



"I began working in HIV when..."

In honor of World AIDS Day 2012, several JSI staff members offered reflections on the personal journeys that led them to dedicate their careers to fighting HIV. Here are their stories, compiled in a blog series entitled, "I began working in HIV when...", originally posted on JSI's blog, *The Pump* (thepump.jsi.com).



Stewart Landers, *Senior Consultant, JSI*

As a 17 year old in 1973, I came out as a gay man and joined the battle for "gay rights," still in its early years. Over the next eight years I fought (successfully) for policies supporting non-discrimination at the two schools I attended, MIT and Harvard Law School, as well as my city of residence, Cambridge. When I first read about AIDS in 1981, I was entering my last year of law school. Words like "Waterloo" and "Armageddon" for the gay community echoed in my mind as the number of AIDS cases grew geometrically, though still remotely, with the epidemic centered in San Francisco, Los Angeles, and New York City.

By 1983, I was working at Fenway Community Health in an administrative position and seeing many of the first AIDS cases as they arrived on our doorstep. Sadly, many of the individuals visited the clinic a few times and then disappeared, quickly stricken down by the mysterious illness. It's impossible to describe the fear and panic felt throughout the gay community back then. Imagine your friends getting sick and dying all around you with barely a passing mention in your local newspaper or TV station. Imagine the government, including public health, providing no communication about the epidemic, except, perhaps, to disparage the victims. Imagine not knowing how this disease is transmitted, yet constantly wondering if you are next.

By 1985, I had my first job as an AIDS researcher, studying health care utilization by patients with AIDS. This evolved into my career in public health, eventually landing at JSI where I continue to study HIV/AIDS as well as other widespread public health problems.



Barry Chovitz, *Deputy Country Director, SCMS/ USAID | DELIVER PROJECT*

I began working in HIV/AIDS as an extension of my work on the [DELIVER Project](#) building capacity in supply chain management. In July 2002, after 10 years in primarily family planning logistics, I took my first field assignment in Tanzania, where I was going to open the first JSI office there and help the MOHSW set up an integrated supply chain. Later in the year, PMTCT [prevention of mother-to-child transmission of HIV] began to be a reality and I participated in an assessment of “readiness” for handling ARVs.

In 2004, the US government agreed to provide branded ARVs for treating up to 44,000 people, which was 10% of the overall treatment goal. I created 23 versions of an Excel spreadsheet that helped estimate the ARV needs for the targeted patients and the costs. I was able to also *reverse* the equation and calculate the number of patients who might be served given a fixed dollar amount which seemed really cool at the time. Later, I helped create what is now called the Procurement and Supply Management plan (PSM) for the Round 2 GFATM proposal from Tanzania.

By the time I left Tanzania in October 2005, my work on the design and pilot phase of the Integrated Logistics System was complete and I returned to DC and joined the [SCMS project](#). I have been working on supply chains for HIV and AIDS programs ever since and I am proud to have worked with JSI’s Deliver and SCMS projects to get those first ARVs to Tanzanians and to have become part of PEPFAR’s broader goals of preventing, diagnosing, and treating HIV and AIDS for millions of affected people.



Deb Lebel, *Partnership Specialist, AIDS.gov, JSI*

Until 1987, I worked in the public affairs office of a statewide Planned Parenthood affiliate. I helped to plan advocacy conferences. A few colleagues talked about this “new” disease, AIDS, but I didn’t see patients and didn’t know much about the epidemic. When I came to JSI in 1988 I worked on conferences for the New England Title X Family Planning Training Center and began to hear more about the disease.

After the passage of the Ryan White CARE Act, JSI provided technical assistance to cities and states under our contract with HRSA’s Bureau of Health Resources Development (now called the HIV/AIDS Bureau). In 1996, I joined the project team. One of my early assignments was to support logistics for a meeting to enable people living with HIV to give input to state leaders on how to plan services. I remember learning that some PLWH only wanted to drink bottled water at the meeting. There was fear that tap water might expose PLWH to germs that would put them at greater risk. I was struck with how frightening and hard it must be to have to plan so many details to protect oneself against ordinary germs that might be devastating. It was my first, tiny inkling into living with HIV.

