HIV Advocates on HIV Advocacy

Past POZ 100 honorees share their advice on activism and empowerment.

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Khafre Kujichagulia Abif

Why do you advocate for people living with HIV?

I advocate for people living with HIV because I have no choice. If I advocate for myself successfully, I believe it is my responsibility to advocate for the collective community.

How do you empower others?

I work to empower others by helping to amplify their voices through my published works like, Cornbread, Fish and Collard Greens: Prayers, Poems & Affirmations for People Living with HIV/AIDS and Sistah's Speak.

What advice do you have for people doing HIV advocacy work?

My advice for people doing HIV advocacy work is to find an area you are passionate about and do it well. Then learn new skills for your toolbox so that you can expand the effectiveness of your work.

Giuliani AlvarengaJeff Singer

Giuliani Alvarenga

Why do you advocate for people living with HIV?

Because laws are in place that oppress folks living with HIV.

How do you empower others?

I empower others with my story, my struggles and my triumphs.

What advice do you have for people doing HIV advocacy work?

If you don’t practice harm reduction, compassion and unconditional love, don’t do this work. We need true allies only.

Judith Auerbach

Why do you advocate for people living with HIV?

I am a native San Franciscan and was raised with a strong social justice ethic. There is no way I would not work in HIV, given the experience of my community as one of the earliest and hardest-hit by the epidemic. I am committed to supporting and advocating with and for people living with HIV because I care (a simple but true answer) and to honor and keep alive the memory of my

youngest brother, Matt, who died of AIDS in 1991.

How do you empower others?

Much of my HIV focus has been on women, who remain a neglected population in the HIV response in the United States. I am cochair of the board of directors of The Well Project (TWP), a nonprofit organization serving women living with and vulnerable to HIV and the people who care for and love them. TWP's approach is to leverage virtual platforms (webinars, blogs, social media) and to convene opportunities (conferences, meetings, now Zooms) to facilitate the trajectory for women living with HIV to gain information and knowledge, to join and build community, to advocate for themselves and others. Our annual user surveys document how our programs and activities contribute to the empowerment of women all over the world in this way.

Additionally, as a sociologist who operates in the biomedical science arena, I try to leverage my standing to lift up emerging (aka younger and early-career) scholars and community members, especially women of color, interested in HIV science—whether by mentoring them, inviting them to meetings or suggesting them as speakers and committee members in the various sectors in which I work: government, nonprofits, community-based organizations, academia, industry, professional societies. As a more senior person in the field now, I try to step back and let these younger and early-career people take the floor and the podium and assume leadership positions.

What advice do you have for people doing HIV advocacy work?

- Your HIV community members are not the enemy—don't let the real enemies succeed in dividing and conquering us!
- Pick your battles! Not everything is equally worth "falling on your sword."
- Appreciate that there are multiple ways of doing advocacy. Some people are best at working inside institutions to try to subvert them; others are best at banging on the doors of institutions to try to change them by force. Both are necessary.
- Make room for love and compassion in your advocacy work.
- Be sure you take time to rest, take care of yourself and breathe.

Rosa Rivera AvilésJensen Larson

Rosa Rivera Avilés

Why do you advocate for people living with HIV?

When I received my HIV diagnosis nearly 24 years ago, I had two paths before me: to let myself die or to advocate for my rights and for others living with HIV who dare not speak publicly. From that day on, I decided that the best legacy I can leave is to create a more dignified life for those with HIV through changes in public policy. My dream is that people with HIV can be treated with respect.

How do you empower others?

I make everyone see the importance of being a person not a virus. That's why I don't say, "I'm HIV." I'm not a virus; I'm a person. I don't say, "I live with HIV" because I don't live with HIV; HIV lives with me. I'm in charge of my house. I empower others with my testimony. I offer talks and presentations to change stigmatizing concepts. I share all the knowledge I acquire in different groups and the internet. I'm available 24/7.

What advice do you have for people doing HIV advocacy work?

The people who choose this path must be clear that this is not a way to seek prominence, positions or personal favors. It is a path that carries a lot of responsibility because on your shoulders you will carry the triumphs or defeats of many. We need you on this path, and if you carry the commitment, you will be contributing to important social changes for a better quality of life. Do the work with love, and you will always have sweet dreams.

Edwin Bernard courtesy of HIV Justice Worldwide

Edwin Bernard

Why do you advocate for people living with HIV?

I've been living with HIV since I was 20. I'm 58 now. When so many didn't survive, somehow I did. It's my duty to use my knowledge and my privilege to fight for the rights of people living with HIV everywhere.

How do you empower others?

When I started the HIV Justice Network (HJN) back in 2012 few people knew or cared about HIV

criminalization. Now there are many dedicated and passionate activists and allies all over the world who are also dedicating their lives to the cause. HJN aspires to empower others by focusing on three core areas: monitoring laws, cases and advocacy so people know what's going on, connecting local advocates and lawyers to the global movement and vice versa, and producing advocacy tools to educate and support people to defend themselves and others from unjust laws and policies that control, surveil and punish people with HIV.

What advice do you have for people doing HIV advocacy work?

One person can change the world, but we can achieve even more when we work together and when our work is adequately funded.

Michelle Braxtonsteve morrison

Michelle Braxton

Why do you advocate for people living with HIV?

