POSITIVELY AWARE
THE HIV TREATMENT JOURNAL OF **TEST POSITIVE AWARE NETWORK**
SEPTIEMBRE + OCTUBRE 2016

A DAY WITH HIV
SHINING A LIGHT
ON STIGMA

INTERNATIONAL AIDS CONFERENCE UPDATE

ONE ON ONE
WITH THE HEAD
OF THE LATINO
COMMISSION
ON AIDS

PrEP FOR
LATINX
COMMUNITIES

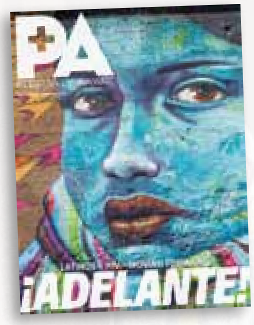
GUBA:
FROM CAMPS
TO ACCOMPLISHMENT

¿CÓMO SE DICE 'VIH'
IN ENGLISH?

LATINOS + HIV: MOVING FORWARD

¡ADELANTE!

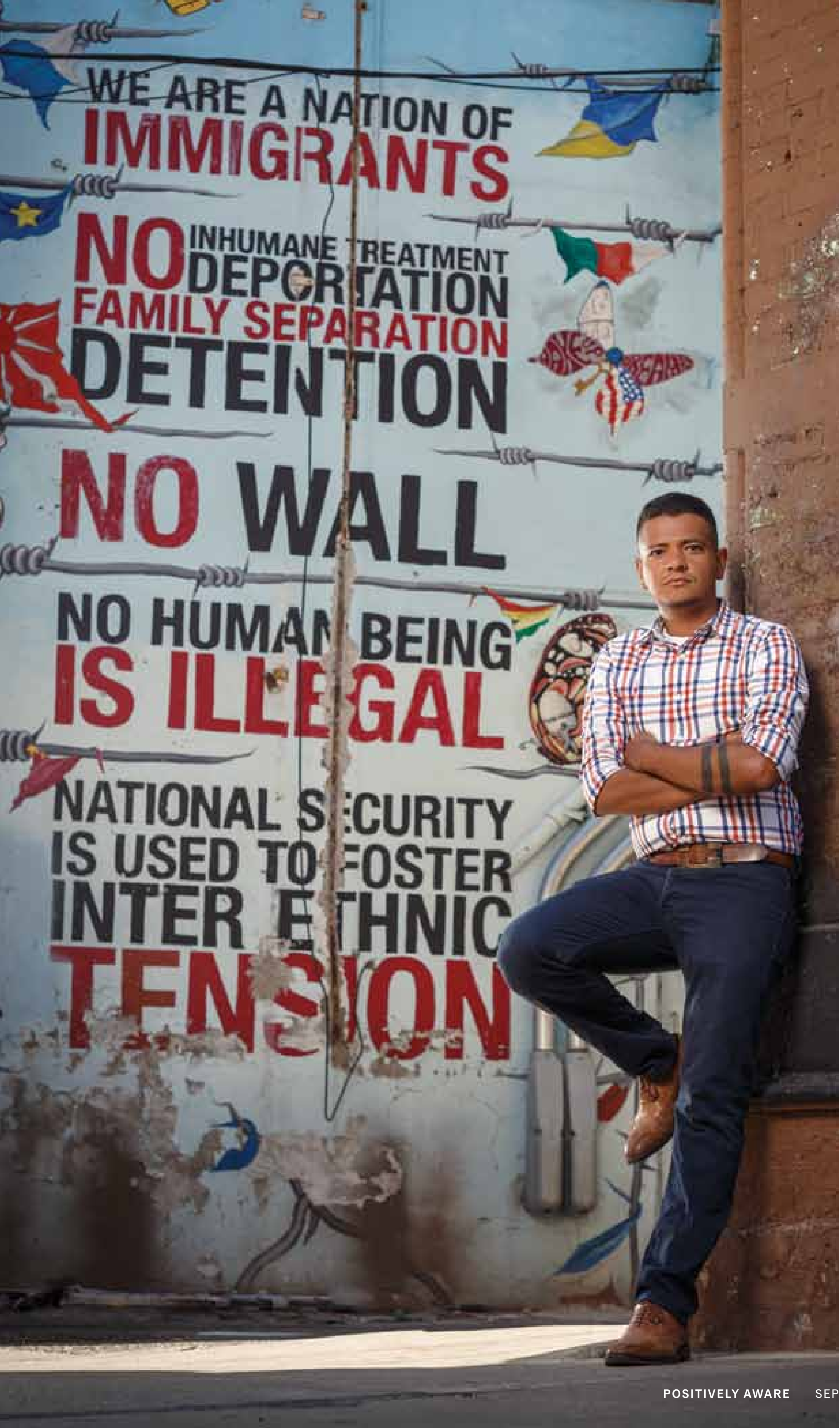
FRONT COVER BACKSTORY



COLORFUL ETHNIC MURALS are scattered throughout Pilsen, a predominently Latino neighborhood in Chicago. Portions of three murals are featured in this issue of POSITIVELY AWARE—on the cover, the contents spread on pages 4 and 5, and on page 28—photographed by **JOHN GRESS**.

Another example of a wall making a statement is the *Declaration of Immigration*. *No human being is illegal*, asserts the mural. Underscoring that message is **GILBERTO ("BETO") SOBERANIS**, 31 (left), diagnosed HIV-positive in 2003, and recently out as undocumented. Soberanis and his family came from the Mexican city of Guerrero, crossing the border on foot in 2006. Although his family has since returned to Mexico, Soberanis remains in the U.S., having been granted Deferred Action for Early Childhood Arrival a few years ago. He is active in Chicago's HIV community, working to overcome stigma and helping to raise funds for HIV organizations.

—RICK GUASCO



DECLARATION OF IMMIGRATION: LEAD ARTIST SALVADOR JIMENEZ, WITH THE ASSISTANCE OF STUDENT ARTISTS. THE MURAL WAS MADE POSSIBLE BY YOLLOCALLI ARTS REACH AND RADIO ARTE, YOUTH INITIATIVES OF THE NATIONAL MUSEUM OF MEXICAN ART.

POSITIVELY AWARE

PERIODISMO. INTEGRIDAD. ESPERANZA.

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"True change in our community
starts with us, one person at a time."

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"Cultural norms are health norms."

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IN EVERY ISSUE

CONFERENCE UPDATE

AIDS 2016 DURBAN

FEATURES

¡ADELANTE!

LATINOS + VIH

◄ **ARMANDO RAMIREZ-GUZMAN PHOTOGRAPHED BY JOHN GRESS**. RAMIREZ, 36, WAS BORN IN GUANAJUATO, MEXICO, AND EMIGRATED TO THE U.S. WHEN HE WAS SIX YEARS OLD. HE WAS DIAGNOSED WITH HIV IN 2003.

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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.

SAFER INJECTION

Great July+August issue of POSITIVELY AWARE! I was hoping to add a detail or two to "Hepatitis C Prevention For People Who Inject Drugs" by Andrew Reynolds. On page 44, in the paragraph under "Set-up your own personal rules...and disposing of syringes," the reader might also consider using empty liquid laundry detergent bottles for syringe/needle disposal when the red sharps boxes are not accessible. Here at the Needle Exchange Program of Asheville (NEPA, est. 1994), we go to local laundromats and collect the hard-plastic bottles in order to make them available to our participants. They are inconspicuous too, sitting on the shelf at home. NEPA has made available to our participants 280,000 needles between January and July 2016! Lastly, one other resource of information is nasen.org, which is the North American Syringe Exchange Network, where there is also a directory of exchanges by state, and some great research data that may be of further interest to some. Thanks for the great work you do. Peace.

MICHAEL HARNEY
COORDINATOR, NEPA
ASHEVILLE, NORTH CAROLINA

EDITOR'S NOTE: *Thank you—these are great tips. Our prevention staff here at TPAN tells us that thick deteregent bottles meet OSHA standards for safe syringe disposal.*

HIV DRUG GUIDE

My gratitude goes to POSITIVELY AWARE for publishing the HIV Drug Guide (March+April). I can hardly believe that PA has been publishing this guide for 20 years now. I remember the very first one in 1997. Each year, the number of pages expanded with more and better HIV drugs. Equally, the design of the guide has evolved as well. It's the only issue of PA that I keep on hand, in a file, so it's ready to go. Every so often, a friend, or someone, asks me about a certain drug. I say, "Hold on, let me get this guide." Sometimes, I make a copy of a single page and mail it. Other times, I read out loud certain passages to someone on the phone. The design is special because each page is portable and stands on its own. It gives all the information I need without being overwhelming. I especially like the "Activist's Comments" because I know I'm getting a richer, fuller description of the drug. When I compare the first guide in 1996 to the guide in 2016, I'm reminded of how far we've come. The drug guide is a symbol of the progress we've made against HIV. Given the breakthroughs over the past 20 years, I'm honestly hopeful about the future. I'm convinced that the guide—someday soon—will include "the cure." For providing us all with easy-to-understand, objective, and lifesaving information over the years, I thank all the remarkable people at TPA Network and POSITIVELY AWARE.

NAME WITHHELD

INSIGHTS FROM A FORMER VOLUNTEER

As a long-term survivor with many friends lost to AIDS, I feel we veteran patients have a wealth of education we must pass along. I have been on Medicaid and have had unaware case managers and doctors, due to the fact that the doctors I get are residents and have a turnover every four years. Case managers leave because they become knowledgeable and go on to better paying jobs. I hope this doesn't offend interns and case managers—this has just been my experience. Because of all this, a patient at end stage of AIDS or kidney or liver issues can fall by the wayside because they often cannot speak for themselves. Case managers like the one I currently have don't know that a resident often doesn't have a clue what and where to put what on a form so they can get services such as crowns for teeth, that Medicaid in California doesn't cover and is often some outrageous amount such as $500, when patients are living on SSI [Supplemental Security Income from the Social Security Administration, or disability] and other entitlements. I have had to educate doctors on what to put on Ryan White forms.

In 1990 I tested positive. TPA [as TPAN was then known] was a new agency. I met hundreds of men and some women. Everywhere I went reminded me of whom I lost.

In a couple of years I will be 60. I lost all of those friends and co-volunteers back then and now it is even more difficult to make friends. I am starting to have kidney problems because of the many years of being on medications to save my life. I am glad for the life I had, but still mourn for those I have lost. If I live to be 100 it will still hurt.

I hope what I write will help others.

BOB BROWN
FORMER TPAN VOLUNTEER

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FOTO: CHRIS KNIGHT

EDITOR’S NOTE

JEFF BERRY

A SENSE OF COMMUNITY

***Community* is a word** we often hear bandied about at various meetings, conferences, and gatherings, but it’s sometimes a loaded word that often means different things to different people, and its definition depends on the setting or context in which it’s used. Community can be based on geography, such as the actual community of Hollywood, Florida, or it can be used to describe those who share a common history, or social, economic, and political interests. Then there is the psychological sense of community, defined as “a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to be together.”

All of our various communities are in flux right now with an overall general increase in awareness of social injustices that exist in our society, and the realization that positive change needs to occur. Some communities have recently come under attack, both literally and figuratively, in the midst of a very divisive political climate.

A direct attack on our brothers and sisters at Pulse nightclub in Orlando was devastating, and touched all of us deeply, and is beyond the realm of understanding. But even in the darkest moments, hope rises up, as seen with the lines of people that grew to be blocks long, waiting to donate blood; the makeshift memorials of flowers and candles that instantly began popping up; the tales of grace and heartbreak that emerged from those who survived. And the faces and stories behind the 49 members of our community who we lost but are not, and will never be, forgotten.

When recently summoned for jury duty at the Circuit Court of Cook County in Chicago, I spent a day with 41 other individuals while being questioned by the judge and lawyers for the plaintiff and defendants in a civil suit. I really didn’t want to be selected because I would have had to cancel a vacation I had been planning for months, but as the day wore on I was fascinated by the process of jury selection, and quite impressed by the knowledge and wisdom of the judge overseeing the case. He kept stressing to all of us in the room how we are the only country in the world in which civil cases are left to 12 members of a community to decide, after weighing all of the facts. He used the word “community” several times throughout the day, and after being in the same room all day with the other prospective jurors, all of us sharing personal details about our lives, education, and work history, I felt a strong sense of community. Yes, we were all very diverse and had different backgrounds, but we were coming together to work towards a common cause, one that I believe benefits us all.

In July I was extremely fortunate to be able to attend the International AIDS Conference in Durban. Shortly after my arrival I was invited by Barb Cardell of Positive Women’s Network-USA (PWN-USA) to participate in a demonstration against HIV criminalization during Tuesday’s opening plenary. We arrived at the convention center early that morning in order to get seats towards the front of the room, a strategic move, I was told, when one is planning a demonstration. I had my chant memorized and my Stop HIV Criminalization T-shirt ready to go, so I felt prepared. Edwin Cameron, the final speaker, stepped up to the podium to give the Jonathan Mann lecture. (Mann was the prominent HIV researcher and activist who pioneered the idea of a link between human health and human rights, and died at age 51, with his wife, in a plane crash in 1998.). Cameron, a judge on the Constitutional Court of South Africa, who is well known for his activism on AIDS and gay rights, is a tall, lanky man with a soft-spoken demeanor, and an eloquent speaker who is living with HIV. As he began talking, the auditorium fell into a hush.

“At the start of a very busy conference, with many stresses and demands and anguishes, I want to start by asking us to pause quietly for just a few moments.

“It has been 35 years since the Western world was alerted to AIDS. The first cases of a baffling new, terrifying, unknown syndrome were first reported in the northern summer of 1981…

“These last 35 years, since then, have been long. For many of us, it has been an arduous and exhausting and often dismaying journey.”