Since that meeting, I have always worked within JSI’s HIV portfolio. I’ve worked with state health departments, HRSA, and now [AIDS.gov](https://aids.gov). I am grateful that every day, my work helps me to remember my friends since lost to the epidemic and to remember the many millions of others who have died. We must end this epidemic in honor of friends, family, and colleagues who fought or fight against the disease and stigma.



Ed Scholl, Project Director, AIDSTAR-One, JSI

I remember first hearing about HIV in one of my MPH classes at UCLA in the fall of 1982. Acquired Immune Deficiency Syndrome (AIDS) was a new disease outbreak reported by CDC the summer before, after one of UCLA's medical school faculty reported the syndrome in a group of five gay men in Los Angeles. It sounded like just another esoteric disease that might show up on one of our quizzes, so I spelled it out in my notebook, never once imagining that this disease might eventually become one of the world's greatest public health and moral challenges of our time. I didn't pay much more attention to AIDS during my public health studies, though soon after it became a focus of national attention, and even hysteria.

The focus of the first half of my career was primarily on family planning and reproductive health. The projects I worked on at that time in Latin America did not deal much with HIV, though there was recognition that family planning clinics should discuss the "dual protection" (from pregnancy and HIV) that condoms provide and refer women (and the occasional male client) at risk for HIV testing and counseling. It wasn't until 2003 and my involvement in a youth-focused, HIV/reproductive health project that I began working equally on HIV and pregnancy prevention in recognition of the fact that young people are at risk of both HIV and unintended pregnancies.

I came to JSI in 2008 because of JSI's global work in HIV and the new [AIDSTAR-One Project](#). Though I now work full-time on HIV through that project, I continue to advocate for programs that integrate HIV, family planning/reproductive health, and maternal-child health programs and appreciate JSI's experience and global leadership in integrated programs.



Andee Krasner, *Consultant, JSI*

The first time I knew I wanted to work to end AIDS was when I was a sophomore in high school. It was 1990. I lived in a small theater town in southern Oregon and attended one of the first “Daedalus Project” theater productions at the Oregon Shakespeare Festival. The night started off with a MC who made jokes with local references. Then there was a series of performances. At the end of the night the mood turned serious and everyone who knew someone who had passed away from AIDS was asked to stand. I remember being struck that I was among a handful of people still seated. Seeing a large outside theater full of adults from my community standing in representation of the loved ones they lost brought me to tears. I was called to action. I knew that if I didn’t do something, it wouldn’t be long before I would be standing or someone would be standing for me.

That year, I organized “Safer Sex Week” at my high school. One of the highlights from the week was a dad who was HIV positive. He came and spoke at the school about HIV. Remember, this was at a time when HIV was heavily stigmatized in the US. It was an act of bravery to come to discuss his status in front of his community. He told us how he found out he was positive and about the importance of safe sex. Having him come speak showed us that HIV was not about other people; it was about *our* families.

This year the Daedalus Project celebrates its 25th year of building awareness for HIV and AIDS, and I have the privilege to continue to work on HIV and STI prevention through my work at JSI. Currently, I provide monitoring and evaluation technical assistance to community-based organizations. I work with a group of passionate people who are standing up and taking action in their communities to stop the spread of HIV.



Rose Musumali Lungu, *PIHIV Manager, SHARe Project, JSI*

I was already involved in public health when I first remember hearing regularly about HIV /AIDS about 12 years ago. But it was peripheral to me and my work and I continued with my business of improving the nutritional status of Zambian children under the age of five, and pregnant and lactating women. Then HIV personally struck me. I was actually one of “the people living with HIV”. The first two years of knowing my status was a turning point in my life, as I integrated the knowledge. Later, I decided to share this turning point with others.

I began working for JSI’s [SHARe](#) project, which gave me “space” to explore my new world and find ways of reaching out to others. In my work, I saw first-hand the loss of self-esteem, the loss of hope in many people that I met and I made it my business to restore that lost esteem and hope. My resolve has been to reach out to people with one simple message: “I have, so can you.”

