



WINTER 2019



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Walldeline Francois-Sainvil is Rising Up!



Walldeline Francois-Sainvil likes to tell you not just the date of key events in her life but the day of the week as well. Her coming-to-terms with being HIV positive began the day her uncle passed away from AIDS. “That was in December, 2011,” she recalls, “on a Saturday.” Acceptance of the man she loves and his inability to deal with his own positive HIV status emerged on August 31, 2012, “on a Friday,” she notes. Marrying him the next year on March 22 was also, “on a Friday.” Now there’s a new date and day marking her calendar, one that’s filled her life with pride and purpose.

“It’s kind of a funny story,” she begins. She took her son to the doctor where not one but three people handed her a flyer about the Ryan White HIV Peer Counselor program. “I thought, if these people are thinking of me, this must be meant for me.” She beams, “An angel came upon me that Monday when I received that flyer.” She began the 12-week course as an HIV

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HIV Today. Do You Know Enough?

Leonard N. Jones

Leonard N. Jones,
Ryan White Part A
Grantee



For most people, their perception of HIV is rooted in the era in which they were born. If you lived through the 1980's, you remember the onset of the HIV epidemic and the devastating ravages of AIDS. If you were born in the decades that followed, HIV transformed into a crusade of prevention and treatment, with HIV testing and medical care made available to all. But for all generations, the facts about HIV today are not nearly as widely known as they need to be if we are going to halt this unrelenting epidemic.

Locally, the impact of HIV is staggering. Broward County remains #2 in the nation for new HIV diagnoses. In 2017, our total population of 1.9 million included more than 20,600 people living with HIV, of which 8,499 accessed Ryan White Part A services. But there remained 3,149 people diagnosed who did not seek treatment. Way too many people are afraid to talk about HIV, much less access care. It's time we open up the conversation. Talk to your family, your friends, your coworkers, tell anyone who will listen: HIV is now a manageable condition and treatment not only prolongs life, it helps prevent the spread of HIV. The discussion should be no more daunting than one about diabetes or any other chronic illness, and it begins with knowing the facts. *Do you know enough?* **Answer the questions below and update your HIV perspective.**

1) The average lifespan in the U.S. is 79 years old. The average life span of a person living with HIV and adherent to

care in the U.S. is A) 38 years old B) 58 years old C) 78 years old. **Answer: C) The average lifespan of a person in the U.S. living with HIV and adherent to care is 78 years old, virtually equivalent to the average lifespan of a person without HIV** (Avert.org, May 15, 2017). With adherence to medical treatment, HIV today is a manageable condition with which one can live a long and healthy life.

2) A person living with HIV who has attained "virally suppressed" status cannot spread HIV. A) True B) False C) Not yet determined. **Answer: A) True: People living with HIV who adhere to medical treatment as prescribed and maintain an undetectable viral load have effectively no risk of transmitting HIV,** even to HIV-negative sexual partners, according to Centers for Disease Control and Prevention (CDC).

3) The populations at risk for HIV in Broward County are A) Black/African Americans B) Hispanics C) Whites D) Senior 50+ E) All of the above. **Answer: E) All of the above.** Black/African American men and women comprise the largest groups living with HIV, followed by Hispanics and Whites, each representing 26% of the County HIV population. Seniors and young adults 20-34 years old are also increasingly at risk, as are transgender women.

4) If I am in a committed relationship or not having sex now, I do not need to be tested for HIV. A) True B) False C) Not yet determined. **Answer: B) False: Everyone needs to be tested regularly for HIV.** CDC attributes 40% of new HIV infections to transmission by people undiagnosed and recommends everyone ages 13 to 64 years be tested for HIV at least once and those with specific risk factors, at least once a year.

For information about HIV care, contact Broward Ryan White Part A at 954-357-9797 or visit our website: Broward.org/RyanWhite.



THE RYAN WHITE PART A PROGRAM OF BROWARD COUNTY QUARTERLY JOURNAL

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Next Issue
FOCUS ON
The Diverse Faces
of Stigma

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Ryan White HIV Peer Counselor-in-Training Walldeline Francois-Sainvil is Rising Up!



Walldeline on her way to celebrate with a fellow Peer Counselor-in-Training, December 2018

The Ryan White HIV Peer Counselor Training and Certification Program is a grant-funded initiative intended to prepare peer candidates for the workforce with the goal of economic independence. Broward County residents living with HIV are educated to assist others in navigating the HIV care continuum in a 12-week training class followed by an 8-week internship. Upon certification, Ryan White HIV Peer Counselors are given access to jobs in the community. **For information or to apply to the program, call 954-357-9797 or email RyanWhitePartA@broward.org.**

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Peer Counselor-in-Training on November 13, 2018, the first of twelve life-affirming Tuesdays.

When Walldeline was told she tested positive for HIV in January of 2010, her mother, who is from Haiti, was with her. Walldeline, pregnant at the time, remembers, “When I got the call from the doctor to come back in, I thought my bad news was another miscarriage.” She had already suffered several. When the doctor told her she had HIV, she says, “I froze. I said, ‘You got me mistaken with someone else.’ I had to translate it to my mom. In Creole they don’t separate HIV and AIDS,” she explains. There is no distinction between living with the virus and suffering AIDS related illnesses. “It’s one word, *sida*. My mom was in disbelief.”

When Walldeline told the father of her child she was HIV positive, his concern was who gave the virus to whom? “That

wasn’t the reaction I was expecting,” she frowns. The question plagued Walldeline as well until she discovered that her boyfriend had in fact been diagnosed the year before they met. They did marry in 2013 and separated a few years later but despite the difficulties, Walldeline says, “He’s the first and only person I’ve truly loved. We are a family. Family fights but still sticks together. That’s my family, just as in Christ.” Their son, who is now 8 years old, was born HIV negative. She also has a daughter almost 18 years old from a previous relationship. “The first year with my son, I had to have a lot of family support,” admits Walldeline, who had slipped into depression. “I didn’t feel connected with him, I was detached, due to my diagnosis.”

At that time her uncle was dying from AIDS. “For three months, I took care of my uncle,” she recounts, “and I never told him about my diagnosis. That first

year, I was struggling with taking my medication.” When her uncle passed away, Walldeline was given his death certificate which listed AIDS as the cause of death. She recalls, “His hospice nurse said to me, ‘You may have HIV but you’re not going to die from it.’ I said, ‘Note to self: That’s right. That’s not going to be on my death certificate!’ That gave me a boost to take my medication.”

It took Walldeline a couple of years to tell her daughter about her diagnosis. “My daughter’s very smart,” she laughs, and at 12-years-old had figured it out. Not long ago, Walldeline was asked to come speak about HIV at a high school. “I told them, ‘I live the HIV life but I don’t have the proper education. I’m not someone who can explain it.’” More recently, Walldeline’s daughter, now a high school senior, was filling out a college application and asked if she could tell how her mother’s story had affected her. “I said go ahead.

Ryan White HIV Peer Counselor-in-Training

Walldeline Francois-Sainvil is Rising Up!



Walldeline's son marching on World AIDS Day, 2014



Walldeline Francois-Sainvil
HIV Ends with Me

Continued from Page 3

I wanted to hear it," Walldeline chuckles. "When she opened that door, the Peer Counseling door opened, too. When I applied for the program, my daughter said, 'Remember when you told them you're not that someone? You are that someone! You're rising up!'"

"One of my biggest struggles in life was I learned differently," discloses Walldeline. "I became that disturbed child, the class clown. I wanted to learn but I couldn't get that one-on-one. They put me in an alternative school, Cross Creek. It helped me conquer a lot. I don't think I would've made it if I weren't there."

Walldeline was the first one in her family to graduate high school and college, earning her associate's degree in medical administration. "When we did that first Peer Counselor class and I heard, 'You're the class of 2019,' I went home and told my daughter, 'You're not the only class of 2019!'"

The rest of Walldeline's "funny story" about applying to the Peer Counselor program was that she almost missed the deadline and was last in line to be interviewed. "I said, 'I don't care, I will be the last person and sit here all day even if I don't get picked.'" Her tenacity paid off; she was one of 22 chosen for the program. "I was happy I pushed myself to do it. I feel like everything I'm doing now is for me. I feel great. I'm no longer telling my story with tears in my eyes. I stopped worrying about how to impress or how people will look at me. What they would think about me if they knew I had HIV. I stopped living the life of 'what if,' the life of tomorrow, and started living today."

Concludes Walldeline, "Every Tuesday, I wake up and put on my clothes. It feels like I have a career. I have success. This is success."



Currently in Broward County there are an estimated 1,970 people of Haitian descent living with HIV. From 2016 to 2017, there was a 30% decrease of new HIV diagnoses in Haitian-born males and a 21% decrease for Haitian-born females. In 2018, Broward Ryan White Part A provided HIV services to 835 Broward residents of Haitian descent.

*Florida Department of Health
& Broward Ryan White Part A,
Provide Enterprise*

Broward County HIV Planning Council Update

Your Positive Voice in the Community

Here's What's New

New Leadership:

Meet Vice Chair Claudette Grant

At the end of 2018, the Broward County HIV Health Services Planning Council (HIVPC) elected Claudette Grant as its new Vice Chair. Over the past 30 years, Claudette has served as a leader in the HIV community of Broward County and will be one of the guiding forces in the continued building of an inclusive and proactive Council. Filling this vacancy allows the Council to maintain a balance in leadership and continue its mission to strengthen and improve the service system for people living with HIV.



Claudette Grant,
Vice Chair of Broward
County HIV Health Services
Planning Council

Membership Drive:

Coming to a Ryan White provider near you!

The HIVPC kicked off its membership drive in January 2019, and is scheduled to visit a Ryan White agency near you! Each HIVPC standing committee will set up shop at agencies throughout the county in an effort to acquaint themselves with the many Broward communities. The goal of the membership drive is to connect with those living with and affected by HIV, and to inspire more community members to become involved in the fight to erase the stigma plaguing the HIV community. During recruitment, members will also take the opportunity to provide education about Broward Ryan White services and promote participation in the Planning Council as an opportunity for community involvement and personal empowerment.

The Planning Council is intended to reflect the varied populations that make up Broward County, particularly those most affected by HIV. Currently in Broward County, non-Hispanic Black males and females are disproportionately impacted by HIV and there is an emerging epidemic in young adults ages 19-24. The Planning

Council is targeting these populations in its outreach and recruitment efforts in the hope of engaging new members to bring forward the concerns and needs of these two groups.

The responsibilities of an HIVPC member include setting Planning Council priorities and determining which services are most important to people living with HIV in Broward County. Members also decide which services get funded and allocation amounts. But key is consistent attendance at scheduled meetings. Committee involvement can include community outreach and education, recruitment of new members, member training and the review of health data and HIV service standards.