I advocate because living with HIV is not a death sentence. I have been living with HIV for 29 years. If you are informed and get tested and treated for HIV, you can live a fulfilling life.

How do you empower others?

I empower people by sharing my journey, especially in the church and through my book, Living With HIV. I also share information about [medical advancements] that have been made.

What advice do you have for people doing HIV advocacy work?

I believe they should hire people like me, who have actually walked through this journey as peer educators.

Gina BrownDaymon Gardner

Gina Brown

Why do you advocate for people living with HIV?

I advocate for people living with HIV/AIDS (PLWHA) because I think it’s important that we all have the same resources. I do most of my work in the rural South, and I see the disparities. There are many reasons not all PLWH are advocating for change. Stigma and shame play a big part in PLWH not speaking up. My advocacy is important, but it’s just as important for me to help the people I advocate for dismantle the many layers of stigma (some of us carry), take the mic and get a seat at the table.

How do you empower others?

I help empower PLWH by giving them tools to empower themselves. I find that most people have that little something in them, I just help expose it, pull it out of them. I also empower them by being visible in my work. I talk openly about my challenges and how I overcame/overcome them.

What advice do you have for people doing HIV advocacy work?

Unless you're doing advocacy for yourself, it's important to get in coalition with other people doing advocacy work. You may be able to lift a table by yourself, but it's a lot less heavy if you have help. Remember: Burnout is real.

Derek CanasCourtesy of Derek Canas

Derek Canas

Why do you advocate for people living with HIV?

Because stigma is still a very strong reason that people don’t get tested.

How do you empower others?

I hope I’ve empowered others through sharing my personal story in person and in podcast interviews. I have a volunteer team called #dreksangelsandwarriors, and they help eliminate stigma everywhere they find it.

What advice do you have for people doing HIV advocacy work?

Stop building small tables for specific groups. Until we can all sit together, I don’t see anything great happening.


Cecilia ChungCourtesy of Cecilia Chung

Cecilia Chung

Why do you advocate for people living with HIV?

As an immigrant trans woman living with HIV, advocating for people living with HIV (PLWH) is all about survival and what I learned when I first began this work. Those days are not something I can leave behind me and by continuing to fight for the rights and survival of PLWH, I am also putting pieces of me back together and hoping no one has to go through what I went through—the stigma, the transphobia, the family rejections, the violence, the mental and emotional turmoil and all.

How do you empower others?

Some of the trans leaders with whom I was fighting alongside are no longer with us today, and it is not enough for just a small number of us to be occupying spaces when there is a vast community of voices that need to be uplifted. As a result, I began organizing the community with the goal of empowering more trans and gender-nonconforming (TGNC) leaders to step forward in spaces of people of color, in LGBT spaces, in spaces with PLWH and spaces of other movement. This was why I organized the first trans march in San Francisco. We walked up and down City Hall to advocate for dedicated resources for TGNC economic development and launched Positively Trans to develop and support TGNC leaders living with HIV.

What advice do you have for people doing HIV advocacy work?

So much has changed since the onset of the HIV pandemic, but sadly, a lot of lessons have been lost because some of the pioneers whose shoulders we stood on are no longer with us today. Please take time to talk to the survivors from the early AIDS crisis. Only by doing this can we ensure we do not repeat history. For the veteran activists, please take time to tell your stories because they represent hope and resilience that we desperately need in these tumultuous times. Lastly, to be an effective HIV advocate means we fight for immigrants, Black lives, people of color, transgender and nonbinary people, women, people with disabilities, sex workers, human rights and those who are at the margins and at the intersections of oppressions.

Orbit Clanton

Why do you advocate for people living with HIV?

I acquired HIV back in 1982 when there weren't any antiretroviral medications. Nevertheless, I'm still alive. I was taught my family motto, "To whom much is given, much is required" This means an obligation towards others and not just to oneself. As a man of faith, it is my responsibility and service to be the voice for those who do not have a voice when it comes to concerns surrounding living with HIV.

How do you empower others?

I try to the best of my abilities to lead by example which means always remaining humble and

grateful for all the blessing that God has given me. I utilize social media such as my Facebook page as a means to educate my more than 3760 followers to the latest information concerning HIV, current guidelines, recommendations and the latest advancements. I encourage everyone to know their HIV status and to get tested. I am open about being a person who is living with HIV. I feel it is critically and extremely important that others along with myself who are living with HIV stand up and put a face to this epidemic.

What advice do you have for people doing HIV advocacy work?

Always remember that no matter your personal situation with regards to living with HIV there is someone else out there who is facing what you have overcome or there is someone whose circumstances are far more distressing than your present or past situations. There will be times when you will become physically fatigued and mentally exhausted. However, remember the true calling of advocacy: you are genuinely speaking for so many individuals who do not have a voice. It is with this mindset and conviction where you find your true strength.

Tori CooperJonathan Timmes

Tori Cooper

Why do you advocate for people living with HIV?

I advocate for people living with HIV because I understand that with greater visibility comes greater responsibility. Each of us must use our privilege to create more opportunities and access to those with less privilege and access and fewer opportunities. None of us achieves viral suppression without help. Finding a doctor and accessing supportive services often come through folks' networks. HIV advocacy is about creating villages of support.

How do you empower others?