For me, working in the area of HIV is through a special, personal experience lens. I help many people realize that they too have this unique lens which can be used in very powerful ways to effect positive change and for connecting with individuals and organizations. A special focus of my work has been with Public Workers living with HIV, through a program we coined PAW (Positive Action by Workers). This has been a rewarding experience, considering the perverse stigma in workplaces and among people in the working bracket. The work has also provided another unexpected reward for me personally, beyond professional satisfaction: true, I have taken the brave step of sharing my personal story in order to help others. But by helping them realize their potential, even amidst HIV, I also created opportunities for people to reach out to me; thus creating a web of support for sustenance. This brings me great joy.



Jeremy Holman, *Senior Consultant, JSI*

I started working in the HIV field in 1998, when I was hired (by Annie Silvia, who now works at JSI) at the Boston AIDS Consortium, a small AIDS service organization for which I later became the Executive Director. At the time, I was beginning my third year as a Ph.D. student at Clark University, but had an urge to start “doing something productive” after so many years in school. I was interested in gay/lesbian politics, and was drawn to HIV/AIDS work because it had been so closely connected to the gay/lesbian civil rights movement.

I knew no one living with HIV, but felt a profound and significant loss within our community. An entire generation of smart, witty, creative gay men died too soon, and their full potential impact on this world would never be realized.

Also, I knew that my new and growing rights as a gay man were owed to those people (gay men, lesbians, and their allies) who literally took to the streets to demand that our government respond to this epidemic. Their courage, their battles, and their spirit propelled the gay rights movement forward in ways that may not have been possible without this epidemic.

The level of citizenship I enjoy today – free to marry my partner, if I wish, and more importantly, simply able to be me, openly and without fear – is because of the impact of HIV on our community. So I continue in this work, nearly 15 years later, to celebrate those who are still with us, and to honor those who are not, and whose loss continues to impact my life each and every day.



Mike Farabaugh, *Senior Advisor, JSI*

In 2000 I joined a volunteer program and began to work with a local NGO in Tanzania. My prior professional experience had been as a Teach For America corps member/school teacher in Texas and helping to resettle newly arrived refugees in Vermont. So I figured that I'd use one of the two professional interests in my work in Tanzania.

I was assigned to work in Mwanza, which is Tanzania's second largest city, located on the shores of Lake Victoria. While trying to figure out where I could best contribute, I began volunteering with street children and it became apparent that they had very little exposure to any HIV prevention. While life-saving ARVs were available at this time in many Western countries, in Tanzania receiving an HIV-positive diagnosis was essentially a death sentence, so primary prevention work was essential.

I began conducting basic HIV-prevention trainings for at-risk youth and then organized the group to conduct drama skits at markets, churches, and mosques. We began offering HIV counseling and testing, trying to prevent others from getting infected. And a large part of my work was organizing a cohort of home health volunteers to visit people who were already infected with HIV. Since we didn't have access to ARVs, we offered antibiotics, malaria medications, and multivitamins to do what we could to keep clients from developing and succumbing to AIDS. It was almost laughable that this was what our arsenal consisted of, except that there was no humor in it. I remember feeling extremely angry that drugs that could keep my clients alive were available in more developed countries but weren't available in Tanzania because of what pharmaceutical companies were referring to as "patent infringement" if generics were developed. I watched a lot of people die that year, and with each death my resolve to do something about it was strengthened.

Upon returning to the U.S. I pursued an MPH at Boston University with a commitment to working in HIV. I joined JSI in 2004 to work on the MTCT-Plus project, one of the first to offer free ARVs to a small cohort of infected patients in resource-limited countries. Since that time, I've worked on [Project HEART](#), which involved quality improvement work at U.S. government-supported HIV treatment clinics in Tanzania and South Africa. Currently I'm the Senior Advisor for [STAR-EC](#), an HIV/TB prevention, care, treatment and support project in East Central Uganda and the [TA-NPI](#) project that works to build the capacity of local organizations to do more effective HIV prevention work.