Set Priorities That Affect You: Join the Annual Review Process

The Priority Setting Resource Allocation (PSRA) Committee is gearing up for its annual PSRA assessment of data which is used to set priorities in the distribution of resources and funds. Data is used to determine the needs of the community and then decisions are made about funding for HIV services throughout Broward County. Through the assessment process, which involves incorporating

research, data analysis, qualitative and quantitative feedback and strategic planning, community members have input into the care and financial support which they themselves receive. It's a sizable effort but a critical one, and proves as worthy as it is rewarding. The PSRA committee meets every 3rd Thursday at 9:00am, kicking off the first quarter of the 2019-2020 fiscal year. **For information on becoming involved in this process and/or committee, please contact the Planning Council via phone at 954-561-9681 Ext. 1343 or Ext. 1295, or email HIVPC@brhpc.org.**



GET INVOLVED! Join the HIV Planning Council or an HIVPC Committee.

We are currently seeking community members to serve on the Planning Council and its committees. As we continue to make decisions and prioritize needs of the populations we serve, it is important that we have PLWHA and HIV advocate representation across the board. If you or someone you know is interested in joining the Planning Council or any of its five committees, please get in touch!

954-561-9681 Ext. 1343

For more information on the Planning Council, please visit:
Brhpc.org/programs/hiv-planning-council/

You're Not Just a Number!

The Florida Department of Health on the Pharmacy & ADAP

A simple motto governs the HIV pharmacy and the AIDS Drug Assistance Program (ADAP) at the Florida Department of Health in Broward County (FDOH-Broward). ***“No client leaves without medication, regardless of ability to pay,”*** says Dr. Paula Thaqi, Director of FDOH-Broward. ***“Second, great customer service is mandatory.”***



Pharmacy Technician Ninan Abraham
*dispensing prescriptions at the Florida
Department of Health in Broward County*

That brings real-life results:

- Average time for a prescription refill: 4 to 12 minutes.
- Average time to fill a new prescription: 16 to 30 minutes.
- Average time for ADAP clients to complete certification paperwork: 30 minutes.

Now, FDOH-Broward has made the service even more convenient in three ways: Eligible clients can get 90-day refills, recertify for ADAP online, and get prescriptions delivered by mail. Those improvements help clients take medications on time and correctly. “The service is way better than it used to be. I’m in and out in, like, 10 minutes,” says Kenya, a Fort Lauderdale pharmacy client for six years. “If there’s a problem, they fix it on the spot.”

FDOH-Broward pharmacies at Fort Lauderdale Health Center and Paul Hughes Health Center in Pompano Beach supply medication monthly to 2,100 clients living with HIV in Ryan White Part A and ADAP programs, 96,000 prescriptions per year. To ensure clients get refills on time, FDOH-Broward takes several steps, including reminder phone calls and staff intervention. The result: 95 percent of clients received medications when due. Of the rest, two-thirds were on time the following month after follow-up by FDOH Disease Intervention Specialists. “The pharmacy goes above and beyond. You’re not just a number,” says Nicholas, a client on and off for 15 years.

To increase convenience, the pharmacy now offers 90-day medication refills instead of monthly, based on physician’s approval. Clients must be eligible for ADAP and enrolled in the 90-day dispense program. So far, 259 of the 656 eligible clients are enrolled. In November 2018, the pharmacy began signing up clients for FedEx prescription delivery, a huge convenience that reduces medication lapses.

ADAP supplies HIV medications to 4,357 clients, at no out-of-pocket cost. About 92 percent of those clients have undetectable levels of HIV, and 99 percent were either very satisfied or satisfied with ADAP services. Clients can now enroll to complete their twice-yearly, federally-required recertification process online at home or at Paul Hughes Health Center. More than 1,000 have enrolled so far. In client surveys, 97 to 100 percent were very satisfied or satisfied with pharmacy services, laudable real life results for FDOH-Broward’s mission to deliver great and accessible customer service.

For information on the pharmacy or ADAP, please call 954-467-4700 Ext. 5629 or 5630.



The average Viral Suppression rate for persons living with HIV in Broward County is 64%; for Broward Ryan White clients, the Viral Suppression rate is 87%. In the 2017 fiscal year, Broward Ryan White Program provided HIV services to 8,499 clients, a 4% increase from the previous fiscal year.

*Broward Ryan White Part A,
Provide Enterprise*

LOCAL HIV HERO: Jean Starkey

The Art of Walking in Someone Else's Shoes



Jean Starkey CDTC SMART Ride Red



Jean and her artwork at Ribbons for the Children 2015

Jean Starkey is famous for her quick smile, generous nature and myriad humanitarian efforts, at least within the Broward HIV community. As a Chronic Care Specialist at Children's Diagnostic and Treatment Center (CDTC) in Fort Lauderdale, Jean counsels clients and implements programs for the 11,000 children served. But her job, though multifaceted, does not define nor limit her contribution to the HIV cause, which began 16 years ago with her involvement in the HIV Planning Council.

"At first I didn't know why I was involved in the Planning Council," recalls Jean, "and then I had this idea: What if we walked in each other's shoes?" Her idea inspired a World AIDS Day initiative in which providers and clients partnered, sharing experiences such as driving to the food bank together. "World AIDS Day helped me find my voice," she claims. "I chaired World AIDS Days for ten years, starting as a volunteer. I just wanted to help." Fellow HIV activist Chuck Williams met Jean 15 years ago on World AIDS Day. "It's a passion for her," he asserts. "She became chair of the World AIDS Day committee 10 years ago because no one else would do it. She would ask, 'Am I doing okay?' and I'd say, 'You're doing great.'"

Volunteering for World AIDS Day led to employment at CDTC as a part-timer and then as full-time Chronic Care Specialist, a role in which Jean thrives. "Just the way she talks about her clients," admires Chuck. "They can call her 24 hours a

day, she's there for them." In addition to counseling, Jean channels her creativity into outreach activities such as "You Matter Mondays," where attendees learn hands-on skills and the CDTC employee favorite, Jean's "Red Tag Sale," a makeshift thrift shop within the agency to benefit the SMART Ride (Southern Most AIDS HIV Ride).

She also serves as the CDTC rep for the SMART Ride. Quips Jean, "There's something about 700 do-gooders," referring to riders and event staff alike. During the two-day, 165-mile ride from Miami to Key West, Jean's job is to make people feel good when they arrive at the pit stops. "For Ride Week, I get to dig in, push my limits, because I care deeply about others. The overwhelming joy, hope and remembrance recharges my commitment to serve others when I return to CDTC."

Perhaps one of Jean's most notable accomplishments was creating the Youth Art Contest, an adjunct event to CDTC's Ribbons for the Children Art Auction which features professional artists. "Jean started the youth competition," says Chuck, who's Board President of Arts United, "because she felt young people today are missing the message about HIV." Contributors include students from schools such as Dillard High where, he stresses, "They're in communities very much dealing with HIV. It gives these youth an opportunity to open up about it."

An artist in her own right, Jean has been donating her paintings to the Ribbons for the Children Auction for the last few years. "We're supposed to be taking art classes together," jokes Chuck but apparently Jean doesn't need them; this year her painting "Joy" elicited a silent-auction bidding war before it sold! In the accompanying Artist Statement, Jean shared some inspiration gleaned from her own prolifically positive life: "One of the greatest lessons I have learned from the clients we serve is that no matter how hard life seems to become, it is important to find moments of joy. No matter how small the moment. For it is those moments of joy that bring light on the darkest of days and hope to the most hopeless situations. It is those moments of joy that remind us that tomorrow will be a new day and our light will shine again." True to her words, Jean's light at CDTC and throughout the HIV community sparkles as bright as ever.



"Joy" by Jean Starkey, auctioned at Ribbons for the Children 2018

“You’re Everything You’re Supposed to Be”

Honor and Inspiration on Trans Remembrance Day

On Transgender Remembrance Day, commemorated on November 20 this past year as it has been every year since 1999, the Pride Center in Wilton Manors hosted an evening memorializing trans community members murdered in brutal acts of transphobia across America. County and city officials spoke in deference to the memory of the victims and offered unqualified support for the trans community both locally and at large. Wilton Manors Mayor Justin Flippen presented a proclamation honoring Trans Remembrance Day which cited the city’s commitment to “ending the epidemic of transgender violence.” A ceremony honoring the 24 trans women who, lamented Jodi Reichman, Transgender Coordinator for the Pride Center, “lost their lives trying to be their authentic selves,” was the evening’s heartrending culmination.

Before the ceremony, TransInclusive Co-founder Tatiana Williams took the podium to introduce the evening’s guest speaker. “Many of you don’t know that since 1999, 368 trans women died due to these violent murders and many of them were women of color, that’s why we’re here,” she informed the packed room, stressing, “It is vitally important that we memorialize those we lost. We must stay visible, we must be vigilant, and we must protect our rights.” Tatiana then relinquished the spotlight to transgender rights activist Lala Zannell with the high praise, “This woman inspires me and I’m a hard woman to inspire.”

Lala is the outspoken force behind the New York City Anti-Violence Project, an advocacy group promoting LGBTQ rights and safety. Fiercely passionate about the trans struggle, Lala implored her audience to, “Celebrate the ones you see every day, the ones who don’t get it.” She challenged



Tatiana Williams, Lala Zannell, Mayor Justin Flippen

those present for the memorial with the pointed question, “What have you done for the ones who are living today?” Lala herself has made a career of furthering trans causes. She even spoke at the White House for the first Women’s History Month briefing to include trans women and the last trans women of color briefing under the Obama administration, which she added, “was not supposed to happen but I made it happen.” She told her trans audience, “I want you girls to do more. You don’t need a policy to be a better human being,” declaring she came all the way from New York to let them know, “You are enough. You are everything you’re supposed to be.”

“

What have you done for the ones who are living today?

Lala Zannell

”

The evening concluded with a solemn memorial ceremony. Projected on the screen behind the podium was a picture of the late trans activist Bishop S.F. Makalani-Mahee with the quote, “Where



Lala Zannell,
the evening’s guest speaker

there is love, there is no separation, there is no divide. The power and spirit of love unite us and make us one.” One by one, images of the trans women murdered this past year were projected on the screen, mesmerizing the room. Each slide included the jarring details of a violent death. And before each name was read out loud, one of the 24 candles glowing on the table beside the screen was blown out, symbolizing just how suddenly a life can end.

As each slide progressed, each candle snuffed out, each picture revealed, audience members spontaneously took over reading the succession of victims’ stories. At one point in the evening, when the trans people present were asked to stand to be honored, half the room rose. But when it came to honoring the memory of those murdered, there was no difference nor divide between trans and any other self-identifying designation in the room. The succession of unified voices proved that those present came together on Transgender Remembrance Day as one community to stand in solidarity with their trans sisters and brothers.

