

*On June 5, 1981, the Centers for Disease Control and Prevention issued its first report about a rare form of pneumonia affecting a small group of gay men in Los Angeles. Thirty years later, that disease, HIV, is a global pandemic, hitting Black communities hard. Here activists, health experts and HIV-positive women and men who've been a part of the fight for nearly three decades share their deeply personal stories*

**BY ERICKA SÓUTER**

### **THE POSITIVE PARENTS**

**BOTH HIV-POSITIVE, LINDA AND NATHANIEL SCRUGGS STRIVE TO SHOW THAT BEING INFECTED DOESN'T MEAN GIVING UP ON YOUR DREAMS OF A LOVING, HAPPY FAMILY**

**L**inda Scruggs was 11 weeks pregnant with son Isaiah when she learned she was HIV-positive at a prenatal appointment. Shocked and scared, she recalls the only thing worse than the news was the way it was delivered. Doctors at the Baltimore medical clinic told her if she chose not to have the baby, she might live five years. But if she had the baby, both would die in three. "It was the day before Thanksgiving and they were closing early," recalls Linda. "They said I had half an hour to decide. I left and never went back." Linda, who contracted the disease through unprotected sex, wed Isaiah's father (who was not positive) while pregnant, but the marriage ended a few years later. She is now married to Nathaniel, an HIV-positive father of two. Fortunately Linda's son, now 20 and with hopes of becoming a firefighter, was not born infected.

A lot has changed for HIV-positive mothers like Linda, now 46. As director of programs for the AIDS Alliance for Children, ▶

# **HIV:** 30 Years Later



After meeting online, Linda and Nathaniel married six years ago, coparenting a blended family that includes Isaiah (center top); Linda's adopted son, Lawrence (not pictured); and Nathaniel's daughter, LaTrice (far right).

Youth & Families, an organization that provides access to care and advocates to improve public policy, she's seen a shift. More physicians are open to working with infected couples who are expecting, and antiretroviral drugs, like AZT, given before and during birth, have reduced in utero transmission rates to fewer than 2 in 100.

Yet HIV-positive parents still face a lot of discrimination. "People don't look at us as having normal lives," says Linda's husband, Nathaniel, 58, a social worker who isn't sure if he became infected after unprotected sex or through former drug use. Like other HIV-positive parents, they encountered wary parents of their children's playmates. "I generally ignored the parents and let the children decide if they wanted a relationship with my sons," Linda says. "The stigma in this community is as painful as the disease."

"As Black people we must have conversations about HIV/AIDS in our schools and faith assemblies," adds Linda. "We have to realize that in some ways this disease is no different than diabetes or hypertension—it can be avoided by altering your behavior." Until then, the deeply religious couple—Linda is an ordained minister—put their faith in God and each other. "You can have love, you can have kids," says Linda. "HIV is in this house, but it is not the centerpiece of this family. Faith is the centerpiece."

## THE LONGTIME SURVIVOR

POSITIVE AFTER A SEXUAL ASSAULT IN HER TEENS, **DENISE STOKES** MADE TEACHING THE REALITIES OF HAVING HIV HER LIFE'S MISSION

**D**enise Stokes never dreamed of living long enough to worry about wrinkles and gray hair. While trying to enlist in the military in 1986 at age 16, she was diagnosed with HIV. At the time, images of AIDS patients with hollowed cheeks and rail-thin bodies blanketed the news. "I thought I would be walking down the hall at school and drop dead," says Stokes, 42, of Atlanta.

She feared discrimination, as infected students were often kicked out of school and shunned by their families. So Stokes suffered in silence, turning to tequila and crack cocaine for comfort. Homeless by 17, she was shaken out of her drug-fueled fog five years later, when a group of teenage drug dealers harassed her one day. "I was so humiliated," she recalls. "But I looked the tallest one square in the face and said, 'Yes, I am a crackhead, but I haven't always been this way and I won't always be this way.'" Soon after, she went to a local rehab clinic demanding help. "I told the lady at the intake window that I had HIV and I was not leaving until I got a bed, because I didn't want to die using," says Stokes. "She was shocked but told me because of a new policy, infected people took treatment priority."

Today more services, like support groups and housing programs, exist to support HIV-positive women. Advancements in medical treatment mean one can live with the condition for decades. "But people need to know that living a normal life with HIV can be hell," says Stokes. Though she has periods of good health, with her compromised immune system she recently suffered her second kidney stone in a month and an outbreak of shingles. "I've had to run back and forth to the ER and take three weeks off work," says Stokes, a program coordinator for AID Atlanta, a nonprofit educational and support center. "And the financial impact is huge. Sometimes you have to choose between medicine and paying the light bill."

Given such realities, Stokes is committed to talking to as many people as she can to stop the spread of this preventable disease. "We talk more openly about sex now—how we want it, when we

"I've come across too many people with the attitude, 'I don't want to get HIV, but if I do, all my friends will rally around me and there are great new medicines, so I will live,'" laments Denise Stokes. The reality is much more complicated.



want it—but when it comes to actually asking your partner about HIV and other STIs, women tend to shut down," says Stokes, who books speaking engagements for colleges and organizations like the NFL at denisestokes.com. "You need to ask your partner questions and accept the fact that, yes, HIV can happen to you."