I empower people by living my best life and modeling what healthy habits look like. Using empowering and inspiring action words is essential to motivating others. Empowerment also means practicing what you preach. I can’t talk about healthy living without practicing it. And, most importantly, empowering others also means meeting people where they are and helping them get to where they want to be.

What advice do you have for people doing HIV advocacy work?

My advice to people doing HIV advocacy work is to understand that we are all in this together. Every advocate has a part to play in ending the epidemic. Use your talents and gifts in ways that uplift others. If you are a basketball player, then help a person with HIV improve their jump shot. If you are a writer, help someone with HIV write their story. If you are a cook, then teach a cooking class. And, most importantly, take care of yourself in the process.

Nancy DuncanBill Wadman

Nancy Duncan

Why do you advocate for people living with HIV?

I remember when I was first diagnosed in 1990, there weren't many HIV advocates in my community. I wanted to be involved in a way that could benefit people living with HIV who needed services but were experiencing barriers accessing them. I joined the Nassau/Suffolk HIV Health Services Planning Council in 2007. I was able to speak out and represent other people living with HIV who were not able to advocate for themselves. I've recently begun advocating for members of the HIV community who are over 50 because we are finding that aging with HIV has mental, social and physical barriers that must be addressed to help our community stay virally suppressed and

healthy. I pride myself on always being able to advocate for myself ,and I believe that has helped keep me healthy and thriving.

How do you empower others?

The best way for me to empower others is to be a mentor to those who seek it out. I try to make time to have open and honest conversations with people to help empower them. It's also very important to be a good listener. I promote and invite others to come to advocacy events because if it's about decisions that affect our lives, it shouldn't be happening without us! Finally, just being a positive role model can inspire others to get more involved so that we can all have a better quality of life and be effective leaders.

What advice do you have for people doing HIV advocacy work?

After 20 years of doing volunteer HIV advocacy work, I would tell others that there is much work to be done to bring awareness to HIV and many ways to go about it. Try to find the type of advocacy that works best for you. Don't spread yourself too thin by doing too much so you will remain healthy and can benefit from the rewards of all that comes with being an effective advocate!

Charlie Ferrusi

Charlie Ferrusi

Why do you advocate for people living with HIV?

I would not be where I am, or who I am, without the tireless efforts of HIV activists. Decades have passed since the beginning of the AIDS epidemic, and we continue to see people living with HIV/AIDS underrepresented in organizational leadership and absent from political decision-making tables. Meanwhile, the current state of the epidemic continues to show a disproportionate impact and neglect of long-term survivors, trans and gender-nonconforming people and folks who are Black or Latinx. People living with HIV/AIDS have dealt with price gouging from big pharmaceutical companies and have been abandoned by the federal government. We must fight for systemic

change at all levels of government, society and medicine to improve the lives of those who continue to be impacted by the HIV/AIDS epidemic.

How do you empower others?

In order to make progress in a movement, we need to empower new and existing leaders and sustain their involvement. We all have specific and crucial roles in the HIV movement. Not everyone is the same type of activist or leader. I empower others by challenging them while also extending compassion and patience. We must be committed and accountable to our own unlearning and relearning. I remind folks that showing up imperfectly is more meaningful than not showing up at all. We all have immense potential, power and influence. It is our job to tap into it, redistribute our resources and leverage our power to help others.

What advice do you have for people doing HIV advocacy work?

HIV advocacy work must operate through an intersectional lens, one that centers racial justice and LGBTQ liberation. Advocacy work is a lifelong process, and we have to continuously rededicate ourselves and strive to be better leaders. We must take time to care for ourselves and avoid burnout. We can show up in genuine ways for the rest of our lives, in both private and public actions, but it is also essential that we take a pause and reset. HIV/AIDS operates in a syndemic paradigm, so it leaves an opportunity for us to be involved and make a difference in various fields and spaces. We all have some degree of power and access, and it is important to strategically use it to hire, support, invest and uplift people living with HIV/AIDS in the spaces we occupy and have control or influence over.

Anselmo FonsecaAngel Valentín

Anselmo Fonseca

Why do you advocate for people living with HIV?

To elevate their voices and express their needs and desires.

How do you empower others?

By listening to their stories and hearing what their needs are—especially for keeping them in care and undetectable—while talking about U=U. By building on their knowledge and skills and getting them involved in decision-making processes to improve their health.

What advice do you have for people doing HIV advocacy work?

If this is not your passion, stay away. If it is, remember this is about survival; get ready for very hard work. You must pace yourself. You are in it for the long haul. Along the way, some will not stay or be with you. Don’t get discouraged; many others will, and those who do will be enough.

Kelly Gluckman

Kelly Gluckman

Why do you advocate for people living with HIV?

I advocate for people living with HIV simply because I love my community. The HIV/AIDS community was there for me when I was newly diagnosed and through my toughest times. In the 10 years that I've been living with HIV, I've grown an intense passion for making sure that every single one of our voices and stories are heard and valued. I approach everything I do through the lens of social justice, and I understand that as a white, heterosexual and cisgender woman in this society, I have access to ears and seats at tables that others may never be given. I feel that this places a responsibility on me to constantly educate myself about the complexities of the challenges we face as a community and to speak out at every opportunity. I've become enraged seeing how the structures of power and influence we're all subject to consistently leave out the most marginalized among us. Until the day comes when our culture and systems treat us all as equally deserving of respect, rights and resources, I will fight.

