



# LIVING HISTORY

40+ YEARS OF HIV SURVIVAL, LEADERSHIP, AND HOPE



RIBBON  
A Center of Excellence

# 2026

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† Dana Smoot passed away after contributing her story to this publication. We honor her memory and her voice.

## **FOREWORD**

For decades, the story of HIV has been told through statistics and tragedy. At Ribbon - A Center of Excellence, we know the truth is much more powerful. The real story is one of endurance, intersectional strength, and the radical act of growing old.

This chronicle is a sacred archive. It brings together the voices of those who have navigated nearly four decades of survival, the leaders who guide the next generation, and the dedicated hands that build our systems of care. By documenting these journeys, we are doing more than looking back. We are providing a roadmap for aging with dignity.

These pages represent our commitment to a vital mission. We must ensure the wisdom of our pioneers is never erased. We must guarantee that the future of this community is rooted in the truth of those who built it. We invite you to listen to these voices, not as relics of the past, but as the foundation of our collective future.

Linda H Scruggs and Vanessa Johnson  
Co-Executive Directors, Ribbon - A Center of Excellence

## Why Long-Term Survivors Matter

For decades, people living with HIV were told to prepare for death, not old age. Many faced stigma, rejection, discrimination, and silence during the height of the epidemic. Entire communities were devastated while fear and misinformation shaped public understanding of HIV.

Still, they survived.

Long-term survivors carry the lived history of the HIV epidemic in deeply personal ways. They remember the years before effective treatment existed. They remember the loss of friends, partners, and community members. They remember fighting to be treated with dignity and humanity during a time when many believed their lives did not matter.

They also helped change the course of history.

Long-term survivors became advocates, caregivers, educators, organizers, and leaders. They fought for treatment, research, visibility, housing, compassionate care, and the right to live openly and fully. Many continue to lead while navigating aging, chronic health conditions, grief, isolation, and the lasting emotional impact of surviving an epidemic that claimed so many lives.

This publication honors those voices and experiences.

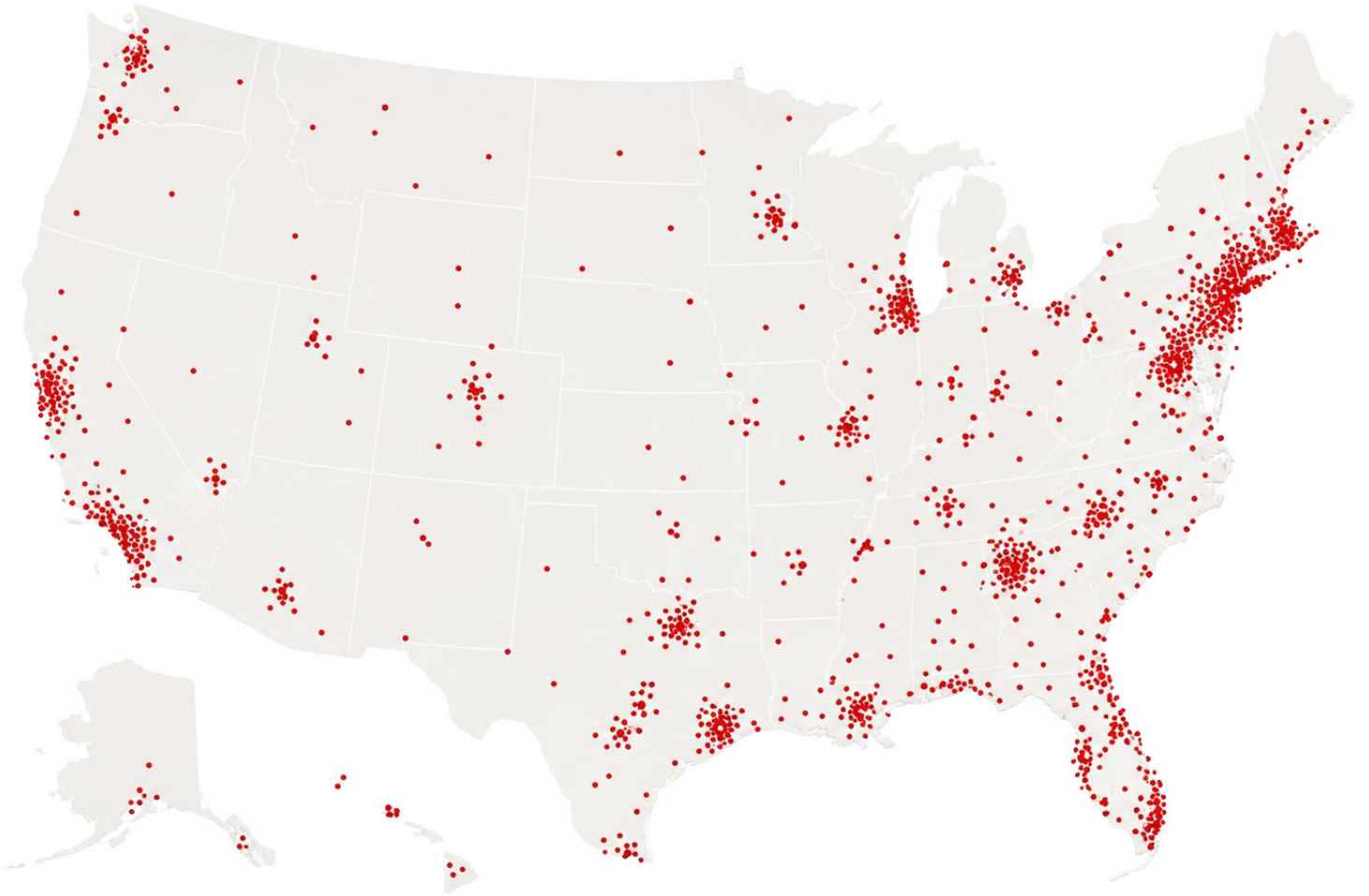
These stories reflect resilience, courage, healing, purpose, and hope. They remind us that the story of HIV did not end. The people who survived it are still here, still leading, and still shaping the future.

Their stories deserve to be heard.

Their lives deserve to be honored.

Their legacy deserves to be preserved.

# A National Legacy of Survival





## Legacy Board /'le-gə-sē bɔ:rd/

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noun

Long-term survivors of HIV (40+ years) who serve as technical advisors and storytelling ambassadors to the HIV aging community. Their lived experience ensures the wisdom, resilience, and voices of our elders shape and guide our work.



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## “A Force to Be Reckoned With”



Richard BERKOWITZ

I was diagnosed with early symptoms of AIDS in August 1982. Everything I'd read said no one survives, because AIDS = death. When I told this to my longtime doctor, he said AIDS was new. There were no experts. So, why would you believe whatever you read or saw on the news? That was the day he saved my life.

