRIVE, the largest trans drop-in space in San Francisco, and a longtime HIV service organization in the Tenderloin.

"Right off the elevator, the vibe is different," explains Lin; like Christie's Place, it is less institutional, cozier. "Thursday is clinic day, and folks just show up." Transgender staff and peers are highly visible; the clinic staff is small, and can be easily accessed outside clinic hours. An open-access model of care counters the difficulty of keeping strict appointments amidst complicated priorities. The space provides opportunities for building community and leaving behind the competitive nature of life on the streets. A wellness group, run by two trans women of color, focuses on topics like gender affirmation (social interaction that affirms one's gender expression—often elusive for trans women, whose gender expression is often not affirmed but defamed), gender empowerment, and finding voice.

"For many clients, HIV is about number nine on their list of priorities," says Lin. For instance, a caring provider typically worries if a patient has a low CD4 count, and may want them to start HIV meds above all else. "That is the *provider's* priority." The client's priority may be finding a place to sleep, dealing with a violent john, or accessing hormone therapy, and may feel pushed to get their HIV under control when other aspects of their life demand their energy. "At best, the approach doesn't resonate; at worst, it comes across as insensitive and out of touch."

Like the staff of Christie's Place, TransAccess staff members recognize that to keep people connected to the program, it has to feel like a home. And what is home, asks Lin, but a place where you can be exactly who you are? Where it doesn't matter if you "fail," or relapse on drugs, or it takes many stops and starts for you to stay connected to HIV care? Where you can feel safe—not only physically and psychologically, but also where there's safety from judgement around the actions you take in your own life?

"I tell trainees I can teach anyone to come up with an HIV regimen; the hard part is in that dance: How do you help a client feel safe—in the environment, and with you?"

Lin and his staff telegraph that sense of safety, in part, by working hard to follow through on their promises. "A lot of trans people have a hard time with trust, may feel let down and betrayed by families as well as providers," Lin says. "If we say we will help you with something or do something, we do it." Using the example of a form for a discount transit pass: It may not seem like a big deal to a provider if they forget, but it may be what's most important to a client—and a host of negative past experiences may leave her wondering whether her provider failed to give her the form because she is trans. "With historical baggage, we have to work harder to prove trustworthiness; we do this by being very transparent."

Another aspect of the TransAccess approach is to invite clients to be involved in their own decisions, and to make sure they have all the information to make them. "Some physicians would feel the need to get a client's HIV in control before they start hormone therapy," Lin explains. "A collaborative approach would mean explaining more, asking questions like: 'Would it make a difference to you if you knew that a more successful gender transition is possible once your virus is under control? We can do it your way—how do you think that might change your feelings about being on HIV meds? If we start hormones first, would it give you a sense of hope and motivation?'"

For clients who have experienced many disparities and may feel that they have very little power, an important step for a provider is to try to level the playing field a bit. This approach is also key to the work of Christie's Place, where informed consent is vital to a client's sense of being a partner in her health care—of knowing her ideas, opinions and decisions matter. "In situations involving intimate partner violence or childhood abuse, there's a power differential," adds Falvey of Christie's Place, pointing to the impact of trauma histories on experiences of care. "Violence can remove that aspect of human dignity."

Even though TransAccess sees some of San Francisco's most complex clients, the percentage of clients whose HIV has reached undetectable levels is quite high: 75 percent or more for women receiving primary care through the project. In keeping with SAMHSA's trauma-informed guidelines, this kind of care "is not about dogged focus on a particular model; it's about the approach—a sense of home and welcome, trust and safety; a place that can be flexible enough to meet needs.

"That's the higher bar I would challenge all of us to hold," he says. "It's not just about an undetectable viral load—in many ways that's the easiest part—but how to help somebody to not be vulnerable to the same forces that can pull them back down? How to get people off the streets? Help them find economic empowerment opportunities?"

In the long view, support for such an approach can even help save costs, according to Lin—the alternative is someone will continue to be stuck and decline until something catastrophic happens to their health.

"Trauma-informed principles are generally good for all populations," Lin muses; "but it is all the more important to carve out time and space to really practice them well with clients most likely to drop out of care—and least likely to walk in your door in the first place."

(**GO TO THE ONLINE VERSION OF THIS ARTICLE** to view videos featuring TransAccess clients, positivelyaware.com)

COMMON THREADS: HEALING WOUNDS, FINDING VOICE

Storytelling is the foundation of Common Threads, a multi-stage community-based intervention that addresses barriers to care and a high quality of life: by increasing disclosure, combatting poverty by fostering economic empowerment, and preparing women with HIV to be advocates on behalf of their communities as well as themselves.

According to founder Vanessa Johnson, the intervention supports women in a healing process around their HIV diagnosis, including how earlier life experiences and even historic experiences within their families may have increased their vulnerability to HIV and/or unfavorable health outcomes. The first stage of the intervention is a three-day training where interactive discussion tools and activities are used to guide participants in thinking about their life stories in different ways, starting long before they became HIV-positive.

"The seed of shame and guilt was planted before HIV," explains Johnson, who has herself been living with HIV since 1990. "When you get your diagnosis, whatever self-esteem issues you had get solidified.

"Before we can move on to helping women live the lives they could live, we have to deal with the initial trauma." Once women create a space to think about themselves differently, says Johnson, they are likely to take better care of themselves.

Further, a requirement for eligibility in the highly sought-after training is that women partner with an HIV service provider or other community organization in their area to support their participation in Common Threads—so that, if the training opens a woman's past wounds, she is already connected to a service provider to address issues that have come up. This connection to a local service provider can help deepen a woman's engagement in care after the first phase of the training.

"Women can be very broken when they arrive at a Common Threads training; they may say something like 'I was told by my case manager that I need to be here—my doctor is saying I need to go on meds, and I don't want to.' It's powerful for them to be in the same room, sharing with other women who may already have crossed that bridge." Another requirement is that a woman must be willing to self-disclose her HIV-positive status as part of the training.

The facilitation team consists of two peer facilitators who are women living with HIV; one group facilitator; and a licensed clinician. The clinician has two roles during the training: to educate about the myriad impacts of trauma and to support women through emotional breakthroughs, or breakdowns, over the course of the training.

"When you break down, you are getting to *you*," Johnson says. "A breakdown is a 'Hallelujah'—an opportunity to cry, or feel, what you have not until then." Part of facilitators' roles is validating that a woman's trauma is not her fault. "No matter how hard it was, you overcame it, because you're standing here."