My eyes started tearing up.

“Since this first report, 35 million people have died of AIDS illnesses—in 2015 alone, 1.1 million people.

“We have felt the burden of this terrible disease in our bodies, on our minds, on our friends and colleagues, on our loved ones and our communities.

“AIDS exposes us in all our terrible human vulnerability. It brings to the fore our fears and prejudices. It takes its toll on our bodily organs and our muscles and our flesh. It has exacted its terrible toll on our young people and parents and brothers and sisters and neighbors.”

Then I began to cry.

“So let us pause, first, in remembrance of those who have died: those for whom treatment didn’t come in

All of our various communities are in flux right now with an overall general increase in awareness of social injustices that exist in our society, and the realization that positive change needs to occur.

@PAeditor

EDITOR'S NOTE
JEFF BERRY

ACTIVISTS TAKE THE STAGE TO PROTEST HIV CRIMINALIZATION LAWS DURING THE OPENING PLENARY SESSION OF AIDS 2016.

FOTO CORTESÍA DE JEREMIAH JOHNSON

time; those for whom treatment wasn't available, or accessible; those denied treatment by our own failings as planners and thinkers and doers and leaders; those whom the internal nightmare of shame and stigma put beyond reach of intervention and help.

"These years have demanded of us a long and anguished and grief-stricken journey.

"But it has also been a journey of light—a journey of technological, scientific, organizational, and activist triumph."

By then I was sobbing, uncontrollably, almost to the point of wailing out loud—it took all I could at that moment to suppress my emotions that came bubbling up to the surface from almost 30 years of living with HIV, and nearly a quarter of a century working in the field. It was as though someone finally gave me the permission to feel all that sadness, shame, neglect, and anguish. It was okay, and I was going to be okay.

Cameron went on to highlight the stunning achievements made by doctors, researchers, but most of all the advocates, without whom we wouldn't be here today. I felt a true sense of community in that moment, and the sense that great things can be achieved when we all come together to achieve a common cause.

So the next time you hear the word "community," think about how wonderful and amazing communities are, and the potential they have and what they can truly accomplish. Changing the world can seem daunting, next to impossible. But true change in our community starts with us, one person at a time. We only have to take the time, and make the time, to reach out, grab our neighbor by the hand, and lift each other up.

Take care of yourself, and each other.

WHEN PLANNING THIS ISSUE, which focuses on Latinos and HIV, we initially discussed the various descriptors we might want to use: Latino or Latino/a (those with cultural ties to Latin America), and the increasingly popular "Latinx" (pronounced la-TEEN-ex) which is more inclusive and seeks to move beyond gender binaries. We ended up using both to help introduce the terms to our audience of readers who may not be as familiar with them, and to engage newer readers who may be picking up POSITIVELY AWARE for the first time.

We've also incorporated parts of this issue into Spanish, including the folio at the bottom of each page, and our interview with Guillermo Chacón (special thanks to Luis Scaccabarrozzi and the Latino Commission on AIDS for translating).

Years ago POSITIVELY AWARE had a quarterly version available in Spanish, *Positively Aware en Español*, but unfortunately due to a lack of funding we had to cease publication in 2007. It was unfortunate because to this day we still get requests for materials in Spanish, especially the HIV Drug Guide, but we have to point people elsewhere. Perhaps this issue will be the catalyst to something new in the future for all of our communities living with HIV.

In addition to Latino Commission on AIDS, special thanks to the all of our friends at NMAC for their help with this issue of POSITIVELY AWARE.

Briefly

ENID VÁZQUEZ

@ENIDVAZQUEZPA

NEW DRUG FOR HEP C, EPCLUSA

In June, the FDA approved a new combination pill for the treatment of hepatitis C virus (HCV), Epclusa, giving it a Breakthrough Therapy designation for a medicine that may offer a major advance over existing options. Epclusa treats all HCV genotypes, 1–6. It consists of sofosbuvir (brand name Sovaldi) and velpatasvir (not available separately). Epclusa is the first single-tablet regimen approved for genotypes 2 and 3 without the need for ribavirin.
For more information, go to **positivelyaware.com/epclusa**.

Treatment guidelines updated

In July, the Department of Health and Human Services updated its HIV treatment guidelines. Descovy has been added to the list of recommended and alternative drugs to use. Kaletra (lopinavir/ritonavir) was removed from the list of "Other" medications to take "because regimens containing this protease inhibitor (PI) combination have a larger pill burden and greater toxicity than other currently available options." The sections on women, pregnancy, hepatitis B, hepatitis C, and tuberculosis were also updated. For a quick review of these and other updates in "What's New in the Guidelines?" go to aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-arv-guidelines/0.

NIH awards grants for cure research

The National Institutes of Health (NIH) announced in July that it has awarded approximately $30 million annually for the next five years to six research teams working towards an HIV cure. The awards, part of the Martin Delaney Collaboratory, promote basic medical science toward a cure.

Bictegravir (GS-9883) goes into Phase 3 study

Preclinical and Phase 1 data on an HIV medication in development, bictegravir (GS-9883), provided proof-of-concept for further research. The drug is now in Phase 3 study as a single-tablet regimen (STR). Gilead Sciences announced the data in a poster at the American Society of Microbiology (ASM) Microbe 2016 Conference in Boston, held in May. The company reported that bictegravir demonstrated an improved resistance profile compared to other drugs in its class, integrase inhibitors.

On treatment, zero transmissions

In the latest news from the landmark PARTNER study, there continued to be zero transmissions of HIV to an HIV-negative partner during condomless sex from a positive partner who had undetectable viral load while on treatment. Suppressed viral load was defined as less than 200 copies. i-Base, in London, put together a question-and-answer factsheet on the PARTNER results in Spanish and English (i-base.info/qa-on-the-partner-study) and Spanish (i-base.info/preguntas-y-repuesta-sobre-el-estudio-partner).

Vitekta voluntarily withdrawn from market

In May, Gilead Sciences announced that it was voluntarily withdrawing its HIV drug Vitekta (elvitegravir) from the market, to take place in February 2017, due to low use—fewer than 50 patients in the U.S. The medication is usually taken as part of the single-tablet regimens Stribild and Genvoya. The withdrawal will not affect those medications.

Kaiser's PrEP data

In July, Kaiser Permanente Northern California health care reported PrEP (pre-exposure prophylaxis) data ahead of print publication in *JAIDS*. Of 972 members who began taking the HIV prevention pill (Truvada) between July 2012 and June 2015 and had at least six months of follow-up, none

VÁZQUEZ: CHRIST KNIGHT EPCLUSA: GILEAD

BRIEFLY
ENID VÁZQUEZ

became infected with the virus while using it. Two who stopped taking PrEP when they lost their insurance coverage, however, did become infected with HIV.

PrEP may reduce new infections by a third

PrEP has the potential to reduce new HIV infections in men who have sex with men (MSM) by a third over the next 10 years, according to a mathematical modeling study published in the *Journal of Infectious Diseases* (JID) in July. According to a press release from the Infectious Diseases Society of America (IDSA), publishers of JID, that decrease may be seen if 40% of MSM who are good candidates for PrEP based on CDC guidelines were actually prescribed the drug and used it consistently.

PrEP video promotes AB 2640

The Los Angeles LGBT Center has created a 2-minute video promoting AB 2640 as well as a petition addressing the California state legislature that can be signed by anyone. According to the petition, "AB 2640 is common sense legislation that would simply ensure that people who test negative for HIV will receive information about all the methods that reduce their risk of infection, including PrEP and PEP, from the healthcare provider who tests them." Go to youtu.be/yeBgXX_pwEA.

More whites taking PrEP

In June, Gilead Sciences released data on uptake of the company's HIV prevention pill, Truvada for PrEP. The number of people taking PrEP increased five times in a period of nearly four years: 74% of them were white, compared to 44% of all new HIV infections in the U.S. being among blacks in 2014. Black people made up 10% of PrEP users in the analysis. Latinos, who made up 23% of new infections in 2014, made up 12% of PrEP users.

Empowered: Trans Women

The Greater than AIDS campaign in July launched *Empowered: Trans Women & HIV*, a powerful video series in which trans women talk about the challenges they've overcome in their lives and about the issues negatively affecting their community's safety from HIV. There are also factsheets on topics such as getting tested for the virus and drug interactions with hormonal therapy. Go to empowered.greaterthan.org.

Phill Wilson to receive GLAD award

GLAD (GLBTQ Legal Advocates & Defenders) announced that Phill Wilson, the founder and President of the Black AIDS Institute, will be the recipient of its 2016 Spirit of Justice Award in October. "I realized early on that the way to save my life and the lives of people I loved was to get involved aggressively in advocacy and in policy work, and really change the systems and the structures to be responsive to this disease," Wilson was quoted in a press release from GLAD.

The will to end AIDS

"Today, combination antiretroviral therapy offers individuals with HIV nearly normal lifespans if they start treatment early and are able to adhere to their therapy. Buoyed by this stunning evolution, in September 2015, 193 United Nations member nations agreed to a bold idea that was once unimaginable-ending the AIDS epidemic by 2030," wrote NIAID Director Anthony S. Fauci, MD, along with Deborah L. Birx, MD, in a guest editorial in a June issue of the online *STAT News*. Read the editorial at statnews.com/2016/06/06/aids-free-generation/.

Aging Awareness Day

September 18 is National HIV/AIDS and Aging Awareness Day. Go to AIDS.gov for factsheets, videos, and more: aids.gov/news-and-events/awareness-days/aging.

National Latino AIDS Awareness Day is Oct. 15

October 15 is National Latino AIDS Awareness Day (NLAAD). The Latino Commission on AIDS (LCOA), the Hispanic Federation, and many other organizations organize this day. The NLAAD campaign works at building capacity for nonprofit organizations and health departments in order to reach Latino/Hispanic communities, promote HIV testing, access to care, and provide HIV prevention information. Go to aids.gov/news-and-events/awareness-days/latino.

The Centers for Disease Control and Prevention (CDC) organizes the campaign "We Can Stop HIV One Conversation at a Time" specifically for Latinos, as part of its Act Against AIDS education efforts. According to the campaign website, "HIV and AIDS affect all communities, including ours. As Hispanics/Latinos, we are the largest and fastest growing ethnic minority in the United States, and we are also one of the groups most heavily impacted by HIV/AIDS.

"More than 1.2 million people are living with HIV in the United States and about 50,000 people become infected each year. As Hispanics/Latinos, we account for 23% of these new HIV infections and of those, 85% were in men and 15% were in women. Anyone can be affected by HIV regardless of age, gender, sexual orientation, or marital status.

"It may not always be easy to talk about HIV/AIDS, but we must talk openly about it to protect our community. By learning the facts about HIV and talking about ways to protect ourselves, our loved ones, and our community, we can help increase HIV awareness, decrease stigma and shame that are too often associated with HIV, and play a part in stopping HIV in the Hispanic/Latino community.

"We all have a role to play. **We can stop HIV one conversation at a time.** Together, all of our conversations can help protect the health of our community and reduce the spread of HIV."

Go to cdc.gov/actagainstaids/campaigns/oneconversation.

According to the CDC, 7 in 10 new HIV diagnoses among Hispanics/Latinos are in gay and bisexual men, and less than half of Hispanics/Latinos living with HIV are receiving medicine for it. In 2013, Hispanics/Latinos accounted for almost one quarter of all estimated new HIV diagnoses, but represented 17% of the total U.S. population. Read more at cdc.gov/hiv/group/racialethnic/hispaniclatinos.

FDA approves once-daily Viekira XR

On July 25, the FDA approved Viekira XR, a once-daily version of Viekira Pak. Both hepatitis C virus (HCV) medications are approved for use by people who are coinfected with HIV. The Viekira XR dose is three pills once daily, taken with food, as compared to two pills in the morning and another one at night for Viekira Pak. For more information, go to positivelyaware.com/viekiraxr and bit.ly/16NhDL5.

VIEKIRA XR: ABBVIE

Clinton campaign releases updated HIV/AIDS plan

Hillary Clinton's campaign released an updated strategy in early August to tackle the HIV/AIDS epidemic both nationally and internationally. The updated plan comes after months of behind the scenes work by leading AIDS activists and over 90 organizations around the country, who met separately with both Clinton and Bernie Sanders earlier this year. The Donald Trump campaign did not respond to requests to meet with activists.

The updated plan includes a commitment to broadening access to bio-medical prevention including pre-exposure prophylaxis (PrEP), reducing the cost of prescription drugs, increasing investment in HIV/AIDS research, and ending stigma and discrimination. What's missing, say some, is a timeline on how exactly to achieve those goals.

"She didn't buy in. She didn't adopt our date and our numbers," activist Peter Staley recently told the *Advocate*, but then went on to explain. "She wants a larger panel of experts to review that. Frankly, that's a pretty reasonable thing for her to counter with—that a larger coalition of experts and community, rather than just those who have been a pain in her ass the past few months, actually determine what an aggressive goal and an aggressive date would look like for ending epidemic levels of HIV transmission."

On a related note, the Democratic Convention in Philadelphia featured prominent AIDS activist Daniel Driffin, who founded Undetectables Atlanta, a group of over 400 gay and bisexual men living with HIV, and co-founded Thriveness, a non-profit service organization. Driffin, a young gay black man from Atlanta, is the first person living with HIV to address the convention since 2004. "We know how

to prevent the virus now. We know how to diagnose the virus now. We know how to treat it and we know how to suppress it... What do we do to fight HIV/AIDS today?" said Driffin during his address to the convention. "We invest in research and education. Expand treatment and prevention," he continued. "And we elect Hillary Clinton."

