The Kids Are Alright

Advocates born with HIV face ongoing challenges.

April 3, 2017 By Karen Iris Tucker

If you could bottle Jake Glaser's optimism, the whole world would be doing a happy dance right about now. The self-described "radically positive" 32-year-old talks in torrents. He matches that freneticism in his daily life with a love for action sports such as skateboarding and surfing in his native Los Angeles. His life directive is simple, if elusive for many of us. "Every day when I wake up, every paddle out that I go when I surf, every wave that I drop into, every single meeting I have in the office, if I don't put my complete energy into it, then I'm not living my life to the utmost value that I can."

Glaser, whom POZ first interviewed in 2006, was born with HIV, a circumstance that he has since come to view as an opportunity. "What I mean by that is, I understand the value of every moment in my life because I'm confronted with my mortality."

Jake Glaser Toky

He is evangelical about that message, so much so that it prompted him to cofound Modern Advocate, an organization that harnesses the lifestyle of alternative sports and activities, such as surfing, skateboarding and street art, to attract and educate kids about healthy living and to break down the stigma of HIV/AIDS.

Part of the problem, he says, is that schools often fail to build HIV education into their curricula. When they do, Glaser adds, they tend to separate discussions about HIV from those about other sexually transmitted infections, such as syphilis and gonorrhea—sometimes even dedicating an entire presentation to HIV.

This, Glaser says, reinforces stigma. Key to solving the problem, he says, is reeducating people through the principle that “the individual comes first, and HIV is simply a circumstance of the life he or she leads.” He often visits classrooms to share that message, along with his own story.

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That commitment to advocacy is an extension of an ongoing role Glaser didn't choose but was born into—that of an ambassador for The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), his late mother's impactful global nonprofit. In 2016, the foundation announced that it had reached 25 million women worldwide with lifesaving services such as HIV counseling, testing and treatment.

His mother cofounded EGPAF in 1988, in the aftermath of contracting HIV via a blood transfusion she received while giving birth to his sister, Ariel, who passed away when she was 7. His mom, who died in 1994, had unknowingly passed the virus on to Ariel through breast milk; Jake contracted the virus in utero.

For many years, Glaser didn't even need to take medication. From his HIV-negative father, Paul, he inherited the CCR5-delta32 gene, which has helped his body delay HIV's onset by restricting how it enters his CD4 cells. The gene, however, hasn't kept the virus completely at bay, so Glaser now takes daily medication.

Beyond that, he says, "I live a lifestyle that is not dictated by HIV." He describes his four-year relationship with his girlfriend, Kerry Corridan, who is HIV negative, as "an incredible experience of growth and education." He has traveled the world as an advocate, including to Durban, South Africa, where he was deeply affected by conversations he had with kids with HIV.

The POZ October 2006 cover

Even with a life this rich, Glaser admits he’s been stung by stigma. He recalls one sunny day he

and friends were filming fellow skateboarders in Venice Beach, California. Someone in the pack, who didn't know Glaser, suddenly became standoffish toward him. "He looked at me and said, 'I don't want to film with you anymore because I've just learned you have HIV.'"

True to form, Glaser saw this as an opportunity to make a connection. "You've got this twisted," he said to the guy. "Let's sit down and talk about this." About 30 minutes later, after Glaser had shown him various research studies on his iPhone, the skeptic had come around. "He looked at me and literally said, 'I feel like such an asshole because of how ignorant I was.'"

That encounter points to a larger societal problem. As the passing years distance us from the height of the AIDS epidemic in the United States, before the advent of protease inhibitors, HIV recedes further into the backdrop of public discourse. This, in turn, has helped sow a variety of misconceptions. There are young people, like Glaser's acquaintance, who are unduly misinformed and alarmed about how the virus is transmitted. Still others are dangerously cavalier about what it means to contract it.

"It is not in people's consciousness in the same way that it was 25 years ago," says Marc D. Foca, MD, a specialist in pediatric infectious diseases at Columbia University Medical Center in New York. "People think it's much easier to treat, which it is, but that doesn't mean it's simple or without complications."

Despite the immense progress made in HIV therapies, Foca notes that he is still seeing sequelae—health conditions that are a consequence of another disease or injury—in people with HIV who have been taking meds since their youth. He cites heart disease and diabetes, which he is seeing at higher rates and at younger ages in this group of patients in his practice. "So while some people may feel like, 'Oh, I can just take one pill a day and everything's going to be fine,' there are still sequelae to the infection that we can't, so far, ameliorate," he says.

