Florida HIV cases increasing — and many people don’t know they have it

By Cindy Krischer Goodman and Caroline Catherman
South Florida Sun-Sentinel, Orlando Sentinel

Dec 01, 2022 at 7:00 am

While many parts of the country have HIV under control, Florida leads the nation in new infections.

Nearly 5,000 people a year in Florida are diagnosed with HIV, a number that hasn’t budged much in the last 10 years despite the nation overall experiencing an 8% decline.

In total, about 120,000 people in Florida live with HIV and as many as 17,700 more are undiagnosed and likely spreading the virus to others without vit.

As the world recognizes its progress on World AIDS day, Dec. 1, Florida is stuck in the past.

“My team in California, they say that Florida reminds them of what it looked like in the middle of HIV crisis in the early ‘90s — that we’re [over] two decades behind in terms of the guidance, policies and infrastructure,” said Elena Cyrus, an infectious disease epidemiologist at the University of Central Florida who has studied HIV across the state and country.

Federal and state programs offer low-income people discounted or free HIV treatments as well as prevention in the form of pre-exposure prophylaxis — PrEP — a daily pill or bi-monthly shot that can drastically lower a person’s chances of getting HIV from sex or injection drug use. In Florida, millions of dollars are coming in from state and federal governments and various organization grants for these purposes.
Tests are available at no cost throughout Florida at clinics and mobile testing sites, and the Department of Health sites in each Florida county offer free at-home HIV test kits.

But these resources aren’t always getting to the right people: young minorities who have multiple sexual partners. Sexual encounters represent the majority of transmissions.

Black and Hispanics, particularly those ages 20 to 39, represent an overwhelming majority of new cases in Florida, according to state health statistics. Communities like Doral and Overtown in Miami-Dade, Oakland Park and Fort Lauderdale’s Sistrunk in Broward County, and downtown Orlando and Orlo Vista in Orange County stand out for their high infection rates.

Stigma, prevalent throughout the Southeast, including Florida, prevents some of the most vulnerable populations from getting diagnosed.

“People are so afraid to get tested for fear of losing their job, or ruining their relationships with family,” said David Poole, director of legislative affairs with the AIDS Health Foundation of Florida. “Stigma keeps people from getting tested and care early and the earlier someone gets tested, the better the health outcome.”

Hispanics account for a rising share of new infections.

Local experts believe there are several reasons: fear of being reported to employers or deported to their native countries, limited HIV risk education in their homes due to religious values, or sexual exploitation that puts them at risk.

“South Florida is a region of immigrants, many are coming with beliefs and cultural norms and information that are completely different from what Caucasians might think and know,” said Stephen Fallon, executive director of Latinos Salud, which operates four wellness clinics in Miami-Dade and Broward counties. “Once a communicable disease takes hold in a community, it tends to exacerbate.”

Fallon said the Hispanics who most need PrEP aren’t getting it, or making appointments and missing them, or starting medication and then drifting away from taking their pills.
He suggests a new approach to enroll the minority gay community on prevention medication.

“It’s best done by people who look like and understand the population they are reaching out to,” he said. “It’s not just about speaking Spanish. It’s about lowering barriers to get people in a particular population on PrEP, and it should be as close to free as possible.”

The majority of people with the virus in Florida are on medications and considered virally suppressed, according to state data. Where Florida falls short, experts say, is in outreach and education.

States like New York, for example, have invested more in marketing the availability of prevention medication.

Eric Schrimshaw, who came to the University of Central Florida after working at Columbia University, says New York puts advertisements for PrEP in every subway and bus station. In Florida, he says, HIV treatment and prevention are discussed in the shadows.

He believes the state Legislature needs to devote more attention and funds to the issue.

“The states that have been successful in this are those who have invested the resources to avoid it,” Schrimshaw said.

A lack of relatable messaging around HIV diagnoses and prevention could be the reason infection rates aren’t falling among young adults in the state, says Sylvie Naar, a professor in the Florida State University College of Medicine.

“Young people are most likely to have an undiagnosed infection, most likely to have poor linkage to care and they have the lowest rates of PrEP uptake,” she said.

She and her research team at the FSU Center for Translational Behavioral Science are working to better understand what the messaging needs to be to reach young people.

“If someone is in a high-risk group, they should be tested every six months,” Naar said. “If they go to get tested and feel uncomfortable, they are not going to go back. That’s a big part of it.”
In Fort Lauderdale, Fallon, of Latinos Salud, tells of a 25-year-old man who was tested in early spring, but he juggles multiple jobs and never returned to the clinic to get on prevention medication. When a clinic worker finally urged him to return for another test months later, he tested positive for HIV.

“There are so many stories like his,” Fallon said.

Naar said several Florida-specific factors contribute to the high rates of HIV in young people: Florida’s limitation on sexual education and HIV prevention in schools, and the state requirement that minors get parental consent to start on PrEP.

“Minority [LGBTQ] youth don’t have sex education that serves them and may not know how to have save safe sex or healthy relationships,” she said.

Daniel Downer, executive director of the Orlando-based Black queer-led grassroots Bros in Convo Initiative, said he’s met multiple gay or queer people of color who have had only abstinence-only education.

“So some of the individuals who come into our doors, we are the first person to talk to them about condoms. We are the first person to talk to them about getting tested, because no one’s ever had that conversation with them. The conversation has always been ‘you don’t have sex,’” Downer said.

In Miami-Dade, the county with a high prevalence of HIV in multiple ZIP codes, Dr. Saint Anthony Amofah is chief medical officer at Community Health of South Florida Inc. Amofah wants to see PrEP and testing recommended at every point of entry in healthcare: primary-care practices, urgent cares, hospitals and community clinics.

“Most of the spread is from those who are not tested, those who don’t know,” Amofah said.

Amofah said barriers to access for testing is a bigger issue now than funding for medications. “There might be pockets in the immigrant communities where persons don’t have time and way to travel for testing or ongoing care. So while funding is available, if someone doesn’t have time or transportation, it’s one more reason not to know your status.”

In Miami, Dr. Maria Alcaide, a professor of infectious disease at University of Miami said testing is key to controlling the epidemic. “We have good treatments that make people living with HIV live longer and healthier lives,”
she said. “If everybody who has HIV is on an effective medication, then there will be no transmission in that population.”

In Florida, about 13.5% of people living with HIV don’t know it, according to state estimates.

Alcaide, who directs the Miami Center for AIDS Research, said she is trying innovative outreach approaches, sending mobile units into pockets of communities with the highest number of new infections. “We have the tools, we just need to get them to the people who need them the most.”

She recommends everyone, male or female, heterosexual or other, gets tested. “HIV is an infection that occurs in both men and women and about 20% of new infections occur in women.”

“We have to recognize all the advances in terms of prevention, treatment, and preventing progression to AIDS,” she said. “But we also have to recognize we have challenges in diagnosing early and preventing new infections.”