Read the full updated plan at hillaryclinton.com/briefing/factsheets.—JEFF BERRY

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ONE-ON-ONE WITH GUILLERMO CHACÓN

THE EXECUTIVE DIRECTOR OF THE LATINO COMMISSION ON AIDS TALKS ABOUT WHAT IT WILL TAKE TO END AIDS IN LATINO COMMUNITIES

INTERVIEW BY **JEFF BERRY**

Since its founding in 1990, the Latino Commission on AIDS has become the largest organization in the U.S. advocating for the health needs of the Latino community in response to the HIV/AIDS epidemic. Also known as Latino AIDS, the commission works with community organizations in developing HIV education, prevention programs, and capacity building. The commission, which began in New York City, now serves Latino communities in more than 40 states and Puerto Rico. Guillermo Chacón has been president of Latino AIDS since 2009.

JEFF BERRY: What do you see as some of the broader issues facing the Latino community?

GUILLERMO CHACÓN: First of all, it's extremely concerning that new HIV infections have increased among young black MSM [men who have sex with men] and young Latino MSM. It's around 21%, for Latinos, of new HIV infections in the latest data. We are always concerned about the effectiveness of our response. And when I say our response, it's the communal one. It's the CDC, it's the community.

One particular segment we recognize is the transgender community, which we need to understand and engage because they are one of the most challenging that we face. That's something that has been reported, but it's not a national commitment. I use "trans" because it's my understanding that there are striations and variances in the community. Someone came to me and said "We prefer 'trans.' "

UNO-A-UNO CON GUILLERMO CHACÓN

EL LÍDER DE LA COMISIÓN LATINA SOBRE EL SIDA HABLA DE LO QUE SE NECESITA PARA DERROTAR AL SIDA EN LAS COMUNIDADES LATINAS

ENTREVISTA REALIZADA POR **JEFF BERRY**
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CORTESÍA DE LA COMISIÓN LATINA SOBRE EL SIDA

JEFF BERRY: ¿Cuáles son algunos de los temas más amplios que enfrenta la comunidad Latina?

GUILLERMO CHACÓN: En primer lugar, es extremadamente preocupante que las nuevas infecciones de VIH se han incrementado entre los jóvenes negros HSH [hombres que tienen relaciones sexuales con hombres] y jóvenes HSH latinos. Alrededor de 21% de los casos, son Latinos, según la última data de nuevas infecciones de VIH. Siempre estamos preocupados

FOTO: YANIRA ARIAS

acerca de la efectividad de nuestra respuesta. Cuando digo nuestra respuesta, es a nivel comunal y del CDC.

Un segmento en particular que reconocemos es la comunidad transgénero, la que tenemos que entender y acercarnos porque son una de las comunidades que enfrenta los retos más difíciles, esto es algo que se ha informado, pero no se ha traducido en un compromiso nacional. Yo uso la palabra “trans,” porque es mi entendimiento de que hay variaciones dentro de esta comunidad. Alguien vino y me dijo: “Preferimos el término ‘trans.’”

Estoy seguro de que tú sabes que cuando observamos a los Latinos en general también es necesario identificar a las mujeres que están también siendo impactadas. Siempre trato de ser cuidadoso y consciente cuando explico a muchas organizaciones comunitarias a lo largo de los EE.UU. la razón por la que la atención se centra en los HSH, y es debido al incremento de las nuevas infecciones por el VIH entre esta población.

Ahora, de igual preocupación para nosotros es el nivel de homofobia que creo que representa un reto importante para nuestra comunidad. El estigma de la homofobia y transfobia está presente a través de todas las instituciones y comunidades.

También cuando revisamos el número de personas que sabemos que están viviendo con VIH que están recibiendo atención médica, no tenemos el número que nos haría más optimista en relación a la reducción de la carga viral que nos gustaría ver logrado en cada individuo en los Estados

But also I’m sure you know that when we look at Latinos in general we also need to identify women who are still being impacted. I always try to be careful and mindful about explaining to many community-based organizations throughout the U.S. that the reason why so much attention focuses on women is because of new HIV infections among this population.

Now, of equal concern for us is the level of homophobia that I believe represents a major challenge for our community across the board. The stigma of homophobia and transphobia is across all communities and all institutions.

We also believe when you look at the number of people that we know who are living with HIV that are connected to care, we don’t have the number that would make us more hopeful about the viral load suppression that we would like to see achieved by every individual in the United States and the territories. That is also another big challenge. I think that we need to review our prevention strategy. We know that low viral suppression equals less transmission.

JB: What barriers and challenges do you see facing Latinos specifically?

GC: In cities like New York, clinical providers, case managers, and health navigators that are not Hispanic or Latino don’t understand who we are. I’m talking more in general in terms of the diversity of the countries of origin. Don’t forget that when we talk about Hispanics and Latinos in the United States, it’s a significant segment of us that are foreign born. It’s a large number that are U.S. born, but the cultural dynamics between those two are significantly different. To understand where you came from will help me as a provider to either work with you to reduce risk behaviors or to stay in care.

HIV testing is another good example. I’m sure you know that Hispanics are labeled as late testers for HIV. Many times when I go throughout the U.S.—we describe ourselves as a local, regional, and national organization—and I go to Texas or Georgia or Los Angeles, and outside of New York City, throughout the state of New York, that is mostly rural, I’m always shocked when people say that most of their testing is only done Monday through Friday from 10 to 6. You and I know that if you are a working person, you may not have the ability to say, “Oh, by the way, tomorrow I’m going to work from home.” That issue is also connected to being labeled as a late tester and the translation of that is in many cases, in less than a year after you receive that HIV diagnosis you will also receive an AIDS diagnosis. That’s because by the time you test, the HIV has been with you for a little while. We know that one thing that we cannot allow is somebody to live with HIV for a long time without being treated,

The best way to begin to break a stigma is to educate yourself about something that you don't know anything about.

because that translates into serious damage of your immune system. It's almost impossible to reverse.

JB: What about the immigrant community? There's probably a unique set of challenges.

GC: Another huge barrier is a giant segment that is undocumented. Of course there's a lot of misinformation that is broadcast every day in mainstream media that undocumenteds are here to take over or to use or abuse social services. Anybody in health and human services knows that by law you cannot access a variety of social services, because it's part of the requirement to access those services to prove your immigration status in this country. But when we talk about those folks who are living with HIV without an immigration status, it's getting worse.

I tell people it makes it very difficult when we talk with partners throughout the U.S. because they tell us, "We were doing a lot of work in these three counties within the state but ICE [Immigration and Customs Enforcement]," the federal agency under Homeland Security in charge of implementing these policies, raiding workplaces and deporting people, "was creating fear in our communities." And again, we understand that this is one of the big headaches in our broken immigration system.

JB: I'm sure a lot of the stigma stems from fear, but it's fear that's based in reality.

GC: Correct.

I like to go to a lot of places that provide services, I just like to see the dynamics and interactions. Let's say I'm a trans person and I walk into this clinic. I try to see how the person in the clinic interacts with the individuals who are coming in. The one thing that I always react to immediately is when I see that somebody is not welcomed or is not offered a glass of water, even at the Latino Commission on AIDS. The level of dignity and respect and offering a free space where the person would feel welcome—that to me is many times the biggest failure in perpetuating the level of stigmatization that our folks face every day. I'm talking about Hispanics/Latinos that we know would feel more comfortable to move forward and seek services or to turn around and walk away. I think we cannot afford that, when we talk about HIV in particular or an STI or any other chronic condition, because sometimes there's just a tiny window of opportunity that we can take advantage of but we may miss that moment.

Also, I want to highlight another big challenge that we have. When was the last time that you saw a congressman or a congresswoman of Hispanic

Unidos y los territorios. Esto es también otro gran reto. Creo que tenemos que revisar nuestra estrategia de prevención. Sabemos que reducir la carga viral equivale a menos transmisiones de VIH.

JB: ¿Qué barreras y desafíos ve usted que enfrentan los Latinos en concreto?

GC: En ciudades como Nueva York, proveedores clínicos, administradores de casos y facilitadores/navegantes para el acceso a servicios de salud que no son hispanos o latinos no entienden lo que somos como comunidad. Estoy hablando más en general, en términos de la diversidad de nuestros países de origen. No hay que olvidar que cuando hablamos de los hispanos y latinos en los Estados Unidos, que es un segmento significativo que nacimos en el extranjero. Es un gran número que han nacido en los EE.UU., pero la dinámica cultural entre los dos es significativamente diferente. Para entender mejor a la comunidad, ayuda mucho conocer de dónde viene alguien y esto nos ayudará como un proveedor de servicios trabaja estrategias para reducir comportamientos de riesgo o para lograr que la persona se mantenga recibiendo atención médica.

La prueba del VIH es otro buen ejemplo. Estoy seguro de que sabes que los hispanos se hacen la prueba del VIH tarde. Muchas veces cuando visito diferentes lugares en los EE.UU.-ya que somos una organización local, nacional y regional—voy a Texas, Georgia y Los Ángeles, fuera de la ciudad de Nueva York, y a través del Estado de Nueva York, que es mayormente rural, siempre estoy sorprendido cuando la gente dice que la mayor parte de sus pruebas de VIH sólo se realizan de lunes a viernes de 10 a 6pm, tú y yo sabemos qué si usted es una persona que trabaja, puede que no tenga la posibilidad de decir: "Oh, por cierto, mañana voy a trabajar desde mi casa. Esta cuestión también está conectada al hecho de que nos hacemos la prueba tarde y esto se traduce, en muchos casos, que en menos de un año después de recibir un diagnóstico positivo al VIH, se les diagnostica también con SIDA. Esto se debe a que cuando decidimos hacernos la prueba del VIH, ya hemos estado expuestos al virus por mucho tiempo. Sabemos que no podemos permitir que alguien viva con VIH durante mucho tiempo sin recibir tratamientos, eso se traduce en un daño grave al sistema inmunológico y es casi imposible revertir el daño causado.

JB: ¿Qué pasa con la comunidad inmigrante? Probablemente hay una serie de desafíos.

GC: Claro, muchos desafíos para un segmento gigante entre los nuevos inmigrantes. Una gran cantidad de información equivocada se transmite todos los días en los medios de comunicación que la población indocumentada llega a este país para apoderarse, usar o abusar de los servicios sociales. Cualquier persona que trabaja en el sector salud y servicios humanos sabe que por ley no se puede tener acceso a una variedad de servicios sociales, porque parte de los requisitos para obtener esos servicios es necesario probar su estatus migratorio en este país.

Pero cuando hablamos de aquellas personas que viven con VIH sin un estatus migratorio, su situación se empeora cada dia. Yo comento lo que escucho de nuestros colaboradores en todo los EE.UU., ya que nos dicen: "Estábamos haciendo mucho trabajo en tres condados de mi Estado, pero ICE [Inmigración y Control de Aduanas]," la agencia federal bajo Seguridad Nacional encargada de implementar estas políticas, sigue haciendo redadas y deportando a estas personas, "creando miedo en nuestras comunidades."

La mejor manera de comenzar a borrar al estigma es comenzar a educarse sobre temas donde no hay conocimiento.

entendemos que este es uno de los grandes dolores de cabeza para trabajar con estas comunidades y que nuestro sistema de migratorio no funciona.

JB: Estoy seguro de que muchos de los estigmas se derivan del miedo, pero es un miedo que se basa en la realidad.

GC: Correcto. Me gusta visitar lugares que ofrecen servicios, me gusta observar la dinámica e interacciones. Digamos que soy una persona trans y llego a una clínica, observo cómo la persona trabaja en la clínica interactúa con las personas que están llegando. La única cosa que siempre provoca reacciones inmediatas es cuando veo que alguien no te da la bienvenida o no se te ofrece un vaso de agua, incluso en el Comisión Latina. El nivel de dignidad, respeto y el poder ofrecer un espacio seguro para que las personas se sienta bienvenida—es muchas veces el mayor fracaso para perpetuar el estigma que nuestra gente enfrenta todos los días. Estoy hablando de los hispanos que conocemos para que se sientan más cómodos y logren buscar servicios o que potencialmente den la vuelta y se alejen. Creo que no podemos darnos el lujo de perder a ninguna persona que busca servicios, cuando hablamos de VIH en particular, o una ITS [infección de transmisión sexual] o cualquier otra condición crónica, porque a veces es sólo una pequeña ventana de oportunidad que debemos aprovechar, pero es posible que se pierdan esas oportunidades.

Además, quiero hacer hincapié en otro gran reto que tenemos. ¿Cuándo fue la última vez que vimos a un miembro del Congreso o una Congresista de origen hispano hablando de una manera muy apasionada acerca de la necesidad urgente de abordar el VIH o el estigma asociado con el VIH? ¿O un líder cívico de una organización hispana de importancia local, regional o nacional?

Estoy diciendo que necesitamos una conversación específica, porque una de las mejores maneras de abordar el estigma es a través del liderazgo, lo que significa ponerle un rostro al tema. Es necesario abordar el estigma y comenzar a proponer políticas, normas y figuras para empezar a eliminar el estigma, comenzando con usted, su propia familia y luego las instituciones que ustedes representan y que tiene algún tipo de influencia.

JB: No es poca cosa.

GC: Lo sé. Es triste. Especialmente con el VIH en los Estados Unidos y los territorios, tenemos todas las herramientas para asegurar que todo el mundo que está viviendo con VIH pueda potencialmente lograr la supresión viral. Si tenemos las herramientas y si podemos prevenir la propagación del VIH, ¿por qué no hacemos lo mejor posible para hacer la diferencia y lograr lo que se conoce como el movimiento para derrotar al SIDA o lograr una generación libre de SIDA? Estos son objetivos que estoy orgulloso en compartir que se ha adoptado en el Estado de Nueva York y que la Comisión Latina está profundamente involucrada. Pero el liderazgo de nuestro Gobernador y Alcalde en la ciudad de Nueva York han sido esenciales y han hecho una gran diferencia. No se puede lograr algo si los individuos que tienen posiciones de liderazgo no se comprometen para lograr los objetivos y así alcanzar esas metas.