How do you empower others?

I currently serve as the project manager of Through Positive Eyes, which is a collaborative photo-storytelling project and traveling museum exhibition that has empowered more than 130 people living with HIV/AIDS in 10 cities around the world to tell their story through their own words and visual lenses. Spanning over a decade, the images and videos by our artivists (part artist, part activist) present a multifaceted view of the epidemic, ranging from everyday imagery to more abstract meditations on joy, grief, solitude and resilience. These voices coalesce around one core tenet: the belief that challenging stigma against people living with HIV/AIDS is the most effective method for combating the epidemic. Their unique perspectives come from all parts of the HIV community, and their voices are profoundly powerful. I'm so excited to support them through sharing their stories with audiences and to experience the impact they'll have on their audiences.

Besides my work with Through Positive Eyes, I also facilitate virtual arts-based workshops with community groups and community advisory boards. I've developed several workshops that employ the use of creative writing, storytelling, poetry, photography and vision board creation activities for self-expression and healing. I love these sessions because I get the opportunity to learn about folks through their creativity and help to facilitate an environment of social support and empowerment. I also intentionally work to create and inspire a sense of joy in these sessions. Lord knows our community needs joy the most during this intense time of sociopolitical unrest and feeling profoundly vulnerable to the raging pandemic. I also believe that joy is, in and of itself, a powerful tool of resistance and revolution!

What advice do you have for people doing HIV advocacy work?

I'm going to give the advice that I probably needed the most when I first started on my advocacy journey: Pace yourself and give yourself grace. We HIV advocates are intensely passionate, with raging fires in our bellies that drive us to constantly take action toward making change in the world. Keep in mind that this work requires unparalleled emotional and intellectual labor that can cause us to burn out quickly. I know it's tough to not be able to see the fruits of your labor but understand that social and political progress will always happen slowly and incrementally. Remember that you are not alone in this fight, and we all stand on the shoulders of the long-term survivors and advocates who came before us. Even though it's not immediately noticeable, real

change is happening as a result of your efforts, and your community is proud of you. Our fight is far from over, so steady does it. Check in with yourself regularly and take breaks when you need them. Make time for self-care, and, perhaps most importantly, find every opportunity to experience joy in your life! Joy will reinvigorate you to get back out there and keep fighting.

Aundaray Guess

Aundaray Guess

Why do you advocate for people living with HIV?

As a longtime survivor, I remember the days when stigma and the fear of living with HIV literally took over my life and the days when I wanted it to take my life due to feeling like “the other.” I’ve

been fortunate to overcome feelings of stigma by living in my truth. Once I said out loud that I was a gay Black man living with HIV, I reclaimed my narrative. My life was no longer dictated by others but by me. Using my long journey and sharing the rawness of my story, I hope to help others live in their truth as well.

The overall reason I advocate for people living with HIV is to let them know whether you live in the big city or rural areas, no matter how you identify or your ethnic background, you are not alone.

How do you empower others?

I empower others by showing my vulnerabilities and my openness to share private details of my life, such as seeking help for depression or dealing with posttraumatic stress disorder as a result of being sexually abused when I was young. In being so open, I feel that my story is others' story. My struggles are their struggles, and when I share my victories, those who have followed my story can see and celebrate their own victories.

What advice do you have for people doing HIV advocacy work?

Self-care—literally—as this work is tiring. Sometimes you're not properly rewarded, if you ever are at all. Your role is seen as insignificant by others despite the impact you make. Facing that wave of negativity, one can be washed away by negative energy and feel defeated. It's important to practice self-care so when you rejoin the battle, you're in a positive light and ready for it. I've always said that you can't make the leaves healthy if the tree is not healthy. One must check on how they are doing.

It's worth nothing that sometimes while working in the field, we don't think we're making a difference. I always remind myself that I may not see a difference happen before me; it may take some years for the seed I planted to grow. I remember working with troubled children who had a traumatic life. One girl in particular was viewed as bad and out of control. I remember thanking her for helping me one day and told her she's a good person. I didn't see her again until the following year. I'll never forget when she came to me and reminded me how I said she was good. That was her memory of me. I don't know if that comment helped her turn the corner, but it shows how we can plant that seed and make an impact and not even know. So never give up on your mission of helping others living with HIV.

Tami HaughtCourtesy of Tami Haught

Tami Haught

Why do you advocate for people living with HIV?

As a person who lived in silence for six years after my HIV diagnosis, speaking out and advocating for PLHIV is so important. Silence = Death, and I don’t plan on being silenced again.

How do you empower others?

People want to be heard. Providing space for people to share their ideas is so important. Not being able to meet in person due to COVID-19 has created challenges, but, as always, the HIV community has adapted to the challenge by hosting a variety of Zoom meetings and webinars to provide an opportunity for people to connect.

What advice do you have for people doing HIV advocacy work?

Never give up. We are persistent advocates.

Fred HerschBill Wadman

Fred Hersch

Why do you advocate for people living with HIV?

Because it is not over! We need to keep people’s attention on this ongoing crisis.

How do you empower others?

I try to be an example of honesty and strength the best I can.

What advice do you have for people doing HIV advocacy work?