Andrew Fuller, *Director of the JSI & WEI Center for HIV & AIDS*

I can't remember a time that HIV *hasn't* been present in my life. As a closeted adolescent in the early 1980s, news of this mysterious illness killing homosexuals, Haitians, hemophiliacs and heroin users (the 4 Hs) spread at about the same time I began a process of accepting, becoming comfortable with and embracing this part of my identity.

In my early twenties HIV was a part of my social life but not so related to my work. After graduate school, that changed. As an openly gay man living with HIV I needed to be part of the response, not on the sidelines writing an occasional check or participating in a walk.

I tried working at a number of different international and US organizations, including JSI. All were good and I learned a lot, but there was something missing. After five or six years away, I was asked to come back to JSI to help establish the [HIV Center](#): Perfect job at the perfect time.

I was finally working with a group of people whose primary calling to public health, for lack of a better phrase, was HIV. JSI was and is committed to the clients—the people at risk for and living with HIV—making sure programs bring together the best ideas to meet the most urgent needs.

At JSI I am surrounded by other passionate women and men living openly with HIV who combine that rich experience with their public health skills to make a difference. With the support of Joel [Lamstein, President of JSI] and other senior staff, we have been given the space to develop a workplace HIV program that is used both here in our U.S. offices and in our overseas field offices, and the means to provide access to HIV treatment to JSI's own staff in Africa, Asia, and Latin American before there was a PEPFAR or Global Fund. I see every day how JSI's commitment to "do good" plays out through our staff implementing programs large and small that truly build capacity and genuinely give hope. This is why I do HIV work and why I do it at JSI.



Mariana Iurcovich, *AIDSTAR-One, Honduras Country Manager, JSI*

In 1988 I was living in NYC, doing my postgraduate courses as a Clinical Psychologist in Systemic Family Therapy. I was videotaping clinical sessions to help pay for my studies. I taped groups of psychologists discussing their cases. I was told that there were some cases of clients living with HIV and no one wanted to videotape those; I volunteered to do it, and that's when I got trapped.

This was during the eighties and I remember the first session I videotaped. It was this man in his forties explaining that he thought he might be HIV positive. The therapist asked him "why do you think you might be HIV positive?" and he explained that he was married with four children, he went to church every Sunday, but during his business trips, he would have sex. The therapist then asked, with a commercial sex worker? The man responded, "I have sex with men, but only when I travel for business."

I got trapped. I started thinking that this was the tip of the iceberg, and that this new AIDS disease was a bio-psycho-social phenomenon, and I wanted to get involved. I wanted to understand human behaviors, people's double lives, and I started taking all the courses I could related to working with partners and families of those living with HIV.

When I went back to Argentina after I got my degree, I got very involved not only with clinical work in my private practice, but also at the University of Buenos Aires. I created seminars and post-graduate courses; I also trained health providers in interdisciplinary approaches to work with PLWHA.

I worked for a county AIDS program, developing community outreach work as well as curricula for schools (kindergarten, elementary, and high school) so that parents, teachers, administrative staff and children could learn about prevention, etc.

I created the first support groups for PLWHA at the University hospital.

I was lucky by then to understand both sides – from the patient as well as the provider perspective. I understood the PLWHA, I heard their feedback. I also recognized the fears of health providers, and this enabled me to create programs that considered all the different perspectives.

PAHO [Pan American Health Organization] funded the project at the University of Buenos Aires and wanted UNAIDS to get to know this program that was taking place at the University as a best practice. From there I began consulting for different agencies (USAID, WHO, UNICEF, GTZ, AUSAID, etc) all around the world until I finally came to JSI/Denver in 2005.

So, for my entire professional life, I have been involved in this field—that's 25 years!



Laurie Kunches, *Senior Consultant, Director of Clinical Research, JSI*

Timing is everything in life” is an adage with great meaning to me, largely because of the way my career in public health evolved, coincident with the onset of the HIV epidemic.

If it was fate, there was nothing subtle about the favorable alignment of factors as I finished graduate school with my MPH in Epidemiology and Biostatistics in 1983. With 10 years of nursing experience (including infection control and clinical trials) and some good personal connections in the public health sector, I was offered and enthusiastically accepted the job as AIDS Surveillance Epidemiologist. At the time, I held the only AIDS-specific job in the Massachusetts Department of Public Health.