"Women in a room together get a lot from each other's stories," says Johnson. "It brings up their shared humanity." Women recognize, perhaps for the first time, that they don't have to bear the whole burden of shame and guilt around HIV—that in light of past history, and what may have happened to them, HIV could have happened to anybody.

In her work, Erin Falvey, of Christie's Place, sees the ability to have a voice about what's happening in one's life as a trauma recovery strategy. In this way, the stories uncovered and developed as part of Common Threads can be tools for advocacy. With Common Threads as one inspiration, WHP and PWN-USA are working to develop an intervention, led and facilitated entirely by and for women living with HIV, combining trauma healing and advocacy training for participants to lift their voices and take action to make changes that affect their lives and the lives of their communities.

The goal of Common Threads in an earlier version was for women to then go out into the community to tell their stories publicly—and, when there was funding available, be paid a stipend for their work. Public

> **‘A breakdown is a *Hallelujah*—an opportunity to cry, or feel, what you have not until then. No matter how hard it was, you overcame it, because you’re standing here.’**
>
> —**VANESSA JOHNSON,** FOUNDER OF COMMON THREADS

VANESSA JOHNSON (THIRD FROM RIGHT) AND FRIENDS AT COMMON THREADS’ MARKETPLACE, USCA 2015.

PHOTO COURTESY OF LEPENA REID

storytelling is an aspect of Common Threads alumnae’s experience, but this economic aspect evolved into the Microenterprise Circle (the ME Circle), the second stage of the Common Threads program. In the ME Circle, women develop an economic collective project, learn crafting techniques, and continue to explore the impact of HIV on their personal stories and communities.

A 2014 article in the *Journal of Health Disparities Research and Practice* explores Common Threads as a gender-responsive vocational intervention for African American women living with HIV. As a board member of the National Working Positive Coalition and the co-owner of her own company, Ribbon Consulting Group, economic empowerment is an important theme for Johnson. However, for her, the role of the ME Circle is to maintain groups of Common Threads graduates as a collective and a mutual support system of women that could accomplish shared goals. (**READ THE *JOURNAL* ARTICLE** on Common Threads: digitalscholarship.unlv.edu/cgi/viewcontent.cgi?article=1250&context=jhdrp.)

“The financial piece,” as Johnson puts it, “is gravy”—and has assisted women in increasing their financial independence. The Common Threads Marketplace—the third stage of the program, in which women participate as vendors at community and conference events and sell their jewelry, pillows, poetry, and other products they’ve produced—has been a feature of the past three United States Conferences on AIDS (USCAs), in addition to numerous local and regional events; Common Threads alumnae are planning for an even more impactful presence at USCA 2016.

Common Threads is primarily geared toward women of African descent. “It’s important to have that commonality,” says Johnson. “We only have three days—we don’t have much time to explain what it means to be Black so we can move on.” In mixed groups, this part can take longer—and versions of the training module have been offered to mixed-race groups of women living with HIV. One-and-a-half-hour and one-day snapshots highlighting Common Threads tools or techniques have also been offered, to share a taste of the program in less than three days. The group then usually works to find funding to bring the full training to their area.

Since 2008, Common Threads trainings have been conducted with groups of women in about a dozen areas—including a number of locations in the U.S. South, where both poverty and HIV among African American women are especially prevalent. One barrier to making Common Threads more widely accessible is the expense. The full three-day training can cost $15-20,000 to feed and house eight to 12 women for three days, as well as pay facilitators.

“It’s an investment; if we want that desired return of trauma recovery, healing, agency, and advocacy, we need to make that investment.

“In the end it will save money, but you have to spend some,” says Johnson. “It would be helpful to be able to say that, if you sent this person to a professional counselor for a comparable experience, it would cost this much more money.”

In Johnson’s experience, transformative interventions like Common Threads can prime participants for engagement in therapy. “They can go to a counselor fertile, ready to speak, knowing what issues they need to take care of,” she says. “Peer-led interventions can be supportive of professionals in that way.”

“Our whole system is builton survival of the fittest,” Johnson comments. “We have to turn in a direction away from this, toward a trauma-informed approach—toward the reality that all humanity is valuable.”

OLIVIA FORD has been engaged with HIV-related media since 2007. She currently works as a freelance editor and writer, and is based in New Orleans, Louisiana.

More than half of women living with HIV will experience some form of domestic violence in their lifetime. Yet, there remains a gulf between women and the resources they need. **ASHLEY SLYE**, a case manager attempting to bridge the gap, and **MARIAH DEPASS**, an advocate who survived domestic abuse, share their experiences.

BEYOND OUR COMFORT ZONE

THE IMPORTANCE OF SERVING SURVIVORS OF DOMESTIC VIOLENCE LIVING WITH HIV

BY **ASHLEY SLYE**

One in four women will be a victim of domestic violence in their lifetime; however, that number drastically increases for women living with HIV. More than half of women living with HIV will experience domestic violence in their lifetime. This shocking statistic is a reminder that the fields of domestic violence and HIV can no longer remain disconnected. For a long time now, both fields have worked in a vacuum, with funding streams dictating what to do, who to work with, and how to assist them—leading to the ineffective and limited services to those most in need.

Partnerships have always been a part of our work, but historically the domestic violence and HIV fields have remained isolated from each other. Maybe we were too scared to address the issues. Maybe we didn't want to add to the work we were already doing. Maybe we thought it just didn't matter. Maybe we kept saying tomorrow. We have let survivors down. Survivors living with HIV looking for assistance at local domestic violence programs have been asked to leave or been treated poorly so they've voluntarily left. HIV programs have been unequipped to discuss domestic violence, so potentially life-saving questions go unasked and victims leave without critical resources.

Only together can the domestic violence and HIV fields better assist survivors living with HIV, providing a path to leave violent abusers and offering a link to essential care. Collaborative efforts are necessary to bring justice, safety, and resources to the individuals we work with.

In our efforts to end domestic violence and reduce the spread of HIV/AIDS, we need to consider all of the intersections to make real change. Each individual we work with brings their own unique experiences with them, needing resources that meet their specific needs, often requiring us to advocate outside of our comfort zone. In order for our programs to be effective, we need to sit with those discomforts, learn from each other and those we serve, and know when we aren't the right person to provide the help needed.

PHOTO COURTESY OF ASHLEY SLYE

To those in the HIV field: the voices of survivors are needed at the table, reach out and hear them. And to those in the domestic violence field: the voices of individuals living with HIV are needed at the table, reach out and hear them. Their experiences will guide us to the change we need.