My activism before AIDS had taught me to fight, to get informed, to question experts, and the necessity of organizing. I joined forces with other gay men with AIDS, and we got to work.

In May 1983, I co-authored the first sexually explicit safe sex guidelines, *How to Have Sex in an Epidemic*. The following month, I joined ten other gay men with AIDS to draft *The Denver Principles*, a historic document that redefined the doctor-patient relationship. Through these works, we showed people with AIDS how to advocate for themselves in the face of stigma, government inaction, and the widespread belief that we were helpless and doomed.

Everything is possible when people come together, share their personal experiences and ideas, and fight as a force to be reckoned with.

Forty years later, despite our achievements, new challenges threatening our lives persist. Our deteriorating health care system is a bureaucratic obstacle course that can wear out the strongest among us, making it harder for aging patients to get the health care they need and deserve. Long-term survival seemed impossible when AIDS began, but we now face AIDS-related health risks that demand our action, our voices, and our love.

## *“Planning to Die, Learning to Live”*



Tez ANDERSON

I moved to San Francisco in 1986 and was starting a new chapter. I was newly in love, in a new city, with a bright future unfolding before me. My boyfriend had taken The Test and knew he was HIV-negative. The only responsible thing to do was for me to get tested. Two weeks after having my blood drawn, I returned for my results. When the earnest social worker asked me, “How would you feel if it came back positive?” I did not answer. My head was spinning, and I beat a hasty retreat.

Four days after my 26th birthday, my new AIDS doctor told me I had less than two years to live. I began making plans to die. As hard as that news hit me, I faced it and made peace with the idea of dying young. At the end of the first two years, I was healthy. I asked, “What now?” He said, “Two more years.” We repeated that dance for a decade. I stopped believing him.

As I approached 50, it finally hit me: “I’m going to be an old man with AIDS.” I was ill-prepared. Facing the possibility that I was going to live caused more upheavals than learning I was dying.

Coming to terms with aging with HIV was transformative and has given me a remarkable perspective on life. Living with one foot in the grave and one in the land of the living taught me the value of embracing paradox and a more profound sense of empathy. It revealed my resilience and showed me that I’m strong. Aging has revealed my purpose and gifted me meaning.

At 66, life is richer than I envisioned.

## *“Acceptance Replaced Shame”*



Joanna ROBINSON

I tested positive for HIV in 1983, at a time when stigma was crushing and society labeled it the “Gay Disease.” Fear and uncertainty consumed me, and I turned to drugs to cope, living each day as if I might not see tomorrow. For decades, I carried a death wish and struggled with crack cocaine, hiding my truth and unsure of who I really was as a transgender woman.

On June 15, 2014, everything shifted. I entered recovery and found myself in a group setting with people living with HIV, just like me. For the first time, I shared the secret I had carried for so long. That day, others poured life into my diagnosis and into me. Acceptance began to replace shame.

From a billboard campaign with PPN to being featured in POZ magazine, I began to tell my story: I am a transgender woman living with HIV. What once felt like a curse of stigma has become a blessing of purpose. Today, I am a married transgender woman, living my best life, free from drugs and alcohol.

We are not dying. We are living. If you need hope, look at me!

## *“More Than a Guinea Pig”*



**Matt SHARP**

Born in 1956 in Odessa, Texas, I received an HIV diagnosis in 1988. Doing the math makes me a survivor for 37 years. If we consider the early years of the epidemic when people first began falling ill, that number becomes 45 years. I was aware of my risk back then, but I postponed getting tested until I visited an anonymous site in Oklahoma City. After receiving the heartbreaking news, I drove home on a stormy night, overcome with tears.

In the years that followed, I experienced both successes and failures while participating in numerous open-label and placebo-controlled studies. I was one of the first individuals with HIV to take at least five newly developed antiretroviral drugs and the second person to take part in a gene therapy clinical trial.

While some might refer to me as a guinea pig, I see it as an opportunity to be a long-term survivor who provides valuable insights to my peers, scientists, and doctors who continue to advance this field.

## *“Love Was the Answer”*



Chip SUPANICH

Over these 44 years of living with HIV, I have felt better equipped to move through difficult times, if only from the knowledge that others were thinking of me.

Around 2010, I began writing a memoir at my father’s dining room table. Seeing me write, he hauled out something he had put together about my life upon learning my HIV status. He had written it to help him sort out his feelings. It was maybe 50 pages, written in his distinct, charming fashion, describing his perspective on my journey.

My life has been rich with loving family and friends, excellent care, and trusted support. Amazingly, in his senior years, my dad shared copies of his story with friends who were estranged from their LGBTQ children. Reading about his love for his gay son helped them see that love was the answer, not judgment or pride. My “martini-and-golf” dad was repairing and reuniting families simply by writing from the heart.

I’m hard-pressed to think of anything in my life that comes close to the emotional impact of what he did, and I have never been prouder of anyone. My father was always on my side and by my side.

## *“An Invincible Warrior”*



Vincent CRISOSTOMO

A woman once told me my name means "invincible warrior who speaks the golden truth." As a proud Chamorro man from Guam who identifies as queer, I have dedicated over 40 years to serving my community, focusing on healing, social justice, and empowering those affected by HIV/AIDS. I like to think I live up to my name.

I acquired HIV in 1986 and learned of my status in May 1989, at age 28. Doctors predicted I wouldn't live to see 30, yet I celebrated my 64th birthday in February 2025. Living with HIV for 39 years and diagnosed with AIDS in 1995, I have nearly 35 years of experience advocating for LGBTQ+ rights and promoting health equity. My journey includes grassroots organizing and international advocacy, with roles at the United Nations and the Coalition of Asia Pacific Regional Networks on HIV/AIDS.

Currently, I serve as the Director of Aging Services at the San Francisco AIDS Foundation. I co-authored The San Francisco Principles 2020 (SFP2020) during the COVID-19 pandemic to spark conversations about systemic failures causing unnecessary suffering and to champion the dignity of long-term survivors.

I believe we must align the fight for HIV long-term survivors with other social justice movements. Communities of color face significant barriers to healthcare access, making solidarity essential. Through SFP2020 and our commitment to intersectional activism, we aim to inspire a unified movement for justice, dignity, and love for all.

## *“Worthy of Love and Respect”*



Rebecca DENISON

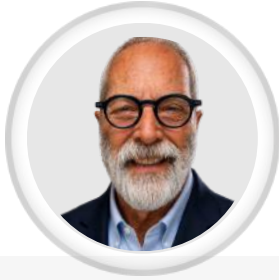
I have been living with HIV for 42 years of grief from losing hundreds of friends, joy at our community’s resilience, rage at stigma and injustice, and gratitude for living to 63.

After my diagnosis, I gave up dreams of law school and babies and joined ACT UP, then started WORLD in my Oakland apartment. I survived thanks to science, the HIV community, and my husband, Daniel, who remains HIV-free after 40 years together.