Professionally this role was amazingly challenging and fascinating, and it was the first step in a long and winding path that has been my public health career at JSI. Even more wonderful, though, has been the opportunity to work with and befriend such remarkable people, whose passion for the cause and integrity under such adversity has touched my life over these 30 years.

Along the way I have seen many breakthroughs and am thrilled that HIV is now a manageable chronic disease, I continue to be inspired by the brave patients with HIV who I have known and the outstanding professionals at all levels who I have worked with in the epidemic. And of course, I am forever grateful for the chance to represent JSI in this battle.



Marc Cunningham, *GIS Advisor/Data Analyst, JSI*

While growing up in Jos, Nigeria, one of my important mentors, Mary Beth Oyebade, started the Mashiah Foundation with her husband to support HIV+ women and widows. Their dedication to meeting the clear needs they saw showed me how relevant and important holistically addressing HIV/AIDS is in Nigeria. I just knew I was going to become a doctor.

During my college years, though taking pre-med classes, I sort of fell into dual degrees in math and humanities. So much for that dream. Models and sociology had shifted my focus more broadly to systems and populations rather than individuals. While deciding where to go next with that, I returned to teach at my old school in Jos, and had the opportunity to volunteer with Halt AIDS, a local NGO. It was my first exposure to true, community-based public health work.

Seeing the challenges my colleagues there faced in advocacy and youth mobilization showed me I lacked the skills needed to be much more than just “boots on the ground”. So, I spent two years at Emory University studying epidemiology and geographic influences on health. While studying, I worked with Susan Allen at the Rwanda Zambia HIV AIDS Research Group who looks at prevention of HIV among discordant couples—where one partner has HIV and the other doesn’t. Dr. Allen shared her extensive passion for the field and her expertise with me—the AIDS epidemic is a huge problem stretching across different sectors, requiring lots of people with lots of resources looking at it from lots of perspectives.

After a year’s training fellowship with the CDC’s geographic analysis group, I moved to JSI, where I use GIS for public health applications—from monitoring and evaluation to creating maps for decision makers. As fate would have it, much of my current work here focuses on HIV prevention work, continuing to involve me in the field which drew my eye to health and service in the first place.



Lewis Holmes, *Consultant/Clinical Advisor, JSI*

In my medical residency program, we had a Family Practice Service where we would care for our own clinic patients and those of local family doctors. AIDS was new, virulent, implacable. Many of the AIDS patients that we treated came at the end, their mouths dry and red with yeast, kidneys failing, emaciated, full of pain and nausea.

The hospital rooms were warm, quiet, full of love and compassion, suffused with fatigue and suffering. Patients lingered, 24 hours a day, until peace finally came. Sometimes the rooms would lie empty for a while; other times they'd be filled with the noisy families of the transiently ill, those with pneumonia or a kidney infection, riding the brush with mortality and then gratefully returning home. Soon another AIDS couple would arrive, one patient, one partner. Each couple came from different walks, moved with different tempos, but shared the same deep pain and exhaustion. ARVs were just coming out, and there was not quite enough available yet. AIDS was almost a chronic disease but for these men, the opportunistic infections still inflicted their gruesome wounds, the available medications their nasty side effects until, finally, their bodies gave out.

As a physician I never felt so helpful, or so powerless. I could blunt the sharpest edges for a bit, providing some brief respite, but time was ever so present. Even now, many years later, I can recall the dark hospital hallway as I walked from the call room to the ward in the middle of the night, acutely aware of the pulse and rhythm of life, and the arbitrariness of death.



Dianne Perlmutter, *Program Consultant, JSI*

I got involved in the AIDS epidemic very inadvertently: A friend of mine who was working at Massachusetts Department of Public Health in the late eighties called and said they needed the expertise of those of us involved in developing community-based, long-term care services for elders. And why? Because at that time, at least some people with HIV were living long enough to come home from the hospital, but still needing services to make it possible to remain safely and with some quality of life at home.