Quiero destacar un tema importante, Puerto Rico, que desafortunadamente ha estado en las noticias debido a su crisis horrible financiera. El problema que genera una deuda nacional de más de 70 billones de dólares, todo va a sufrir, en función de sus prioridades, en función de su presupuesto. Más de 20,000 personas viven con el VIH en la pequeña isla de Puerto

background talking in a very passionate way about the urgent need to address HIV, or the stigma associated with HIV? Or the Hispanic civic leader for a major local, regional, or national Hispanic organization?

I'm saying we need a specific conversation, because one of the best ways to address the stigma is through leadership, meaning that you need to put a face on the issue. You need to address stigma and begin to put forth policies and rules and figures to begin to remove that stigma, beginning with you and your own family and then the institutions that you represent and that you have some type of influence in.

JB: No small feat.

GC: I know. It's sad. Especially with HIV in the United States and the territories, where we have all the tools to ensure that everybody that is living with HIV could potentially achieve viral suppression. And if we have the tools and if we can prevent the spread of HIV, why would we not do our very, very best to make the difference and achieve what is known as the end of AIDS or achieve an AIDS-free generation? These are the goals that I'm very proud to tell you that in New York State the Latino Commission was deeply involved in developing. But the leadership of our governor and our mayor in New York City made a difference. You cannot expect to do something if the individuals that have those leadership positions will not take those goals to the finish line.

I want to highlight one thing, and it's Puerto Rico, which unfortunately has been in the news because of the horrible financial crisis. But the problem is when you are facing over 70 billion dollars of national debt, everything will suffer, in terms of your priorities, in terms of your budget. Over 20,000 people are living with HIV on the tiny, tiny island of Puerto Rico. There has been a very good response from CMS [Centers for Medicare and Medicaid Services], from CDC, but many times you will see reports from institutions in the United States talking about the state of HIV in the United States, and you realize they're talking about the 50 states. They do not highlight the territories. To me, that is irresponsible, because the territories belong to the United States. From a public health perspective we need to recognize that.

JB: You recently helped launch an anti-stigma campaign, "Podemos Detener el VIH." Can you tell us more about that?

GC: We're convinced that stigma is a major barrier and we need to create strategies to begin to approach and work with different institutions within the Hispanic/

Latino community, like the National Hispanic Medical Association, the National Association of Hispanic Nurses, and the Latino Social Workers Organization. The best way to begin to break a stigma is to begin to educate yourself about something that you don't know anything about. It's even better to have a direct experience, like when you start to know more clients and members of our communities, you realize that they have the same aspirations and many of the same challenges as any other segment that we have. And I always remind my trans sisters, and the trans community in general, that they have to be in a strategy from their perspective to engage the community as a whole.

I'm always concerned when groups say, "Oh, we're doing a stigma reduction campaign," and what are they doing? "Oh, we made a poster." I say I think posters help, but we need something more comprehensive and also more tailored to where some institutions or organizations are. Now the question is, the medical associations, state by state, must be a target for each of us. If we have an ethnic or racial association, even better. And we cannot ignore that media creates news and we need to engage them. Also when we talk about stigma we need the academic institutions to work with some of those communities that have been suffering for so many years a great deal of stigma and isolation. They have to be part of a better understanding of which strategy would help us create a more welcoming setting for individuals to feel more comfortable and able to access whatever they need.

I think that New York State is a good lab right now with the ending of the epidemic, with the [New York State's Blueprint to End the AIDS Epidemic] that was adopted by the governor being fully implemented throughout the state. And one component of that is stigma reduction. And when I spoke about leadership, it's very important to realize that it didn't drop from the

Rico. Ha habido una muy buena respuesta por parte de la CMS [Centros para Servicios de Medicare y Medicaid], de los CDC, pero muchas veces podrás ver informes de instituciones en los Estados Unidos que hablan sobre el estado del VIH en los Estados Unidos, y te das cuenta de que están hablando de los 50 Estados de la nación, reportes que no incluyen los datos de los territorios. Para mí, eso es irresponsable, porque los territorios pertenecen a los Estados Unidos. Desde una perspectiva de salud pública, tenemos que reconocer eso.

JB: Recientemente ayudaron a lanzar una campaña contra el estigma, "Podemos Detener el VIH." ¿Puede decirnos más sobre eso?

GC: Estamos convencidos de que el estigma es una barrera importante y tenemos que crear estrategias para comenzar a acercarnos y trabajar con diferentes instituciones dentro de la comunidad Hispana/Latina, como la Asociación Nacional Médica Hispana, la Asociación Nacional de Enfermeras Hispanas, y las organizaciones de trabajadores sociales Latinos. La mejor manera de comenzar a borrar al estigma es comenzar a educarse sobre temas donde no hay conocimiento. Es incluso mejor el poder tener una experiencia directa, como cuando se empieza a conocer más clientes y miembros de nuestras comunidades más afectadas, te das cuenta que tienen las mismas aspiraciones y muchos de los mismos problemas que cualquier otro segmento en la comunidad. Es importante siempre recordar a mis hermanas trans y la comunidad trans en general, que tienen que estar involucradas para entender su perspectiva. Siempre me preocupa cuando algunos grupos dicen, "estamos haciendo una campaña de reducción del estigma," y les pregunto ¿que es lo que están haciendo? "Oh, hicimos un poster." Digo, creo que los pósteres ayudan, pero necesitamos algo más amplio y también que se logre adaptar para algunas instituciones u organizaciones para ser más efectivos.

Ahora la pregunta es la importancia, de las asociaciones médicas, Estado por Estado, deben ser un objetivo para cada uno de nosotros. Si tenemos asociación étnica o racial médicas, aún mejor. No podemos ignorar que los medios crean noticias y tenemos que lograr su participación. También cuando hablamos de estigma, necesitamos las instituciones académicas para trabajar con las comunidades que han estado sufriendo durante tantos años y enfrentando una gran cantidad de estigmas y aislamiento. Tienen

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que ser parte para lograr una mejor comprensión de las estrategias que ayudaran a crear un entorno más acogedor para que cada persona se sienta más cómoda y capaz de acceder cualquier servicio que necesiten.

Creo que el Estado de Nueva York es un buen laboratorio en este momento con el esfuerzo para derrotar la epidemia, con el [Plan del Estado de Nueva York para derrotar la epidemia del SIDA], que fue adoptado por el Gobernador y se está implementando en todo el Estado. Un componente clave de este plan es la reducción del estigma. Cuando hablé sobre el liderazgo, es muy importante darse cuenta de que no cayó del cielo este esfuerzo. Existe una asombrosa unidad entre las organizaciones comunitarias que se unieron en una sola voz para hablar con el Gobernador y pedirle: "Necesitamos su liderazgo." Y el Gobernador estaba listo, una vez más, un buen líder es un líder que sabe escuchar, reflexionara, e inmediatamente actuará para movemos en la dirección correcta.

JB: Es un gran proyecto, felicitaciones al respecto. ¿Hay algo más que de lo que quería hablar?

GC: Yo también quiero destacar que las personas interesadas en comprender mejor y responder a las necesidades de la comunidad Hispana/Latina, número uno es comenzar a conectarse con nuestras comunidades, con nuestras organizaciones y número dos, las organizaciones Latinas/Hispanas en los EE.UU. y sus territorios necesitan empezar a trabajar más para conectarse con nuestras autoridades Estatales. Muchas personas quieren entender mejor lo que somos como comunidad, porque somos una de las poblaciones de más rápido crecimiento. En cuanto a edad, somos uno de los segmentos más jóvenes de la población EE.UU.

Acabamos de abrir OASIS en la ciudad de Nueva York, un nuevo Centro LGBTQS y la "S" significa en Ingles "straight," [heterosexual] porque creemos que es necesario involucrar a nuestros hermano/as heterosexuales, para unirse y respetarnos mutuamente. Pero el centro comunitario se dirige especialmente a los jóvenes Latinos HSH o Latinos gay/bisexuales y mujeres trans que no sólo sean parte, sino también que se conviertan en protagonistas en el campo de su salud, incluyendo la prevención del VIH y las ITS.

Es importante para nosotros desde una perspectiva histórica, tomar en cuenta que hicimos para derrotar la epidemia del SIDA en nuestras vidas. Creo que esa es la aspiración que todos nosotros podemos tener.

sky. There was an amazing unity among community-based organizations that came together in one voice to talk to the governor and say, "We need your leadership." And the governor was ready because, again, a good leader is a leader that will listen, will reflect, and immediately will act and move in the right direction.

JB: It's a great blueprint, kudos on that. Is there anything else that you wanted to talk about?

GC: I also want to highlight that people interested in better understanding and responding to the Hispanic/Latino community, number one is to begin to connect with our communities, our organizations and number two, the Hispanic/Latino organizations throughout the U.S. and the territories need to begin to work more to connect with our state authorities. Many people want to better understand who we are as a community, because we are one of the fastest growing populations. In age, we are one of the youngest segments of the U.S. population. We just opened in New York City a new LGBTQS center and the "S" stands for "straight," because we believe that we need to engage our straight brothers and sisters, to join and to respect all of us. But the center especially targets young Latino MSM or Latino gay men to not only be a part of the center but also to be leaders for their health, including the prevention of HIV and STIs.

It is important for us to be in the history books, what we did to end the epidemic in our lifetime. I think that's the aspiration all of us can have. PA

FOR MORE INFORMATION go to latinoaids.org and LaRedHispana.org/detengamosvih.

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A NEW ERA
IN THE FACE OF OLD BARRIERS

PROMINENT ADVOCATE **MOISÉS AGOSTO** SAYS INNOVATIVE STRATEGIES NEEDED TO FACE THE CONTINUING CHALLENGES OF THE EPIDEMIC

BY **ENID VÁZQUEZ** PHOTOGRAPHY BY **JONATHAN TIMMES**

LONGTIME NATIONAL HIV treatment advocate Moisés Agosto, a native of Puerto Rico, says the challenges facing Latinos in the epidemic haven't changed much over the decades. Problems with housing, jobs, and education, along with other social determinants of health, continue to hurt prevention and treatment: Immigration status. Language barriers. Access to physical and mental health care. Access to food.

What's different, he says, is the new medicalization model of treatment and prevention, and how that fits into those social determinants. What good is medicine to prevent infection or AIDS if people don't have access to health care?

"We have a new paradigm for HIV," said Agosto. "We can think we have the same issues as before, but they're going to play out differently now because we're moving more towards biomedical prevention. We're moving more towards a medical approach to treatment—getting people tested and getting them on medication."

Today, medication helps stop people from becoming infected and helps those already living with HIV from being infectious as well as staying healthy. It's a one-two punch against the spread of HIV.

That strategy won't work if people don't know about these medications, or face stigma over them, or simply don't have access.

All of which raise the same old questions about such things as poverty and lack of health insurance. Perhaps insurance is a greater concern today when medication works better than condoms to prevent transmission, and when medication can keep an HIV infection from progressing to AIDS.

In his work as Director of Treatment for NMAC (formerly the National Minority AIDS Council), Agosto promotes the use of PrEP (pre-exposure prophylaxis) for HIV prevention, but notes that this biomedical approach—currently consisting of a daily pill for prevention—requires access to health care.

"I'm an activist and I'm HIV-positive, and I advocate for PrEP for young gay men of color, black and Latinos," said Agosto. "At the same time, while I put emphasis on PrEP and biomedical prevention, I can forget that access to those interventions will require access to health care."

Recent figures provided by Gilead Sciences, the only company with an HIV PrEP medication on the market, show that most of the men who have sex with men (MSM) taking it are white (75%). Yet it is black and Latino MSM who are at greater risk for HIV infection. "So, those who need it the most are not getting it," says Agosto.

He says that means continuing to promote the use of condoms, because "it will take longer for the Latino community to get into PrEP." (Although the Truvada for PrEP label says it should be used along with condoms and other prevention methods, it's largely seen by the public as an either/or thing for HIV prevention.)

But the strategy of condom distribution (which one young black gay man called "old school") needs to be updated. Agosto said that while prevention workers still like to pass out condoms in gay bars, millennials like to stay home watching Netflix and meet men online.

Still, the new paradigm needs to fit into the old barriers, not the least of which is plain old stigma. In the HIV epidemic, even accessing prevention continues to be stigmatized. Why would you need protection if you're not some kind of slut? Or so the stigma goes.

He said the "Truvada whore" label attached to the PrEP pill continues to negatively affect uptake. "That's why I think the whole behavioral component of HIV prevention is so important, because it's not all about getting people onto PrEP and behaviors that make them adherent to medication. These are people who already have stigma, just for being gay. Then you add to that equation, 'Do you want another stigma?' No. So if they want care, they might have to find it away from the people who potentially may be supporting them, like their family. So, it's tricky. It has so many dimensions."

Behavioral interventions therefore remain important in the age of the medical model, he said. Emotional support can help people access the new world of medical care, and can help them overcome the stigma that keeps them from getting there.

At the same time, he said, it's important for testing and biomedical prevention to take a more holistic approach. "It's an overall health issue. Not only could you be taking care of HIV prevention or treatment, but you could be taking care of other health issues. This gives the context of the importance of caring for your health, even if you're young and you think you're super-powerful."

Where Latinos are concerned, he says it's important to remember the differences among them. "Access to health care plays out differently in the Latino community—and I would say, Latino *communities*.

"You have on the border a population that's extremely poor, that doesn't have electricity, that doesn't interact with health care workers because they're afraid they're going to be reported to immigration. So they don't proactively look for health care or any kind of education. The border is a whole different scenario," said Agosto.