On Participating in HIV Vaccine Trials

With Dr. Janine Maenza and Dr. Hyman Scott



Dr. Hyman Scott

The HIV Vaccine Trials Network (HVTN) has been orchestrating clinical trials for close to a decade, with 79 clinical trials involving 22,000 study participants conducted in nine countries. Dr. Janine Maenza of the Seattle Vaccine Trials Unit and Dr. Hyman Scott of Bridge HIV in San Francisco, both medical directors for HVTN studies, speak about their interactions with the trial participant community.

How did you get involved in the field of HIV?

Dr. Janine Maenza: In medical school in New York City in the late 1980's, I worked with HIV-positive people for the first time. HIV was the epidemic of my generation. I was asked to work in HIV treatment trials and realized that what I loved about clinical trials was the idea of working one-on-one with participants and fostering relationships with people.

Dr. Hyman Scott: In my first year of medical school at Yale, I worked with an HIV physician. I saw firsthand that if a medication or preventive tool interferes with somebody's life, they're not going to use it. There's also a clear need for work to eliminate the disparities that exist and to include disadvantaged populations. That's how I got interested in HIV prevention: we need to understand how to address the disparities that are driving the epidemic.

What is the relationship between a study participant and an investigator?

JM: I always see the relationship between myself and a study participant as two people sitting across a table from each other, I think it's symbolic and simplistic. When discussing the possibility of joining a clinical trial with a potential participant, I make sure the individual has enough knowledge about the study to join, while I'm gathering information about them. It's a very bidirectional process. In my role,

I'm translating science to give information in a way that isn't just immunology data. I constantly work with the participant to make it make sense on a personal level, in a way that applies to their own life.

HS: As a clinician, I try to be humble and understanding of the experiences people have had that lead them to distrust the medical community. There's a long, well-documented history of violating that trust. We respect that trust is earned, and we do all that we can to foster trust and provide support. This is an ongoing process. Because participants trust us, they can talk to us about the science and things they may not otherwise feel comfortable discussing with others. We show that we care about people as they are, and not just as study participants. That becomes a human connection we want to foster, the foundation for trust.

What do you believe it means for someone to be part of a clinical trial?

JM: To me, it's a person choosing to participate, becoming a part of the overall efforts being made to defeat HIV, and making sure that decision is right for them. As the field of prevention research changes and as their circumstances change, we continually check in with new information and they do, too. Our participants see our clinic as an available repository of information; they can come in and ask any question about HIV research or epidemiology.

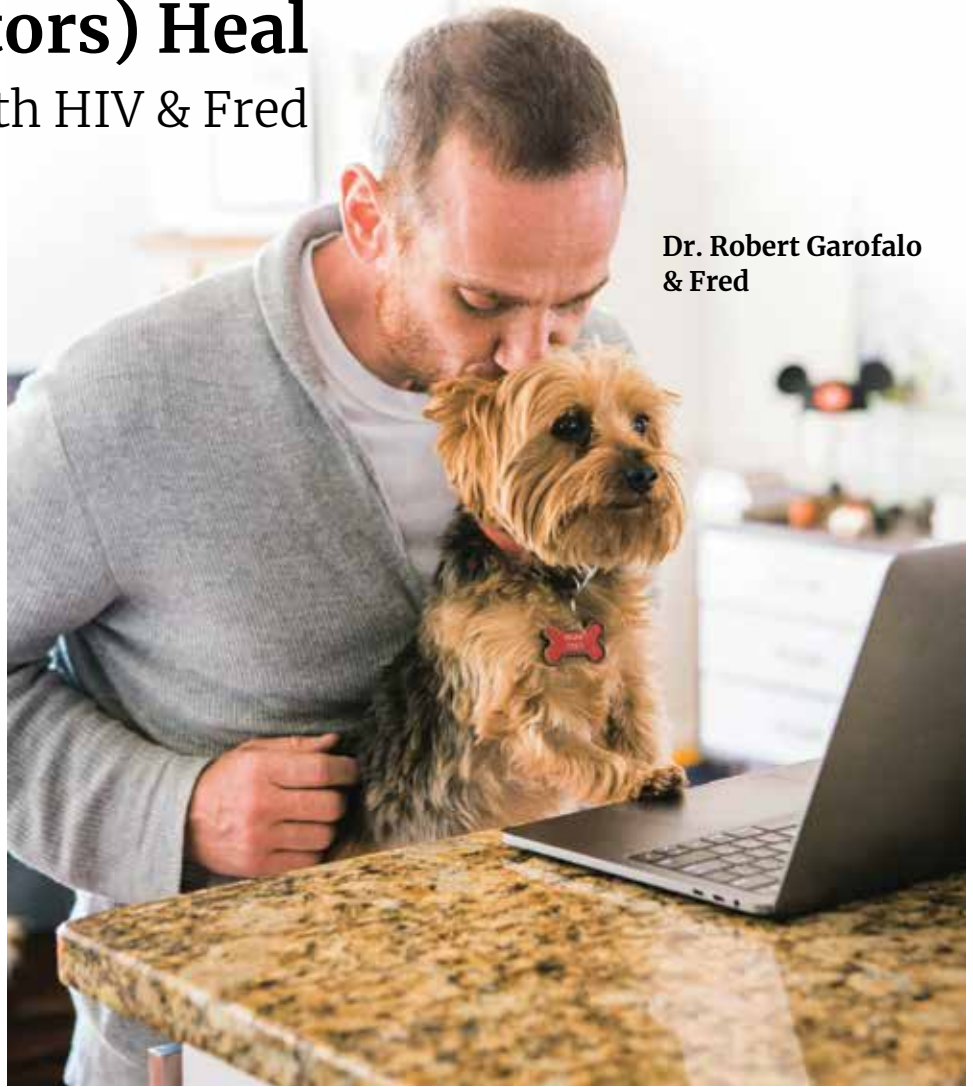
HS: From what I've seen, the biggest motivators for a participant are altruism and being a part of something bigger. Again, there's a tremendous amount of trust that our participants put in us, volunteering to help us find something that may or may not work, with the reality that there will likely not be direct benefits for them. It's inspiring as an investigator to be able to work with people who are willing to volunteer for a clinical research trial.

There are an estimated 5,000 new HIV infections daily around the world. The HVTN is the world's largest publicly funded collaboration facilitating the development of vaccines to prevent HIV and has, together with global partners, demonstrated significant scientific progress in pursuit of a safe and effective HIV vaccine.

When Dogs (and Doctors) Heal

Dr. Robert Garofalo on Living with HIV & Fred

On World AIDS Day 2015, Dr. Robert Garofalo, Chief of Adolescent Medicine at Ann & Robert H. Lurie Children’s Hospital in Chicago, launched an online study to demonstrate that owning a dog yields health benefits for people living with HIV. For Dr. Garofalo a.k.a. Rob, the study, published in June 2017, was just the first step in his bigger mission to have dog ownership acknowledged within the HIV community as a positive influence on health outcomes and funded for those in need. “Some of the best ideas I’ve ever had are the simple ones,” notes Rob, whose inspiration behind this idea was highly personal; he credits his own dog Fred with saving his life after he himself was diagnosed with HIV in 2010.



Dr. Robert Garofalo & Fred



Fred
Halloween 2018:
The Holy Hound

“**W**hen I was diagnosed,” Rob confesses, “it challenged me in way I had never been challenged before. I led a privileged life. Had a great job, great partner at the time, a supportive family, all the things you’d think you’d need. But still, the diagnosis brought me to my knees.” Rob lost himself to isolation, admitting, “I shamed myself.” But in January of 2011, he had what turned out to be perhaps his best idea: Rob was going to adopt a dog. “I decided to get a dog when I was pretty suicidal,” he recalls. “It was the most impulsive thing I’ve ever done. I had never even had a pet. I googled ‘puppies in Chicago’ and within 12 hours, Fred was mine.” Fred, a charismatic Yorkie with apparent star potential, was not a “rescue” dog per se, Rob notes but, “The rescue was mutual. That dog brought me back to life. He enabled me to find a peace and a joy that I thought I may never have again.”

Rob was one of five authors of “A Web-Based Study of Dog Ownership and Depression Among People Living with HIV,” which assessed that dog ownership had a “positive impact on psychosocial outcomes” for people living with HIV.

It cited that people living with HIV are approximately twice as likely to be depressed than HIV-negative individuals and noted depression is associated with low antiretroviral therapy (ART) adherence. “Noncurrent dog owners had 3 times higher odds of depression in comparison with current dog owners,” the study concluded. “Depression influences not only the psychological health of [people living with HIV] but is a correlate of overall HIV disease progression as well. Support for, or promotion of dog adoption and ownership may be a novel intervention to positively impact depression and, in turn, positively affect other HIV-related health outcomes.”

“The study was just to get ‘skin the in the game,’” explains Rob. “I wanted a published research paper on the impact of HIV in people living with dogs.” His greater vision is a grant from the National Institutes of Health (NIH) to make dog ownership among people living with HIV a sanctioned option funded for those in need. The provision would not be

exclusively for people living with HIV but intended for anyone with a chronic illness who would benefit in this way from owning a dog. Rob, who prides himself on his grant-writing expertise, feels he's "cracked the code" on writing NIH grants and it's just a matter of time before he succeeds in getting one.

He's managed to succeed in a variety of philanthropic ventures, with a little help from Fred. In 2013, Rob founded Fred Says, which to date has raised more than \$300,000 for agencies who do "creative work" with HIV services. The charity, a 501(C)(3) nonprofit, focuses on supporting adolescents living with HIV, whether it's for medical services or helping them buy shoes. In addition to the Fred Says website, Rob has harnessed Facebook to spread the Fred Says message. Fred does most of the "talking" and posing, and that furry little face has made him a lovable canine HIV ambassador with 40,000+ Facebook page likes.

One of Rob's most ambitious projects is "When Dogs Heal," a traveling photo essay of people living with HIV and their pets. Rob scoured the country with dog photographer Jesse Freiden, "recruiting people who had amazing stories of dogs that healed." He cites Brad, a meth dealer who got clean for his former fight dog Thor. And Paolo, a Hurricane Katrina evacuee who contracted HIV through rape and credits his French bulldog Stud with "truly saving my life." The exhibit has traveled to eight U.S. cities so far but its reach is both international and universal. "I got an email from someone battling depression in Thailand and another from a woman in Spain with Lupus who wrote how much these stories with dogs meant to her. It's specific to HIV," observes Rob, "but it touches everyone."

Rob attributes the success of his HIV advocacy to candor and transparency. "Being really open about who I am has made me relatable," he maintains.

Continued on Page 14



People living with HIV are twice as likely to have depression compared to those who are not infected with HIV.* In 2017, 54% of Broward Ryan White Part A clients were treated for clinically diagnosed depressive related symptoms.