In 1995, when people thought HIV-positive women shouldn’t get pregnant, I did. I spent months on bed rest and was advised not to breastfeed. Today’s guidelines have changed. Our twin daughters, who kept me engaged with life when it wore me down, were born HIV-free and will turn 30 next year. In the 1990s, I joined clinical trials to save my babies’ lives and my own. Today, I participate to honor the ancestors who made better treatment options possible.

Managing fatigue, sleep apnea, ventricular tachycardia (a wonky heart), high cholesterol, melanoma, obesity, depression, menopause, and PTSD feels like a full-time job. But I am mobile and mostly pain-free. My HIV providers have been excellent, but specialists vary. My dermatologist and dentist are kind. My cardiologist is dismissive. One OB-GYN left me bleeding on a table, and another asked how I got HIV before I even sat down. So, I fired both and found a better one. We aren’t germs. We aren’t vectors. We are people living with HIV, worthy of love and respect.

## *“Instead of Dying, I Aged”*



Harry **BREAUX**

In December 1996, I collapsed with three diseases: PCP, MAC, and cryptococcal meningitis. The doctor said, “Mr. Breaux, I’ve seen all three of these diseases, but never in the same person at the same time. I give you a 50/50 chance to survive.” Instead of dying, I aged.

I have learned over my 45 years of being HIV-positive, including 29 years with an AIDS diagnosis, that nothing can be taken for granted about this disease or the response to it. I know what it took for me to survive. The discipline to stay on schedule with my medications each day was key, as was staying informed of the latest treatments.

Often, I find myself educating younger providers to expand their knowledge or teaching them the sensitivity needed to address someone who has lost so many friends and now faces an age they never dreamed they’d achieve. I find great sadness in how little is told of the debilitation this virus can cause.

The most powerful gift I can give is to let others know what the needs of long-term survivors are and how younger people can avoid contracting the virus. I do this by speaking the truth of my experience and acquired knowledge. In March 2025, I was gratefully surrounded by friends at a restaurant to celebrate my 80th birthday. Life is good when you stay engaged.



## Legacy Circle /'le-gə-sē 'sɜ:kəl/

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noun

Long-term survivors of HIV (40+ years) who contribute their time, resources, and voices to advancing healthy aging and community resilience. Their ongoing engagement helps sustain the leadership, experiences, and perspectives of persons aging with HIV and strengthens our collective work.



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## *“The Life I Never Thought I’d See”*



Gregory F SANDRITTER

I am so very fortunate to be turning 79 this October. I seroconverted in July 1981, a summer etched in my memory. I was battling strange, unexplainable symptoms, and within just a few months, headlines across the nation read: GRID. That terrifying national moment and my personal illness are forever linked in my story.

Fear hit me like a deer in headlights. Long before tests even existed, I knew. I believed I had only months left to live. Then came a miracle: the “cocktail” medications. They brought so many of us back from the brink and gave us something we hadn’t dared hope for: a future.

How did I survive what felt like a death sentence, especially in places where people like me were treated as outcasts? I survived because of the heroes who encouraged me to fight, to stay resilient, and to never stop caring for my body and my spirit.

Over the years, I remained committed to rebuilding my self-worth. Having AIDS demanded that I stay vigilant. At one time, the diagnosis had dismantled my confidence, but through self-advocacy, I learned to rise again with a stronger mind, a healthier body, and a renewed sense of purpose. Today, I live with gratitude for the life I never thought I’d see, and I celebrate each day as a gift. Gracias a la Vida!

## *“Go Home to Die”*



Dayna Marie **WAHEEDAH**

My journey began in 1977 when my partner died. The doctors couldn't or wouldn't tell me how or why. All I knew was that he was strong and healthy, 6'9" and 300 pounds. He had never been sick. In 1981, I became ill with PCP and later developed toxoplasmosis. Eventually, I was told I had GRID, or "gay-related immune deficiency." They said I would die. I was discharged with the instruction: "Go home to die."

So, I went home and told someone. But that was the worst thing I could have done. News in the gay community traveled fast. I was shunned by everyone I told. Stigma, fear, and isolation became my only companions. As a child, I had endured physical, sexual, and mental abuse at the hands of my father. I prayed to die every day. But through a 12-step program, one I still attend, I learned who I truly am. I love myself completely.

Today, my CD4 is 690 and my viral load has been undetectable for 10 years. At 64, I began hormone replacement therapy. At 66, I completed my gender reassignment surgery. Now, at 68, I'm living my most authentic life. And though I've recently been diagnosed with cancer, I'm ready to fight. I've been fighting my whole life.

## *“Standing In the Gap”*



Steven JOHNSON

I am a 57-year-old African American man who has been thriving with HIV for 25 years. I work for Philadelphia FIGHT, connecting our community to housing, legal services, and support. Life is good now, but it has not always been. For 30 years, my life was defined by drugs and jail.

I received my diagnosis in the state penitentiary and hid it for 13 years. I wanted the respect of my peers, so when they spoke negatively about people living with HIV, I joined them. I saw how my mother treated my brother, making him bleach everything he touched. The person I feared being rejected by most was myself; I became deeply depressed and turned to more drugs to numb the pain.

At my lowest point, I stood waiting for a train, ready to jump. In that moment, I felt a call to go to the rehab down the street instead. There, I was placed on a floor where everyone was just like me. For the first time, I no longer felt ashamed. I was able to lift my voice and replace my suffering with peace.

Today, my health is good, but I see the toll of this journey in my wife. She deals with many complications, yet she smiles through it all. I am grateful for the life I lived and the life I am living. I will never give up. I will stand in the gap, lift my voice, and go wherever I am needed.

## *“Our Stories Are Our Legacies”*



Linda C DOUGHTY

I am 71 years young, a lifelong Philadelphian, living, thriving, and aging gracefully with HIV. After receiving my HIV diagnosis in 2015, I carried deep embarrassment and shame that led me into isolation. Everything began to change when my doctor connected me with support groups and Project TEACH at Philadelphia FIGHT. Through that community, I realized I was not meant to walk this journey alone. I needed to stretch myself, my faith, and my ministry.

I became a peer educator to encourage others not to allow HIV or AIDS to define their worth or silence their voice. I began helping people move beyond fear, isolation, and stigma so they could step into healing and purpose. I also provide outreach and presentations for HIV-negative individuals to raise awareness about PrEP and the importance of education, compassion, and prevention. One of my proudest accomplishments has been helping my place of worship establish a ministry that supports individuals and families affected by HIV through people-first language, understanding, and care.