## THE CHANGE MAKERS

MOM AND DAUGHTER **BETTY AND VANESSA SMITH** PERSUADE CHICAGO CHURCHES TO OPEN THEIR DOORS TO THE INFECTED

**B**etty Smith was deeply disturbed by what was happening in her community. Working as a respiratory therapist at a Chicago hospital in the 1980's, she witnessed an explosion of AIDS cases among Black men. "But the media wasn't saying anything about them," she says. Smith recalls some staff had concerns about drawing their blood. More alarming to Smith, a deeply spiritual

Christian, was the fact that some clergy turned their backs on these patients. The final straw came as a young man lay dying and a pastor was called on to pray with him. "The minister gloved up, gowned up, masked up and just kind stuck his head in the door," says Smith. "He wouldn't give this person comfort in his hour of need. I was just livid."



OPENING SPREAD: PHOTOGRAPHY, VANESSA VICK/REUX.COM; GROOMING, DEMETRESS VALENTINE/KENBARBOZA.COM; CLOCKWISE FROM TOP LEFT: STOKES; PHOTOGRAPHY, JAMIE HOPPER; HAIR AND MAKEUP, VALERIE HAMILTON/KENBARBOZA.COM; FENTON; PHOTOGRAPHY, JAMIE HOPPER; THE SMITHS; PHOTOGRAPHY, RASHOD TAYLOR; HAIR AND MAKEUP, D'LONZO/KENBARBOZA.COM.

Inspired to change the isolation that so many HIV patients experienced, she founded the South Side Help Center in 1987 to educate the religious community. It was a tough road. Funeral homes were refusing to embalm HIV patients, and churches would not host their services. But Smith was undeterred. Going door-to-door with daughters Vanessa and Valerie, she targeted the first ladies of the churches, the pastors' wives. "They had sons they were concerned about," Smith says, noting that her organization went on to help hundreds of churches start their own HIV-prevention ministries.

Today the Smiths' not-for-profit dedicates most of its resources to educating youth about the disease. Both Betty and Vanessa admit some hurdles remain when working with churches. "Some are open to us bringing the message, but it can't happen on a Sunday morning or in the sanctuary because they feel it's not the business of the Lord," says Vanessa, who took over as executive director when her mother retired in 2008. "And sadly, a lot of churches are still homophobic and think of HIV as a gay disease."

For Vanessa, another worrisome development is that the face of HIV/AIDS now includes a growing number of seniors. People with HIV are growing old with the disease, but her staff is also seeing more previously uninfected women in their fifties and sixties test positive. "They just don't think they are at risk," she says. Still, she insists it is not too late to loosen the epidemic's stronghold. "If you belong to a church, make sure it is addressing HIV and AIDS in your community by educating members," Vanessa advises. "Our message has always been that it's not who you are; it's what you do that puts you at risk for HIV."

## THE PREVENTION SPECIALIST

**DR. KEVIN FENTON** DEVELOPS PREVENTION PROGRAMS NATIONWIDE WHILE PUSHING FOR A CURE

**E**ven as a teen growing up in Jamaica, Dr. Kevin Fenton understood the gravity of AIDS. "I can vividly remember the harrowing images on television," he says. "Young men and women suffering from cancers, extreme weight loss and disfiguring Kaposi's sarcoma are still clearly etched in my heart and memory." Struck by what he had seen, Fenton worked with HIV patients in hospice care while in medical school. "The lack of knowledge about HIV and the fear associated with it meant that these people were not always treated humanely," he says. "All these experiences inspired me to become involved in the fight against HIV/AIDS."



Kevin Fenton has followed the epidemic for almost 30 years.

As director of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at the CDC since 2006, Fenton, 44, is at the forefront of the struggle to stop the spread of HIV. Working closely with the Obama administration, he helped implement the Act Against AIDS campaign in 2009. Two primary goals: provide grants to Black grassroots organizations and get the word out that this disease is still a crisis. Noting a survey by the Kaiser Family Foundation that showed concern about HIV among young African-Americans has declined, he says, "We need to wake up to the fact HIV is in every corner of our community."

While Blacks represent just 14 percent of the U.S. population, they account for almost half of the 510,100 Americans living with HIV. The reasons why are manifold. According to Fenton, the incarceration of so many Black men can disrupt stable relationships and may lead to risky sexual behavior. STIs, which are at higher levels in Black communities, make it easier to contract HIV. And the stigma tied to this disease keeps many Blacks from getting tested or seeking treatment.

Yet there is hope. The number of Blacks infected has been stable for more than a decade. To reduce that number, three things are required of us, says Fenton: getting tested regularly, having fewer sex partners and engaging in honest conversations with young people about condoms. "We must prevent new generations from becoming infected," he says, adding that recent medical advances, including early signs of an effective HIV vaccine and a vaginal microbicide gel to prevent infection, are promising. "Little breakthroughs occur every day. I firmly believe we can end this epidemic in my lifetime." □

*Learn how you can help in the fight against HIV; go to greaterthan.org.*

**Ericka Souter** writes for *Us Weekly*.

*One in 32 Black women will become HIV-positive, though the disease is preventable.*

SOURCE: CDC.GOV/HIV