Born Free

Dispelling misconceptions about conception and HIV

February 13, 2017 By Olivia G. Ford

Lolisa Gibson-Hunte never thought she wanted kids. But now Lolisa, who is HIV positive, and her husband, Daryl Hunte, who is HIV negative, have two children—and both kids are free of HIV.

Not long after the two met, in 2008, she became pregnant with their first child. Her husband, who always wanted a house full of kids, succeeded in getting her excited about the coming baby, also named Daryl. For their second child, they decided to plan ahead. Memory Amya, was born October 29, 2016.

Daryl Jr. and Memory AmyaRonnie Andren

“We’re older, more established,” explains Lolisa, who has been living with HIV all her life, though she was diagnosed in her teens. “With the first pregnancy we were still getting to know each other.”

She was also able to gain control over her health. During Lolisa’s first pregnancy, her HIV medications wouldn’t stay down; neither would her viral load. With Memory, she was on a different treatment regimen and had no problem taking her meds. Her viral load stayed undetectable.

One thing that remained the same was Daryl’s lack of worry or fear about HIV. He has known Lolisa’s status since their second date. He’s knowledgeable about HIV and has other loved ones who are living with the virus.

“Me and my wife always have open dialogue when it comes to her health,” he says. He’s taken Truvada as pre-exposure prophylaxis (PrEP) for HIV prevention in the past, but it’s not something he wanted to do forever. Their son, Daryl, was born in 2009, before the Food and Drug Administration (FDA) approved PrEP in 2012, and PrEP wasn’t a part of Memory’s conception.

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Anna Shevel-Vreeland wanted to be a mom since she was a little girl. “I was that odd kid on the playground who was tending to my dolls instead of playing with other kids,” she says.

So when, as a freshman in college, she fell in love with Reed Vreeland, a sophomore from her dorm who was living with HIV, she started Googling. At about 19, she learned terms like serodiscordant and sperm washing on the Internet.

“I didn’t look into the cost of sperm washing [the process of separating sperm, which don’t contain HIV, from seminal fluid, which can]. I just knew that Reed and I were going to [eventually] have kids, and the only way that it could happen was sperm washing.” However, it wasn’t ultimately the approach they took to conceive their daughter, Mila, born September 28, 2016.

Reed and Anna have been together for 11 years. “I always knew I would be a good father,” Reed says. “It was about me being able to have a sense that I could play that role, as a healthy father, that my mother wasn’t able to play for me.” When Reed was 10 years old, his mom died of complications from AIDS. Being able to envision, and commit to, a future when the loss of his mom weighed heavily on his past was a process for him.

Changing his meds, getting his viral load to undetectable and taking treatment that cured his hepatitis C were part of that process. “[To] feel like I really have that under control,” he says, “and not feel that internalized stigma in terms of my status and feel like I can be a healthy person and have HIV has been a really important part of our decision to have Mila.”

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The first great triumph of HIV treatment as prevention (TasP) came in 1994, with the revelation that HIV meds could dramatically lower the likelihood of a woman living with HIV having an HIV-positive baby. Men and women living with HIV have had babies throughout the epidemic, regardless of what research indicated. “Now, they’re saying, ‘If you’re undetectable, [your HIV is] untransmittable,’ but for people who are positive, we kind of already knew that,” Lolisa notes.

Still, the results of several large studies are continuing to shift the culture around conception and HIV. One such study is PARTNER, in which 58,000 total acts of condomless sex between members of heterosexual and gay serodiscordant couples (couples where one partner is living with HIV and the other is not) resulted in zero new HIV acquisitions.

“We know that treatment really can be prevention, and couples are starting to get that message,” says Rodney Wright, MD, an ob/gyn at Montefiore Medical Center in the Bronx. He has seen many unintended pregnancies in 15 years of caring for people living with HIV; in his patient community, more than 50 percent of pregnancies are unplanned. “But now, there is much more of a sense of reassurance: that there are treatment options, that they can conceive safely.”

One of those treatment options is PrEP to help ensure the HIV-negative partner doesn’t contract the virus while the couple tries to conceive. But those who plan ahead often have other strategies.

“The couples who are motivated to have preconception counseling and to see me or other providers for starting on PrEP are usually couples where the positive partner is very well engaged into care and is most often undetectable themselves,” Wright explains. “Sometimes the negative partner has not wanted an additional intervention.”