*nimh.nih.gov/health/topics/hiv-aids/index.shtml

Broward Ryan White Part A, Provide Enterprise



Facebook Post
"I put on my best bow tie to remind you that the Ride for AIDS Chicago is coming"



Rob and Fred at home
World AIDS Day 2017.

The Music Lives On

Los Doctores and their Songs of HIV Education, Prevention & Hope



Rosalia and Louis Curbelo
on their CD Los Doctores

My name is Louis Curbelo. I was born in Brooklyn, New York. I am Puerto Rican; my parents are from Puerto Rico. I have been HIV positive since 1987. I came from a time that HIV was a death sentence. Between 1987 and 1992, I lived a life of destruction thinking I was going to die. I got more into drugs and alcohol. I lost my family, home, material things and became homeless. It was in 1992 that I decided to seek help.*

In a concert together as *Los Doctores* on World AIDS Day, 2009, Rosalia and Louis Curbelo performed, from their bilingual repertoire about HIV, *I Remember*

You. “Te recuerdo a ti, hoy igual que ayer. I remember you like it was yesterday,” they sang. Unbeknownst to them at the time, that was to be their last performance together. Five months later, Louis passed away from AIDS. But in the course of their six-year musical career together as the singing, conga-playing, maracas-shaking *Los Doctores*, the couple wrote and performed 60 original compositions about HIV and AIDS, in English and Spanish, promoting education, prevention and hope. And when she talks about it today, Rosalia clearly remembers the music and above all else, Louis as if it were only yesterday.

I went to a clinic, got a doctor and started going to a support group, and I started building

a relationship with my daughter. She was five years old. From 1992 till now, I continue doing the support groups, seeing my doctor and getting my life together. In 1998, I met Rosalia. We spoke about my being positive and her being negative. And we compromised that our relationship was going to be “condoms forever.” We got

married in 2004. Things weren’t easy but we don’t regret it.*

Says Rosalia about her husband, “He was for real. Talented. Humble. But for real.” When he came up with the idea about making music together about HIV, she glows, “Immediately we started thinking. We came up with the name. We couldn’t sleep, it was fantastic!” recalls Rosalia with some of the same enthusiasm.

On July 15, 2004, I woke up very depressed, realizing I could no longer do things I used to do. Going through the sickness and the medications, I thought, “This is it!” Then I started playing one of the congas and after a while I noticed the negative thoughts I had in my mind were not there anymore. That maybe I could use the music to bring a message of education, prevention and hope about HIV/AIDS. I spoke with my wife and she agreed. That day, *Los Doctores* was born.*

“

Don’t let the virus stop your dreams.

Louis Curbelo

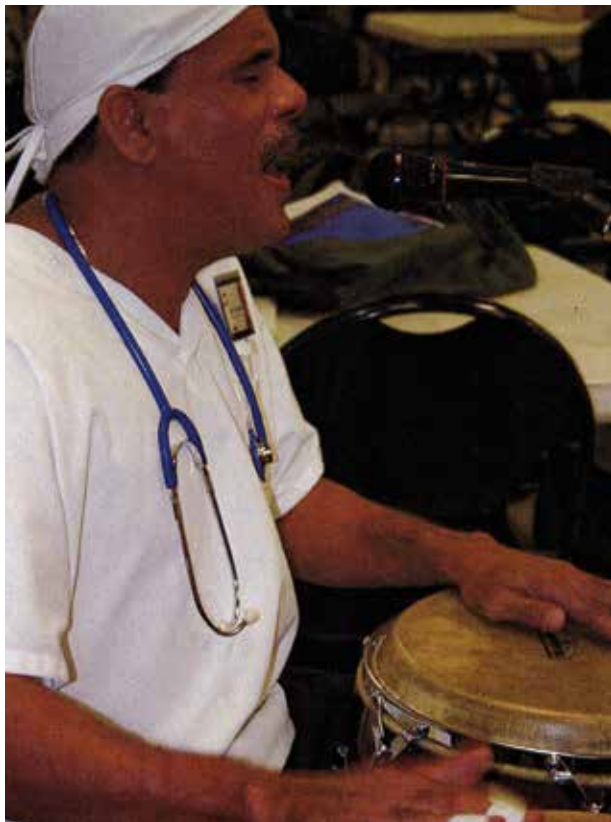
”

Los Doctores performed from 2004 through 2009 for HIV support groups and local events around the county. But they played some big gigs, too. “The Campaign to End AIDS was important to us,” Rosalia recounts, which was right after Hurricane Wilma in 2005. “We had no electricity here. They flew us out to D.C. in our wrinkled clothes. We were nervous. When you increase your audience, you have to be really focused. We started singing and when we saw people dancing, we said okay.” In 2006, they played the United States Conference on AIDS. “USCA was a big thing,” remembers Rosalia. “People came from all over the country. At the beginning

My name is _____ I was born in Brooklyn N.Y. I am Puerto Rican my parents are from Puerto Rico. I have been HIV positive since 1987. I came from a time that HIV was a death sentence. Between 1987 and 1992, I lived a life of destruction. Thinking I was going to die! I got → more into drugs + alcohol. I lost my family, home, material things and became homeless. It was in 1992 that I decided to seek help. I went to a clinic, got a doctor and started going to a support group, and I started building a relationship with my daughter, she was 5 years old. From 1992 to till now I continue doing the support groups, seeing my doctor and getting my life together. In 1998 I met Rosalia. We spoke about my being positive and her being negative. And we compromise that our relationship was going to be “condoms forever.” We got marry in 2004. Things wasn't easy, but we don't regret. On July 15, 2004 I woke up very depress, feeling and realizing I no longer could do the things I use to do. Going through the sickness and the medications I thought, is this it! I started playing one of the congas and after awhile I notice the negative thoughts I had in my mind was not there anymore. Ah idea came to me. That maybe I could use the music to bring a message of education, prevention and hope about HIV/AIDS. I spoke with my wife and she agree. That day *Los Doctores* was born. I decided to show my face, but I first had to speak to my daughter, because I didn't want to harm her in anyway. In case her friends were to recognise me, I didn't want to get negative feed back. She said, if that were to happen then they were really not my friend, so go for it Dad. If any of you ask me now, what have help me to keep going. I have to say my daughter, my beautiful wife, my family, the medications, the support groups and *Los Doctores*.

*From a speech written and delivered by Louis Curbelo on National Latino AIDS Awareness Day, October 15, 2006

*Los Doctores
in March, 2006*

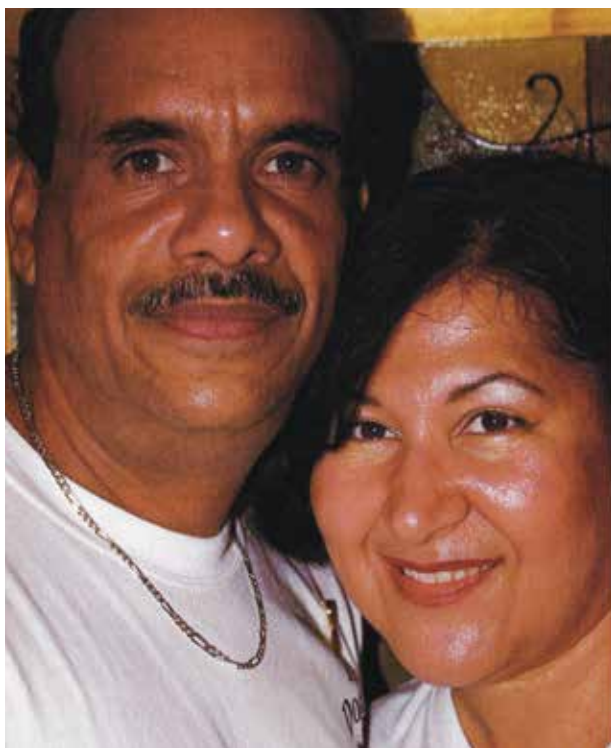


**Louis's instruments and painting
"El Jibaro"**
by Guillermo Santiago



people were serious, listening, but when we saw people dancing, again we said, okay. USCA was very important to us. We wanted people to listen to the message."

*Don't let the virus stop your dreams. I know it is not easy. It took me five years to start going to a doctor. It took twelve more years to show my face and disclose my status in public. I feel now is my time to do my part and help stop the cycle of more Latino brothers and sisters getting infected. Only you know how many years it can take you or if maybe today is the day. And when that moment comes, stand up, no shame, no fear! We are Latinos and proud. Let our voices be heard!**



Louis and Rosalia

In a sunny corner of her apartment, which doubles as an art gallery, Rosalia has a shrine of sorts to Louis and his music. Amid walls lined with paintings and drawings by and of Rosalia, who continues to express herself as a social artist chronicling social issues, Louis' three conga drums are displayed in a small alcove, along with bongos and panderos hanging on the wall behind them. Above the instruments hangs a painting, "El Jibaro" by artist Guillermo Santiago, which Rosalia acquired because, she says, it reminds her of her husband: a Puerto Rican jibaro, or country boy, captured in the city in

I Remember You/Te recuerdo a ti

I remember you
I remember you always now and then
I remember you

You were always there
To give me strength
I remember you
Like it's yesterday
And today I hope
I can honor you
With respect and love
This song is for you

*Te recuerdo a ti
Te recuerdo a ti
Hoy igual que ayer
Te recuerdo a ti*

*Tu eras para mi
Fuerza y corazón
El ayer es hoy
Te recuerdo a ti
Y hoy quiero you
Dedicarte a ti
La canción que hoy
Canto para ti*

*Canto para ti
Con todo mi amor
Ay, esta canción
Te dedico a ti
Hoy extraño yo
Como fue el ayer
Cada día es
Recordandote*

*Te recuerdo a ti
I remember you
Te recuerdo a ti
I remember you*

©2005 Louis Curbelo and Rosalia Curbelo

vibrant, sketchy color. The instruments are promised to his daughter's four children. "His daughter was his biggest motivation," says Rosalia of her stepdaughter. "He wanted her to be proud of him." Before they actually began performing, Louis made sure his daughter who was a teenager at the time, was good with it. In fact, she was very supportive and would come to hear *Los Doctores* perform and cheer them on. Now his legacy will pass one day to their grandchildren: the eldest grandson gets the congas, the other grandson and two granddaughters the panderos, bongos and a keyboard. But for now, they light up a small corner of the room with big memories filled with music and Louis Curbelo, talented, humble, still real.

When Dogs (and Doctors) Heal

Dr. Robert Garofalo on Living with HIV & Fred

Continued from Page 11

“That’s helped me raise money for my programs. I’ve had people come up to me on the street and say, ‘Are you that guy with the dog?’ I was in a coffee shop in L.A. and this random person came up to me and said, ‘Is that Fred?’” But being open about his HIV status is something of an anomaly in his professional life. “When you’re a physician and you’re HIV positive, you don’t talk about it,” he notes. “I talk about it a lot. I’ve had other colleagues [who are HIV positive] come over to me and say it’s great that I’m opening up. They think if they talk about it, it’s going to make them appear weak or damaged. I’m not weak or damaged, I’m free! There’s something liberating about shouting it from the rooftops,” Rob declares, adding, as if it weren’t as evident as the adorable button nose on Fred’s furry face, “I consider it my mission to make the world a better place. Transparency about my life has always been my friend,” he affirms. “When I talk about it, I take back the power.”