The Reunion Project connected me with a true community of long-term survivors and reminded me that our stories matter. They are powerful, healing, and necessary. As a proud member of the PA HIV Justice Alliance, I now use my voice to support efforts to end HIV criminalization and advocate for dignity and justice. I am no longer sitting still. As a 2025 Legacy Circle Scholar, I am building a legacy not only for myself, but for my son and three grandsons. I have a life-giving ministry, and I intend to share it with the world.

## *“Stop Being Ashamed”*



Sherkila Yvette SHAW

July 18 will mark 23 years since I was diagnosed with HIV. In the beginning, I was afraid to share my status with anyone, especially my children, who were very young at the time. Because people were misinformed and uneducated, some were scared to drink or eat after me. Feeling ostracized, I became a shell of myself until I became more knowledgeable and realized I could live a long, productive life.

With the right doctors and years of therapy, I was finally able to share my story and stop being ashamed of living with HIV. I took stigma by the arms, looked it dead in the face, and vowed not to let others' ignorance define who I am.

Today, I am a model, spokesperson, and advocate for people living with HIV. My children have embraced me and tell me every day how proud they are of me for not letting HIV or the world beat me down. I speak openly and honestly and use my voice to educate others.

## *“I Controlled the Narrative”*



Tom HUGHES

I was diagnosed with HIV in 2000. At the time of my diagnosis, I was the Chief of Staff for the Lieutenant Governor of Illinois. She was very supportive, as was the Governor. I was lucky to work in that environment, and that, within itself, was news.

Much to my surprise, the State Journal-Register newspaper was notified of my diagnosis, and I was asked for an interview. The decision to go public with my HIV status was frightening, but it was also a chance to end speculation about my situation. I decided that if I spoke about it then, I controlled the narrative. It was the best thing I could have done. It was liberating and empowering!

Today, I serve as the Executive Director of the Illinois Public Health Association.

## *“Death Can Wait”*



Yves GEBHARDT

Diagnosed with HIV in 2002, I had to quickly learn a whole new vocabulary while also battling stage 4 lymphoma. I realized early on that I had to become my own best friend. So, I gave each medication and chemo agent a funny nickname. That’s how “Big S,” “Sweet Christine,” and others became part of my daily routine.

As new issues arose, I built a dependable, knowledgeable medical team. I believe in science and trust my doctors to help keep me thriving until there is a cure for HIV and, hopefully, for all.

Yes, I’ve slowed down. Yes, I write things down. Yes, I listen to my body and adjust to stay ready for whatever comes next. I’ve even learned to enjoy gluten-free, sugar-free, alkaline foods! Over the years, I’ve uncluttered my life. Keeping things simple and authentic works best for me now. I stay away from negativity and surround myself with people and things that bring me joy. I remain curious, connected, and eager to learn.

Death can wait; I don’t have time to die. I’m doing things, and I’m way too busy living.

## *“The Dreams I Thought I Had Lost”*



Phillip HARPER

I've lived with HIV for nearly 40 years. I needed mental strength from the very beginning after being assaulted on my 21st birthday in college. It took everything in me to report the assault to campus police and testify against the perpetrators, who later died in prison from AIDS.

On February 2, 1987, I was diagnosed with HIV. I had to accept that I might never get married or have children, that my modeling career was over, and that I wouldn't be pursuing Olympic trials, acting on Broadway, or becoming a musician. I took AZT despite fears in the Black community that it was deadly. I told myself, "Let's get creative with life since you're going to die soon and nobody will hire you because of HIV."

It took strength to open my heart to the LGBTQ community, the ones fighting for treatment and justice. I reinvented myself and pursued the dreams I thought I had lost. I played sports for LGBTQ charity events, modeled for health fundraisers, and marched in Pride parades playing snare drums. I lived my artistic dreams as Anita Mann, actor, dancer, choreographer, and Miss Gay USA Classic 2007. I even had a relationship of 13 years. That took mental well-being, too.

I owe my resilience to my faith. God has been with me every step of the way. As it says in Revelation 21:4: "And he will wipe out every tear from their eyes, and death will be no more. Neither will mourning nor outcry, nor pain be anymore. The former things have passed away."

## *“I Am Still Standing”*



Alicia RHODEN

My health challenges have included AIDS, two strokes, diabetes, epilepsy, and mental health issues. I've had to learn how to manage all of it physically, mentally, and emotionally.

I had to teach myself not to walk in fear, but instead walk in truth, strength, and self-care. I've learned the importance of attending my doctor appointments, taking my medications, and being honest about how I feel. I've learned to love who I am and to celebrate the woman I've become.

My illnesses do not define me, but I do have to take care of myself, especially as I age. That means watching what I eat, taking my medications, keeping up with appointments, managing stress, and practicing real self-care. Having AIDS does not own me. I am still here, and I am still standing.

You can live with many health challenges. You can make it, but you have to be real about it and take the necessary steps to care for yourself. And I'm doing just that.

## *“More Than A Patient”*



Vadi VÉLEZ-GONZÁLEZ

I've had time to reflect on what it truly means to age with HIV, not just to survive, but to live. Over the years, HIV has become just one part of a more complex picture. Today, I'm managing multiple chronic conditions like high blood pressure, neuropathy, and diabetes. These comorbidities bring their own challenges, and they don't wait for HIV to take a break.

The truth is, aging with HIV means my health requires a layered approach. There are days when the fatigue is overwhelming or when I feel like I'm juggling too many pills and too few answers. Some doctors still treat me like I'm only an HIV patient, not a whole person with aging bones, nerves, and a beating heart that's been through a lot.

I am learning to reclaim my voice. I know I deserve care that sees all of me. I've started honoring rest as part of my healing, speaking up when something feels off, and connecting with others who've walked a similar path. Aging with HIV and comorbidities isn't easy, but it's powerful. It's a reminder that I'm still here. I am still growing and still thriving.

## *“Not Just Existing, But Living”*



Jose VALDEZ

Living with HIV for 31 years has been a journey of survival, resilience, and adaptation. When I was first diagnosed, there was so much fear, stigma, and uncertainty. Back then, long-term survival felt like a distant dream. But I held on to hope, to treatment, and to life itself.

Over time, surviving HIV became just one part of a much more complex health journey. As I aged, comorbidities began to surface. Hypertension and high cholesterol crept in, demanding lifestyle changes and more medications. GERD made eating unpredictable and uncomfortable. Cancer brought fear back into my life, forcing me to face the possibility of loss all over again. On top of that, chronic pain from joints, muscles, and nerves became a constant companion.

Managing all of this isn't easy. My days often revolve around medication schedules, medical appointments, lab results, and fatigue. But I've learned how to advocate for myself in a healthcare system that doesn't always see the full picture of aging with HIV and multiple chronic conditions.

Still, I press on. I've learned to balance care with compassion, not just for my body, but for my spirit. I give myself grace for the hard days and celebrate the good ones. After 31 years, I'm still here, not just existing, but living with intention, dignity, and strength. We are not invisible. We are not broken. We are powerful survivors who deserve to age with dignity, respect, and support.