The National Network to End Domestic Violence (NNEDV) developed the Positively Safe Program in 2010 to fill the gaps in services to survivors living with HIV and the risk that survivors face. Together with NNEDV's Domestic Violence & HIV/AIDS Advisory Committee, we developed a training curriculum to reach the fields. To date, we have trained over 300 domestic violence and HIV advocates on the intersection between the two fields. The Positively Safe team has also developed a toolkit with resources on safety planning, risk reduction, discussion guides, and more. The NNEDV team is available to provide support and technical assistance to the domestic violence and HIV fields.

NNEDV is proud to stand with the Positive Women's Network in a call to action to end violence against women living with HIV.

ASHLEY SLYE is a Transitional Housing Specialist for the National Network to End Domestic Violence (NNEDV), providing technical assistance to over 150 transitional housing programs. Go to nnedv.org.

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TAINTED PASSION

BY **MARIAH DEPASS**

I thought he would be the man to save my life. But, instead, he was the one who nearly ended my life.

PHOTO COURTESY OF POSITIVE WOMEN'S NETWORK-USA

He was my best friend. When he said he wanted me to be his wife and mother of his child, even though I'm HIV positive, I believed it must've been true love. We couldn't get enough of each other; the relationship was filled with so much passion. No matter how many times he cheated on me, I still wanted him.

Soon, he started calling me an "AIDS infected bitch" during our arguments. The first time I heard him say those words, it felt like he had ripped my heart out of my chest, squeezed the blood out of it, and then shoved it into my throat. Even though it crushed me, still, I wanted him. Each time he said it, I became more numb to the words, but I didn't see how those words were taking a toll on me. It killed a piece of my spirit every time I heard him say it.

Soon, things escalated to physical abuse. He did awful things, but the day he bit me in my face and threw me down to the ground, I thought I was done. But I wasn't; being without him amplified my feeling of loneliness. I couldn't see any other man falling in love with an "AIDS infected bitch" the way he did, so I continued to go back to him. If it meant sharing him, if it meant fighting with him every day, I didn't mind. At least I had love. That's all I wanted out of everything, after all.

Whenever things got bad, I would always remember the nights we would stay up talking about life and our plans for the future, the walks through the park when nothing else would matter but us and our love, and the times he would make me laugh more than anyone else could. He made me feel like I was the most beautiful person in the world, but he also made me believe that he was the only one who saw that beauty. I felt free when we were happy and I never wanted to lose those moments. Despite that those moments were tainted by chokeholds and the numerous times he threw me into walls, I desperately held on to them. So, I went back every time.

Of course, the happy times couldn't last with the way our relationship was. We were no longer loving each other, we were literally trying to kill each other. All the pain that I had repressed in order to keep him had slowly started to surface. I hated all the things he had done to me and all I wanted to do was love him but he was becoming a monster and I was becoming more and more angry. I could no longer ignore the severity of how unhealthy our relationship actually was. The man whom I trusted with my life was standing over me beating the life out of me.

In that moment, I prayed, "God, if you let me live, I promise I'll leave. Just don't let him kill me." The pain that came after that last beating was the worst because it was the end. I was experiencing the pain throughout the entire relationship all at one time. Everything was being revealed to me.

I realized that the God I was praying to was myself. I had to beg myself to live. To love myself enough to live, even if it meant being alone. I was willing to die for him and him for me, but it came to a point where one of us had to love ourselves enough to allow us to be happy. That person is me.

WATCH Mariah Depass' YouTube channel, youtube.com/user/Mariah863.

REPRINTED WITH PERMISSION from PWN-USA.org. If you are experiencing domestic violence, seeking resources or information, or questioning unhealthy aspects of your relationship, call the National Domestic Violence Hotline at (800) 799-7233.

WOMEN AND HIV BY THE NUMBERS

WOMEN ACCOUNT FOR **ONE IN FIVE** NEW HIV DIAGNOSES AND DEATHS CAUSED BY AIDS IN THE U.S.

APPROXIMATELY ONE IN FOUR WHO ARE LIVING WITH HIV IN THE U.S. ARE WOMEN.

86% OF WOMEN WHO HAVE BEEN DIAGNOSED WITH HIV CONTRACTED THE VIRUS THROUGH HETEROSEXUAL SEX.

63%

OF WOMEN DIAGNOSED WITH HIV/AIDS IN 2013 WERE AFRICAN AMERICAN.

AFRICAN AMERICANS AND HISPANICS REPRESENT 28% OF ALL WOMEN IN THE U.S., BUT THEY **ACCOUNT FOR 80%** OF HIV CASES AMONG WOMEN.

SOURCE: U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION, HIV SURVEILLANCE REPORT 2013

AMBASSADOR KATE

KATE BURTON BUILDS ON THE AIDS LEGACY OF STEPMOTHER ELIZABETH TAYLOR

BY **JEFF BERRY**

Many know Kate Burton as an actress, most recently portraying the right-wing Vice President Sally Langston in the hit TV show *Scandal*, and in *Grey's Anatomy* as Dr. Ellis Grey, the former surgeon and mother of lead character Dr. Meredith Grey, who dies of Alzheimer's.

But what some people may not realize is that Burton, daughter of actor Richard Burton, also serves as an ambassador for the Elizabeth Taylor AIDS Foundation (ETAF), which her stepmother founded. "People know, and people knew, my stepmom as a famous movie actress," said Burton in a 2014 interview, "but at her fundamental core, she was a caring, compassionate person who advocated for the neediest of the needy."

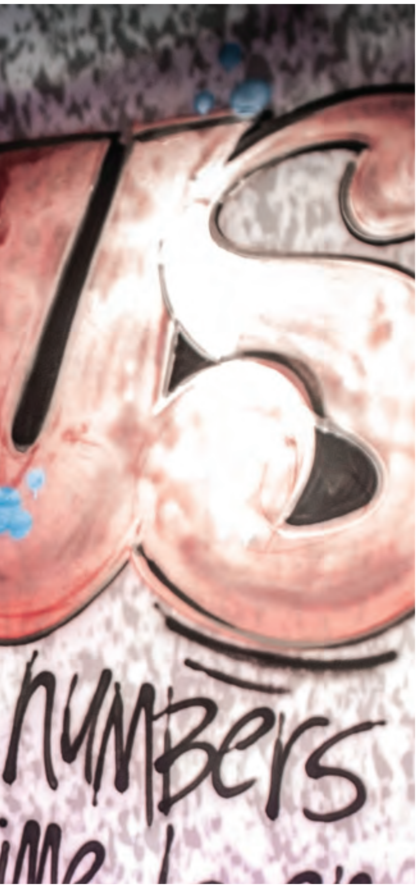
Burton, in an email to POSITIVELY AWARE, says she's been involved in raising awareness about HIV since her dear friends Meghan Robinson and Michael O'Gorman died from AIDS. "From that time on, I knew that it would be a fight I would devote myself to. It was thrilling to me that Elizabeth became such a passionate advocate for AIDS awareness. As we all know, she and Dr. [Mathilde] Krim put this fight on the map."