Photo Credit:
Jesse Freiden



Send Positively Speaking Your Pet “Rescue” Story

Share with us the story of a pet that made your life with HIV a better one. Please include a picture of you and your FBF (Furry Best Friend)

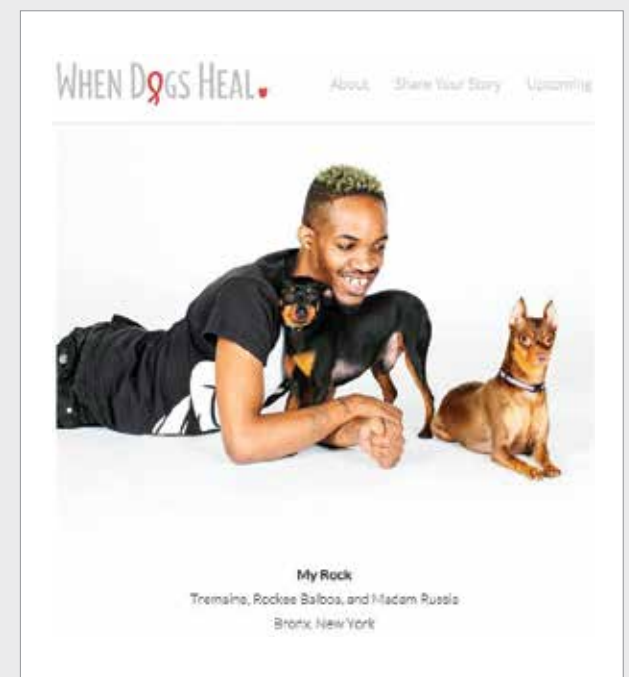
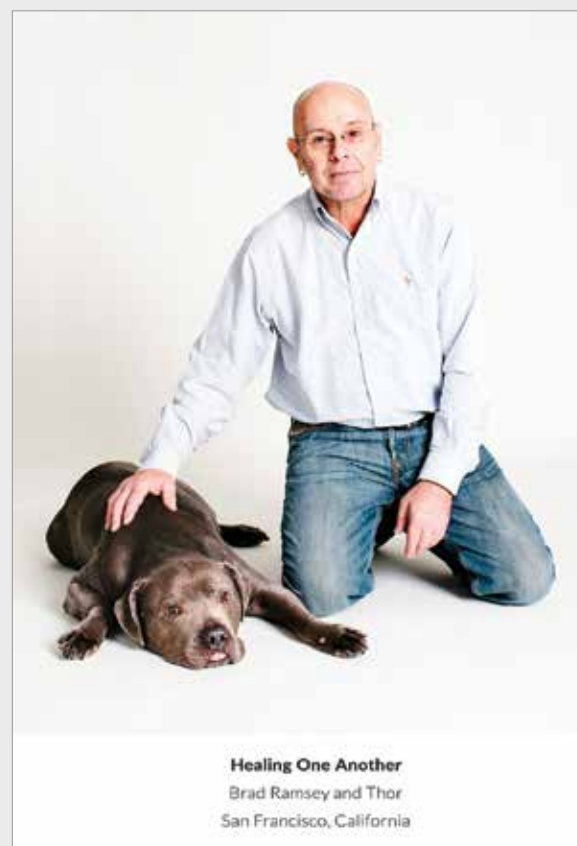
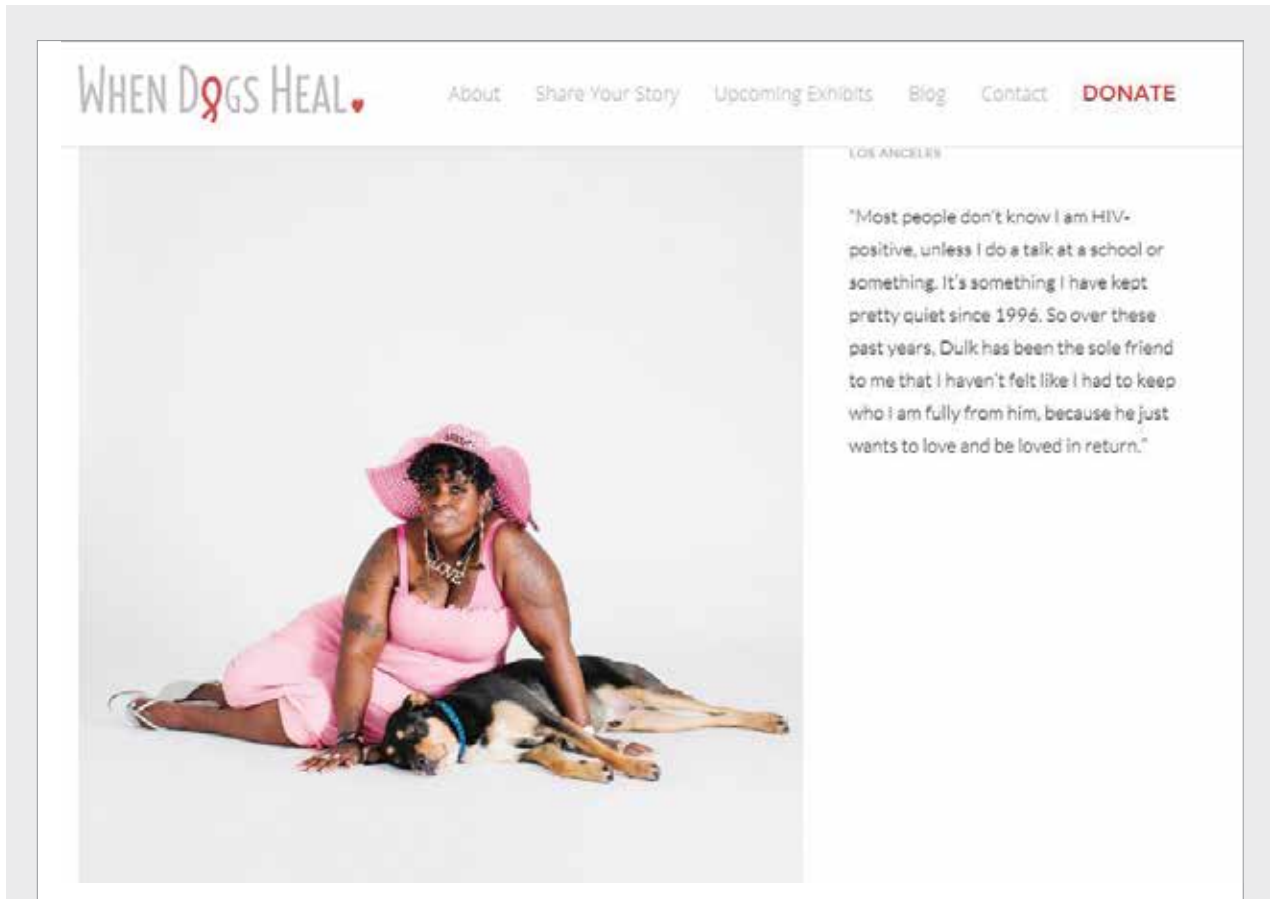
Email Lauren Gold, Publication Specialist, at Lgold@broward.org.

Pet Adoption & Support Resources
Broward County Animal Shelter
Broward.org/Animal
954-359-1313

Humane Society of Broward County
Humanebroward.com
954-266-6815

The Pet Project
Assists people living with HIV/
AIDS whose financial or health
challenges impede their ability
to care for their pet.
Thepetprojectfl.org
954-568-5678

Please Note: Along with its
benefits, pet ownership entails
responsibility, and should only
be entered into by those who can
make the necessary commitment.



When Dogs Heal
Stories of People and the Dogs Who Saved Them.
Photographic project created by Fred Says.
Wdhproject.org



25 Years Strong

El Grupo de Consuelo's Momentous Anniversary

One Saturday evening this past November, a dozen diverse friends – gay, straight, trans – gathered to celebrate the 25th anniversary of *El Grupo de Consuelo* or Consuelo's Group, a Latino HIV support group. Founded by therapist Dr. Consuelo Moreno, LCSW, the group began in Miami-Dade County, then settled in Broward in 2000. For 15 years, the group met every Thursday and while it no longer meets weekly, Consuelo's Group has remained the vital source of love and support it was the day it began 25 years ago. Which for those present at the celebration was technically 25 years and twelve days before, but who's counting? *They are.*

It started back in the day counting everything from T-cells, to meds, to weeks and months, precious years and far too many people lost. Which is to say, on October 22, 1993, a group of local Latinos living with HIV began counting the days and making them count together in *El Grupo de Consuelo*. Dr. Moreno spoke with *Positively Speaking* along with veteran members Denise and Diana about sharing their hearts, their lives, their low points and triumphs, and all the moments in between.

Denise has been living with HIV for 27 years. "I started being an HIV activist for Latino women, empowering them, sending out my message," she recalls. "I was the only woman activist at that time in Miami." This was 1994. "Other people would disguise their face and their voice. My message was always, 'There is no shame.' How could I send a message to 'fight discrimination' if I was hiding myself?"



Dr. Consuelo Moreno,
LCSW

When Diana was diagnosed in 1993, she says, "It was very hard but within 24 hours I had a support group. A few months after that, we started one with Consuelo. This support group has been very important to me. I learned I have tools for living my life with HIV. Consuelo's group provided a safe space for us to share our fears, gain confidence and view ourselves as women of strength. It was our 'date' every Thursday, no matter what."



My message was always,
'There is no shame.'

Denise, Group Member



"It was an open group," says Dr. Moreno. "At times 60 people attended the group, men and women from all walks of life and diverse sexual identities. I always planned something for them. I would study and take classes just to have tools for them. Whatever I knew, they knew. My father was from India. From a very early age, he would have me close my eyes and listen to my inner voice. We talked to the virus

in meditation. We wrote a letter to the virus," smiles Dr. Moreno. "Then we wrote a letter from the virus." Which, Diana asserts, helped her live with the virus. "I told 'him' if he wanted to live with me, he has to let me live!" They celebrated holidays together and when there was no official place to meet, they met at people's houses. They would do the group at the beach or wherever they could until Dr. Moreno found an office. "Wherever I had a job," she says, "My group went with me."