## *“Marked by Endurance”*



Mayfield PHILLIPS

Twenty-seven brain surgeries for cerebrospinal fluid shunts between March 1980 and December 1994 steeled me for a long-overdue HIV diagnosis in May 1998 and gave me the resolve to survive 43 years now with the virus. According to NIH researchers, strong genetic factors have also played a significant role in my long-term survival.

After struggling through college between 1980 and 1985 amid 21 surgeries and a coma, I went on to complete my first master's degree with honors in 2009. In 2016, I earned a Master of Public Health, where my research focused on the unique psychological experiences of depression and demoralization in individuals living with HIV.

My journey has been shaped by both physical and emotional trials, but it is also marked by endurance, education, and advocacy. Living with HIV and complex comorbidities is not easy, but it has fueled my passion to understand, uplift, and support others navigating similar paths.

## *“Do You See Me?”*



Angelia FLEMING

Thirty years ago, I received an HIV diagnosis that changed everything. In those early days, I felt broken, alone, and afraid. HIV touched every part of my life and every part of how I saw myself. The shame was heavy, and some days I struggled to imagine a future.

But even in my darkest moments, I was not alone.

Friends, community members, and healthcare providers showed up for me when I could not show up for myself. They reminded me that I was still worthy of love, care, and respect. When I lost sight of who I was, they helped me find my way back.

Over time, I stopped seeing myself through the lens of HIV and started seeing the woman underneath it all. A woman who was stronger than she realized. A woman who had survived. A woman who refused to give up.

Today, I live with pride, purpose, and gratitude. I share my story because I want others to know that support matters, compassion matters, and hope matters.

When I look in the mirror now, I ask, “Do you see me?”

Yes.

I see Angie.

## *“The Spiritual Medicine of Support”*



Dennis LICKTEIG

I have been HIV-positive since 1987. I am now almost 71, which means I've been living with HIV for more than half my life.

I want to express my deep gratitude for the amazing support I've received throughout this journey. This spans from the public health doctor who first delivered the news of my diagnosis with care and empathy, at a time when there was no treatment and the future seemed uncertain, to my current doctor, who always takes the time to truly listen and understand where I am medically.

That professional care, along with the love and support of my friends and my family, both biological and chosen, and especially my husband, has made all the difference. He has been by my side since our very first date, when I shared my status. Twenty-three years, two strokes, and a heart attack later, he is still steadfast at my side. While I am profoundly grateful for the advances in HIV treatment over the years, I believe that the spiritual medicine of support, love, and compassion has been just as vital to my survival and my ability to continue thriving.

## *“I Stood Proudly in Who I Am”*



LEE KIDD

When I was first diagnosed with HIV in 1990, I was in denial. The symptoms felt familiar, things I had experienced before as a young man. I got tested at a clinic in Markham, Illinois, and when I told my doctor the results, she retested me. The results were the same. She put me on Bactrim, but after a year, she said I needed more treatment and referred me to Cook County Hospital.

At my first appointment, I saw a nurse I knew. I panicked and ran out, but my friend chased me down and connected me with Dr. Lorenzo Shearer. He started me on HIV medication and encouraged me to join support groups. That’s when everything changed. I embraced my diagnosis and began learning all I could. I also saw a therapist, since my family couldn’t support me the way I needed at the time.

It was the support of community agencies, medical staff, and those living with HIV that kept me going. I’ve now been living with HIV for 36 years because of the knowledge, care, and encouragement I received. That journey made me an advocate. I accepted my truth, came out to my family and friends, and stood proudly in who I am. I’m 71 now and still fighting for those who can’t fight for themselves.

## *“Your Life Matters”*



Santos SERRANO-CRUZ

I've been living with HIV for over 30 years. When I first began treatment, I was taking 36 pills a day, each one part of the fight to lower my viral load. Along the way, I lost family and friends to this disease. Today, I take just one pill that keeps me undetectable. I never imagined living to see this stage of life.

Aging with HIV means facing more than just the virus. It also means managing other health conditions that come with time. It's a journey that takes balance, strength, and support. Thanks to medical advances, I've been able to navigate these challenges with hope.

Programs like Premier Platinum gave me the space to prioritize my well-being. As a patient liaison, I helped develop activities that uplift others in our community. Support groups have played a big role in my healing journey. By showing up, listening, and sharing, I've helped others stay on treatment, and they've helped me, too. My life is a testament to resilience, and I carry my experience with pride. I want others to know: your life matters. Care for what you love. Care for yourself.

## *“Resilience Beyond Survival”*



Rebecca LUTZ

I was diagnosed very young. The news was devastating, especially because my son was born HIV-positive. The weight of that broke me in ways I didn't yet know how to name. My mental health suffered deeply, and for a time, I turned to substance use to cope with the fear, grief, and trauma.

Support didn't come easily back then. I felt isolated and overwhelmed. But over time, I found my people. Community saved my life. Being surrounded by others who truly understood gave me the strength to heal emotionally, spiritually, and physically. That support helped me find purpose again.

Now, I use my voice to advocate for others and to break the silence around stigma, prevention, and mental health. I know how powerful it is to feel seen, to feel heard, and not to feel alone. Aging with HIV brings its own challenges, especially when society assumes we're "fine" just because we've survived. But I'm still here, and I still matter.

I'm grateful for the science that keeps me going, but even more for the resilience that support helped me build. Our stories deserve space not just to be remembered, but to lead, inspire, and create change.

## *“It Doesn’t Have to Be a Death Sentence”*



Donna COVINGTON

I've been living with HIV for 18 years. Today, I'm 59 years old, and I share my story to help someone else living with HIV.

My story is a little different. I've never really encountered stigma myself. I've lived with sickle cell all my life, and during one of my health crises, I was tested for HIV. I don't remember being asked, but after all the hospitalizations and blood transfusions, they tested me and the results came back positive. I wasn't scared. I was told that if I took my medicine, I'd be okay.

At the time, I thought sickle cell would be my death sentence until my youngest daughter told me she had been diagnosed with HIV, too. Because of the stigma, she didn't tell anyone right away. By the time she did, she was resistant to all medications. She passed away on my birthday, January 28. It has been six years.

So, I'm here to say: Don't be afraid. Don't let stigma stop you from getting the help you need. HIV and AIDS are still around, and without proper care and support, they can still be a death sentence. It doesn't have to be.

## *“When Will I Stop Being Invisible”*



Andre L MCGUIRE

It has been disheartening to see how heterosexual Black men are stigmatized and discriminated against within the HIV community. As an attorney trained to advocate for others, I never expected that I would continually have to fight against the divisions within the very community I sought to serve.