Remember that your mission is to keep HIV/AIDS front and center and beyond politics.

Kathie HiersCourtesy of Kathie Hiers

Kathie Hiers

Why do you advocate for people living with HIV?

I advocate for people living with HIV first and foremost because it’s personal. I lost my two best

friends as well as many dear pals and colleagues, so I will never stop this work—even if I retire! Secondly, I see how HIV impacts the most vulnerable of my sisters and brothers. My sense of social justice is inflamed by the lack of access to care and medications, the stigma and biases against people living with HIV, the struggles of so many people living in poverty while trying to stay healthy, the disproportionate impact of HIV (and COVID-19) on the lives of minority populations and, of course, the systemic racism that our minority communities have lived with for hundreds of years.

How do you empower others?

At AIDS Alabama, one of our core principles is that people living with HIV are the people who should guide our programming, advocate for fair policies and funding and lead the charge to end HIV as an epidemic. Our agency hires many people living with HIV, helps to develop and nourish their abilities to advocate for themselves and places them in leadership positions. We also work closely with the HIV community to provide tools, support and education, which includes paying people for their services.

What advice do you have for people doing HIV advocacy work?

One thing I have learned in my 30 years of work in the field of HIV is that change is slow. But don’t let that stop you! We can create positive change if we fight together in smart and determined ways. I know we are all living through a very challenging time in our country’s history, but we must persevere! The one thing we cannot do is give up. So hang tough, my friends. As the great John Lewis advocated, let’s continue to make good trouble.

Stacy JenningsJonathan Timmes

Stacy Jennings

Why do you advocate for people living with HIV?

I advocate for people living with HIV because I’m a woman living with HIV. It does my life good to know that we can all join in this fight together and stand tall through it all.

How do you empower others?

I empower others by sharing my life story and experiences as a woman living with HIV for 25 years. I also empower others by sharing my gift and talent of writing, and I recite spoken-word pieces that everyone can relate to on many levels.

What advice do you have for people doing HIV advocacy work?

Speaking up and speaking out will give you the freedom to live, love and be yourself. I've been an advocate since birth. When I was born, my cries were my advocacy tools to be fed, to be changed, to be held and to be loved. We need to continue to speak out in advocacy because advocating will get you everything you need and desire.

Jeremiah JohnsonSean Black

Jeremiah Johnson

Why do you advocate for people living with HIV?

I’m grateful to say that 12 years after my diagnosis, I am thriving, but I realize that I am enormously privileged in that way. Thanks to consistent coverage of my comprehensive health care, relatively uncomplicated access to medicine, non-stigmatizing medical care, a strong network of friends and family and extensive mental health support, I have been able to overcome the many complex emotional and health-related threats posed by this virus and the stigma associated with it. Not everyone living with or at risk for HIV has those resources, and I am ready to spend my life dismantling and rebuilding the systems that keep people from comprehensive care and prevention.

How do you empower others?

I believe in the wisdom of The Denver Principles and that any work that is done without the communities most impacted by HIV is doomed to failure. The most important part of my work right now as an HIV advocate is to demand that we invest in leadership from communities that have been disproportionately represented in the epidemic but underrepresented in all levels of our collective efforts to address it. Any major HIV stakeholder—whether it be a company, a coalition, a health department, a key government body or an organization—that does not have significant and proportionate representation from communities of color and transgender populations at their highest levels of leadership must have a plan to rapidly bring in new representatives.

What advice do you have for people doing HIV advocacy work?

Self-care is strategic, especially in these challenging times. Prioritize and do what is needed to counteract feelings that overwhelm—hopelessness, apathy, despair, fear or debilitating rage—before they do lasting damage. This is different from escapism. Engage in enough self-care today to turn down the volume on extreme negative emotions, restore your strength and then get back to the fight.

Bryan JonesJensen Larson

Bryan Jones

Why do you advocate for people living with HIV?

I advocate for people living with HIV because it keeps me alive. I've learned helping others helps me. I was diagnosed in 1984, and there weren't any services or groups to help, so I found the will to live by helping others. I found the will to live by speaking for those who couldn't or didn't know how to speak for themselves.

How do you empower others?

Hopefully, I empower others through education and giving them the tools with which to navigate

the system. Also, by holding our health departments and AIDS service organizations accountable for funding received. And finally, by sharing my authentic self—the good, the bad and the ugly. Even in my worse moments, I show up and keep fighting.

What advice do you have for people doing HIV advocacy work?

I would advise them to read and learn to embody The Denver Principles because they are so relevant and important to understand. As you advocate, there may be times when you have to voice an unpopular decision or opinion, and it may make people in the room uncomfortable. But why should you stay silent? My rule is, if I'm uncomfortable, everyone in the whole damn room is going be uncomfortable because I'm going to speak my voice loud and clear.

Paul Kawata

Why do you advocate for people living with HIV?

I've been advocating for people living with HIV for more than 30 years in honor and in memory of all those I lost to the epidemic. I want to do everything in my power to finally end this epidemic. And I want to make sure that we recognize and address the racial inequities when it comes to not just HIV but health care in general. It's long past time that we recognize these inequities exist and we do everything we can to get rid of them.

How do you empower others?