Nor are Latinos necessarily alike just because they live in the same area. He said that there's a lot of diversity in the Northeast. Regional differences do exist, as well, such as those between Latinos in California and those in Texas.

"It's a whole different cultural expression. People have highlighted that. It's very interesting the identity and specific cultural expressions that are not shared by all Latinos. We need to think about those differences. 'I'm going to go here and there'—it's a generic approach. 'We will distribute condoms; we will develop contacts; we will give information; we will give referrals.' All those efforts that we are so used to doing need to change in order to be effective, especially with this new generation of young Latino people," Agosto said.

He added that it's therefore important to do prevention work with people individually when possible in order to tease out those issues, and help figure out what someone needs for prevention. The same goes for getting people on treatment.

"We also need to acknowledge that in the past we used to advocate for everyone, but now we need to be more intentional and individualized in our efforts. You have seen that with the black MSM. They have organized themselves, and they have developed prevention programs for themselves, while I noticed that the Latino representation in the discussions about PrEP, the discussions about biomedical prevention, is lacking," he said. "We don't have enough representation. So we have to foster leadership among young MSM, in Latinos."

Finally, he believes that addressing structural barriers may sometimes be even more important than simply providing clinical care.

"The biggest obstacle may not even be health care. Housing ... is treatment. Housing ... is prevention," he said. "All those socioeconomic aspects of living your life need to be addressed to not just access HIV meds or PrEP or care, but to stay there. And not just to stay, but to be able to achieve viral suppression."

Agosto said he finds the latest incidence figures of HIV infection for Latino MSM worrisome. "I'm concerned about the incidence of infection. When you look at the latest statistics, we see that whites are going down and blacks were stabilizing, but with the Latinos there was a slightly increase. That tells me that HIV infections are starting to go up. We see—and I'm not saying that it's bad—very active outreach to black MSM but you don't see the same reaching out to Latino MSM. That worries me, because we're not paying attention to what's happening to that population."

AUTHOR'S NOTE: *Moisés Agosto Rosario is a poet and fiction writer. His books include* Plagas del Deseo *and* Nocturno y Otros Desamparos.

'ACCESS TO HEALTH CARE PLAYS OUT DIFFERENTLY IN THE LATINO COMMUNITY—AND I WOULD SAY, **LATINO *COMMUNITIES*.**'

PrEP FOR LATINX COMMUNITIES

SHIFTING OUR APPROACH

BY KEN ALMANZA

DURING A HOLIDAY BREAK in 2013, I told my mother about my decision to start taking Truvada as PrEP (pre-exposure prophylaxis). I sat on her couch and also explained that I was going to share my PrEP-taking journey on Facebook to educate more people like myself. I waited for an argument to erupt. Discussion about sexual health and freedom were usually met with negative feelings in our household.

"¿Proph-a-que?" she shouted across the room. I replied back with equal intensity: "It's medication to prevent HIV infection, mom!" Without missing a beat, she fired back with an arsenal of questions: Isn't HIV medication toxic? Why would you take a pill if you are not sick? How are you going to pay for it? What will people think of you? Do you already have HIV? Each question became more and more saturated with uncertainty, fear, and misinformation. It almost seemed as if I were "coming out" as gay all over again. But why was I having this conversation with my mother in the first place? Let me explain.

I come from a poor Mexican background and rarely talked about sexuality, health care, or preventative medicine. In our household, you would only go to the doctor if you were sick. Going to the doctor also involved spending money and taking time off from work, which potentially meant losing money. We were always trying to make ends meet, so unless your arm was falling off, seeking medical care wasn't a top priority. Sex was something you learned about on your own, and the gay thing? That was just something the family knew about but didn't talk about openly.

Growing up under those conditions amid a high-context Mexican culture still influences my adult life today. In the theory of high-context culture, relationships are emphasized, with such matters as tone of voice and facial expressions more important than mere words, giving way to respect—and trust. These cultural differences can influence access to health care.

No matter my age, education, or how progressive I think I am, maintaining a positive open relationship with my family supersedes everything. Even at 28 years old, I was still seeking acceptance. I am just one of many Latinx people who are bound by unique cultural and socioeconomic drivers. These drivers can positively or negatively affect our health outcomes. PrEP access for the Latinx community means attachment to cultural constructs that community educators, health centers, and medical providers are not always familiar with.

For PrEP to be fully realized in the Latinx community we can't just translate English language resources into Spanish and call it a day. We must reframe the entire conversation to address real barriers many Latinx people face.

At the same time, we must propose realistic solutions starting at the local level involving those who already serve this population. We have the resources to implement PrEP on a larger scale, but we must tailor our efforts to reflect the current needs of Latinx people.

Recent data from Gilead Sciences noted that from 2012 to 2015 over 49,000 PrEP prescriptions were filled at pharmacies across the nation. However, only 12% of those PrEP users were Hispanic. This number did not surprise me. I know firsthand how immigration status, stigma, culture, language, and gender identity can directly affect PrEP uptake in the Latinx community.

Let's look at one of the

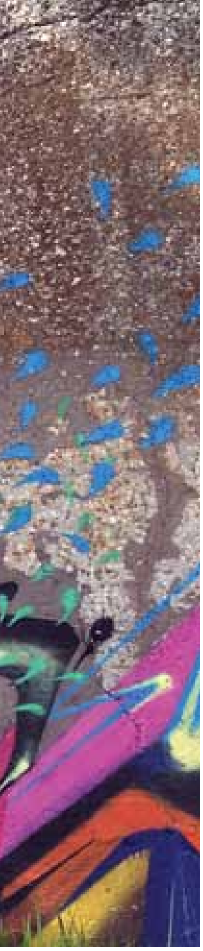


FOTO: JOHN GRESS

FOR PrEP TO BE FULLY REALIZED IN THE LATINX COMMUNITY, **WE CAN'T JUST TRANSLATE ENGLISH LANGUAGE RESOURCES INTO SPANISH AND CALL IT A DAY.**

largest and most vulnerable groups: The uninsurable undocumented population. Millions of Latinx people are completely shut out of health insurance programs such as Medicaid and the Affordable Care Act (ACA). This group stays largely dependent on community clinics to address their health care needs. However, unless a patient is located in a large urban city, there are very few health centers actually dispensing PrEP in a community clinic setting. To compound the problem, many clinics do not openly advertise to undocumented populations, let alone understand how to implement culturally competent services.

According to the CDC, Hispanics accounted for almost one quarter of all estimated new HIV diagnoses in 2013 (go to cdc.gov/hiv/group/racial-ethnic/hispaniclatinos). A large portion of that Hispanic population is also undocumented, yet we have no comprehensive health care or sustainable access points for this group, meaning that funds run out and care is discontinued. Basic costs for PrEP include co-pays for doctor visits, routine lab work, and medication. Finding a sustainable payer source to cover these costs is just one part of the equation. Most U.S.-born Latinx people have the ability and luxury to sign up for insurance programs such as Medicaid, ACA, or employer-sponsored insurance plans.

However, even if successfully linked to an insurance plan, cultural barriers can still slow PrEP uptake.

For many Latinx people, medical providers are often seen as authority figures and adhering to authority and power is a cultural imperative. Because of this, medical providers will often need to take the lead and initiate conversations about PrEP and HIV prevention.

Activities and decisions among many Latinx cultures are also based on interpersonal, face-to-face relationships. If a bond is not developed from the beginning, a patient may not return for subsequent visits.

A high level of self-efficacy is usually required when requesting PrEP from a medical provider. Yet, many Latinx people come from highly stigmatizing backgrounds where their own sexuality or gender identity may have been scrutinized. For those with a strong attachment to traditional gender roles and expectations comes another set of barriers.

As a result, a Latinx patient may not always possess the confidence or feel the need to advocate for their own sexual health behind closed doors. A deep-rooted fear of judgment or retaliation can sometimes block a Latinx patient from engaging in these types of conversations, if at all. The situation can become a missed opportunity if the medical provider does not fully understand the patient's sexual risk.

Health literacy and language also serve as a substantial barrier. If a Latinx patient is not able to understand health care systems or communicate ideas using English, PrEP will not appear as a viable option. We must continually explore all of these indicators in great detail, for they become the determining factor on whether the Latinx community will choose to take PrEP and also whether they will properly adhere to it.

HIV care providers have tirelessly worked through the years to ensure that HIV-positive patients stay engaged in care. A similar amount of work will be required to link and maintain HIV-negative patients in care as well. We don't necessarily need to reinvent the wheel; we just need to tailor our approach to make PrEP relevant to the communities we wish to serve.

It's also highly important to note that PrEP is not always the best HIV prevention option for every person. By no means should we have an entire Latinx population dependent on biomedical prevention for life. We don't need to put it in the water.

We do, however, stand to benefit from having an entire population successfully linked to comprehensive health care. The common denominator is ensuring healthier, stronger communities. Even if a patient chooses to come off of PrEP, they leave much more informed and engaged with their health care than ever before.

Now is the time for community educators, health centers, and medical providers to step up to the plate and deliver culturally competent PrEP services. Local leaders can also push local health officials into crafting better policies around PrEP access and engagement. Latinx-based CBOs (community-based organizations) outside of HIV prevention also play a role in PrEP uptake and awareness. In order to make waves, we must change the narrative and develop a new approach. We must bridge alliances, coordinate our efforts, and contribute to a common goal.

The National HIV PrEP Summit (NHPS) is a new NMAC conference that promises to contribute to that goal. Slated for December 3–4, 2016 in San Francisco, the meeting will be a partnership between national and community-based organizations along with health departments to focus on the implementation and infrastructure needed to turn the promise of the science into an effective community HIV prevention option.

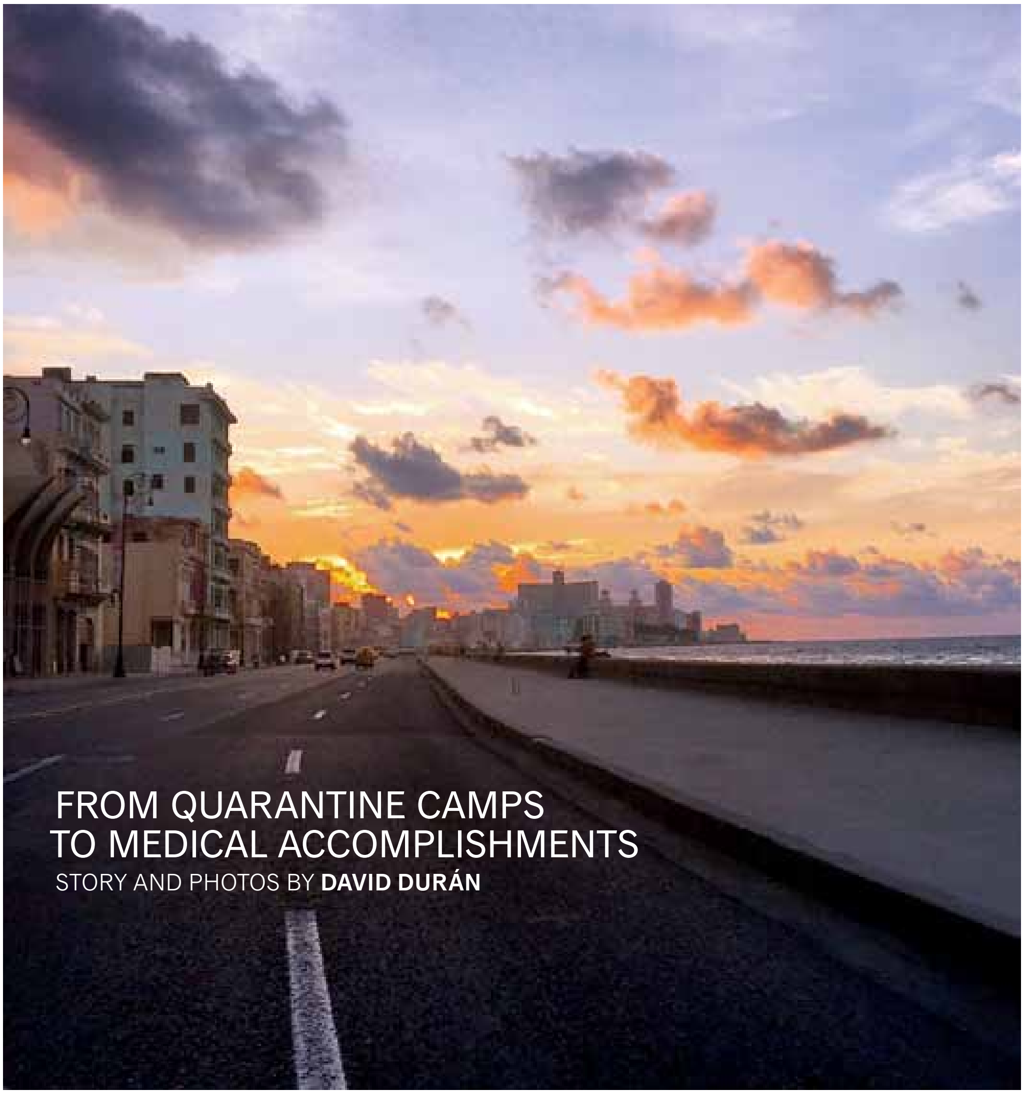
Workshop sessions will focus on PrEP access and engagement for various communities of color. Sessions will also cover research, educational campaigns, program implementation, training programs, health care providers, and policy. (To register and learn more go to hivprepsummit.org.)

It's 2016 and I have gone from educating my mother in her living room, to educating constituents on a national level on how to implement PrEP for people like me. After almost three years, I am still adhering to my own PrEP regimen and believe it or not, my mother has become an active PrEP supporter as well. It took time and education, but she now advocates for health care access and PrEP use within her own social networks.