Elizabeth Taylor founded ETAF in 1991 to support organizations delivering direct care and services to people living with HIV and AIDS, often to the most marginalized populations, according to their website. Today, Taylor's friends and family work together as ETAF ambassadors to help keep the issue of HIV/AIDS "top-of-mind" for the public. Taylor's trust covers the operating costs of ETAF, ensuring that 100% of donations go directly to people affected by HIV/AIDS.

"My work as an ETAF ambassador entails many things," says Burton, "but primarily I serve as a spokesperson or a message deliverer when called upon, although the hard 'on-the-ground' work is delivered by [ETAF Managing Director] Joel Goldman and his wonderful staff."

Following the devastation of Hurricane Katrina, NO/AIDS Task Force, the largest HIV provider in New Orleans, had no offices and its patients nowhere to turn. Taylor wanted to help, and through her foundation was able to provide a mobile treatment unit so that clients were able to continue to access their medications and other lifesaving services, uninterrupted.

Taylor, understanding how successful the model was and that it didn't need to be limited to a natural disaster, began to replicate it in other locales. She knew that chronic lack of access to healthcare was the biggest barrier in the battle against HIV and AIDS, according to a recent ETAF statement, and said, "If people cannot get to healthcare, why can't we bring healthcare to people?" Since 2008, seven GAIA (Global AIDS Interfaith Alliance)/Elizabeth Taylor Mobile Health Clinics have been delivering care to the people of Mulanje and Phalombe districts in Malawi.



Recently, in collaboration with the Elizabeth Taylor Trust and The Elizabeth Taylor AIDS Foundation, Getty Images Gallery in London produced “Grit and Glamour,” to mark 30 years since Taylor first began her leadership in the fight against HIV/AIDS. Taylor’s son Christopher Wilding’s “major new photographic exhibition offered Elizabeth Taylor fans the chance to view previously unseen images of the Hollywood icon in a celebration of the British actress’ 30-year campaign to raise awareness on HIV and AIDS,” according to the *Daily Mail*.

In her day job, Burton has garnered two Emmy nominations for her portrayals of strong characters developed by Shonda Rhimes, the creator of *Grey’s Anatomy* and *Scandal*. “Shonda Rhimes has been incredibly important to me in my life as an actress,” say Burton. “She chose me to play Ellis Grey in Grey’s Anatomy 12 years ago, which changed my professional life but more importantly, put advocacy for Alzheimer’s research front and center on network television and in the national conversation. Seven years later she chose me to play the larger than life, devout and conservative Vice President Sally Langston in *Scandal*. I initially thought that this character was not based on reality...until I saw the current crop of Republican candidates! Sally would fit right in amongst them, alas!”

In February hundreds of HIV advocates from across the country will descend upon Washington D.C. for AIDSWatch 2016, the largest constituent-based HIV advocacy event in the U.S., to educate Congress about the policies and resources needed to end the HIV epidemic, and ETAF is the lead sponsor.

“The work that AIDSWatch does to elevate the voices of people living with and affected by HIV is crucial, and very much aligned with Elizabeth Taylor’s passionate approach,” said Joel Goldman of ETAF. “She used her enormous platform to advocate for those whose voices were being ignored, just as AIDSWatch is doing today. ETAF is thrilled to be the presenting sponsor for the second time and to see the impact of this exciting event continue to grow.”

As for Burton, she says her advocacy for AIDS research and the search for a cure will continue throughout her life. Along with her work at ETAF she also serves on the board of Broadway Cares/Equity Fights AIDS.

In September of last year at the 2015 United States Conference on AIDS (USCA), Burton presented the Elizabeth Taylor Legacy Award to House Leader Nancy Pelosi for her tireless work in the fight against HIV. “Presenting the ETAF award to Leader Pelosi on behalf of my stepmother was one of the greatest honors I have ever had,” says Burton. “I will always cherish the memory.”

FOR MORE INFORMATION on the Elizabeth Taylor AIDS Foundation and AIDSWatch 2016, go to etaf.org and aidsunited.org.

ACROSS GENERATIONS. OPPOSITE PAGE: **KATE BURTON** ADDRESSES USCA 2015 IN WASHINGTON, D.C. ABOVE: **ELIZABETH TAYLOR** SURROUNDED BY PIGEONS IN LONDON’S TRAFALGAR SQUARE, 1948.

KATE BURTON: MICHELLE ANTOINETTE NELSON
ELIZABETH TAYLOR: HULTON ARCHIVE/ COURTESY OF GETTY IMAGES

Anti-alcohol drug could be useful in future cure strategies

A new study has found that a drug commonly used to treat alcoholism may prove to be useful as part of a combination strategy that could one day hypothetically lead to a functional cure of HIV.

The drug (disulfiram, brand name Antabuse) is used in some people with chronic alcoholism, and keeps them from drinking due to the unpleasant side effects that can occur when they consume alcohol.

Disulfiram has previously been shown in the lab to **"wake up" sleeping reservoirs of HIV**, which could then potentially be targeted using a "kick and kill" strategy. In the study, published in *The Lancet* in November, 30 HIV-infected individuals on antiretroviral therapy who were virally suppressed were given varying doses of the drug.

According to a report in *Aidsmap*, "The researchers found that doses of disulfiram up to four times larger than the licensed dose produced modest but sustained increases in HIV RNA inside reservoir cells; the largest dose also produced a doubling of the amount of HIV RNA outside cells, in the bloodstream.

"This did not produce a viral load in any study participant detectable by standard tests, but is an indication that the cells in which HIV hides are being prodded into activity and thereby revealing themselves to the immune system."

Once the reservoirs are flushed, the theory is that they could either be killed off by the immune system itself, or with help from a vaccine or antibodies.

Principal Investigator Professor Sharon Lewin from the University of Melbourne (Australia) told *Aidsmap* that, "The dosage of disulfiram we used provided more of a 'tickle' than a kick to the virus, but this could be enough."

VIEW THE FULL REPORT at aidsmap.com/Widely-used-anti-alcoholism-drug-wakes-up-dormant-HIV-infected-cells/page/3015794/.

CDC awards HIV training grant to gay journalists' group

The National Lesbian & Gay Journalists Association has received a grant renewable for up to five years from the Centers for Disease Control and Prevention (CDC) to deliver **journalism training in covering HIV/AIDS**.