People I consider friends and advocates often make comments when a Black man identifies as heterosexual, saying things like, “Yeah, right, another one on the down-low.” During virtual meetings, I often try not to speak up because I’m either ignored or labeled “an angry Black man.” Instead, I put my thoughts in the chat.

At a Leaders of Color Conference, I was asked why I, as a heterosexual Black male, was even attending. When I pointed out that not a single session in the three-day agenda addressed heterosexual Black men, that truth was acknowledged; however, I was told that no new slides would be added and perhaps I should develop my own program.

I’ve attended conferences where the agendas claim to support everyone living with or at risk for HIV, yet they never mention heterosexual Black men. As a five-term Co-Chair of two planning councils, I’ve reviewed entire state programs and found nothing specifically for us. I once stood at a national conference and asked, “When will I stop being invisible?” I continue to fight. Can you see me?

## *“My Voice Still Matters”*



Dana SMOOT (†)

I was diagnosed in 2003. From the beginning, I chose to live with honesty and courage, but sharing my truth hasn't always been easy. When I told friends, some drifted away. One person even disclosed my status without my consent. A neighbor I once called a friend now walks past me as if I don't exist. It's painful because I know these reactions were born out of fear and misunderstanding about HIV.

Still, I refuse to let stigma silence me. I remain rooted in my community as the neighborhood “candy lady,” sharing smiles and treats with the children. For over 10 years, I've cooked for my church, where I'm welcomed and loved just the same. One of my proudest moments was speaking on a panel at Bowie State University to over 100 women and receiving a standing ovation that reminded me that my voice matters.

Aging with HIV brings its own set of challenges. I now rely on food banks, I need help preparing meals, and I depend on aid for daily needs. Resources are harder to reach, but my determination remains unshaken. I choose to keep showing up, speaking out, and celebrating life. My journey is proof that while HIV may shape my path, it will never silence my spirit.

## “Me Accepting Me”



Joe AMRHEIN

Stigma told me it wasn't okay to be me, so I isolated myself because I was afraid. I wanted people to like me, but I feared that if they really got to know me, they wouldn't. I contracted HIV in June 2001, and my life went into a downward spiral. Somewhere along the way, I met people who loved and cared about me, not just with words, but through their actions. As a result, I began to heal.

I realized: me accepting me is much more important than you accepting me. I had to like myself, even the less-than-ideal parts, if I was going to change my future trajectory. My recovery journey included exercise and fitness, resilience, self-discipline, healthy eating, returning to school, getting honest, and volunteering to help others.

At 43 years old, I returned to school as a first-generation college student with only a high school diploma. Two years ago, I earned a Master of Public Policy from the prestigious Humphrey School of Public Affairs on a merit-based, full-tuition scholarship. My graduate research focused on the transportation experiences of underserved populations, the social return on investment in affordable housing at 30% and 50% AMI, and sound practices for better consumer engagement for Ryan White Program subrecipients.

## *“A Witness and a Storyteller”*



Ronald L. CHANEY

Thirty-two years. That’s how long I’ve lived with HIV. When I was diagnosed in 1993, I felt completely alone. I didn’t tell anyone except the person who infected me. I was young, scared, and unsure who I could trust because of the stigma surrounding HIV/AIDS. I didn’t know what life would look like, but I kept my faith and moved forward.

Living with HIV for over three decades hasn’t just affected my mindset; it has shaped who I am. Back then, everything felt urgent. The medications were limited and harsh. I lost friends and partners because there weren’t better options. I stopped taking the early treatments for about four years because of the severe side effects, but things changed. New antiretroviral therapies gave me my life back. I’ve never been hospitalized or seriously ill due to HIV. I stayed strong, stayed adherent, and eventually became an advocate, sharing my story to help others.

Now, I’m aging with HIV in a world that still struggles to understand us. There’s power in surviving a storm no one thought you’d outlast. I’ve become a witness, a storyteller, someone who can say: “Yes, you can live, love, and age with HIV.” Aging with HIV is more than survival. It’s about reclaiming life, day by day. I never expected to be here. But now that I am, I intend to keep living out loud for myself and for those we’ve lost.

## *“Thriving and Proud”*



Shay TUCKER

Even today, I still face stigma not just for being HIV positive, but also for being a Black trans woman. I've shared my story many times in hopes of helping others going through similar experiences, whether it's living with HIV or navigating life as a trans person.

One of the hardest battles I've faced was disclosing my status to my family. I didn't know how they would react: whether they would judge me or take the time to educate themselves about HIV. The fear and uncertainty made it incredibly uncomfortable to open up.

Living as a Black trans woman, life can be much harder. It's not just HIV or gender identity; it's also age, race, and gender. All these layers play a role in how safe and respected I feel in the world. But being open about who I am has made me stronger. The stigma I've experienced has fueled my passion to reach out to others and remind them they're not alone. We are not ashamed of our lives. We have a voice, and we deserve to be heard.

I'm grateful for the opportunity to share my story in hopes of making things better for my community and for others like me: living, thriving, and proud.

## *“Good Trouble Still Matters*



Jerome CUFFEY

In 1988, I received a diagnosis that nearly ended my life. What could have been the end of my story became the beginning of my purpose. As a Black man who came of age during the Civil Rights Movement, I learned early that silence rarely creates change. That lesson has guided me through nearly four decades of living with HIV.

Over the years, I have witnessed remarkable progress in treatment, care, and advocacy. I have also seen the persistence of stigma, discrimination, and inequity. Today, as a Health Educator with the San Francisco AIDS Foundation and Community Co-Chair of the HIV Advocacy Network, I continue working to ensure that the voices and needs of people living with HIV are heard and respected.

The current social and political climate has strengthened my resolve. Attempts to erase history, silence marginalized communities, and weaken protections for vulnerable people remind me that advocacy remains necessary. Inspired by Congressman John Lewis’s call to make “good trouble” and guided by my grandmother’s belief that a closed mouth does not get fed, I know that speaking up is both a responsibility and an act of hope.

My life has taught me that courage is not the absence of fear. It is choosing to stand up anyway. As long as there is work to be done, I will continue to use my voice to advance dignity, justice, and human rights for all.



## The Mentors /ðə mən,tərz/

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noun

Experienced leaders living and aging with HIV who provide peer-to-peer guidance, advocacy, and emotional support. Through intentional partnership, they translate their personal triumphs and challenges into a roadmap for others to navigate the complexities of health, stigma, and wellness.



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## *“Family Is My Anchor”*



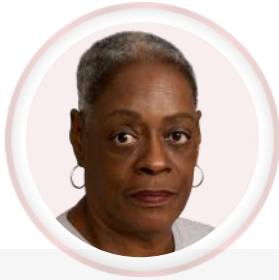
**Nathaniel SCRUGGS**

I have been living with HIV for over 30 years. Now at 73, I find myself thinking about how family has been both my anchor and, at times, a complicated place of tension. Their love, presence, and prayers carry me through, especially when health challenges come. Yet, I still wrestle with what to share and what to hold back about my HIV journey and the realities of aging. Sometimes silence feels safer, but silence can also create distance.