If my own mom is doing outreach, there is no reason you can't as well. Let's get to work and change our approach. We have a community to protect.

KEN ALMANZA is an HIV prevention and health advocate and currently serves as Program Associate for NMAC. Originally from Los Angeles, Ken has worked extensively in communities of color as an HIV/STD test counselor, behavioral intervention specialist, and PrEP navigator. His ultimate goal is to help create safe, healthy environments through open, honest discussion and effective community collaborations.

LIFE WITH HIV IN CUBA



FROM QUARANTINE CAMPS TO MEDICAL ACCOMPLISHMENTS

STORY AND PHOTOS BY **DAVID DURÁN**

IT'S A TINY ISLAND 90 miles off the coast of Florida, easily dismissed by many as a communist country with a depressed economy. Like many other places in the world, HIV remains a serious concern. But what some people don't know is that Cuba has achieved a milestone in HIV prevention that has made the world stand up and take note.

Early in the AIDS epidemic, Cuba was notorious for its mandatory HIV quarantine program. Seventeen facilities dotted the island, housing anyone who tested HIV-positive. The largest facility was the sanatorium at Santiago de las Vegas, located just outside of Havana.

From 1986 to 1993, Santiago de las Vegas segregated people living with HIV from the general population, an action that was highly politicized by the rest of the world in a time when HIV and AIDS fear was most rampant. Forced quarantine ended in 1993, but for years afterward, the government continued to maintain strict control over anyone living with HIV. Those that were permitted to live outside of the camps had to disclose their sexual partners and encounters had to be reported to the government. On the world stage, Cuba's approach towards those living with HIV only served to further tarnish its already diminished reputation throughout the world.

Fast forward more than 20 years later and Cuba is suddenly leading in breakthrough studies and most recently was the first country to receive what can be considered as a global seal of approval—the World Health Organization (WHO) validation—for essentially eliminating transmission of HIV from a mother to her baby. By 2014, more than 40 countries, including the United States, Canada, Anguilla, and Barbados, were testing and treating pregnant women in programs and studies to achieve the same, but Cuba was the first to go through the WHO monitoring program. The program requires data on transmission for a period of at least two years as well as onsite visits by WHO members who examine care in all parts of the country, including even the most remote and underserved parts of a country.

Cuba was able to achieve this accomplishment mainly because its health care system is so highly regulated. HIV tests are commonplace during routine doctor visits and patients who are HIV-positive are put on a treatment regimen and monitored. When a Cuban national goes to see their doctor, they will eventually, at some point, have an HIV test, regardless if they ask for one or not. Women who become pregnant and are HIV-positive are referred to a clinic with a higher level of expertise in HIV, where they will be monitored closely and started on oral antiretroviral

ACCORDING TO CUBA'S MINISTRY OF PUBLIC HEALTH THERE ARE CURRENTLY 15,936 RESIDENTS ON ANTIRETROVIRAL MEDICATION; 7,448 OF THEM IN HAVANA. Reported new HIV cases last year reached 1,090. Eighty percent of all HIV cases in Cuba are among men. The ministry reports there are more than 20,000 people living with HIV in Cuba. Since data collection began in 1986, there have been 3,918 AIDS-related deaths.

treatment, which has shown to reduce transmission to newborns to less than 2%.

At approximately 38 weeks into pregnancy, at the discretion of the doctor and the woman, the mother gives birth via cesarean section, another method proven to reduce transmission of HIV, instead of through the birth canal.* Women are also instructed not to breastfeed their newborns. Additionally, the infant receives antiretroviral treatment for up to six weeks after birth.

The United States has achieved the elimination target at a national level as the rate of transmission of HIV through pregnancy and childbirth is below the two percent mark, which meets the standards of WHO. The problem is that criteria for validation must be met in an equal manner, even in subgroups of the lowest performing areas, and in the United States, the rates of HIV transmission to infants are higher in poor and underserved areas, and communities of color.

Things have dramatically changed for those living with HIV in Cuba since the days of the quarantine. Over the past four years, according to research documented on the government's official websites, new infections of HIV have been maintained at the same level, and have neither declined nor risen. With regards to the number of new infections, when compared to the small population of the island, the numbers are low. Of every 10 new infections, eight are men, and of those, 88.6% are men who have sex with men, which is the group most at risk.

Beyond the free medical treatment and resources provided by the government, various organizations offer assistance and support. Linea de Apoyo ("helpline" in English) is an organization made up of volunteers, which is funded by Fondo Mundial (known in English as The Global Fund to Fight AIDS, Tuberculosis, and Malaria) and ONUSIDA (UNAIDS). Those organizations all come under the umbrella of the government's Plan Estratégico Nacional (PEN, "national strategy plan" in English), which is now the law, created in response to the HIV epidemic. PEN has been approved through 2018. It was developed in cooperation with the public and Cuba's Ministry of Public Health. Through PEN, the government pays 100% of all HIV services, including medications and lab work.

Beyond medical care and services, those living with HIV in Cuba are given supplementary rations of food. Cuban nationals receive rations of food each month as mandated by the government. It typically is very little, and includes rice, beans, and a very small amount of meat. Those living with HIV are put on a special diet plan that includes three bags of powdered milk, six pounds of fish, thirty eggs, and two pounds of beef. The additional food is considered to be needed by someone on antiretroviral medications.

Cuba still faces stigma because of its form of government and its history since its revolution, but the country has drastically changed in the past decade since Raúl Castro took power. More rights have been granted to its citizens, including the right to travel outside of Cuba. LGBT advancements

have also taken place within the island nation, and now with improved relations with the United States, there may be better days to come for the Cuban people. The country is still under a dictatorship and although treatment and care for those living with HIV is more civilized than it was in the past, people there are still being controlled. But under that control, fortunately, those living with the virus are generally living a normal life and receiving proper medical care. The country as a whole is working towards lowering and perhaps one day ending HIV transmission in Cuba.

* EDITOR'S NOTE: U.S. guidelines do not recommend cesarean section, because there is no significant risk reduction over the use of antiviral therapy.

DAVID DURÁN is a Cuban American freelance journalist writing about LGBT, HIV, and travel news for such publications as *The Advocate*, POSITIVELY AWARE, *The Huffington Post*, and *Fodor's Travel*.

‘I’M NOT SOMEONE WHO GETS SCARED.’
—**JAVIER MUÑOZ**, THE NEW LEAD IN BROADWAY’S *HAMILTON*

THE ROLE OF A LIFETIME: JAVIER MUÑOZ

When Javier Muñoz took over the lead role in Lin-Manuel Miranda’s Tony Award-winning smash hit musical *Hamilton* in July, he was thrust onto the national stage overnight. Muñoz, who is 40, openly gay, HIV-positive, and had a recent bout with cancer, has been candid and outspoken about both his HIV status and life as a cancer survivor.

Born to Puerto Rican parents and the youngest of three boys, he grew up in the Linden Projects in Brooklyn’s East New York.

“We grew up relatively poor in a first-floor apartment with gates on every window,” Muñoz told the *New York Daily News*. “It was scary coming home, because it was a rough and violent neighborhood.”

Muñoz was diagnosed with HIV in 2002, and discovered he had cancer last October, while serving as understudy to Miranda’s *Hamilton*.

“I’m not someone who gets scared,” he told *People* magazine, sharing that he has lived with numerous health problems since childhood and credits his physical challenges with his first introductions to music and art. “It’s a very rare occasion that I genuinely feel just fear. I can get anxious, apprehensive about things. It’s a rare thing in my life to find myself face-to-face with something I’m scared of, and I was scared of this. I had never been more scared in my life.”

In talking about when he found out he had cancer, he told *The New York Times*, “I have been living with H.I.V. since 2002, and I’m undetectable. I’m healthy, I’m strong, and I’m very out about that because of the stigma still attached to it. But I’ve had a healthy fear about my health since I tested positive, and I asked how to test myself for lumps, because both my parents had cancer. And very early on in my learning how to do a self-examination, I found the lump. I wasn’t immediately worried because of where it was—and I do want to keep that private because that’s the only thing that’s mine in this. But I brought it up to my doc, and that’s what led to further testing and discovery.”

Following surgery and radiation last fall, and after missing weeks of performances in *Hamilton*, he has been back in the cast for months. He told the *Times* in July he feels strong—the virus is undetectable, the cancer screenings negative—and is raring to go. “I had my first follow-up in March, and all green lights,” he said. “I’m good.”

“Coming out of this, it’s sort of reinvigorated my passions,” he told *People*. “If success comes with those things in some way—and everyone has their own definition of success—that’s great. But it’s the art that’s my goal. It’s the work that’s my goal. It’s creating something wonderful.”

FOTO: ALEX WELSH

¡CÓMO SE DICE ‘VIH’ IN ENGLISH?

A SPANISH TO ENGLISH GLOSSARY

adherencia: adherence
Administración de Alimentos y Medicamentos: Food and Drug Administration (FDA, siglas en inglés)
antibiótico: antibiotic
anticuerpo: antibody
antifúngico: antifungal
antígeno: antigen
antirretroviral: antiretroviral, ARV
antivírico: antiviral
asociación en dosis fijas: fixed-dose combination
bacteria: bacteria
bactericida: antibacterial
biopsia: biopsy
cáncer del cuello uterino: cervical cancer
cáncer relacionado con el SIDA: AIDS-related cancer
candidiasis: candidiasis
cardiovascular: cardiovascular
carga viral: viral load; also called “ARN del VIH”—ARN stands for **ácido ribonucleico. Prueba de la carga viral:** viral load test
carga viral indetectable: undetectable viral load
célula T: T-cell
Centros para el Control y la Prevención de Enfermedades: Centers for Disease Control and Prevention (CDC)
clase de medicamentos: drug class
complejo de demencia causado por el SIDA: AIDS-related dementia complex
complicaciones neurológicas del SIDA: neurologic complications of AIDS
condón: condom (plural: **condones**); also called **preservativo**
confidencial: confidential
confidencialidad: confidentiality
contraindicación: contraindication; **contraindicación absoluta:** absolute contraindication
control vírico: viral control; también **reducción viral:** viral reduction
efecto secundario: side effect
efecto adverso: adverse effect
enfermedad de transmisión sexual (ETS): sexually transmitted disease; **infección** [infection] **de transmisión sexual**
ensayo clínico: clinical study
fracaso virológico: virologic failure
glóbulo blanco: white blood cell
glóbulo rojo: red blood cell
gonorrea: gonorrhea
hemoglobina: hemoglobin
hepatitis: hepatitis; **virus de la hepatitis C (VHC):** hepatitis C virus (HCV)
hepatotoxicidad: liver toxicity
el hígado: the liver
hongo: fungus
infección: infection
infeccioso: infectious
interacción medicamentosa: medication interaction
malestar: ill feeling; pero; “No me siento bien”—“I don’t feel well.”
maligno: malignant
microbio: microbe
neumonía: pneumonia
neuropatía periférica: peripheral neuropathy
Institutos Nacionales de la Salud: National Institutes of Health (NIH)
paciente [con o sin] tratamiento previo: treatment-experienced or -naïve patient
pareja concordante o discordante: serocondordant or serodiscordant couple
personas con el VIH/SIDA: people living with HIV/AIDS
profilaxis posexposición: post-exposure prophylaxis (PEP, siglas en inglés)
profilaxis preexposición: pre-exposure prophylaxis; (PrEP, siglas en inglés); tambien se llama “la pastilla para prevenir el VIH”—“the pill to prevent HIV”
prueba de resistencia: resistance test
los riñones: the kidneys
SIDA: AIDS (siglas en inglés)
sífilis: syphilis
sistema inmunitario: immune system
transmisión: transmission
uso de drogas inyectables: injection drug use
VIH: HIV (siglas en inglés)
VIH-positivo: HIV-positive
virus: virus

PARA MÁS TERMINOS, vea el glosario del Institutos Nacionales de la Salud:
TO READ more terms, go to the National Institutes of Health’s glossaries:

infosida.nih.gov/contentfiles/spanishglossary_sp.pdf

aidsinfo.nih.gov/contentfiles/glossaryhivrelatedterms_english.pdf

HIV TREATMENT, HEPATITIS C, STIGMA, AND MORE

BY **ENID VÁZQUEZ**

NELSON MANDELA'S GRANDSON, KWEKU MANDELA, ADDRESSED THE INTERNATIONAL AIDS CONFERENCE ON ITS OPENING DAY.

THE 21ST INTERNATIONAL AIDS Conference (AIDS 2016) returned to **Durban, South Africa** July 18–22. It was 2000 when the conference first took place in a developing country—meeting in Durban.

More than 18,000 delegates attended this conference organized by the International AIDS Society (IAS), the leading independent association of HIV medical professionals.

The theme of this year's conference was Access Equity Rights Now. Emphasis was given to addressing the needs of transgender people, men who have sex with men (MSM), and injection drug users at this year's conference. View webcasts devoted to these populations online.

Following are a few of the highlights at AIDS 2016.

DUAL THERAPY STUDY

The PADDLE study showed good results for dolutegravir plus 3TC (DTG/3TC)—basically, Triumeq without abacavir. This was a two-drug combination used alone for one year. All 20 patients put on DTG/3TC reached undetectable viral load (less than 50 copies) at eight weeks. At 48 weeks, 90% (18 out of 20) had undetectable viral loads.

The advantages to dropping abacavir from the single-tablet drug combination is not having to take a genetic test to check for allergic sensitivity to abacavir and not having to deal with the lingering questions about abacavir's potential effect on heart condition.

ISENTRESS ONCE-DAILY

Isentress taken once a day was found to be non-inferior to its FDA approved twice-daily dose. The ONCEMRK study used a pill available only in research, a 600 mg formulation of raltegravir (brand name Isentress). Two of them were taken once a day. The approved Isentress dose is a 400 mg tablet taken twice a day.