The grant is part of CDC's Partnering and Communicating Together to Act Against AIDS program, administered by its Division of HIV/AIDS Prevention's Prevention Communication Branch (PCB). Other grantees include organizations addressing media or health issues and/or focused on serving the African American, Latino and LGBT communities.

With the grant to NLGJA, $130,000 in the first year through fall 2016, the association of LGBT journalists will provide a series of in-person and web-based trainings, fellowships and specially designed online resources.

"NLGJA will make the most of this opportunity, made possible by the CDC, to provide trainings and resources to enhance journalism skills and strategies in covering HIV and AIDS," said Adam Pawlus, NLGJA's executive director. "We know this is particularly important for coverage of those experiencing health care, income and other disparities and who are highly impacted such as people of color and the trans community."

JOURNALISTS INTERESTED in these free trainings and resources, available to those regardless of NLGJA membership, should contact PACT@nlgja.org. **FOR MORE INFORMATION,** go to nlgja.org.

Life insurance for people living with HIV available

Prudential Financial Services, Inc., in partnership with Aequalis, a financial services company which focuses on providing insurance to people with HIV, announced it will begin making life insurance coverage available to people living with HIV, **the first major company to do so**.

People living with HIV will be eligible to obtain 10- to 15-year individual convertible term life insurance products, "provided they meet the underwriting qualifications."

"As medical technology advances, we continuously evaluate and update our underwriting criteria, which has resulted in our ability to offer insurance to people dealing with various medical or chronic conditions," said Mike McFarland, chief underwriting officer, Prudential Individual Life Insurance, in a company statement.

In response to an inquiry from POSITIVELY AWARE regarding the underwriting criteria, McFarland said in an email that, "As with any individual who applies for life insurance, there are two tiers of medical underwriting review. The first tier addresses the general health of the individual and the second tier is a detailed review of any specific disease processes that the individual may be living with. Like any other disease process, HIV has specific disease characteristics that we would pay attention to."

Specifics of the criteria include

- Applicants must be between ages 30 and 60 years;
- Applicants must be permanent U.S. residents;
- An applicant's lowest ever recorded CD4 count must be greater than 200, and there must be no history of an AIDS-defining condition;
- It must be more than one year since HIV-positive diagnosis and, if being treated, more than six months since antiretroviral therapy (ART) was initiated;
- CD4 count and viral load must be recorded within six months from the time of the application;
- CD4 count was at least 350 when last measured;
- The applicant must be free of hepatitis B, hepatitis C, tuberculosis and non-tuberculosis mycobacterial infection.

Aequalis' founders Andrew Terrell and Bill Grant have both been deeply affected by the challenges experienced by close family and friends who were or are living with HIV.

"Our relationship with Aequalis is another way we are extending our reach into underserved markets," said McFarland. "We're passionate about our efforts to offer this community a way to help achieve their financial goals through the protection life insurance offers."

TO LEARN MORE or access the application go to myaequalis.com. **READ** the entire statement at news.prudential.com/article_display.cfm?article_id=7316.

MORE THAN 4,700
USERS RESPONDED TO
A SURVEY ABOUT PrEP
CONDUCTED BY GRINDR.

1 out of 4
OF THOSE WHO TOOK
THE SURVEY SAID THEY
WERE ON PrEP.
AN ADDITIONAL 55.7%
WERE INTERESTED
IN GOING ON PrEP.

HALF OF THOSE WHO AREN'T
ON PrEP, BUT WANT TO BE, SAID
THEY DIDN'T KNOW ENOUGH
ABOUT IT. 37.3% OF THOSE WHO
WERE NOT INTERESTED IN PrEP
SAID LACK OF INFORMATION
WAS PART OF THE REASON.

1 out of 10
ON PrEP SAID THEY HAD
TROUBLE GETTING THEIR
DOCTOR TO PRESCRIBE IT.
BLACK MEN REPORTED HAVING
TWICE AS MUCH DIFFICULTY.

GRINDR AND PrEP

THE POPULAR GAY MOBILE dating app Grindr and its offshoot Grindr for Equality, which provides education and support for sexual health in addition to work for LGBTQ rights, unveiled the results of a survey about PrEP use among its users in a blog on their website on World AIDS Day 2015.

Working with the San Francisco AIDS Foundation (SFAF) and with help from the Centers for Disease Control and Gilead, they fielded a survey and heard from Grindr users who shared their experiences.

1,213 users (25.5% of those surveyed) reported currently being on PrEP. An additional 2,655 (55.7% of those surveyed) were interested in taking it in the future. Latinos were the least likely demographic group to be currently taking PrEP.

51.4% of those who aren't on PrEP but want to be said they didn't know enough about it. 37.3% of those who weren't interested in taking it at all said lack of information contributed to their disinterest.

Rural respondents faced a variety of increased hurdles to accessing PrEP, notably including lack of access to LGBT-competent doctors and community clinics.

For those who were currently on PrEP, 1 out of 20 respondents rated the anxiety they had about bringing it up with their doctor at a 1 or 2 on a 5-point scale, with 1 being the most nervous. 17% of respondents who weren't currently on PrEP but want to be said anxiety about talking to their doctor was part of why they hadn't started. 3.9% of those who were not interested in taking it said anxiety about talking to their doctor contributed to their disinterest.

One out of 10 respondents who were currently on PrEP reported they had trouble getting their doctor to prescribe it for them. This figure was double for black respondents. Of those who were not currently on PrEP but want to be, 5.7% said their doctor refused to prescribe it.

35.2% of those who weren't taking PrEP but would like to said they were anxious about having to take a pill consistently every day. Conversely, over 90% of respondents currently on PrEP said they had taken all seven doses over the past week.

There was some concern over immediate side effects among respondents, but there is much more anxiety about PrEP being new and the possibility of facing long-term side effects or unknowns in the future.

3.6% of those who are currently on PrEP said they were not "out" to their doctor. 21.2% of those who weren't on PrEP but would like to be said not being out to their doctor was a factor. 7.6% of those who were not on PrEP and don't want to be said that not being "out" to their doctor contributed to their disinterest.

A large majority (91.2%) of respondents were accessing PrEP through their health insurance, with only 1.9% reporting they did not have any insurance. More than half of respondents currently taking PrEP were making use of Gilead's copay or medication assistance programs. Of those who were not currently taking PrEP but would like to, 16.8% said one of the reasons was a lack of health insurance. 13% of those who were not currently taking PrEP but would like to, said they have insurance but it won't cover PrEP. 19.3% of those who are not interested in taking PrEP said issues of insurance contributed to their disinterest.