While Dr. Moreno's professional focus has broadened over time, for the first 20 years her sole focus was HIV and AIDS. "In the early 1980's," she says, "right at the beginning of the AIDS pandemic, my friends were dying. For ten years, I went every day to various hospitals in Miami. I would help people die and assist the family or partners deal with the loss. There were 50 or more people dying in a week." Dr. Moreno ended up counseling the doctors also. "We would sit in the hallway and just cry," she remembers. "I would talk to them and assist them, too."

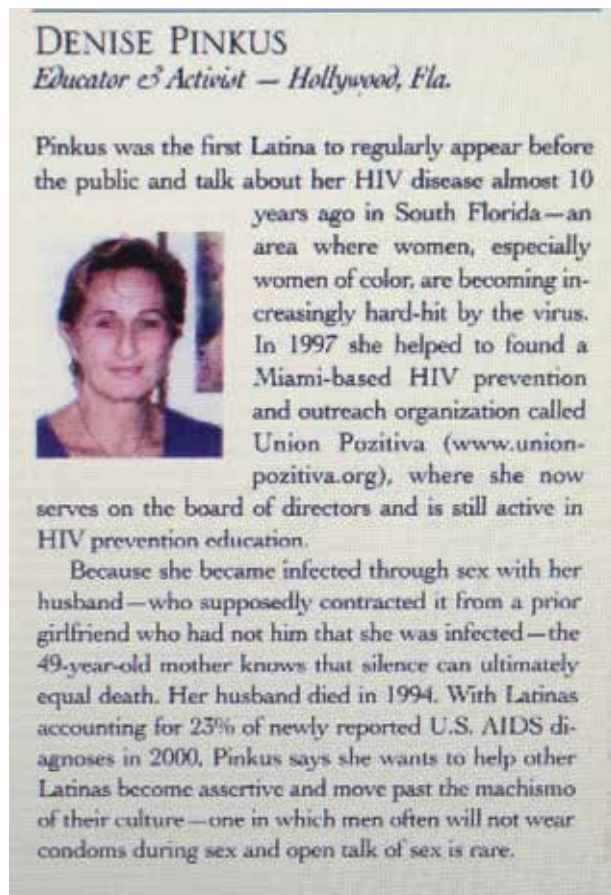
Denise came here from Venezuela in the early 1990's. Her husband was diagnosed in 1993 and passed away ten months later. "He'd probably contracted it ten years earlier," she speculates. "He was a Latin musician from New York, a lot went on in the night life." After her husband passed away, she herself tested positive for HIV.

Diana, also from Venezuela, came here in the mid-1990's for work. Her husband, visiting from Venezuela for a few days, was tested and was also positive. She

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25 Years Strong

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Denise, HIV Activist and Educator, in 2001



SMART Ride volunteer Denise in 2017



Denise at El Grupo de Consuelo's 25th Anniversary celebration, November 2018

believes he contracted HIV from an immunization in 1988. Her husband passed away in October 1996. “I decided to stay here,” she recalls. “I was forty-two years old. I said, ‘I’m not going back to Venezuela.’ I couldn’t do it.”

But here too, and in most Hispanic communities, explains Denise, no one deals with HIV. “They still don’t get it. Anything related to sex is taboo.” Says Dr. Moreno, “In the Latin community and most communities, sex is something private that you don’t discuss with anyone. You’re kind of stuck with the secret or the shame.” Denise adds, “If you get HIV, you’re a slut. That’s the mentality.” Diana concurs, “The first thought is, ‘You are positive! Wow! I didn’t think that about her.’” “There’s a lot of shame and judgement attached to the diagnosis,” laments Dr. Moreno. “That’s why people don’t get tested. They don’t want to know.”

But for those who did know they were living with HIV and found solace in *El Grupo de Consuelo*, life was bolstered by camaraderie and hope and for many, like those who celebrated 25 momentous years, a future realized. “We were laughing the last time,” recalls Dr. Moreno with glee, referring to a group meeting two months before. “Do you realize no one mentioned HIV? It was all, how was our week, our projects. We didn’t talk about HIV at all.” Adds Denise, “We only talk about HIV



In 2017, 27,250 people living with HIV in Florida were Hispanic, which was 23% of the total 116,944. They also accounted for almost a third (31%) of new HIV diagnoses. In 2018, Broward Ryan White Part A provided HIV services to 1,591 Hispanic Broward County residents.

*Florida Department of Health
& Broward Ryan White Part A,
Provide Enterprise*

when we have a newly diagnosed person in the group. That’s when we realize we have HIV.”

“To me that’s a testament to their strength and how much they’ve grown,” says Dr. Moreno. “To see this kind of transformation is a precious gift. I feel so blessed because everyone I touched has been a source of inspiration and motivation for me to be the best that I can be, and to continue being of service.”

“She’s an angel,” insists Diana. “I always told her that. For us, who are still alive, we are very thankful. She gave us all that she is. She gave us *us*.”

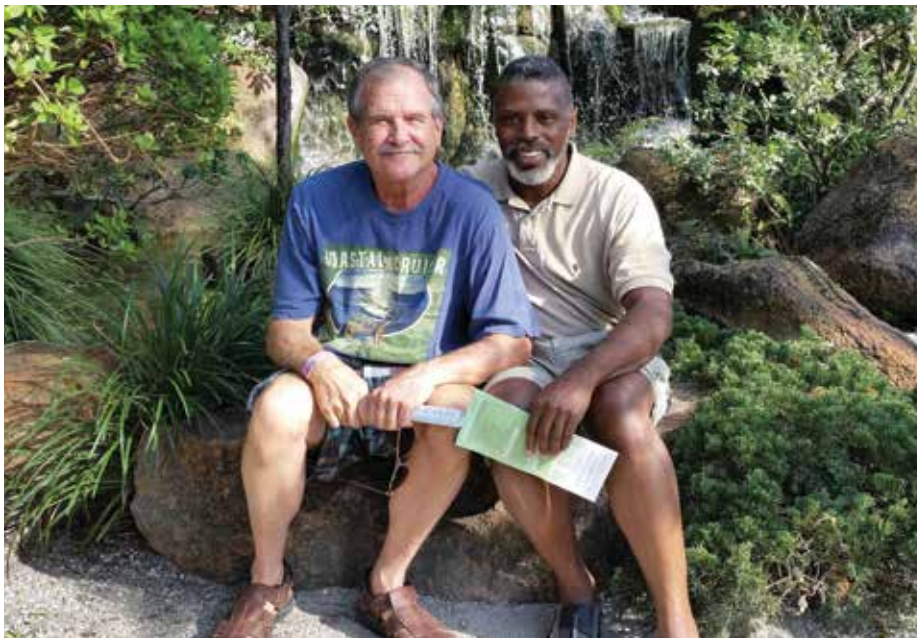
For a listing of HIV support groups throughout Broward County, turn to page 21.



“Roar” and Other Terms of Endearment

Brian Baker & Bob Hoff on Good Love, Long Life and HIV

Brian Baker and Bob Hoff split their time between Rehoboth Beach in Delaware, Washington D.C. and Oakland Park, Florida. They’ll assure you it’s not the jet-setter life, they simply own property in each location, but clearly they’re a couple on an uncommon journey and we’re not just talking geography. Both treasure their marriage of three years and their life as a couple for 16. But beyond their appreciation of a life lived together is a sense of awe, and the inescapable gravity of their respective long lives lived with HIV.



The happy couple:
Bob Hoff, left, and
Brian Baker

Bob, now 70, cites the notable distinction of being on record with the National Institutes of Health (NIH) as the person living longest with HIV in the United States today. He was first diagnosed with HIV in 1984, but a few years later, blood samples he had given for an earlier NIH hepatitis vaccine study were retested and traced his positive status to 1978. “However, my counts remain normal, I have zero viral load and take no medication,” Bob reports. “Think of it this way: you have immune cells that are like generals and tell the other cells what to do. HIV attaches itself these “general” cells, which are like golf balls, only in my general cells the holes are closed, so HIV doesn’t attach and don’t affect the other cells. NIH calls me a Long Term Non-Progressor.”

Bob grew up in Des Moines, Iowa. “As a straight person,” he says, “it would’ve been great.” As a gay young man, he relays, he spent a lot of time driving to Chicago and other more cosmopolitan places where he could access gay culture and events. “In Des Moines,” he recalls, “you couldn’t do those things; you’d be ostracized.” In fact, his mother who passed away in 2008, didn’t talk to him for twenty years, although eventually she came to accept her son.

For Bob, nostalgia for his youth is tainted with the outbreak of the AIDS epidemic. He had a house on Fire Island for 20 years and a list of 650 friends from that time who passed away. “All my friends who came to stay there are dead,” he sighs. “You know that song ‘Empty Chairs at Empty Tables’ from ‘Les Mis’? The kid survives and all his friends die? Survivor’s syndrome, it’s a form of PTSD. I have that in spades.” It isolated Bob from people, that is, until he saw Brian. “In 2001, they had a gay pride parade in D.C.,” recounts Bob. “I saw this beautiful black man walking down the street and I took a picture of him.” The next year they met. “Memorial Day, 2002,” Bob reflects. “That was our connecting point.”



Survivor’s syndrome,
it’s a form of PTSD.
I have that in spades.

Bob Hoff



In cultural contrast to his husband, Brian grew up in the projects in Perth Amboy, New Jersey, one of eight children. Brian’s

Continued on Page 18



In 2017, 52% of people living with HIV in Florida, or 60,888 of the total 116,944, were older adults. In the same calendar year, people 50+ years old accounted for 50%, or 4,326, of the total 8,609 people accessing Broward Ryan White Services.

*Florida Department of Health
& Broward Ryan White Part A,
Provide Enterprise*

“Roar” and Other Terms of Endearment

Continued from Page 17

parents separated when he was 7 years old and his family relied on the welfare system. “I remember being young and having feelings for girls and guys. But when I hit my teens,” he recalls, “I knew the feelings for guys were greater. I came out to my mom in 1982. She was accepting.” In 1988, Brian moved to Maryland near D.C.

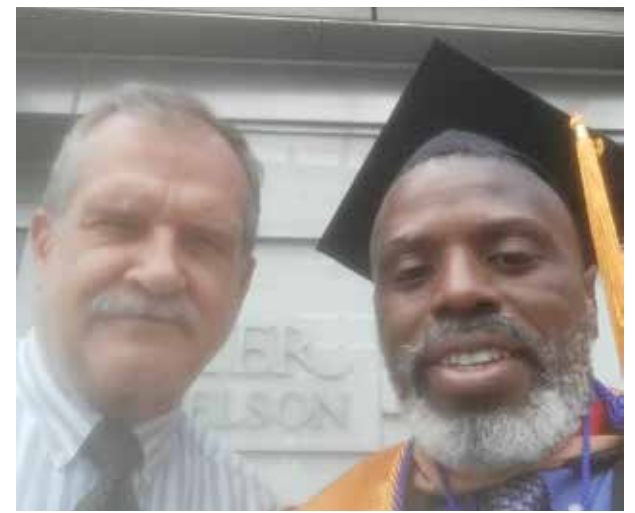
Brian was diagnosed with HIV in January, 1993. “I felt like a toxic person,” he declares. “In the gay community, it was automatically thought of as a death sentence. Other gays were afraid to date you, even in a nonsexual relationship. In the African American community, it was hard to accept someone who’s HIV positive. HIV was assumed to be a gay disease that only affected Caucasians or needle users.