Of the 732 participants reaching 48 weeks of study, 88% achieved undetectable viral load (less than 40 copies), whether they were given a once-daily or twice-daily raltegravir regimen.

LONG-ACTING INJECTION: CABOTEGRAVIR

A monthly shot (every four weeks) was chosen as the dose going forward into Phase 3 for research with the intramuscular injectable regimen of cabotegravir and rilpivirine in the LATTE-2 study. About 90% of nearly 300 people on one of three different doses had undetectable viral load of below 50 copies at 48 weeks. The treatment was considered well tolerated. LATTE-2 will also continue to evaluate an injection taken every eight weeks, however.

EPCLUSA IN HIV

Although the new hepatitis C virus (HCV) medication was approved by the FDA in July without a specific go-ahead for people who are also living with HIV, the drug continued to show good results in people who have both viruses.

The ASTRAL-5 study reported a 95% SVR (sustained virologic response, or cure) for the 106 coinfected participants in the study. The researchers reported that the medication was effective and well tolerated regardless of past treatment experience or cirrhosis. >>

FOTO: ©IAS-ABHI INDRARAJAN

HIV TREATMENT FOLLOWING PREGNANCY CONTINUES TO BENEFIT WOMEN

A large international study of 1,652 women found that staying on HIV therapy following pregnancy benefited them more than discontinuing the meds. They experienced fewer AIDS-related complications than did the women randomized to stop their HIV treatment.

There was a high rate of virologic failure, however, for nearly a quarter of the women, which the PROMISE 1077HS research team said was "underscoring the need to improve adherence."

UNAIDS REPORT

UNAIDS produced a report detailing the state of HIV around the world along with goals, such as "Zero Discrimination," stating that, "Ignorance and misunderstanding continue to undermine efforts to end AIDS. In the worst cases, discriminatory attitudes and behaviors are facilitated by punitive laws and policies." Read the report at unaids.org/en/resources/documents/2016/Global-AIDS-update-2016.

STIGMA PERSISTS IN THE 'UNDETECTABLE' ERA

"In an era of widespread HIV treatment and undetectable viral load, stigma remains a persistent feature in the lives of almost half of people living with diagnosed HIV in the UK, according to findings from The People Living with HIV Stigma Survey UK 2015," reported Roger Pebody at aidsmap.com, the official news site of the conference. "Nevertheless the majority of people living with HIV score high on measures of psychological resilience, enabling them to cope better with stigma." The anonymous online survey was filled out by 1,576 individuals. Read the report, which also covers other stigma reports at the conference, at aidsmap.com.

GO TO aids2016.org for webcasts, abstracts, and slides. See also aidsmap.com/aids2016 (official provider of scientific news reporting for IAS 2016) and hivandhepatitis.com.

PREVENTION WITH PrEP

Prevention with the use of a daily pill again dominated an HIV conference. Several reports brought good news and not so good news on the use of Truvada (TDF/FTC) for PrEP (pre-exposure prophylaxis).

THE INTERNATIONAL TEAM behind the open label extension of the IPERGAY study reported that "Open-label on demand PrEP with oral TDF-FTC continued to be highly effective [97% risk reduction] in high risk MSM [men who have sex with men] to prevent HIV infection and had a good safety profile."

IN MORE THAN 1,000 African couples with mixed HIV status, providing PrEP to the negative partner until the positive partner could begin antiviral treatment (shown to reduce infectiousness when undetectable viral levels are achieved) provided a 94% reduction in risk of transmission, according to the Partners Demonstration Project.

THE NUMBER OF people starting PrEP in the U.S. is greatest in the states with the most new HIV cases, but, "Despite positive trends in Truvada for PrEP use, utilization must increase to ensure lifetime risk seroconversion decreases in areas of high prevalence HIV in the U.S.," reported Gilead Sciences, the maker of Truvada.

PrEP WITH TRUVADA needs to be studied in teenagers before it can be prescribed for them, but a U.S. study reported that of nearly 3,000 males ages 15 to 17 contacted for enrollment, only 260 were eligible, 152 refused participation, 108 were screened, and 79 enrolled. Then 40% of these (37 of the 79) dropped out of the study before week 48. "Non-adherent participants were significantly more likely than adherent participants to report worry that others would think they had HIV if they saw their PrEP pills," lead author Sybil Hosek reported in an oral presentation.

A RESEARCH TEAM looking at six clinical trials and one demonstration project reported that "rapid third generation antibody tests are sufficient to minimize the overall risk of drug resistance from PrEP." The report noted that drug resistance to one or both of the medications in the PrEP pill occurs primarily in people who have acute (new) HIV infection when starting or re-starting PrEP.

A NUMBER OF presentations looked at the biological reasons why PrEP has shown evidence of less effectiveness in women. Watch a webcast on the vaginal microbiome and more at programme.aids2016.org/Programme/Session/1257.

WHAT'S IN A THEME?

THE FOLLOWING is from AIDS 2016, which took as its theme "Access Equity Rights Now."

Access Equity Rights Now is a call to action to work together and reach the people who still lack access to comprehensive treatment, prevention, care, and support services.

Access Equity Rights Now is a call to action to strengthen the commitment to HIV research evidence-based interventions.

Access Equity Rights Now is a call to action to all HIV stakeholders to unite and overcome injustices caused by violence and the exclusion of people on the basis of gender, class, race, nationality, age, geographic location, sexual orientation, and HIV status.

Access Equity Rights Now is a call to action to repeal laws that infringe on people's human rights and deny communities the ability to participate in the world as equals.

Access Equity Rights Now reminds us that all our gains will be lost if we do not continue to push forward and build a strong global movement to change the course of the epidemic.

THE STATE OF CURE RESEARCH

BY **JEFF BERRY**

WHILE HIV CURE RESEARCH IS STILL IN ITS INFANCY, there are advances continuing to be made that were highlighted at this year's conference. Australian cure researcher Sharon Lewin, who along with Dr. Stephen Deeks chaired the Towards an HIV Cure pre-conference symposium, spoke during a press conference about the difference between the "aspirational" goal of completely eliminating HIV from an individual, and the more intermediate goal of remission. HIV remission is defined as the ability to stop antiretroviral therapy (ART) and remain healthy, while keeping the virus under control. Lewin points out that we have an improved toolbox to measure the virus in blood and tissue in people on ART, but we don't have perfect biomarkers on who can achieve remission, and more research is needed on where the virus persists, why it persists, and how to harness the immune response to eliminate it. Most importantly, as reported in this publication previously, a cure needs to be scalable, affordable, and available to everyone.

THE UPDATED Towards an HIV Cure strategy, released just prior to the conference, outlines the need for increased focus on key populations including those treated early in infection who tend to have lower levels of virus in their blood, and pediatric patients treated early who have different hiding spots for the virus due to distinct immune systems from adults. A tremendous amount of funding is going towards developing a protective vaccine (a large phase 3 study opens in November), which may help inform development of a therapeutic vaccine for those already infected. New gene therapy and gene editing tools have the potential to remove virus from cells (in test tube models currently), and to make cells resistant to HIV.

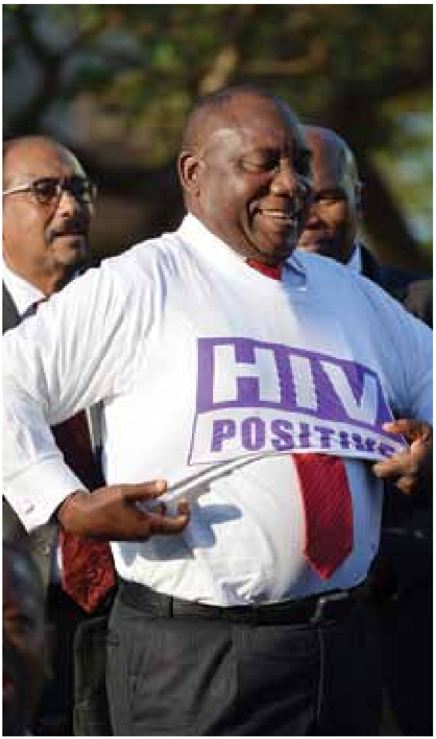
IN EPISTEM, a collaborative observational project of HIV-positive people with life-threatening hematological conditions who require stem cell transplantation, there was a report of 24 patients from various European countries, 15 of whom received a transplant. All 15 saw a decrease in the viral reservoir that has not been seen before in other cure strategies, according to Annemarie Wensing during a press conference. The result was consistent whether or not the transplanted cells had the genetic mutation that "befriends" the CCR5 receptor on the CD4 T-cell, which HIV uses as an entrance into the cell. In one patient there was no trace of HIV in the blood and only trace amounts in tissue, and in another patient no trace of HIV in either the blood or tissue. However we don't know if these patients are "cured" because all of the patients remained on therapy throughout the study, and are still on treatment.

Timothy Brown, also known as the Berlin Patient, is the only person ever cured of HIV using stem cell (bone marrow) transplantation, and remains HIV free after more than seven years off therapy. Transplants are extremely risky; there was 60% mortality in this observational study, re-emphasizing the fact that while this is not a feasible cure strategy on a broader scale, it may help us gain a better understanding for future strategies.

ANN CHAHROUDI of Emory University presented data on an animal model that uses SIV, the simian (monkey) version of HIV, in infant macaques. This is a novel *in vivo* platform to test cure strategies in infants, and moving forward it can be used to assess different ways to promote remission or test new cure strategies such as monoclonal antibodies, vaccines, and others. These animal models will be increasingly important in moving the field forward, as it would otherwise be extremely difficult to conduct these types of studies in humans.

TIME TO viral rebound is the amount of time it takes for the virus to bounce back in the absence of therapy. This is an intense area of research as a better understanding and measures of time to viral rebound will be needed when designing studies that use analytical treatment interruptions (ATIs) to test cure strategies. In some individuals who start therapy during primary HIV infection (PHI), stopping treatment is not followed by viral rebound, but rather a period of remission or viraemic control. Transient viraemic control can also occur in untreated PHI before the viral load becomes detectable. In a poster by G.E. Martin and colleagues, in a study comparing untreated and treated controllers, the duration of control did not vary between treatment groups, showing that some untreated patients during PHI experience prolonged viral control. The authors concluded that this suggests the impact of early ART on post-treatment control may be overestimated if the dynamics of viral rebound in untreated individuals are not considered.

IN ONE of the most thought-provoking presentations in the closing lecture at the HIV cure pre-conference, John Wherry from the University of Pennsylvania addressed the many common mechanisms that affect both cancer cells and HIV-infected cells. In the fields of oncology and HIV cure, researchers want to improve immune control, and many latency-reversing agents (LRAs) being studied in HIV cure research originated in the cancer field. In oncology, LRAs are used in combination, and for a prolonged period of time, and the same will most likely will be needed to achieve HIV remission. Wherry concluded with the astute observation that the two fields will need to talk and work more closely together and in collaboration going forward.



➤
"We value some lives more than others. Men more than women. Straight lives more than gay. Whites more than Blacks. The rich more than the poor.... **HIV is not just transmitted via sex; it is transmitted by sexism, racism, poverty, and homophobia."**
—**CHARLIZE THERON**, ACTOR AND NATIVE SOUTH AFRICAN

➤➤
South African Deputy President **CYRIL RAMAPHOSA** dons an activist T-shirt at the treatment access march as UNAIDS Director **MICHEL SIDIBÉ** looks on.

➤
SOUTH AFRICAN GRANDMOTHERS GATHERING—an organization of grandmothers, many of whom care for children whose parents have died from AIDS—stage a march and rally prior to the conference.

➤➤
On the final day, **VOLUNTEERS** are congratulated on a job well done.

"PrEP got a huge bump here in Durban. I hope we can harness the vast amounts of accumulating science, energetic advocacy, and sexy creativity into greatly expanded access and programming everywhere in the world, especially sub-Saharan Africa. And I hope we continue to push forward with new PrEP innovations (rectal and vaginal microbicides, injectables, inserts, implants) so people have prevention choices that fit their lives and enhance pleasure, intimacy, and peace of mind...ideally options that can include STI and unwanted pregnancy prevention with protection from HIV. And even better, stuff that works in both 'compartments'—the coot and the boot!"
—**JIM PICKETT**, DIRECTOR OF PREVENTION ADVOCACY AND GAY MEN'S HEALTH, AIDS FOUNDATION OF CHICAGO

"I witnessed the first HIV Prevention Trials Network research study that was led by African American, gay principal investigators, HPTN073, that tests the readiness and acceptability and adherence of PrEP in African American gay populations in three U.S. cities. The uptake of PrEP was high and the self-reported adherence data tracked well to the biological data that tests a participant's adherence. Very proud of the work the Black Gay Research Group and the National Black Gay Men's Advocacy Coalition has conducted that has increased the number of funded Black gay researchers by several times. It was a great day."
—**ERNEST HOPKINS** DIRECTOR OF LEGISLATIVE AFFAIRS, THE SAN FRANCISCO AIDS FOUNDATION

THERON: ©IAS-STEVE FORREST-WORKERS' PHOTO TODAS LAS DEMÁS FOTOS: JAN BRITTEENSON

UNANTICIPATED CONSEQUENCES OF AIDS SURVIVAL

SPECIAL REPORT LOOKS AT PAST, PRESENT, AND FUTURE CONCERNS

BY **MATT SHARP, THE REUNION PROJECT**

FOTO: MATT SHARP

THE REUNION PROJECT IN PHILADELPHIA, MAY 2016.