For many years, as Anna found in her early research, sperm washing and invitro fertilization (IVF) were touted as the only way for men living with HIV to safely have biological children with HIV-negative women. Such interventions can be costly and are available to HIV-affected couples at only a few fertility practices in the United States.

Reed Vreeland and Anna Shevel-Vreeland and Mila.Ronnie Andren

One of those is the Center for Women's Reproductive Care (CWRC) at Columbia University Medical Center in New York City. Until 2014, it, too, offered only IVF as an option when the parent providing sperm was living with HIV. After CWRC providers published articles about their experiences, they were criticized for their approach.

"Why are we doing all this ART [assisted reproductive technology]?" Nataki Douglas, MD, PhD, an infertility specialist at CWRC, remembers being asked. "These people are not typically infertile—we're really just subjecting them to expensive, highly technical procedures."

As PrEP trials were ongoing, CWRC providers spoke with colleagues in Columbia's infectious disease (ID) department about how they might use PrEP in their practice. In January 2014, they began offering sperm washing and intrauterine insemination (IUI), which is less expensive and invasive, along with PrEP, to some clients.

"Our [infectious disease] colleagues thought that giving PrEP on top of sperm washing was overkill," Douglas recalls. As early as the 1990s, European studies had shown that sperm washing and IUI alone were safe and effective. But at CWRC, providers figured PrEP couldn't hurt.

Partners conceiving “the old-fashioned way” may benefit from the anxiety reduction that PrEP can provide. “Truvada was the simplest and cheapest option,” Anna says. By the time they began preparing to conceive, Anna had talked to Reed’s doctor and updated her research.

She knew that Reed’s undetectable viral load meant her risk for HIV acquisition was virtually zero. In fact, she didn’t feel a need to take PrEP, but Reed did. “He is someone who doesn’t like to take risks,” she explains.

PrEP also allowed the couple to enjoy sex without condoms for the first time since they have been together—which, Reed shares, opened new frontiers of closeness in their relationship.

“We were thankfully able to allow and enjoy that newness, without having to think every time about conceiving,” he says. “[TasP and PrEP] can allow for different kinds of intimacy. Stigma can be a barrier, but there are ways that love, conversations and these new prevention tools can conquer those barriers.”

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PrEP and TasP are both part of the World Health Organization’s global HIV guidelines, but that doesn’t translate to universal access. In 2015, fewer than half of all people living with HIV across the globe were taking HIV meds, according to UNAIDS (the number rises to 77 percent among pregnant women), and viral load testing is often unavailable in resource-limited areas of the globe.

Through its PrEPWatch.org website, AVAC: Global Advocacy for HIV Prevention tracks PrEP availability and advocacy worldwide; rollout is spotty at best.

Even in the two U.S. states with the highest numbers of PrEP users—New York, where Wright practices, and California, home to HIVE (the former Bay Area Perinatal AIDS Center) and its visionary director, Shannon Weber—PrEP is not reaching everybody who might need it.

In a recent study, Weber, Wright and colleagues reviewed charts of 27 female clients at “substantial risk” of becoming HIV positive. Most women who were offered PrEP before, during and after pregnancy were willing to take it, but some women were not given the option. One of the women became HIV positive within a year of giving birth.

“We don’t have a strong, robust, trustworthy health infrastructure to start with,” says Dázon Dixon Diallo, founder and president of SisterLove, Inc., an HIV and reproductive justice organization in Atlanta. As the convener of the U.S. Women and PrEP Working Group, Dixon Diallo has been part of PrEP rollout since day one.

According to Dixon Diallo, PrEP access barriers aren’t different in the U.S. South—where Dixon Diallo is based and where HIV rates are high. But they occur more frequently. These include lack of providers offering PrEP in an informed, unbiased way; lack of health care access, especially in areas that rejected Medicaid expansion under the Affordable Care Act; and perceptions that PrEP

care is unaffordable, even where programs exist to cover costs.

A key benefit of PrEP for receptive partners is that they control it. Among nearly a quarter of the women in Weber and Wright's study, ongoing intimate partner violence was one of the factors rendering them vulnerable to HIV.

