You, Too, Can Be an HIV Advocate!

10 simple ways to fight the virus every day

January 10, 2017 By Casey Halter

For most people living with HIV, being a full-time AIDS advocate is not realistic. But that doesn't mean most folks with the virus can't do something to fight the epidemic.

Below are 10 ways you can do your part, along with advice and encouragement from several longtime HIV/AIDS advocates.

1. Get Political

This year is likely to be marked by many setbacks for people living with and at risk for HIV—including the Trump administration's promises to repeal the Affordable Care Act (ACA), defund Planned Parenthood and cut the budgets of integral social service providers across the board.

So what's the best way to speak out on behalf of the community against these injustices?

"One of the biggest pieces of advice I have is to join a network of people living with HIV," says Scott Schoettes, HIV project director at Lambda Legal, the oldest and largest national legal organization dedicated to the LGBT community and people living with HIV/AIDS. "Being part of a group will help plug people into all sorts of political options, whether it be making a phone call to a legislator, writing a letter, showing up at a protest or showing up to lobby a state legislature on a designated lobby day," says Schoettes.

Joining these groups can also help focus your HIV advocacy and link you to a number of powerful people in the community to help give your words weight. Depending on your passions and the amount of time you're able to commit, you can choose a large and general organization, like the Global Network of People Living with HIV (GNP+) or the Positive Women's Network, or a highly targeted one, like the Positive Justice Project, which focuses on HIV criminalization.

Click here to learn more about advocacy and the differences it can make for people living with HIV/AIDS.

2. Know Your Rights

Despite major medical advancements, increased awareness and the establishment of specific legal protections for the positive community over the last 30 years, HIV discrimination is still a problem across the United States. According to Schoettes, one of the best forms of self-advocacy for people living with HIV is to know your rights and to speak out and take action against those who discriminate.

“The fact is that there is no job that I can think of that a person living with HIV cannot do safely,” explains Schoettes, who has plenty of experience defending HIV-positive people in court. So if you’re fired or not hired because of your HIV status—whether you’re a doctor, a food handler or a tattoo artist—know that that’s not legal.

Under a wide array of laws, such as the Americans with Disabilities Act (ADA), the Fair Housing Act, the Affordable Care Act (ACA) and more, your rights as an HIV-positive person also extend to housing, medical care, public facilities, education, transportation and more.

If you believe you or a fellow person living with HIV has been discriminated against, click here to learn more about the legal tools you have to fight back.

3. Reach out in your community

If you’re intimidated by the thought of joining a national advocacy group, there are plenty of smaller-scale community-based organizations, or CBOs, across the United States focused on HIV that need both volunteers and employees to help keep them running.

As a community health worker, or CHW, you can help out by doing HIV testing or community outreach or simply by lending emotional support to other people living with HIV when they need it the most.

“A lot of the work that CHWs do involves going to clients’ homes, meeting clients at coffee shops—or other places where the clients will be comfortable—to have conversations,” explains Abby Charles, a senior program manager at the Institute for Public Health Innovation who helps link hopeful HIV advocates to positions in the community.

Often, there are opportunities at these organizations requiring various levels of commitment, from volunteering once a month to full-time employment. “Knowledge of the disease or the issue being addressed and knowledge of the barriers that affect persons’ ability to access care or stay retained in care are some of the things that we look for,” says Charles. Plus, thanks to grant-savvy public health workers like Charles, community health workers are increasingly becoming paid positions (meaning you can get paid for the work you do reaching out to the community).

Click here for a list of CBOs and AIDS service organizations (ASOs) where you can volunteer or work to help others living with HIV.

4. Be a mentor

Conduct your HIV advocacy on an even more personal level by joining a support group or becoming a one-on-one mentor for other HIV-positive people. For a lot of people, an HIV diagnosis can be very scary and isolating. Showing the newly diagnosed the ropes of how to access essential services, such as signing up for health insurance, joining clinical trials and securing housing or other supportive services can help them live better with HIV.

“We’re always looking for people who are well-trusted or well-known in the community who themselves have gone through this health condition or are dealing with some of the other social barriers that affect linkage to and retention in care,” says Charles.

Plus, talking to others about your issues around things like HIV treatment, side effects, adherence, dating, family and the dozens of other challenges with the virus you may be experiencing day-to-day will probably help you too.

To become involved in a mentoring or peer group, Charles suggests linking up with your local CBO. Sharing information and support online, via forums or virtual support groups, can also help make a big difference. Or reach out to HIV-positive friends directly just to make sure they know they are not alone.

Click here to learn more about why peer support is so important for people living with HIV.

5. Help Raise Money

Donating to HIV-related causes is one of the easiest forms of HIV advocacy you can do. It can be anonymous, it’s tax-deductible and it may take only minutes of your time—especially with the ease of the Internet.

Strapped for cash? A lot of HIV advocates also help raise money and advocate for HIV-related causes in more grassroots ways, for example, by reaching out to venues in their communities to host parties, bake sales or fundraisers.

“In 2015, I was able to help plan and execute a bar fundraiser called Code Red, which helped support those affected by HIV/AIDS,” says Cortlen Yarbrough, a community health worker based in Washington, DC, who has been working and volunteering with the Institute for Public Health Innovation over the last three years. “We raised $800 and were able to give that to Casa Ruby, which helps homeless LGBTQ and the trans community.”