“The strange thing about the diagnosis,” Brian relates, “is a few months down the road, you go through this emotional turmoil. I was smiling a lot less. I was going to a therapist, I just felt bad.” In his relationship at the time, he remembers, “I felt more like a son. It wasn’t until I met Bob that I felt I was on equal ground. He gave me the courage to go to college.” Brian graduated cum laude in business management in 2015 and now, at 55 years old, he states proudly, “I’m thinking about getting my master’s.”

“So what does a black guy from the projects in Jersey and a white guy from the Midwest have in common?”

Bob poses. “I could give you at least fifty things!” The partial list includes Bette Davis movies, comic books, June Allyson in the ‘40’s musical “Good News” and Peter Lawford in anything. “Brian continually astounds me,” says Bob, who considers himself a music aficionado. “I’ll say, ‘That’s the Andrews sisters,’ and Brian will say, ‘No!’ It’s bizarre how he knows these things,” Bob marvels. They don’t have a vast social life and lament how things have changed. “I’ve noticed the community has gotten more segregated,” says Brian. “I think social media has changed the way we relate. You can create a persona online but when you meet them you’re catfished.” Bob agrees, “Everyone ‘orders’ online, you might say. These days you just swipe right.”

Bob and Brian, married for three years, say they’ve been “emotionally monogamous” for 16. They cite a sound bite from South Park to exemplify the depth of their relationship. The character Stan, walking through a gay animal sanctuary, passes a gay lion who delivers a perfectly half-hearted roar. Brian and Bob adopted that as their signature greeting. “Every time we say goodbye, we say ‘roar,’” offers Bob. “Roar means more than love; it means commitment, love and dedication.” Brian concurs, “Roar means fully committed.” Says Bob, in summation of their shared life well lived – so far – “We’re the luckiest people I’ve ever met.”



Brian graduated with a degree in business management in 2015

There’s a grief that can’t be spoken
There’s a pain goes on and on
Empty chairs and empty tables
Now my friends are dead and gone

Oh, my friends, my friends forgive me
That I live and you are gone
There’s grief that can’t be spoken
There’s a pain goes on and on

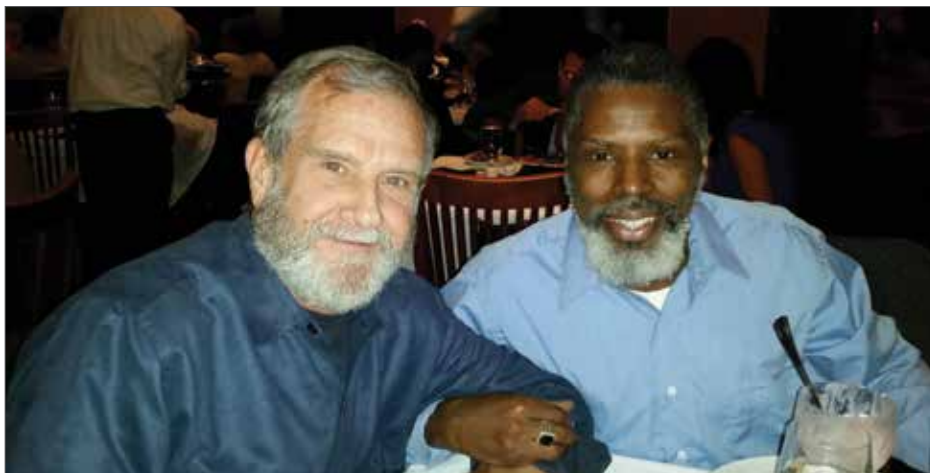
“Empty Chairs at Empty Tables”
from *Les Miserables*

Songwriters: Alain Albert Boublil / Claude Michel Schonberg / Herbert Kretzmer
© Warner/Chappell Music, Inc.



The average lifespan for Americans in 2016 was 79 years old; for people living with HIV and adherent to care, it was 78.

Avert.org/news/life-expectancy-people-hiv-now-near-normal



The bearded couple, Bob and Brian



Brian and Bob enjoying the beach

A Culture of Caring

Dr. Paula Eckardt on Passion & Success in Treating HIV



Dr. Paula Eckardt
MD

When it comes to treating HIV, Dr. Paula Eckardt, Medical Director of the Division of Infectious Disease at Memorial Healthcare System in Broward County, is an unflappable optimist, and her positive resolve is saving lives. “I’ve taken people out of hospice,” she discloses. “I have the hope they’re going to get better because I’ve seen them recover. I’ve seen the magic HIV medication can do if you take it. It’s like when you water plants. Every day they blossom until they’re back to normal.” As Dr. Eckardt speaks, it becomes clear that the “magic” refers as much to her passionate brand of medical care as it does to the medication itself.



Dr. Eckardt, Super HIV Specialist, with Gerardo Marin, Medical Assistant (left) and Jean-Raymond Alexandre, Non-medical Case Manager (right)

“The best part of treating HIV is seeing patients get better,” she glows. One patient was so ill, he had to be rolled in to be seen in his wheelchair. He’d hid his medications, trying to hide his positive HIV status from his wife. When he got sick and couldn’t access his medications, his health deteriorated. A physician referred him to hospice. “But the day he was supposed to see that doctor, he saw me instead,” recalls Dr. Eckardt. She had him admitted to one of the Memorial Healthcare System hospitals and immediately began a treatment plan. Not only did he regain his health, she laughs, “he started scuba diving to get lobsters. When he came to see me, his big concern was requesting medications for his ears to go diving!”

Dr. Eckardt’s goal is to help as many people living with HIV as she can. “It’s like a passion,” she says. “How can we get them in care and keep them in care? I have a list of those who have high viral loads. Sometimes I call them myself and say, ‘Where are you? Why are you not here?’ and they try to show up.” She runs her practice like a family. “We all care for each other. If patients see you care for what you do, and you want them to live healthy lives, they’ll adopt the same culture.”

But with all the positivity Dr. Eckhardt and her staff exude, her practice is still handicapped with stigma, a reflection of the HIV community as a whole. When she opened the office, she hung a sign on the outside of the door announcing her specialty, but her patients objected so she took it down. “We have to be very sensitive and protective,” she concedes. “They feel everyone is looking. Now you go to my door, you don’t know what kind of office this is.”

The same stigma, Dr. Eckardt admits, permeates her personal life. “I don’t have HIV but I treat people who do,” she relays. “Some people look at you like, why would you do that?” When her children were little, parents at school would ask if she was scared to work with HIV. “I’d tell them I feel proud. Today,” she smiles, “My daughter tells people, ‘My mom is an HIV doctor.’” In her women’s running group, Dr. Eckardt says, “They’ve never heard about HIV. I wear my t-shirt ‘End AIDS Now,’ just to put it out there for people who are not normally in contact with it.” Last year, she had the whole group wear red for World AIDS Day. This past year she ran her first full marathon, Team to End AIDS, in Chicago. “A lot of my friends

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A Culture of Caring

Continued from Page 19

Facebook post
promoting
Team to End AIDS



Running Team to End AIDS Marathon 2018
Chicago

don't know I work with HIV. I posted about the marathon on Facebook and it was interesting to see people supporting something that has been stigmatized like that."

But she has no doubt that HIV is her calling. "I think life takes you where you're supposed to go," muses Dr. Eckardt who has been an infectious disease doctor since 2004. But it wasn't until she came to Memorial in 2008 that she began specializing in HIV care. "There were maybe 130 HIV patients here," she recalls. So many [HIV] patients in South Broward were traveling to North Broward because they didn't know we were here." But they know now, evidenced by the fact that her practice now provides HIV care for upwards of 1,200 patients.

Her staff has grown along with her patient base to include Juan Lemos-Ramirez, MD, Kenneth Poon, MD and Tara Griffin, ARNP. Together they go to great and innovative lengths to service their patients. They work with case managers and remind patients of appointments by phone and text message and even a

mobile app. They also utilize telemedicine, communicating with patients via camera on their computer or phone. "It's not a substitute for office visits, but it works for short consultations," Dr. Eckardt says, adding, "It might also help with adherence with some of our younger patients. A lot of time they don't show up because of transportation but they have a phone."

Dr. Eckardt also spearheads an HIV testing initiative in one of the healthcare system's emergency room, the only one of its kind in Broward County. With the "Opt Out" program, patients in the ER need only give verbal consent to be tested for HIV. "We tell you we are going to do an HIV test unless you opt out," she explains. "We were able to get more people back in care with Test and Treat," a program that facilitates immediate HIV care for people who test positive. "Some of them are already undetectable. People are very grateful for the testing, and very happy." Now she's working on getting more doctors on board. "If you're motivated, everyone gets motivated," she enthuses. "And I think we can do so much more."

Dr. Eckardt strives to treat each patient – each person – on a case by case basis. "You have to work with difficult patients with different strategies." She has homeless patients who adhere to treatment and are undetectable. "We have patients who show up when they can. If they arrive at 10 o'clock when they had an appointment at 8, and they took two busses to get here, I would never refuse them their meds." She's flexible, she says, because she knows each patient has their individual challenges. Ultimately, Dr. Eckardt concludes, "We want the patients to be healthy so the community is healthy and we stop the transmission of HIV."



Broward Ryan White Part A Program served 679 Test & Treat clients in its first year, which began May 2017; of the 369 enrolled for at least 90 days, 83%, or 306 were virally suppressed.

*Broward Ryan White Part A,
Provide Enterprise*

Awareness Days

February 7

National Black HIV/AIDS Awareness Day



March 10

National Women and Girls HIV/AIDS Awareness Day



March 20

National Native HIV/AIDS Awareness Day



April 10

National Youth HIV & AIDS Awareness Day



April 18

National Transgender HIV Testing Day



May 18

HIV Vaccine Awareness Day



May 19

National Asian & Pacific Islander HIV/AIDS Awareness Day



HIV/AIDS Support Groups

Amigas

Women, Hispanic
2nd & 4th Thursdays of the month
Call for location & information
Ana Bahena 954-549-0632

Angels of Hope

African American, Tuesdays 6:30pm
MODCO
401 NW 9th Avenue
Ft. Lauderdale, FL 33311
954-767-9919

Gay Men's Empowerment Group

Thursdays 7:00pm-8:30pm
Pride Center
2040 N. Dixie Hwy
Wilton Manors, FL 33305
954-463-9011

Hispanic HIV Support Group

Latino, third Wednesday of the month,
12:00pm
Care Resource
871 W. Oakland Park Blvd.
Ft. Lauderdale, FL 33311
Argenis Aguilera 954-567-7141 X104

HIV Gay Men Support Group

MSM, Thursdays at 2:00pm
Care Resource
871 W Oakland Park Blvd.
Ft. Lauderdale, FL 33311
954-567-7141 X142

HIV Lunch and Learn

For All, 4th Thursday of the month
12:30pm-2:00pm. Lunch is provided.
Broward Health Comprehensive Care
1101 NW 1st St.
Ft. Lauderdale, FL 33311
Trudy Love 954-356-5037

HIV+ Women's Group*

Sunserve
2312 Wilton Drive
Wilton Manors, FL 33305
Elena Naranjo 954-764-5150 X185
*Coming soon! Call for details.