Last year, I faced one of the hardest seasons of my life. I spent 84 days in a health crisis, hospitalized and uncertain if I would return home. The recovery that followed was long and grueling; it required more support than I ever imagined needing. Family stepped in by driving me to appointments, helping with meals, and sitting by my side when I felt weak, reminding me that my life still matters. Their presence became my strength, even when words about my diagnosis remained unspoken.

Today, I continue to walk the line between openness and privacy. My family's role is significant: they are my lifeline, my community, and my comfort. Our relationship is evolving as I learn to trust them with not just my survival, but my truth. And that, too, is part of my healing. HIV has not silenced me; it has made me stronger, more compassionate, and more committed to breaking the silence around stigma.

## “Finding My Voice in the Silence”



Margot KIRKLAND

I received my HIV diagnosis in 1991. From the moment I was told, the way the news was delivered made me feel stripped of my identity; I was no longer seen as a “nice woman,” but as someone unworthy of rights and respect. Suddenly, I was left alone with the fear of navigating the unknown. Like so many others at that time, I was told to “go home and make arrangements.” But how does one prepare for the end without information, support, or hope? Believing I had no future, I hid my diagnosis from the world.

Ten years later, when I finally sought care at a local hospital, all my fears about stigma became reality. The whispers, stares, and inappropriate questions from medical staff were demeaning and painful. I often felt less than human, never truly safe, respected, or able to trust the care I was receiving.

Over the past 34 years, I have had to push through hurt, inadequacy, and fear to find my voice. I discovered safe spaces in women-focused programs and in the solidarity of other women living with HIV. Their voices gave me the strength and courage to speak openly about my own journey. Today, I continue to use my voice and talents to keep myself physically and mentally healthy, while also lifting others in need of care and support.

## “Building from Zero”



Luis NAVA MOLERO

I was born and raised in Venezuela, where I had the honor of serving as a professor at the Universidad Simón Bolívar. My career and community gave me purpose and dignity. But life changed dramatically when I immigrated to the United States. Suddenly, I was starting from zero.

Living with HIV as an immigrant has not been easy. I have faced discrimination for being gay, for speaking Spanish instead of English, and for living with HIV. Many times, I felt invisible; I was judged or reduced to only one part of my identity. The sense of loss was overwhelming: the loss of status, language, and belonging.

Yet, this journey has also revealed my strength. I learned how to rebuild, step by step. I found community among other Latinos and people aging with HIV, and I realized that my experience as an educator could still make an impact. Today, I use those skills to raise awareness, advocate for health equity, and support others who feel alone.

## *“The Choice of Happiness”*



**Sylvester ASKINS, JR.**

I have lived with HIV for 35 years, am approaching my 70th birthday, and have recently retired. For as long as I can remember, isolation has been a constant companion. From a young age, I knew I was different. As an only child, I lacked siblings to confide in or share my feelings with; my HIV diagnosis only deepened my sense of isolation and loneliness. Years of drug addiction and reckless choices followed, much of it fueled by that feeling of being alone. Looking back, I see how isolation influenced many of the decisions I made.

However, I want this to be a message of hope, not one of sadness. Over time, I've learned to make peace with my feelings of isolation and loneliness. Surprisingly, I've even found joy in embracing them. Through strength, resilience, and faith in God, I rise each morning ready to face another day. I refuse to see isolation as a negative force in my life. Instead, I choose happiness and gratitude for the life I have.

I won't allow isolation to rob me of the joy that life still offers. Life is defined by the choices we make. Choose happiness.

## *“From the Moon Back to Community”*



**Ed BARRON**

1986: “The day I began to live on the moon.” These are the words author Paul Monette used to describe living with HIV, and this was the year it began for me.

Walking out of the doctor’s office, a gray cloud appeared above me. At the time, I was living in a home with two friends; however, as the years passed, I watched my chosen family, friends, and loved ones die. With each passing moment, the isolation grew, and my social life began to fade. Feeling alone and depressed, I turned to substance use. The stigma surrounding an HIV diagnosis only deepened my isolation.

I remember the first person I told I was HIV positive. He refused to have dinner with me and drove me back home. In that moment, I felt unworthy, less than, dirty, and undeserving of intimacy. I believed I was destined to live the rest of my life alone.

In 1990, when the Ryan White CARE Act was passed, new services became available, including support groups. There, I met others living with HIV. I was able to move from isolation back into community, and I began to find my voice. I used my time and experience to advocate, mentor, and fight for our community as we continue to look ahead toward a better future.

## “The Boldface Truth”



Cynthia RODGERS

I received my diagnosis over 25 years ago. I was flooded with a myriad of emotions: disbelief, fear, shame, and a rush of racing thoughts. But in the inner recesses of my soul, I knew I would live and not succumb to AIDS. I had every intention of holding on to life like a bulldog holds onto the leg of the postman!

During this 25-year journey, post-traumatic stress disorder (PTSD) coupled with clinical depression have been two foreboding enemies with which I've had to contend. HIV was not the worst thing that has ever happened to me; I've experienced an innumerable amount of intimate partner violence, sexual violence, abandonment, serial homelessness, and poverty, to name a few. I am well-acquainted with mental instability; however, my Creator has wired me to eventually tell the truth about the exact nature of my issues, behaviors, and choices. I say "eventually" because the fear of rejection normally surfaces before I express my authentic, boldface truth.

The divine guidance of God, as I understand Him, in conjunction with counseling, mentoring, and medication, has afforded me a life with purpose and love. I cannot forget the benefits of antidepressants and a community of brothers and sisters who share the diagnosis of HIV. In closing, I leave you with the words of my late and beloved Madea: "Keep living!"

## “The Soil Where Healing Grew”



Kneeshe PARKINSON

I was just a teenager in 1997 when my world shifted. An HIV diagnosis felt like a sentence: filled with silence, stigma, and fear. I worried love and family might never be mine.

But family has a way of showing up. My mother’s prayers, my relatives’ resilience, and simple rituals of care became the soil where healing grew. They reminded me I didn’t have to walk this road alone. Wholeness, I learned, isn’t about escaping pain; it’s about carrying it together. As I cared for my mental health, my family cared for me. In that exchange, we all grew stronger. Love became not something I feared losing, but the foundation I could stand on.

Now, as I age, I see my family as both anchor and legacy. My story is not just survival but resilience turned into generational strength. I often say: “Miracles cost extra, especially for Black women. But what if we rewrote the price tag for the next generation?” That’s what family has done for me; they have turned survival into a story my children and their children will inherit.