At NMAC, much of our programming works to build new leaders in the HIV community. The BLOC (Building Leaders of Color) program, the Youth Initiative, the 50+ Strong & Healthy program and the Gay Men of Color fellowship all work to create leaders who can work within their communities to fight HIV. Any movement needs constant refreshing with new leadership. And there is very little HIV-focused leadership training that focuses on people of color. NMAC's programming works to empower people of color to take strong leadership to end the epidemic.

What advice do you have for people doing HIV advocacy work?

Never give up. It's a long, hard journey and there will always be setbacks on the way. But the work and the goal are too important to quit. We fought long and hard to get where we are today, and it will take even more work to finally bring this epidemic to an end. But it will happen!


Tammy KinneyCourtesy of Tammy Kinney

Tammy Kinney

Why do you advocate for people with HIV?

For so long we have been living in silence and not addressing all of the issues that concern people living with HIV/AIDS. Conversations need to address whole health, which includes substance use, trauma, mental health concerns, housing, healthy love, sex and domestic violence.

How do you empower others?

By sharing my survival journey with HIV.

What advice do you have for people doing HIV advocacy work?

Be sure to ask yourself why you are doing this work. Sometimes advocates have to get uncomfortable to help a person living with HIV. Remember to practice self-care, and be willing to step back and let someone else step up. We have a new generation of advocates. Let them learn from those who were fighting in the ’80s, and we need to be willing to learn from them.

John Barnes, Funders Concerned About AIDS; Kali Lindsey, Elton John AIDS Foundation; Darwin Thompson, Gilead Sciences

Kali Lindsey

Why do you advocate for people living with HIV?

I advocate for people living with HIV because no one should acquire HIV or die from it without full access to information and the opportunity to prevent or manage their sexual health or drug use. I

advocate because I will not tolerate my brothers and sisters having our agency or choices denied or not respected.

How do you empower others?

I reject the premise that we have the ability to empower others. I believe that we are all inherently powerful, and I can help others see light when they feel consumed by darkness and invite those who wish to join me in living and loving freely.

What advice do you have for people doing HIV advocacy work?

Try not to take anything personally, and give yourself as much grace as you can. We can become distracted by losses rather than celebrate our victories. Progress doesn’t come in an instant, and your only competition is in your mind. Learn from yesterday, live for today, hope for tomorrow.

Arianna LintJonathan Timmes

Arianna Lint

Why do you advocate for people living with HIV?

As a trans Latina immigrant who is living openly with HIV in the South, I've been fortunate to be mentored by a number of people from my community. They helped me become an advocate and empowered me to start my own organization that ensures that transgender women of color have access to HIV testing and linkage to care and prevention. People living with HIV have so much to offer, and yet our voices are so often left out of the conversation and ignored because of stigma. If I can use my voice to empower and lift up those in my trans community living with HIV, I see it as my duty and privilege. I'm also honored to be a worldwide ambassador for the U=U campaign and educate my community about adherence and stigma.

How do you empower others?

My organization, Arianna’s Center, empowers people living with HIV by offering advocacy trainings and case management to address holistic well-being and by providing opportunities for those with lived experience to take on roles of leadership as trans peer navigators. Also, by being me. I’m a real human, and my sisters and brothers know that. I’m proof that your dreams can come true in America.

What advice do you have for people doing HIV advocacy work?

Visibility is everything. Use every opportunity you can to speak publicly or contribute your knowledge and power. The more visible we are, the more we chip away at the stigma surrounding HIV. I’d also recommend having a self-care plan. Our work can be stressful and challenging, and it’s important that we take time to recharge and center ourselves.

Tiommi LuckettCourtesy of Tiommi Luckett

Tiommi Luckett

Why do you advocate for people living with HIV?

I advocate for people living with HIV because HIV stigma is real. I advocate so that society understands HIV is a human condition and a racial justice issue. Many who are not living with HIV or do not know their status tend to stigmatize people living with HIV.

How do you empower others?

I empower others by educating them about what it means to have a life with HIV. I have learned

that I empower others simply by being visible as a person living with HIV and advocating for our needs. Through social media, high school classmates have contacted me to thank me for my advocacy and activism. They were inspired to live in their truth openly.

What advice do you have for people doing HIV advocacy work?

My advice for anyone doing advocacy work is to be kind to yourself. You do not have to do everything or be a part of everything. You must take time for yourself because the fight will continue. Fatigue and burnout will happen if you do not pace yourself in advocacy.

Jack Mackenroth

Why do you advocate for people living with HIV?

I've been living with HIV since I was 19 (32 years), and I'm lucky to be alive. I'm so thankful for groups like ACT UP, so I feel obligated to do my part. I remember what it felt like to be all alone and receive the diagnosis. Now, I go out of my way to respond to anyone dealing with HIV issues.

How do you empower others?

I try to reach people where they are at, mentally and emotionally. Because of social media, I get a lot of HIV-related requests and questions from all over the world. I try to take away the fear. It's usually people who are newly diagnosed who are freaking out. There is a lot of misinformation dispensed globally. I try to keep it simple: Get tested, and confirm your HIV status; get on antiretrovirals as soon as possible, and take them as prescribed; get your CD4 cell count up and your viral load undetectable so you can't transmit it to other people (#UequalsU); and resume your normal life.

What advice do you have for people doing HIV advocacy work?