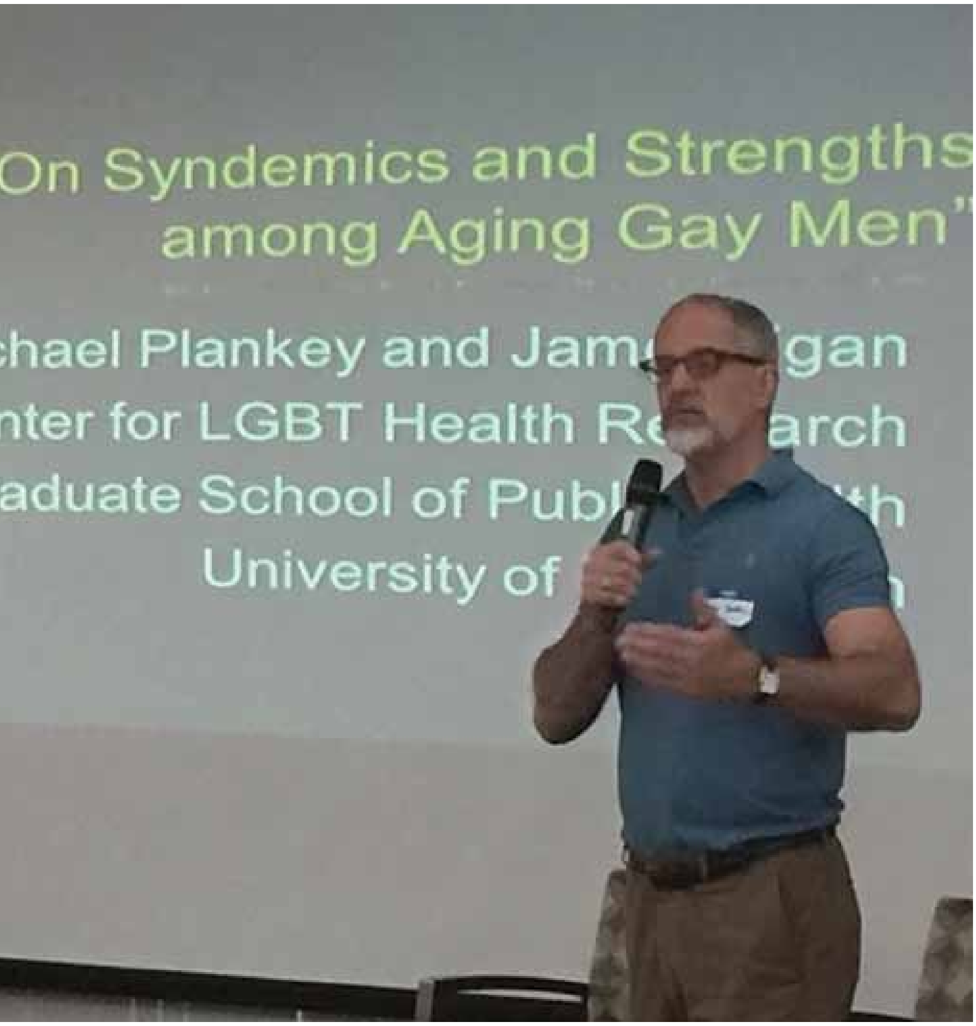
Earlier this year, I was commissioned to write a comprehensive report about HIV/AIDS long-term survivors. As a 28-year survivor, and one of a handful of AIDS activists leading mobilization efforts for survivors in San Francisco, later nationwide with The Reunion Project, this writing has been my own inspirational catharsis. But hopefully, The Unanticipated Consequences of AIDS Survival will engender discussion and stir creation of new research, new interventions, policy recommendations, advocacy, and programming before today's long-term survivors are gone. The full report, supported by Bristol-Myers Squibb, will be launched at the United States Conference on AIDS in Hollywood, Florida September 15–18.

I have written an attempt to tell the story and unpack the recognition and awakening of a considerable proportion of HIV-positive survivors, mostly in the United States, who for the past several years have been experiencing unintended negative consequences of a life with HIV. Their issues consist of co-morbid mental health conditions, unprocessed grief from decades of back-to-back losses, the mash-up of the physiologic and psychological effects of aging, and practical day-to-day issues. These consequences are layered, intersecting, and synergizing, one on top of another, year after year and together have created a groundswell of concern, now becoming a wake-up call for HIV/AIDS survivors and the rest of the world.

We know that, tragically, 95.5% of all people with AIDS did not survive in the first decade. HIV cases were not reported back then, but were simply estimated. Therefore, it is unknown how many total HIV/AIDS survivors are with us today. There has not been an epidemiological accounting of survivors and when they were diagnosed.

There are also untold HIV-negative men and women, family members, caregivers, and community members who fought for the lives in their communities while fearing for their own. They are survivors of a different kind, but have similar unprocessed grief and trauma. For the sake of issuing

CONTRASTING THE EARLY AIDS YEARS WITH TODAY
PROVIDES AN IMPORTANT PERSPECTIVE ON HOW FAR WE HAVE ALL COME.



RON STALL DISCUSSES HOW MANY GAY MEN HAVE EXPERIENCED TWIN EPIDEMICS, HIV/AIDS AND A CULTURE OF VIOLENCE AND VICTIMIZATION WHILE GROWING UP, AT THE REUNION PROJECT IN PALM SPRINGS, NOVEMBER 2015.

FOTO: MATT SHARP

a concise report its focus will be on HIV-positive survivors.

As survivor stories are heard, each one is unique with bits and pieces that are woeful, sometimes horrific, but always revealing. Listening and telling these stories is healing and may help those who were unaware and may have kept issues suppressed, or were simply isolated and uninvolved. Discussion, advocacy, further research, policy direction, and interventions will hopefully develop as more and more survivors come forward to tell their stories and advocate for themselves and other survivors.

Through looking back at HIV/AIDS, a context is made for our survivor history, including an understanding of the issues, the intensity, and a vivid perspective that many did not witness, or may not recognize.

Contrasting the early AIDS years with today also provides an important perspective on how far we have all come. All the successes certainly provide evidence for survival, and show the extent of what can be attained if a community comes together. Most survivors are thankful to be alive, and some have also fared well due to resilience, successful careers, and continuous social and intimate relationships. Unfortunately, there is confusion, misunderstanding, and downright apathy from many who see HIV survivorship as simply a reward of the benefits from a collective response to AIDS. Survivors tell of being given a congratulatory nod to finally reaching undetectable viral loads, but only left to fend for themselves without the intense years of support they had seen for years from medical providers, policy makers, and even families. Priorities shifted as AIDS deaths decreased, leaving many survivors with inadequate psychosocial support follow-up.

For the past several years, survivors in some jurisdictions such as San Francisco have been mobilizing, socializing, participating in advocacy councils, lobbying city government for policies and funding, participating in research and helping to develop research, and essentially creating new hope for themselves and their peers, and all people with HIV who will live long lives.

Social media has had a tremendous impact on survivor mobilization. There have also been many print, film, and media stories from AIDS organizations and websites, national broadcast stations, many Facebook group pages, and four major documentary films that have opened in film festivals and other showings. Of course the internet is awash with stories and film clips on HIV/AIDS survivors.

Survivors all over the country are reading and hearing the news, they are getting involved by coming together to socialize and share their stories, or are helping to make changes in their communities. Some are stepping up to advocate for policy changes that will help to provide services, especially in urban centers, where the majority of survivors live. Survivors are spawning research that is looking at the positive and negative consequences, the impact, and the connotation for longer, healthier, happier lives.

The report will also highlight some of the longest standing survivor mobilization and advocacy groups across the country.

In spite of the cards they were dealt, long-term HIV-positive survivors are living into their senior years, a kind of miracle no one expected to come out of the devastation of AIDS. Now that a considerable amount of time has passed many want to just make some sense of it all, and are beginning to come together to try and pick up the pieces of an interrupted life full of sickness, death, and unparalleled emotional strife.

MATT SHARP is a long-time HIV/AIDS activist and a member of the The Reunion Project's national organizing committee. The Reunion Project is funded by an educational grant from Bristol-Myers Squibb and in partnership with TPAN, the publisher of POSITIVELY AWARE.

ON TRACK

NINA MARTINEZ CONTINUES TO SHINE A LIGHT ON STIGMA

BY **RICK GUASCO**

FOTO CORTESÍA DE NINA MARTINEZ

For POSITIVELY AWARE's anti-stigma campaign, A Day with HIV, Nina Martinez submitted a picture of herself last year preparing to run a marathon. So, how did she do in the race?

"I finished," she said, pausing before sheepishly adding, "My time was 6 hours, 34 minutes."

Although she had previously run in half-marathons, raising money for youth-focused HIV prevention organizations, this was her first 26.219-mile race.

"I clearly did not train enough for it," the 33-year-old said. "Around mile 17, things started to hurt. When I started reaching my pain threshold, I just started reciting in my mind all the clinical pain I have overcome: This is no worse than having C diff [*Clostridium difficile*, a common cause of bacterial diarrhea among people living with HIV]. That's how I talked myself through it."

A DIFFERENT TRACK

MARTINEZ AND her twin sister were born 12 weeks premature in San Jose, California. At the time, in the early 1980s, blood needed to be drawn frequently for lab tests. As a result, both Martinez and her sister developed anemia, requiring blood transfusions. Six weeks after she had been born, Martinez became HIV-positive through a transfusion. (Her sister was being treated in a different hospital and does not have HIV.)

"I don't want any other child to go through what I went through," Martinez said. It's that desire to protect and educate others that propelled her to work in public health, focusing on HIV and sexually transmitted infections.

It wasn't until she was eight years old, however, that Martinez was diagnosed with HIV.

"At that age, you don't even know what HIV is," she said. "Being the only person in your family who has HIV is a very isolating experience."

HIV isolated Martinez even from her twin sister.

"It's even more difficult when you have a sibling with whom you're supposed to have a lot in common, but she didn't have to grow up with what I grew up with," Martinez said. "In many ways, [my sister] was reflective of the life I could've had. That was difficult for me to accept. My life could have been different—not only because of the virus, and because of having to take a number of medications, but because of stigma.

"Certain things are just not talked about," Martinez said. "A lot of the communication—or lack of communication—about HIV in my family was driven by Latin culture. Saving face is a very Latin thing, but I think there would be a lot less stumbling around in life if people just talked about things. Even if you don't know what to say, just the fact that you're trying can do so much. You can't know what the right thing to say is if you don't say anything at all.

"I didn't have the opportunity to process any feelings about being HIV-positive because it was just never brought up,” she said. “Since I wasn’t sick, my family felt there wasn’t the need to talk about it.”

FROM A DAY WITH HIV 2015

12:31 PM: ATLANTA, GEORGIA. Nina Martinez: Day 11,739—32 years, one month and 20 days—of living with HIV. In another 33 days, I’ll be running the Marine Corps Marathon!

STIGMA AND RACISM

MARTINEZ LEFT HOME for Washington, D.C. to pursue a college education, which she completed in 2005. Being a Latina living with HIV, she sees a connection between stigma and racism.

“I knew had a clinical understanding of HIV, but it wasn’t until I moved to Atlanta that I started to learn about other HIV-related issues such as HIV criminalization, and how that’s a form of stigma, and the role that race plays in HIV prevention and treatment,” she said. “I’m certainly more aware of many forms of stigma, and it hurts me. I have friends who are gay and HIV-positive, and it saddens me that people look down upon my friends just because of who they love, or their HIV status. Homophobia and racism—these are things that I did not grow up with.”

Martinez recalled her first encounter with racism, aboard a city bus soon after she had moved to Atlanta to pursue graudate work in public health.

“Someone asked me where I was from,” Martinez said. “For military kids, that question is complicated to answer. My father was in the Navy; we moved to eight cities while I was growing up. I mentioned I had just moved from Washington, D.C. The gentlemen said, ‘No, where are you from?’ I thought that was weird. He then asked, ‘Where were you born?’ I told him, California. But he persisted. ‘No,’ he said, ‘where’s your mom’s family from?’ Texas, I answered. ‘Where’s your dad’s family from?’ he asked me. New Mexico, I said. I was confused where this was going. And then his son piped in, ‘You’re not answering his question! You’ve got some Mexican in you, don’t you?’ That was my first overt experience with racism.”

Since then, Martinez’ education efforts have focused on addressing stigma and racism.

“A lot of conversations these days are centered on race,” she said. “How does race play into your everyday interactions? How does race make it easier or more difficult to do this, that, or the other thing? You could replace ‘race’ with ‘HIV’ and still have the same sort of conversation.”

A DAY WITH HIV

MARTINEZ SEES A Day with HIV as another way to educate while combating stigma.

“A Day with HIV is different because it gives a glimpse of what life with HIV is, or can be, beyond the bottles of pills,” she said. “What it does is allow people to shine a light on any particular moment of their lives beyond HIV. Most of the pictures that are submitted have nothing to do with pill bottles. A Day with HIV tells people that our days with HIV look much like yours. It sends the message that you can still live your life and still do the things you had planned on doing. That can make a big difference to someone who is scared of getting tested or of getting into treatment.”

On Thursday, September 22, take part in POSITIVELY AWARE’s anti-stigma campaign. **A DAY WITH HIV** displays 24 hours in the lives of people living with and affected by HIV. On September 22, **GRAB** your smartphone or digital camera and capture a moment of your day. **WRITE** a caption that includes the time of day, location, and what inspired you to take your photo. **POST** your picture and caption with the hashtag **#adaywithhiv.** You can also **UPLOAD** your photo submission at adaywithhiv.com or **EMAIL** it to photo@adaywithhiv.com, and it will be included in our online gallery. Select photo submissions will be featured in the November+December issue of **POSITIVELY AWARE**. Four photos will be chosen for four different covers of the magazine. **FOR DETAILS**, go to adaywithhiv.com or email photo@adaywithhiv.com.

#adaywithhiv

A DAY WITH HIV
SEPTEMBER 22, 2016

FOTO CORTESÍA DE NINA MARTINEZ