Among those who are currently on PrEP, only 2.9% rated their concern over stigma as "extreme" whereas 52.3% said "unconcerned." 14.6% of those who are not currently taking PrEP but would like to said stigma played a role. 7.2% of those who were not interested in taking PrEP said lack of insurance coverage contributed to their disinterest.

Most respondents said they found out about PrEP from their friends. Only one in 10 reported hearing about it from their doctor.

The blog went on to state that, "All of this information has helped us to craft a nuanced plan for 2016 as we increase the number of pro-bono PrEP-related in-app messages. For example, seeing that Latinos were so much less likely to be accessing PrEP, we will prioritize the circulation of PrEP information in Spanish. And seeing that many don't know where to get it or are nervous to ask their usual doctor, we intend to undertake a mapping project of LGBTQ clinics in the country so more people will know what their options are."

'SOMETHING MORE IMPORTANT THAN FEAR'

MY JOURNEY BACK TO TREATMENT

BY **RICK GUASCO**

Last October, I came out. Everyone who knows me was surprised. Although I've been openly gay most of my adult life, and I've been HIV-positive since 1992, I have only been on treatment for a very short time. Three years ago, I fell out of care completely and was no longer on meds.

You'd think I would know better. I'm a fairly intelligent person, even if admittedly opinionated and stubborn. Plus, I work for an HIV treatment magazine, so I'm aware of the importance of—well, HIV treatment.

Except that I had become tired and afraid. I think that as long as I have lived with HIV, I've always lived with some measure of fear. It didn't matter how healthy I was, or how sick I felt, fear has always lurked in the background.

In the summer of 1992, I developed blotches on my skin. I had never been tested, and I was afraid what an HIV test would reveal. The purplish spots continued to blossom, about five new ones a week. When the fear became too much, I got tested that December: I was HIV-positive—and the spots were likely Kaposi sarcoma (KS), an opportunistic infection that the Centers for Disease Control and Prevention had labeled as an "end-stage AIDS-defining illness."

"Good luck," my post-test counselor said as he handed me three publications.

The fear of KS was overwhelming. So many had died of KS in the dark days of the early 1980s, and it seemed I was next. More than 100 lesions covered my body, 50 on my head alone. I looked like I had two black eyes and a swollen lip.

I was numb as I started to review my new reading materials. One of the three handouts was an issue of POSITIVELY AWARE, the other two were also published by Test Positive Aware Network (TPAN). The more I read, the more my fear gradually subsided to a level where I could start to think. That was when I realized information was the key to getting a grip on my situation.

Kaposi sarcoma is a disease in which malignant tumors can form in the skin, mucous membranes, lymph nodes, and other organs. Chemotherapy was the standard treatment for KS, but it often killed the weakest patients. I had a boyfriend who stuck by me during this time. He told me how his uncle had died, not from KS but from the chemo he had received. My boyfriend said he was damned if he was going to see another person he loved die the same way.

Let's just says his insistence inspired me to find another course of treatment.

I learned about a clinical trial that used interferon, a known cancer-fighting drug, alongside a recently approved HIV medication, to treat KS. This early form of the HIV drug was a horse pill that tasted like chalk. Worse, it made everything else taste like chalk. Even pizza. I lost my appetite, and within a month I lost nearly 15 pounds. My doctor was so worried about my weight loss, she allowed me to drop the HIV med.

Interferon was a different story. I'm so afraid of needles, it took more than two weeks before I could bring myself to begin the daily course of a self-administered injection into my upper thigh. Whenever I jabbed myself, I always closed my eyes and looked the other way.

Imagine having the body aches of the flu—every day. That was the major side effect of interferon. At its worst, I would rock back and forth at my desk, like someone experiencing withdrawal. If I skipped a dose, the following night would bring wild lucid dreams, repeating themselves like a broken record throughout the night. But the interferon worked. Within two years, nearly all the lesions disappeared.

In 1997, protease inhibitors, the first class of effective HIV drugs, appeared. But soon afterward, HIV patients began to report side effects from the long-term use of HIV medications and from having lived so long with the virus. Some people experienced a redistribution of body fat, giving them gaunt-looking faces, or swollen bellies, or the appearance of a slight hunchback.

So, quite frankly, I was grateful for my interferon side effects. My KS treatment was apparently keeping me healthy enough that I could justify skipping HIV treatment. Having experienced a disfiguring disease, I was afraid of medications that could affect my physical appearance.

My insurance eventually no longer covered interferon, and so I stopped taking it. For a few years, I coasted. I still refrained from HIV treatment because I "felt healthy enough." Then in 2011, a familiar purplish spot appeared, just below my left ankle.

My KS was back. Once again, fear took hold. As months went by, I watched as the spot slowly grew. It was only the fear that another spot might soon appear that made me see a doctor. A biopsy confirmed the diagnosis.

Interferon is no longer used for HIV-related KS. These days, the only treatment is to go on HIV medication. Reluctantly, I did, going on one of the first single-tablet regimens. The spot began to shrink, then disappear, and my viral load and T-cell count improved.

The side effects came with almost the first pill. Repetitive dreams nearly as bad as those from interferon. And during the day, a depression was beginning to settle in. I was afraid that this was my new normal.

I struggled for 11 months until I found a justifiable out. Up to that point, my meds had been covered by ADAP. By this time, I had returned as POSITIVELY AWARE's creative director, and TPAN's insurance was about to cover my pre-existing condition. However, the paperwork transitioning me from ADAP to private insurance had gotten lost, and I now had no way of paying for my next refill. The thought of jumping through bureaucratic hoops to ensure experiencing side effects only seemed to add insult to injury. I felt justified in telling the pharmacy to keep their drugs, and I walked away from treatment.

I was afraid, however, of being called irresponsible—or a hypocrite. I didn't want anyone to know what I had done—or rather, what I was no longer doing. *Do as I say, not as I don't.* So, when asked, I didn't lie, I just let people think I was still on treatment. I told myself that my healthcare (or lack of it) was a personal decision.

After all, I still "felt healthy enough." But fears lingered in the back of my mind, often pressing to move forward. I had once been afraid I wouldn't live to see 30; having passed 50, I was starting to fear what might lie ahead.

My fears led me back to when I first faced KS. I'd made it this far, I was damned if I was going to die like it was 1985.

That's when I decided to get back onto treatment.

PHOTO: ENID VÁZQUEZ

I don't like doing things that I'm supposed to do. I wasn't happy having to go see my new HIV specialist. But she is smart, witty, and calls me out on the stuff I try to get away with—exactly the kind of doctor I need.

There are some issues that need to be identified—Dr. Patel is "concerned, but not worried." Four weeks after starting treatment, my numbers had already significantly improved.