Bless you. It's hard work and often financially thankless. But you are saving lives in real time. There are so many more options now than there were 30 years ago. Please stay vocal. I appreciate you.

Glenna McCarthyBill Wadman

Glenna McCarthy

Why do you advocate for people living with HIV?

I remember when some people (including me) were ostracized and even disowned by our families. Misinformation still exists, and everyone needs to have a safe space to build their foundation and self-awareness.

How do you empower others?

By being brutally honest in my past, present and future hopes, fears and dreams. I’m a blogger on

POZ.com, and I have written two books about my journey—Damaged Goods and Recycled Human (available on Amazon).

What advice do you have for people doing HIV advocacy work?

Although policies and procedures are present, remember you are working with people, not numbers. Do not rely solely on incentives such as food to get participation in groups because, although it may be effective at getting numbers, it’s not teaching new skills or helping people learn how to engage without instant gratification rewards. Remember self-care because we are all works in progress.

Jesse Milan, Jr.Courtesy of Jesse Milan, Jr.

Jesse Milan

Why do you advocate for people living with HIV?

I advocate for people living with HIV because I have experienced so many people dying with HIV, and I never want to experience that again. I advocate for prevention, treatment, care and support, and for policies and funding for HIV so that no one has to suffer because of HIV or ever die because of HIV again.

How do you empower others?

I try to support other's personal agency to speak their truth, speak their mind, and do their best to achieve their goals. I try to guide others to find and create their own answers and solutions. And I try to inspire and encourage others to join forces and find consensus for building and strengthening our community.

What advice do you have for people doing HIV advocacy work?

Tell your personal story! It's always the best story to be told. Don't be afraid to ask for what you need and for what is right. Do your homework and be strategic in choosing who to advocate to and when is best to reach them, so you don't waste your time or theirs. Most importantly, you don't have to do your advocacy alone, there's always strength in numbers.

Mark MilanoCourtesy of Mark Milano

Mark Milano

Why do you advocate for people living with HIV?

When I was diagnosed in 1982, the doctor said he had no advice for me. I said, “OK, I’ll take care of myself.” I learned that the only way we can thrive is by learning what care we need, demanding that the system provide it and raising hell until we get it.

How do you empower others?

I give “Take Charge of Your Health” workshops that help people with HIV understand their meds,

drug resistance, how to read lab results, how to advocate for themselves, etc. Hundreds have attended them in person, and now they're available online.

What advice do you have for people doing HIV advocacy work?

Progress never comes without struggle. We need to put our bodies on the line if we are to change the system. But don't forget self-care! I've had to take breaks in order to keep my sanity.

Joyce Mitchell

Joyce Mitchell

Why do you advocate for people living with HIV?

As president and cofounder of Capital City AIDS Fund (CCAF) in Sacramento, bringing much-needed awareness to the forefront of public health is essential. HIV/AIDS has not gone away, yet it's still 100% preventable. We must continue to be vigilant. During the COVID-19 pandemic, CCAF is working with establishments that cater to young people, either on college campuses or restaurants that provide outdoor dining, to provide education and prevention materials and messages. In Sacramento, our volunteers distribute condoms and now hand sanitizers in a dual chamber dispenser CCAF created. We know our work is far from finished. During this current pandemic, we don't want people also contracting HIV/AIDS. That's why I continue advocating for both HIV/AIDS awareness, services and people infected and affected. It's still a matter of life and death.

How do you empower others?

CCAF empowers college students living with HIV by providing college scholarships to help them attain a higher education. This year, CCAF increased the amount to help overcome some of the more specific challenges students are facing because of COVID-19. To date, since 2002, CCAF has raised and distributed $300,000 to fund college scholarships. We have dozens upon dozens of graduates with BA, MA and PhD degrees, most working in fields helping people living with HIV/AIDS. By empowering students who become college graduates and work to change the world, it's a personal investment in people as well as our community.

What advice do you have for people doing HIV advocacy work?

The advice I have for people working with HIV/AIDS is don't stop until there's a cure. I've been working with HIV/AIDS since 1986. I refuse to "get tired" because there's still much to do. A year or so ago, Anthony Fauci, MD, said during an international presentation that several cities in our country remain HIV/AIDS hot spots. Sacramento is one of them. Yet little is being discussed about it. I have advocated before Sacramento's public health officers, the board of supervisors and the mayor's office because a prevention message is imperative. I will not stop until we have a cure.

Murray PennerCourtesy of Murray Penner

Murray Penner

Why do you advocate for people living with HIV?

HIV has changed. We can prevent it, and we can prevent transmissions through treatment. Many people with HIV are suffering from shame, stigma and discrimination and are not achieving optimal health outcomes. People with HIV need to know they can live a long and healthy life and live and love without fear of stigma and discrimination.

How do you empower others?

People are empowered when they have information and are treated as equals. In all my advocacy, I act with kindness and support, regardless of a person's situation. When people have information and know about what's happening with their bodies, they are more apt to take care of themselves and to speak out on behalf of themselves and others.

What advice do you have for people doing HIV advocacy work?

Be yourself. Speak out about what you are comfortable speaking out about. Practice with trusted friends and relatives so you know how it feels to advocate. And don't be afraid to be vulnerable and share your struggles. That often inspires others.

Lepena Reid

Why do you advocate for people living with HIV?