Ready to start raising money? Click here to check out the POZ Calendar, where you can check out what other people are doing to help fund HIV-related causes, join other grassroots initiatives or publicize your own event.

6. Speak up about your status

Speaking out about HIV with your family, friends and other trusted people in your social circle isn’t just a good way to find support—it can also help put a face to the epidemic and educate your

loved ones about what it's like to live with HIV today.

"I knew enough of the basics to talk regularly with friends and family. Just by starting the conversation, I realized how deep-rooted HIV-stigma is in the community," says Yarbrough. According to the advocate, his work as a community health worker has proved to him that "what researchers, policy makers and providers might think is common knowledge about HIV, advancements in treatment and access to care is not trickling down to the community effectively."

Aside from having regular in-person conversations with people who are HIV negative, speaking out on social media can also be a great way to share your status and information about HIV. Whether it's proudly telling a story about recent advancements in treatment, creating an anonymous blog about HIV or even sharing a banner on one of many HIV awareness days, you can make a difference.

Click here to learn more about how HIV advocates are using social media to help raise awareness and educate the public about the virus.

7. Shop smarter

Put your money where your mouth is. There are plenty of opportunities to spend smarter on all of your fashion and gift choices. Consider Bono and Bobby Shriver's Project (RED), which famously donates a portion of its proceeds to The Global Fund to Fight AIDS, Tuberculosis and Malaria, or Mondo Guerra's SEE eyewear boutiques, which help raise funds and awareness for amfAR, The American Foundation for AIDS Research.

Wearing your support, whether in the form of a simple red ribbon or a "Silence = Death" pin on your jacket also helps normalize HIV/AIDS and bring the fight against the epidemic into the public consciousness on a regular basis. Think of wearing your advocacy as a potential conversation starter and as a way to help you identify with people who share your beliefs.

On the flip side, you can also make an effort not to spend your hard-earned cash on organizations known for suppressing LGBT rights, civil rights or promoting policies that may adversely affect at-risk communities. Skip the Chick fil-A sandwich, or avoid Hobby Lobby when shopping for your next crafting project. There are plenty of other organizations that need your money that won't negatively impact the fight against the epidemic.

Click here to check out some more gift ideas that help raise money for HIV/AIDS-related causes.

8. Get educated about HIV

If you want to effectively advocate for your medical needs as an HIV-positive person—whether it be quizzing your doctor about HIV treatment at your viral count check-in or talking to your pharmacist about potential drug interactions—you're going to need to be armed with knowledge about the virus. In fact, simply getting educated about HIV is often the first step into HIV advocacy and community health work.

“I talk and educate clients about their medications to make sure they understand the importance of viral suppression,” explains Sabrina Heard, another community health worker with the Institute for Public Innovation. “I also teach condom use so that the transmission of the virus can be stopped or lowered [if] a person is [HIV]-positive.”

According to Sabrina, taking that first step and educating herself about HIV not only allowed her to make better decisions about her own care, but it also allowed her to do her work around HIV more effectively with others.

Plus, “I am not only helping the community,” says Heard. “I am helping the medical profession to give care to those who would otherwise not access the medical services that they need.” That’s because knowledge about HIV goes both ways, and unless you’re vocal to your providers about what you and other HIV-positive people may need, you may not be getting the care you deserve.

Newly diagnosed? Click here for a variety of “HIV Basics” lessons on treatment, what it means to be “undetectable,” living with HIV long-term and more.

9. Accompany a friend to get tested for HIV

This one’s easy. One of the only ways we as advocates are going to end the HIV/AIDS epidemic is if everyone knows their status. Getting tested for HIV regularly helps stop HIV transmission in its tracks—and making an HIV test a routine in your life can also help normalize regular check-ins for others.

If you already know you’re HIV positive, talk to your friends and colleagues about why getting an HIV test is so important. If you have a partner or a friend who is worried about his or her status, take him or her with you to the clinic. Aside from just testing, you can help hook up a friend with new forms of HIV prevention, like Truvada as pre-exposure prophylaxis, or PrEP, a daily pill that can help keep them negative.

The CDC recommends that everyone between the ages of 13 and 64 get tested for HIV at least once, regardless of perceived risk. Click here for more information about HIV testing.

10. Disclose your HIV status.

Although opening up about your HIV status to others isn’t always easy, disclosure is one of the simplest ways to support other people living with HIV. For one thing, being honest about being HIV positive helps defeat stigma and damaging myths about people living with the virus. It also helps weed out people from your life who may discriminate against you or hurt you because of your status.

If you’re about to hook up with someone, also know that in many states, it is illegal not to disclose your status before an intimate exchange (see the above “Know Your Rights” section for more information). Disclosure helps protect you and other HIV-positive people from these damaging laws.

On the flip side of being a pro-disclosure advocate, also honor other HIV-positive peoples' privacy by not sharing their status without their permission. To be a good advocate, you also have to be an ally to other people living with HIV. Whether you're HIV positive or you're HIV negative, we're all in this together.

Click here to learn more about disclosure and tips on how best to open up to someone about your HIV status.

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