I've always believed that those of us who live with HIV should live by example as well as we can—to educate, enlighten and give courage to others. No one wants to admit to being afraid. Fear can make you feel helpless and isolated. But the truth is, *you are not alone*. If you learn how to use it, fear can be a good thing. It can remind you that there is something more important than fear.

RICK GUASCO has been Creative Director of POSITIVELY AWARE since 2010. He occasionally posts on Facebook about his return to HIV treatment.

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8


7

25 YEARS—AND

PA THROWS ITSELF AN ANNIVERSARY PARTY

BY **ENID VÁZQUEZ** PHOTOS BY **JOHN GRESS** AND **JULIE SUPPLE**

For more than 25 years, POSITIVELY AWARE has brought information and support to hundreds of thousands of people living with HIV. In October, more than 200 friends joined PA at the Chicago's Museum of Broadcast Communications to celebrate our anniversary—and all that we have accomplished, not the least of which is survival.

Covers of milestone issues were blown up and on display during the event, alongside images from A Day with HIV, POSITIVELY AWARE's anti-stigma photo campaign. A mock photo shoot allowed guests to pose for their own PA cover.

Editor-in-Chief Jeff Berry talked about the campiness of the early issues, and how that made everything less scary as he dealt with the deaths of his friends and his own newly discovered diagnosis.

"I loved that we covered every


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COUNTING

1: PA EDITOR JEFF BERRY. **2:** SWARUP MEHTA OF MERCK (LEFT) AND TANIA DAILEY OF EMD SERONO (RIGHT) WITH A FRIEND. **3:** BRIAN COX WITH FIANCÉ, FORMER PA ASSOCIATE EDITOR KEITH R. GREEN. **4:** KEYNOTE SPEAKER DR. TONY MILLS. **5:** PA ADVERTISING MANAGER LORRAINE HAYES, TPAN CEO PATTI CAPOUCH, AND FRIENDS. **6:** TPAN STAFF CHRISTINA JOLY, KIMBERLY ROGERS, ASSOCIATE EDITOR ENID VÁZQUEZ, AND PAUL HAIDER. **7:** TPAN BOARD MEMBER APRIL WHITWORTH AND FRIEND. **8:** TPAN STAFF MEMBER GARY NELSON AND PA DISTRIBUTION MANAGER DENISE CROUCH.

little bit of people's lives—stress, spirituality, sexuality, and all in an approachable way," said Jeff.

The event's program book featured a safer sex ad from POSITIVELY AWARE with a retro image of a suggestively smiling woman in a bath full of bubbles declaring, "She really loves her water-based lube!"

Former International Mr. Leather Tony Mills, MD, flew in from Los Angeles to talk about the place POSITIVELY AWARE holds in the history of the epidemic. Mills recalled seeing the magazine when he was newly diagnosed in Atlanta in the early '90s and thought, "This is for *us*." Today, he is the medical director of the Tony Mills medical practice and Assistant Professor of Clinical Medicine at UCLA.

While POSITIVELY AWARE still maintains a heavy focus on medical treatment, it is the personal stories that speak best to the spirit of the struggle.

Former editor Bob Hultz, now in Los Angeles, wrote us: "Thinking back to the 1980's, it was hard for TPA's earliest members to imagine we'd still be alive in 2015, let alone celebrating 25 years of POSITIVELY AWARE. Although many of those earliest members have passed on, the publication has survived and grown. In its earliest days, we'd go from one printing store to another, asking them to donate free copies of our newsletter. It was an enormous breakthrough the day a huge, clunky Xerox machine was moved into [founder] Chris Clason's apartment. Years later, another giant milestone was reached when we began printing POSITIVELY AWARE on a web-press, providing HIV treatment and prevention information and support to tens of thousands of readers nationwide.

"Throughout the epidemic, our magazine has been lovingly and carefully nurtured by scores of volunteers and dedicated staff. I'm deeply grateful to be alive and thriving, thanks in great measure to TPA Network and POSITIVELY AWARE. I celebrate with you in continuing our earliest motto, 'Committed to Living.'"

SEE MORE photos and stories at positivelyaware.com.

Brief Summary of Patient Information about GENVOYA

GENVOYA (jen-VOY-uh)
(elvitegravir, cobicistat, emtricitabine, and tenofovir alafenamide) tablets

Important: Ask your healthcare provider or pharmacist about medicines that should not be taken with GENVOYA.

There may be new information about GENVOYA. This information is only a summary and does not take the place of talking with your healthcare provider about your medical condition or treatment.

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

GENVOYA can cause serious side effects, including:

- **Build-up of lactic acid in your blood (lactic acidosis).** Lactic acidosis may happen in some people who take GENVOYA. Lactic acidosis is a serious medical emergency that can lead to death. Lactic acidosis can be hard to identify early, because the symptoms could seem like symptoms of other health problems. **Call your healthcare provider right away if you get any of the following symptoms, which could be signs of lactic acidosis:**
  - feel very weak or tired
  - have unusual (not normal) muscle pain
  - have trouble breathing
  - have stomach pain with nausea or vomiting
  - feel cold, especially in your arms and legs
  - feel dizzy or lightheaded
  - have a fast or irregular heartbeat
- **Severe liver problems.** Severe liver problems may happen in people who take GENVOYA. In some cases, these liver problems can lead to death. Your liver may become large and you may develop fat in your liver.

  Call your healthcare provider right away if you get any of the following symptoms of liver problems:
  - your skin or the white part of your eyes turns yellow (jaundice)
  - dark "tea-colored" urine
  - light-colored bowel movements (stools)
  - loss of appetite for several days or longer
  - nausea
  - stomach pain
- **You may be more likely to get lactic acidosis or severe liver problems if you are female, very overweight (obese), or have been taking GENVOYA for a long time.**
- **Worsening of Hepatitis B infection.** GENVOYA is not for use to treat chronic hepatitis B virus (HBV). If you have HBV infection and take GENVOYA, your HBV may get worse (flare-up) if you stop taking GENVOYA. A "flare-up" is when your HBV infection suddenly returns in a worse way than before.
  - Do not run out of GENVOYA. Refill your prescription or talk to your healthcare provider before your GENVOYA is all gone.
  - Do not stop taking GENVOYA without first talking to your healthcare provider.
  - If you stop taking GENVOYA, your healthcare provider will need to check your health often and do blood tests regularly for several months to check your HBV infection. Tell your healthcare provider about any new or unusual symptoms you may have after you stop taking GENVOYA.

What is GENVOYA?