Foca notes that while there were probably fewer than 200 children in America born with HIV in 2016, "There is an epidemic of HIV among adolescents and young adults that we are not yet handling well." Most people this age who are admitted to the hospital with severe complications relating to HIV don't even know they have the virus. "We still have work to do in terms of detecting people with HIV and getting them into care," Foca says.

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Key to reaching those youths and educating them about HIV is the savvy delivery of a nonclinical, down-home message. So says Hydeia Broadbent, also an ambassador for EGPAF, whom POZ first interviewed in 1997, when she was just 13. A public speaker and advocate since age 6, Broadbent has honed the compelling, honest way she engages with her audiences. "I'm not a doctor. I don't really like going into the science of it because you lose people, and that's when you go over their heads," she says.

Hydeia BroadbentJacob Kepler

Having been among the first generation of children born with HIV, Broadbent says her goal is to ensure it remains at the forefront of people's minds. She points to several important messages she relays as a guest speaker on college campuses. "We still need to let people know that there's no cure," she says. "Some people don't understand the medical regimen of someone living with HIV or AIDS. It is not just about popping one pill a day."

Broadbent also mentions the financial burdens. As someone who works for herself and doesn't have health care coverage through an employer, she had struggled to pay for her medication before enrolling in a plan under former President Barack Obama's Affordable Care Act. "We have to make sure that people are aware the medicines do cost money—that you do have to get help with insurance," she says.

Perhaps one of the most famous young people to speak publicly early on about her firsthand experience with the virus, Broadbent has appeared with celebrities on prime-time television programs since her youth. This includes The Oprah Winfrey Show, on which she shared her story of

contracting the virus in the womb from her birth mother, an IV-drug user, who abandoned her in a Las Vegas hospital. Her parents, Pat and Loren Broadbent, adopted her when she was 6 weeks old, shepherding her through the many times the disease almost took her life.

That heartfelt admission resonated deeply with viewers around the nation, leading Broadbent to become one of Winfrey's most requested guests. Recently, she has been in talks with television cable channels, with the hopes of producing and developing her own special on HIV/AIDS geared toward young people.

The POZ October 1997 cover

Broadbent says her health is now good, though she has encountered some common obstacles particular to people who have lived with the virus for decades. “You have your struggles with medication—what medications will work for you,” she explains. “You have complacency issues because as you grow up, you get tired of taking the medication. But now as I’m older, I’ve been able to do really well,” she says.

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Contending with depression a few years ago, Broadbent attended therapy sessions and took antidepressants. The experience ultimately informed the advice that she gives doctors with regard to their patients with HIV: “Make sure their mental health is in check. If that’s not in order, they’re not going to take their medicine like they should,” Broadbent says. “If a person has depression or family issues, taking their medication is not going to be at the top of their list.”

Broadbent credits her supportive family with helping her to be outspoken about HIV and its many implications. “A lot of my friends couldn’t tell their grandparents or their best friends,” she recalls.

“In my house, we would talk openly about my HIV status. That helped me know that there’s nothing really wrong with me, and if people have an issue with me, it’s their issue because I’m not going anywhere.”

Donna Futterman, MD, who directs the Adolescent AIDS Program at Children’s Hospital at Montefiore in the Bronx, has been treating people born with HIV since the mid-’80s, before the first HIV med, AZT, hit the market.

Over time, she has witnessed the dramatic evolution in protocols to prevent perinatal transmission. “In New York, not one baby was born with HIV in 2015. That’s absolutely amazing,” Futterman says. Given that progress, she is deeply distressed that the medical community has failed to make better inroads in curtailing transmission in every age group.

In particular, Futterman notes an alarming uptick of certain patients in her own practice. “Gay kids of color are so much more at risk,” she says, citing a 2016 study by the Centers for Disease Control and Prevention that says that if current HIV diagnosis rates persist, about one in two Black men who have sex with men (MSM) and one in four Latino MSM in the United States will be diagnosed with HIV during their lifetime.

She estimates that 80 percent of her patients contract HIV through sex and about two thirds are MSM. “It’s the epidemic that keeps going. The idea and fear of AIDS are not front and center for young people.” Part of the problem, she says, is that discussing sexuality with youth remains controversial. As a result, clinicians and community advocates are failing to reach the populations most at risk.