When you recognize a void, a lack of information or a lack of hope “You Advocate.”

Advocating is a synergy, a push to move beyond the comment of “let someone else do it.” As I reflect on the AIDS pandemic of the ’80s I see the lost dreams. Today, I see the newly diagnosed inflicting self-stigma because of their own inner fears.

How do you empower others?

Among the many ways I have advocated for others, the best approach for me has been one on one conversations, whether it is with a Mom, youth, an executive or a complete stranger—connecting to the heart with facts and compassion is empowering. Changing structural inequalities and health disparities, which marginalize Black and Transwomen, are areas where change is necessary. I’m a member of PWN-USA, and I currently

co-facilitate a virtual bi-weekly quality of life group for Black women called “Love Your Life,” in partnership with Iris House in New York City. The conversations are rich and help to improve isolation, especially during COVID-19.

What advice do you have for people doing HIV advocacy work?

My advice to other advocates, is the same advice I give to with myself. Live healthy, eat well, rest, pace yourself, be persistent, determined and find your calm in life. Some of my favorites are long walks and laughter. We need people on all levels so work in collaboration. Super Sheroes/Heroes know how and when to seek assistance. There is strength in numbers.

Matthew RoseCourtesy of Matthew Rose

Matthew Rose

Why do you advocate for people living with HIV?

I got into this field to understand the conspiracy theories that Black people have around HIV. As I dug into the roots of these conspiracies, I gained an understanding of the truth, and the reality that people who look like me have much higher rates of HIV was laid bare. The longer I worked in the field, the more I realized so much of it is a question of equity, of the haves and the have-nots. Certain policies created the system that allows others to be cast aside. My people are not more vulnerable to HIV from a biological standpoint. Yet the conditions of their lives have made the virus flourish. The ability to live a long and healthy life should be within everyone’s grasp. But policy decisions deny them that opportunity. I deploy my skills to win the fight so that others can live a

life that they imagine for themselves without having to worry, so that regardless of one's HIV status, a person is given life-affirming, life-extending, culturally responsive care.

How do you empower others?
I try to help others realize their own power by making sure people can speak their truth to power. I serve as a bridge of common understanding and help people connect to make changes informed by their experience and in ways that are relational to their lives—empowering them to make informed decisions.

What advice do you have for people doing HIV advocacy work?

Do not forget to always speak truth to power. Our current space was created and is maintained by people with bold visionary ideas that helped move the world forward. It's a legacy that we tap into when claiming the space of speaking for those affected by HIV.

We need to see the world not as it is but as what it could be. But remember what it takes to make things move. You can be a data-driven, evidence-based person and push for transformative action. We must never accept the status quo of slow change. We must take aggressive steps to demand what is truly ours because the struggles of the HIV community have never been about just a virus. The virus is a clarion call for equity and accountability. In the words of Angela Davis, "I am no longer accepting the things I cannot change. I am changing the things I cannot accept."

Matt SharpCourtesy of Matt Sharp

Matt Sharp

Why do you advocate for people living with HIV?

I have always advocated for people living with HIV/AIDS from the moment I knew I could join the fight. Advocacy and activism are in my bones, and I can’t imagine not supporting others and fighting HIV for the rest of my life. It’s simply what I wake up to do every day.

How do you empower others?

In the past, people living with HIV/AIDS have told me that I have empowered them by leading by example in the specific work I do by speaking up and speaking out—proudly but with experience

and knowledge—always participating, always being a part of positive change, making a concrete difference, setting an example and, most importantly, staying persistent, never giving up.

What advice do you have for people doing HIV advocacy work?

Being an advocate means the work you do is not about you or your organization. Leave your ego at home, and keep your eye on the prize, not on your own success. Your work will be appreciated, but you may never be thanked. Stay humble, and be persistent, and keep your nose to the grindstone.

Masonia TraylorCourtesy of Masonia Traylor

Masonia Traylor

Why do you advocate for people living with HIV?

I started speaking up for people living with HIV/AIDS because I believe that no one should feel alone through this diagnosis in their life’s journey.

How do you empower others?

I empower others by speaking life. I show up with integrity, transparency and authenticity. I push through traumatic adversities while spreading love through my own pain. I bring light and bright colors into dark spaces. I empower others by being heart-centered and trauma-informed.

What advice do you have for people doing HIV advocacy work?

Check your why! Be in it “until the last one!”

Jennifer VaughanCourtesy of Jennifer Vaughan

Jennifer Vaughan

Why do you advocate for people living with HIV?

I advocate for those who can’t, those who need a voice when it can’t be their own.

How do you empower others?

I hope that showing my life with HIV through social media gives others hope and strength.

What advice do you have for people doing HIV advocacy work?

Know that you are making a difference. It never matters how small or big it is, it just matters.

Michael “Zee” Zalnasky

Why do you advocate for people living with HIV?

I advocate for others to make life living with HIV much easier. After all, living openly in public and educating others is the only way HIV stigma is erased.

How do you empower others?

I empower others by offering a public platform, The Digital Living Quilt, where I encase personal selfies in powerful inspiring stigma-ending frames to make them feel like rock stars and remove any shame.

What advice do you have for people doing HIV advocacy work?

My best advice is be true to yourself. Stand tall and share your story to inspire and encourage others.

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