## The Architects /ðə är-kə-tekts/

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noun

The dedicated facilitators and practitioners who manage the structural integrity of our mission. By providing logistical coordination, professional expertise, and consistent advocacy, they create the framework that allows the community's stories and legacy to be preserved, shared, and elevated.



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## “The Strength to Speak Up”



Linda H SCRUGGS

I've lived with HIV for over 30 years. Now, in my 60s, I still face stigma. Even though I've shared my story to help others, people still treat me differently because of my diagnosis.

One of the hardest places is at the doctor's office, especially when it is not an HIV clinic. I get nervous: I worry the doctor might judge me or not take me seriously. Even a slight change in their voice or body language can make me feel uncomfortable or ashamed. As a Black woman, it's even harder. I deal with stigma not just from HIV, but also because of my age, race, and gender. All these factors make it tough to feel safe and respected at times.

Because I live openly with HIV, many people don't think I experience stigma, but I do. Stigma doesn't just hurt my feelings; at times, it makes it harder to speak up and take care of my health. I have to remember my care is about me, so I must use my voice. I refuse to feel small because of HIV. I am sharing my stigma story because I want to make things better for myself and for others aging with HIV.

## *“The Testament of a Long Life”*



Vanessa JOHNSON

At sixty-seven, I carry the story of survival in every line on my face and every ache in my body. Living with HIV for decades has been a journey I never expected. Yet here I am: still here, still breathing, and still fighting. Aging has brought with it a tenderness I did not know in my younger years, but also a heaviness. The early signs of chronic disease creep in quietly: blood pressure rising, joints stiffening, and energy dipping in ways I cannot always explain. Sometimes I wonder if it is age, the virus, or the environment that has worn me down; perhaps it is all three at once.

I think about how the places I've lived, the air I've breathed, and the food I've had access to have shaped my health and wellness. I consider the family traits that run through my bloodline, as well as the diseases I am vulnerable to. And I reflect on society: its choices, neglect, and blind spots that have made aging with HIV for a Black woman like me much harder than it should be.

Still, I wake each morning feeling thankful. The pills on my nightstand remind me of science, but also of my strength. I've endured times when women like me weren't expected to live long enough to grow old. Now, every wrinkle, scar, and laugh line shows I am still here. Aging with HIV isn't just about survival; it's a testament.

## *“The Power of a Safe Space”*



Faye MARSHALL

In my 30-year journey of living with an HIV diagnosis, I have come to value the importance of family love and support. Family acceptance is essential to the emotional, physical, and mental well-being of individuals living with HIV. My family embraced me with compassion rather than judgment, creating a safe space that empowered me to seek treatment, stay healthy, and live with dignity.

Over the years, I've witnessed the devastating impact that stigma and isolation have had on others who were not fortunate enough to have that support. Often, that lack of connection leads to harmful, even deadly, outcomes. For me, unconditional love, open communication, and informed support from family and friends have helped break down barriers, reduce fear, and promote healing on every level.

No one should have to face HIV alone. I consider myself truly blessed to have a strong, supportive family who has been my anchor throughout this journey toward hope, resilience, and long-term wellness.

## “Resilience Is My Legacy”



Denise DRAYTON

Aging with HIV is a journey I never expected to take, but it has shaped me in ways I could never have imagined. Diagnosed in 1993, I faced fear, stigma, and the uncertainty of whether I would live to see another year. Decades later, I’m still here: thriving, evolving, and bearing witness to the incredible resilience of our community.

With age has come wisdom, but also new challenges: managing comorbidities, navigating a healthcare system not always equipped for older adults with HIV, and pushing back against the erasure of long-term survivors. But I’ve also gained clarity about what matters; I have found connection, purpose, and the strength to use my voice to uplift others.

I carry the memory of those we’ve lost and the strength of those still fighting. I advocate not just for myself, but for others aging with HIV who deserve visibility, dignity, and care rooted in compassion. Aging with HIV is not a burden; it’s a testament to survival. I am still learning, still growing, and still deserving of joy. My life’s work is proof that we are more than our diagnosis. We are leaders, storytellers, and living history. And our story is still being written.

## *“The Strength to Let People In”*



Kim MOON

When I first received my HIV diagnosis, I was scared and uneducated. I isolated myself and pulled away from everyone: I didn't answer calls, I didn't go to gatherings, and I barely went to work. Many days, I sat in my closet asking myself if today was the day HIV would kill me. I didn't understand my diagnosis, and I didn't think anyone else would either.

At the time, I didn't know anyone living with HIV, so it felt safer to be alone. But my fear didn't just keep me away from people; it changed the way I lived. I was so afraid my children would catch HIV from me that I broke any plates or glasses I used. When I ran out, I started buying paper plates, cups, and plastic utensils. To this day, I still use them; it is not because of stigma, isolation, or depression anymore, but because it became a habit. It feels like a routine now.

It took ten years before I met someone else living with HIV who understood exactly what I was going through. She invited me to a support group, and slowly, I began letting people back into my life. I still have moments when I want to shut the world out, but I don't stay there for long. Because the truth is, we all need somebody; sometimes, it's just someone willing to sit with us in the quiet.

## **AFTERWORD**

The voices shared throughout this chronicle reflect strength, resilience, truth, and survival. They remind us that the history of HIV is not only marked by loss, but also by courage, advocacy, leadership, and the determination to keep living in the face of unimaginable uncertainty.

For many long-term survivors, aging was never guaranteed. Yet today, they continue to shape communities, mentor others, advocate for equitable care, and carry forward the stories of those who are no longer here to tell their own.

Their experiences challenge us to think differently about aging, healthcare, stigma, and human dignity. They call on us to build systems rooted in compassion, equity, and respect for the full lives of people living with HIV.

This publication was created to preserve these stories, honor these journeys, and ensure that the voices of long-term survivors are never forgotten or overlooked. Their wisdom matters. Their leadership matters. Their lives matter.

May these pages encourage continued dialogue, deeper understanding, and a stronger commitment to supporting people aging with HIV today and for generations to come.

With gratitude and respect,

Ribbon - A Center of Excellence  
The Center 4 Healthy Living with HIV

## **Share Your Story**

Every story in this publication represents a life, a journey, and a voice that matters.

Ribbon invites long-term survivors and older adults living with HIV to share their personal stories for possible inclusion in Community Voices on Ribbon's website. Your experiences may help others feel seen, understood, remembered, and connected.

If you would like to share your story, please email:

[roc4aging@ribbon3.org](mailto:roc4aging@ribbon3.org)

Subject line:

**Community Voices Story Submission**

We thank you for trusting us with your experiences and your voice.



The history is written. The legacy is living. The future is ours to build.



Website:  
[ribbon3.org](http://ribbon3.org)

Facebook:  
<https://www.facebook.com/RibbonTrainingCenter>