“We need to be able to answer the question, ‘What does AIDS mean to a young person today?’ and update our messages and approaches,” Futterman says.

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Yonas Meredith might be a good person to answer that question. A high school freshman on the football team in Louisville, Kentucky, Yonas, 15, has an uncommonly deep understanding of what it's like to grow up with the virus. Born HIV positive in Ethiopia, he was adopted and brought to the United States at age 4 by Suzan Stirling and her husband, Clay Meredith. In the early days, Yonas recalls, he had to wake up at odd hours to comply with taking 13 pills a day. Over the years, he has tapered that number down to his current regimen of just one pill daily.

His parents have shared his HIV status with his football coach. He has also confided in some trusted friends at school, all without any issues. There have, however, been moments when he's had to set people straight.

"I remember I once drank out of someone's water bottle when we were at a game," Yonas recalls. "Some kids from the team were like, 'What are you doing? Don't put your mouth on it.' I later figured out that they thought you could get HIV from saliva. That makes me question the level of intelligence of some people my age."

In such cases, Yonas has attempted to educate his schoolmates about HIV, only for them to dispute his information. "That part cuts me up. I just laugh and say, 'I've had this for 15 years—tell me how many years you've had it.' And then they're like, 'Yeah, you're right.'"

Before adopting Yonas, his parents had endured a dramatic and life-altering journey, which his mother first shared with POZ readers in a personal essay in 2008. It all began when their daughter, Alee, and son Mitchell grew deathly ill with unexplained illnesses. After numerous hospital visits, they discovered that both Alee, then 5, and Mitch, a newborn at the time, were HIV positive. Stirling had unknowingly contracted the virus nearly a decade earlier before she married Clay, who is HIV negative, and passed it on to her children in utero.

The POZ January/February 2008 coverToky

Fortuitously, the year the Meredith family was contending with their diagnoses—1996—was also

the year the class of drugs known as protease inhibitors became available. While both Mitch and Alee had been brought to the brink of death—Alee had even had a stroke—the two gradually grew healthy once they began taking the new treatment.

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Alee, now 26, says that she, her mother and Mitch have been very lucky since then. “We take our medication every night like we’re supposed to, but we can really focus a lot on other things that ‘normal’ people focus on because we’ve been so blessed with our health.” A schoolteacher with a master’s degree in middle and secondary education, Alee and her husband of two years recently moved from North Carolina to Kentucky to be closer to the tight-knit Meredith clan.

When they first started dating, Alee told her husband, who is HIV negative, that she had been born with the virus. “His first question was, ‘Are you going to die?’” she recalls. “We had a really long discussion about what a viral load is, that mine is undetectable, what a CD4 count is. I just broke it down for him that way, and he felt more comfortable with it,” she says.

The couple plans to search for a starter home soon. Alee is hoping to find the house of her dreams in suburbia, where the pace is a bit slower than in downtown Louisville. “We want a place that we’ll grow into but not super big because that means I have to clean a lot more,” she jokes.

Mitch, now 21, is currently studying business at the University of Louisville and also works part-time with UPS. Outside of work and school, he hangs out in his apartment watching Netflix with Clyde, an anxiety-ridden whippet/black Lab mix he adopted from a shelter a year ago.

Despite enduring a threefold diagnosis ofHIV in just their immediate family, the Meredith siblings appear to lead happy, exceedingly healthy lives. Mitch is thankful for the many years they have had of uninterrupted good health. “Last time I got my blood work done,” he says, “everything was perfect. No blips. I think we’re all very healthy, you know, ordinary kids.”

Clockwise from top left: Yonas, Mitch and Alee MeredithClay Cook

Modern antiretrovirals make it possible for people with HIV, like the Meredith siblings, to achieve near-average life spans. That, along with the fact that the medical community has all but eliminated mother-to-child transmission of HIV in the United States, has been a game changer in

the quest to fight the virus here. Yet clinicians continue to see the worrying trend of adolescents and teens falling through the cracks—a trend both Futterman and Foca call an epidemic.

How to reach those kids? Jake Glaser offers advice. “I never say, ‘Get tested,’ I say ‘Know before you go. Be empowered through education,’” he says. “We need to use that new dialogue to let people know that they don’t have to be afraid of their HIV status. There is an open and accepting community in this world that will not judge them for what they have but will treat them as the human beings they are.”

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