L.I.F.E. Program

MSM
The Pride Center at Equality Park
2040 N. Dixie Hwy
Wilton Manors, FL 33305
Call for info. 954-463-9005

Positive Social

PLWH, affected by PLWH
or at risk for HIV
Every other Tuesday at 7:00pm
Latinos Salud
2330 Wilton Dr.,
Wilton Manors, FL 33305
Call for info. 954-765-6239

Positive Attitudes

MSM, Wednesday, 7:00pm
World AIDS Museum
1201 NE 26th St. #111
Wilton Manors, FL 33305
Steve Stagon 954-390-0550

SOFFA: Significant Others, Family, Friends, and Allies

Transgender/Gender Variant
2nd & 4th Saturday of the month
SunServe
2312 Wilton Drive
Wilton Manors, FL 33305
Santi Aguirre 954-764-5150 X112

Women of Empowerment

HIV+ Women, meets monthly
Dates vary, call for info.
Care Resource
871 W Oakland Park Blvd.
Ft. Lauderdale, FL 33311
Jennifer Palmer 954-567-7141 X101

Online HIV/AIDS Support Forums

hiv.supportgroups.com

Facebook HIV/AIDS Support Groups

AIDS HIV Survivor Living Memorial

For All
facebook.com/groups/1716936251671905/

Heterosexual POZ Heterosexual

facebook.com/groups/126252234585822/

My AIDS Campaign For All

facebook.com/groups/213320955360312/

I'm Poz & Proud For All

facebook.com/groups/pozandproud/

If you would like to add a support group to this listing, please email the information to Lauren Kettler Gold at Lgold@broward.org.

BROWARD RYAN WHITE PART A SERVICE PROVIDERS DIRECTORY

The Broward Ryan White Part A Program provides medical and support services for uninsured or underinsured people living with HIV. In order to access Ryan White Part A services, individuals need to be deemed eligible by Centralized Intake and Eligibility Determination (CIED) provided by a Broward Regional Health Planning Council. CIED representatives are located at the following sites. **For an appointment, call 954-566-1417 Ext. 1242 or Ext. 1279.**

- MEDICAL
- PHARMACY
- CASE MANAGEMENT
- MEDICAL CASE MANAGEMENT
- DENTAL
- SUBSTANCE ABUSE
- HEALTH INSURANCE CONTINUATION PROGRAM
- CENTRALIZED INTAKE (CIED) & ELIGIBILITY DETERMINATION
- MENTAL HEALTH
- LEGAL SERVICES
- FOOD SERVICES

● ●
Broward Regional Health Planning Council
Hollywood 954-561-9681

●
Broward Community and Family Health Center
Pompano Beach 954-970-8805

●
Care Resource
Ft. Lauderdale 954-567-7141

●
The Poverello Center
Wilton Manors 954-561-3663

●
Broward House
Wilton Manors 954-568-7373

●
Memorial Primary Care Center
Hollywood 954-265-8410

●
Children's Diagnostic & Treatment Center
Ft. Lauderdale 954-728-1088

●
Broward Health - Specialty Care Center
Ft. Lauderdale 954-527-6064

●
Broward Health - Comprehensive Care Center
Ft. Lauderdale 954-467-0880

●
FL Dept. of Health in Broward County
Ft. Lauderdale 954-467-4700

●
FL Dept. of Health in Broward County - Paul Hughes Health Center
Pompano Beach 954-566-1417

●
AHF Healthcare Center - One River Plaza
Ft. Lauderdale 954-767-0887

●
AHF Healthcare Center - Oakland Park
Oakland Park 954-561-6900

●
AHF Healthcare Center - Northpoint
Ft. Lauderdale 954-772-2411

AIDS HEALTHCARE FOUNDATION (AHF)

●
Wilton Manors Pharmacy
Wilton Manors 954-494-8013

● ● ● ● ●
Northpoint Healthcare Center
Ft. Lauderdale 954-772-2411

●
Sunrise Pharmacy
Ft. Lauderdale 954-462-9223

●
AHF Healthcare Center
Ft. Lauderdale 954-767-0887

● ● ● ● ●
Oakland Park Healthcare Center
Ft. Lauderdale 954-561-6900

● ● ● ● ●
Fort Lauderdale Downtown Healthcare Center
Ft. Lauderdale 954-767-0887

BROWARD COMMUNITY & FAMILY HEALTH CENTERS

● ● ● ● ●
Health Center
Pompano Beach 954-970-8805

● ● ●
West Park Center
West Park 954-966-3939

● ● ●
Central Broward Community Health
Lauderhill 954-583-4710

● ● ●
Hollywood Center
Hollywood 954-967-0028

BROWARD HEALTH

● ● ●
Comprehensive Care
Ft. Lauderdale 954-467-0880

●
Children's Diagnostic & Treatment Center
Ft. Lauderdale 954-728-1088

●
Bernard P. Alicki Health Pharmacy
Ft. Lauderdale 954-527-6042

●
Broward Health Medical Center
Ft. Lauderdale 954-522-3355

● ●
Cora E. Braynon Family Health Center
Ft. Lauderdale 954-759-6600

● ●
Annie L. Weaver Health Center
Pompano Beach
Medical 954-786-5903
Case Management 954-786-5929

● ● ●
Specialty Care Center
Ft. Lauderdale
Medical 954-463-7313
Pharmacy 954-463-7313
Case Management 954-527-6064

● ● ●
Comprehensive Care Center, Broward House
Ft. Lauderdale 954-522-4749

FL DEPT. OF HEALTH IN BROWARD COUNTY

●
Paul Hughes Health Center
Pompano Beach 954-213-0638

PROVIDER SPOTLIGHT

● ●
Fort Lauderdale Health Center
Ft. Lauderdale 954-467-4700

BROWARD HOUSE

● ● ●
Broward House
Ft. Lauderdale 954-523-9454

●
Broward House West
Plantation 754-701-6911

● ● ● ●
Broward House
Wilton Manors 954-568-7373

CARE RESOURCE

● ● ● ● ●
Care Resource
Oakland Park 954-567-7141

LATINOS SALUD

●
Latinos Salud
Wilton Manors 954-765-6239

LEGAL AID SERVICES OF BROWARD COUNTY

●
Legal Aid Services of Broward County
Plantation 954-765-8950

MEMORIAL HEALTHCARE SYSTEM

● ● ●
South Broward Community Health
35th Ave., Hollywood 954-265-6130

●
Memorial Center for Behavioral Health
Hollywood 954-276-3422

NOVA SOUTHEASTERN UNIVERSITY

●
Nova Southeastern University
Ft. Lauderdale 954-262-7530

●
Nova Southeastern University
Cypress Creek 954-262-7530

POVERELLO CENTER

●
Poverello Center
Wilton Manors 954-561-3663

SUNSERVE

●
SunServe
Wilton Manors 954-764-5150

“We Heard the Message Loud and Clear” AHF Holds Town Hall to Address Trans Healthcare Issues



Queen Victoria Ortega addressing the AHF Trans Town Hall

This past September 2018, AIDS Healthcare Foundation (AHF) in Broward County hosted a town hall meeting to assess the healthcare needs of its trans clients and better understand their experience in accessing that care. “Our intention is be as open and accepting of the trans community as we possibly can,” affirms Michael Kahane, AHF Southern Bureau Chief. “We want our staff to be literate in the ways to treat and care for the trans community, and we realized in some areas we were lacking in that fluency.”

The afternoon event, which drew more than 50 attendees, was cohosted by the support group TransInclusive and led by its co-founder Tatiana Williams, along with Queen Victoria Ortega, co-chair of FLUX, a division of AHF working to raise the profile of the trans and gender-nonconforming community. Everyone was encouraged to participate in the discussion, which began with all attendees and continued in smaller groups.

The overall topic was how to create policies and a culture within AHF that would better support the transgender community. Kahane, addressing the group, vowed to implement improvements in the AHF trans experience based on the forum’s findings. Cites Asher McQueen, a young trans man in attendance, “Normally the people you don’t get to see are the people who have to deal with our questions directly. I was very

shocked to see them there, that was a really positive move.”

“One of the things that came out was that there weren’t job opportunities for the trans community,” says Kahane, who vowed at the town hall to remedy the situation. Since then, he cites, “We’ve hired a trans intern who is going to be rolling out new courses and training for current employees and orientation for new employees,” all of which will focus on trans healthcare. Initially the program was to be only for managers, but it was decided all AHF employees throughout Florida, about 800 in total, will attend because, asserts Kahane, “It’s important to have someone from the trans community sitting in front of you and talking.” AHF also hired Tatiana Williams and Queen Victoria Ortega as consultants on trans issues.

The town hall was a first step to further AHF’s trans initiatives and support. “We’re taking it very seriously and doing everything we can,” Kahane asserts. “I really appreciate that the trans community came forward. We heard the message loud and clear, and we’re going to act on it.”

For information about AIDS Healthcare Foundation locally, call the Southern Bureau at (954) 767-0273 or visit Aidshealth.org.



AIDS Healthcare Foundation is a global nonprofit organization that has been providing cutting-edge medicine and advocacy to over 1,000,000 people in 43 countries since 1987. It funds its mission to rid the world of AIDS through a network of pharmacies, thrift stores, healthcare contracts and other strategic partnerships. In 2018, its projected operating budget was \$1.5 billion. AHF South has its headquarters in Fort Lauderdale, along with a full service dental clinic, and Wellness and Healthcare Centers located through Broward County.

GET CARE. BE THERE.

If you're living with HIV and adherent to medical treatment, you can attain "undetectable" status. That means the virus is undetectable in you and you cannot transmit it.*

It also means you can live a long and healthy life: In 2017, the average lifespan in the U.S. was 79 years old; for someone living with HIV and in care, it was 78.**

**So get care and stay in care.
Live like there is a tomorrow.**

*According to the NIAID (National Institute of Allergy and Infectious Diseases)
**Avert.org, "Life Expectancy for People with HIV is Now Near-Normal," May 15, 2017

**HIV Care Starts
with Ryan White Part A**

954-357-9797