Shortly after this conversation, I found myself interviewing for a position at the AIDS Action Committee (AAC) which was looking for someone to do public policy advocacy and organizing around developing community-based support services for people living with HIV (PLWH). Accepting the position with some trepidation (“who was I, with minimal knowledge or experience in HIV?”), I quickly became caught up in my work, the community that was AAC, and the activism and politics of the epidemic—an absolutely life changing experience.

It’s both hard and gratifying to think back to those times: *Hard* because of all those whom we lost due to the ignorance, stigma, and outrageous absence of response by those in a position to make a difference (with resources and moral leadership to combat the insidious stigma surrounding those affected). *Gratifying* because of the synergy between my ‘job’ and my activism; the opportunity to finally be really ‘out’ in the work place; and the incredible friendships that were forged during those times.

I have continued to feel compelled by and drawn to ongoing work on HIV since those early days, with increasing hope for the future and immense sadness that many I knew weren’t able to take advantage of the incredible advances we have seen. My journey took me from AAC, to a degree in public health (to add to my MSW) and then on to the Massachusetts AIDS Bureau, the Cambridge Health Alliance AIDS Program and finally, to JSI. There is still much work to be done, at so many levels, if we are going to truly be witness to an “AIDS-free generation.” I hope and plan to be part of that as long as I can continue to make a difference.



David S. Hausner, *Country Director, AIDSTAR-One India, JSI*

During my last semester of high school in 1983, I had an internship with a pathologist. For my final report, he suggested that I write about a new disease. It was an exciting idea because no one knew the cause of the disease and it was so different from anything seen until then. That was the first time I had done any work related to AIDS.

Fast forward to public health school at Columbia University in New York City in 1990. I started working with a professor in the AIDS Center at Mount Sinai Medical Center. We put together a weekly conference series where medical providers and public health specialists could present their work with AIDS patients and people at risk for HIV infection. We also put together some of the early infection control trainings for hospital staff because the fear of HIV infection was palpable.

But it was at amfAR where I became emotionally committed to helping stem the AIDS pandemic. I worked in the international division during 1992-93. We were in the second decade of the epidemic, but until then I hadn't really known anyone with HIV. My involvement with AIDS was professional and academic, but not personal. At amfAR, this changed. Many people at amfAR were living with HIV and most had a family member or friend with HIV. As I got to know my colleagues and they became my friends, the personal and emotional side of AIDS started to wear off on me and I knew that this was the work I needed to do.

I have been working for a world without AIDS ever since then, in Cambodia, India, Central Asia, and elsewhere. There are many aspects of public health worth working for, but for me, working towards a world without AIDS is more than that. It's personal.



Mindy Nichamin, *New Media Coordinator, AIDS.gov, JSI*

I was born in the 80s, the same decade that the HIV epidemic began. Yet I was too young to remember the fear, the lives lost, the activism, and the scientific advances of the first decade of the epidemic. Fast forward to the 2000s where I found myself and my peers, as young people in the United States, unacquainted with the reality of HIV around us.

HIV became my doorway into public health after a summer spent volunteering with [World Camp](#) during college, where I taught basics about HIV prevention to primary students in Malawi. The statistics about the global AIDS epidemic that I'd heard in the classroom became real for me there, as did the overwhelming notion that there was no easy, fix-all solution for eradicating this disease. I am grateful for my undergraduate experience at [The University of North Carolina at Chapel Hill](#) that offered many ways to continue to stay involved – through HIV testing and awareness events, educational opportunities, research, and fundraising.

Those HIV experiences brought me to JSI, where my projects focus on the HIV epidemic here in the U.S. JSI was a reawakening for me that the domestic epidemic is still a critical public health issue. People at JSI, our clients and partners, and especially community members with whom I work are doing powerful, inspiring work in many facets of HIV.

Through the [AIDS.gov](#) project and work with the [Santa Clara County](#) and San Francisco Departments of Public Health, I'm reminded of how far the epidemic has come. And I'm excited to play a part in the new direction it is going in this decade – the beginning of the end of AIDS.