"The fact that you have a tool that someone can use without having to negotiate with someone else is important enough to call it sexual and reproductive justice," says Dixon Diallo. She was among the Black women activists in the mid-1990s who coined the term reproductive justice—a framework that links sexuality, health, human rights and intersectionality in understanding people's reproductive lives.

"We're working toward more equity, for women to have more options," says Dixon Diallo. "PrEP is a step in that direction."

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All HIV-affected individuals everywhere would have access to a suite of family-building options and support in choosing which option works best for them, if it were up to Shannon Weber, HIVE's director. "Depending on who you are, who your partner is and how you want to have a baby, you really need access to all those options," she says.

HIVE provides preconception and prenatal care, as well as affirming informational resources to HIV-affected individuals. Weber notes that folks' objections to assisted reproductive technologies often have to do with cost, but some may just not need it.

“That being said, just having timed intercourse or TasP or PrEP as an option isn’t enough for folks who are having fertility issues or for people who want to have a coparent or be a single parent by

choice, have a surrogate or for trans folks," she says, ticking off a variety of scenarios the average provider may never have imagined exploring.

Weber notes that one of the biggest barriers to access to such options is that people affected by HIV, as well as queer- and trans-identified individuals, aren't routinely asked whether they might want to have children at some point.

"We don't even know what people's desires and dreams are," she says. Further, federal regulations have not caught up with either the science or the reproductive desires of HIV-affected communities.

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When Detroit resident Bré Campbell, who is living with HIV, and her partner realized their relationship would likely be a long-term one, they started talking about having a baby. At that point, HIV was the furthest thing from Bré's mind.

"I was more concerned about my partner carrying a baby," she explains. Because he's a transgender man undergoing prenatal care could be traumatic for him. Both Bré, who is a trans woman, and her partner had had negative experiences in medical settings due to ignorance and bias; they both anticipated this would be their biggest obstacle in seeking reproductive care.

As they researched their options, the idea became more real to them. "We got really excited," Bré remembers, "talking about names and how we wanted to raise our child." Bré, who was 30 at the time, and her partner, who was 25, weren't ready to have a child immediately.

They decided to cryopreserve, or freeze, Bré's semen and her partner's eggs for future use, whether by her partner or a surrogate. "I knew that HIV [she was diagnosed in 2010] would complicate [the surrogacy process]," but she also knew about sperm washing.

They found a clinic in the state where Bré's partner was then living. Its website offered "LGBTQ-friendly" services, with a section outlining how the clinic helped trans people become parents. When she called to make an appointment, she was asked her HIV status, and she shared that she was living with the virus.

Clinic staff were flummoxed. They put Bré on hold and then gave her several sets of conflicting information. Eventually, she was informed that the facility was not equipped, by FDA guidelines, to process or store HIV-positive semen. Further, they weren't able to supply the name of a clinic that was. "That should have been an easy referral," Bré notes.

At this point, their plans for having a biological child are on pause. "We get told no too many times," she explains. "If it happens for us biologically, yay, but I don't think we're holding our breath for that anymore.

"It was mind-boggling to me," Bré adds, "that this place was really trans-centric and then didn't

plan for people living with HIV. Especially with trans people being at high risk [for the virus].”

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Weber has been part of several advocacy campaigns toward equal access to fertility interventions in California and nationally.

They include ongoing efforts to lift the FDA’s prohibition on anonymous sperm donation from men who’ve had sex with another man—a cousin to the infamous “gay blood ban.” But getting a large number of fertility practices to support the reproductive desires of people living with HIV is still an uphill climb.

“We create systems that are supposed to help people, and they really keep people out,” Weber says. “Then you add on this layer of judgment around queer reproductive health or HIV-affected reproductive health. There are all these judgments from clinicians and from our guidelines. What are we telling people? ‘Stay away.’

“For me, all of these are opportunities to come in—come to the clinic or come on this phone call—and talk.”

Lolisa and Daryl, as well as Anna and Reed, expressed a similar bottom line: They’re raising kids. They’re living their lives. HIV is not their top-of-mind concern. It’s part of their normal.

HIV is also part of conversations not just about death—the terrible “normal” of the early years—but about life. “Becoming empowered with my doctor and becoming undetectable have been part of a conversation about life, and the future,” Reed says. “Having a child is the literal embodiment of that conversation.”