GENVOYA is a prescription medicine that is used without other HIV-1 medicines to treat HIV-1 in people 12 years of age and older:

- who have not received HIV-1 medicines in the past **or**
- to replace their current HIV-1 medicines in people who have been on the same HIV-1 medicines for at least 6 months, have an amount of HIV-1 in their blood ("viral load") that is less than 50 copies/mL, and have never failed past HIV-1 treatment

HIV-1 is the virus that causes AIDS.

GENVOYA contains the prescription medicines elvitegravir (VITEKTA®), cobicistat (TYBOST®), emtricitabine (EMTRIVA®) and tenofovir alafenamide.

It is not known if GENVOYA is safe and effective in children under 12 years of age.

When used to treat HIV-1 infection, GENVOYA may:

- Reduce the amount of HIV-1 in your blood. This is called "viral load".
- Increase the number of CD4+ (T) cells in your blood that help fight off other infections.

Reducing the amount of HIV-1 and increasing the CD4+ (T) cells in your blood may help improve your immune system. This may reduce your risk of death or getting infections that can happen when your immune system is weak (opportunistic infections).

GENVOYA does not cure HIV-1 infection or AIDS. You must stay on continuous HIV-1 therapy to control HIV-1 infection and decrease HIV-related illnesses.

Avoid doing things that can spread HIV-1 infection to others:

- Do not share or re-use needles or other injection equipment.
- Do not share personal items that can have blood or body fluids on them, like toothbrushes and razor blades.
- Do not have any kind of sex without protection. Always practice safer sex by using a latex or polyurethane condom to lower the chance of sexual contact with semen, vaginal secretions, or blood.

Ask your healthcare provider if you have any questions about how to prevent passing HIV-1 to other people.

Who should not take GENVOYA?

Do not take GENVOYA if you also take a medicine that contains:

- alfuzosin hydrochloride (Uroxatral®)
- carbamazepine (Carbatrol®, Epitol®, Equetro®, Tegretol®, Tegretol-XR®, Teril®)
- cisapride (Propulsid®, Propulsid Quicksolv®)
- ergot-containing medicines, including: dihydroergotamine mesylate (D.H.E. 45®, Migranal®), ergotamine tartrate (Cafergot®, Migergot®, Ergostat®, Medihaler Ergotamine®, Wigraine®, Wigrettes®), and methylergonovine maleate (Ergotrate®, Methergine®)
- lovastatin (Advicor®, Altoprev®, Mevacor®)
- midazolam, when taken by mouth
- phenobarbital (Luminal®)
- phenytoin (Dilantin®, Phenytek®)
- pimozide (Orap®)
- rifampin (Rifadin®, Rifamate®, Rifater®, Rimactane®)
- sildenafil (Revatio®), when used for treating lung problems
- simvastatin (Simcor®, Vytorin®, Zocor®)
- triazolam (Halcion®)
- the herb St. John's wort or a product that contains St. John's wort

What should I tell my healthcare provider before taking GENVOYA?

Before taking GENVOYA, tell your healthcare provider if you:

- have liver problems including hepatitis B infection
- have kidney or bone problems
- have any other medical conditions
- 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.

  Pregnancy registry: there is a pregnancy registry for women who take HIV-1 medicines during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Talk with your healthcare provider about how you can take part in this registry.
- are breastfeeding or plan to breastfeed. Do not breastfeed if you take GENVOYA.
  - You should not breastfeed if you have HIV-1 because of the risk of passing HIV-1 to your baby.
  - At least one of the medicines in GENVOYA can pass to your baby in your breast milk. It is not known if the other medicines in GENVOYA can pass into your breast milk.
  - Talk with your healthcare provider about the best way to feed your baby.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Other medicines may affect how GENVOYA works.

Some medicines may interact with GENVOYA. **Keep a list of your medicines and show it to your healthcare provider and pharmacist when you get a new medicine.**

- You can ask your healthcare provider or pharmacist for a list of medicines that interact with GENVOYA.
- Do not start a new medicine without telling your healthcare provider. Your healthcare provider can tell you if it is safe to take GENVOYA with other medicines.

How should I take GENVOYA?

- Take GENVOYA exactly as your healthcare provider tells you to take it. GENVOYA is taken by itself (not with other HIV-1 medicines) to treat HIV-1 infection.
- GENVOYA is usually taken 1 time each day.
- Take GENVOYA with food.
- If you need to take a medicine for indigestion (antacid) that contains aluminum and magnesium hydroxide or calcium carbonate during treatment with GENVOYA, take it at least 2 hours before or after you take GENVOYA.
- Do not change your dose or stop taking GENVOYA without first talking with your healthcare provider. Stay under a healthcare provider's care when taking GENVOYA.
- Do not miss a dose of GENVOYA.
- If you take too much GENVOYA, call your healthcare provider or go to the nearest hospital emergency room right away.
- When your GENVOYA 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 GENVOYA and become harder to treat.

What are the possible side effects of GENVOYA?

GENVOYA may cause serious side effects, including:

- **See "What is the most important information I should know about GENVOYA?"**
- **Changes in body fat can happen in people who take HIV-1 medicine.** These changes may include increased amount of fat in the upper back and neck ("buffalo hump"), breast, and around the middle of your body (trunk). Loss of fat from the legs, arms and face may also happen. The exact cause and long-term health effects of these conditions are not known.
- **Changes in your immune system** (Immune Reconstitution Syndrome) can happen when you start taking HIV-1 medicines. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your healthcare provider right away if you start having any new symptoms after starting your HIV-1 medicine.
- **New or worse kidney problems, including kidney failure.** Your healthcare provider should do blood and urine tests to check your kidneys before you start and while you are taking GENVOYA. Your healthcare provider may tell you to stop taking GENVOYA if you develop new or worse kidney problems.
- **Bone problems** can happen in some people who take GENVOYA. Bone problems may include bone pain, softening or thinning (which may lead to fractures). Your healthcare provider may need to do tests to check your bones.

The most common side effect of GENVOYA is nausea.

Tell your healthcare provider if you have any side effect that bothers you or that does not go away.

- These are not all the possible side effects of GENVOYA. For more information, ask your healthcare provider or pharmacist.
- Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

General information about the safe and effective use of GENVOYA.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use GENVOYA for a condition for which it was not prescribed. Do not give GENVOYA to other people, even if they have the same symptoms you have. It may harm them.

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

For more information, call **1-800-445-3235**
or go to **www.GENVOYA.com.**

Keep GENVOYA and all medicines out of reach of children.

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Genvoya™
elvitegravir 150mg/cobicistat 150mg/emtricitabine 200mg/tenofovir alafenamide 10mg tablets

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