Leading Women

Honoring 30 years of SisterLove

February 24, 2020 By Olivia G. Ford

The red carpet is unfurled. The stage is set. Flashbulbs pop as hundreds of impeccably dressed individuals enter Atlanta City Hall's atrium. At the center of the attention are 30 women, the most resplendent in the crowd.

Most of the 30 are women of color, both cisgender and transgender. Twenty of them have been living with HIV for two decades or more; all are established leaders and change makers in communities across the United States and beyond. They are members of the 10th annual class of the 2020 Leading Women's Society (LWS).

On this night—October 18, 2019—we gathered to thank these women for their innumerable, often unheralded contributions to the HIV movement. We also attended to honor SisterLove, the organization that brought them together.

In 2019, SisterLove also marked 30 years of serving women living with and vulnerable to HIV in Atlanta, across the South and around the globe. The group has fought alongside these women for their rights, agency and access to care and dignity within a reproductive justice framework. In 2019, its satellite program in South Africa marked 20 years in operation.

Dorothy Grant (left) and Gena GrantKaty Beltran

“Putting your names, faces and bodies on the front line of the fight to end HIV, while simultaneously eradicating other oppressions at the intersections, cannot go without recognition and appreciation,” wrote Dázon Dixon Diallo, MPH, SisterLove’s powerhouse founder and president, in a letter printed in the gala program. “We see you, and we follow your lead.”

LWS consists of both awardees and inductees. Nominated by someone in their communities, inductees are selected for their HIV leadership and become awardees once they’ve lived with the virus for 20 years. For the most recent classes, only existing LWS awardees could nominate new members.

LWS members are clinical trial advocates, community health workers, policy experts, poets, international speakers, sex-positive opinion writers, parents fighting institutional stigma to make space for their children and much more.

“We really do get those unsung heroes,” says Linda Scruggs, who was honored in the inaugural class in 2009. “They may never make it to the International AIDS Conference or the stage at USCA [United States Conference on AIDS, the nation’s largest HIV meeting], but they are reaching women. They’re making phone calls, they’re [driving women who need transportation], they’re speaking locally, they’re helping program, they’re case-managing. Nobody would know them if it wasn’t for something like this space.”

Scruggs, who lives outside Washington, DC, tested HIV positive in 1990 and has been working with women in the HIV field just about as long. With Vanessa Johnson, JD, MPA, another 2009 LWS honoree and a veteran of networks of people living with HIV, Scruggs co-owns Ribbon Consulting

Group, the only national provider of organizational development, community-building and mobilization owned and operated by two Black women living with HIV. For the past several years, Ribbon has coordinated the LWS weekend, including a daylong institute offering these strong leaders opportunities to reflect, through workshops and group conversations, on what leadership and service mean to them.

“SisterLove doesn’t just acknowledge the work you do,” says Scruggs. “It’s creating a whole new network and resources of support.”

***

“If we don’t have celebrities who can disclose their HIV [status because of stigma], then we need those who have disclosed their HIV to be the celebrities,” says Dixon Diallo. “It starts with acknowledging the ones who are open and are leaders.”

In 2009, SisterLove had already existed for 20 years. That same year, a beloved and prominent member of SisterLove’s community, Juanita Williams, was celebrating 20 years living with HIV—though for Williams, celebrating the date she was diagnosed was an annual event. She always made it a big production, “a red-pump affair,” Williams says. “Twenty years [is] a long time after you’ve been told you got six months to live.”

For SisterLove’s 20th anniversary, Dixon Diallo, inspired by Williams, organized an awards ceremony honoring 20 women who had each been living with HIV for at least 20 years and who used their HIV status to respond to the epidemic in powerful ways in their communities. Thus were born the 2020 Leading Women’s Society Awards. The accompanying gala would become the group’s signature annual event.

The women are feted not just at a gala but during an entire weekend of festivities, pampering and a heartfelt private induction ceremony. Williams was among 2009’s honorees.

Williams is known in the SisterLove community as the first client ever to seek out the organization for help. She tested HIV positive in 1989 in South Carolina, where there were virtually no services for women with HIV.

Meanwhile, in Atlanta, SisterLove had begun to fill some of those vast gaps in services. Williams connected with the organization AID Atlanta, one of SisterLove’s early homes, and soon moved to the city. “SisterLove became family,” Williams remembers, “and a vehicle for my voice.”

Tiffany NicoleKaty Beltran

Among SisterLove's first services was a small support group. A nurse Dixon Diallo knew from her days working at Atlanta's iconic Feminist Women's Health Center (FWHC) asked whether SisterLove could expand the group to Grady Hospital, where she had started a women's HIV clinic one half-day a week but lacked the capacity to offer the emotional support women needed.

"I literally would sit in the waiting room" on clinic mornings, Dixon Diallo says. When a few women had arrived, "I would turn off The Phil Donahue Show—that's how long ago this was—circle up the chairs and then just [start] talking," she says. She would offer a question for discussion, and they would go from there.

One day, a woman shared that she had left home because family members treated her like a pariah due to their ignorance about HIV. Another woman's sister was so relentless about keeping the house bleached that she locked her out of the bathroom at night. Another was prohibited from using her house's washer and dryer. And then there were the anecdotes so devastatingly familiar to many people with HIV about the use of disposable plates and flatware.

"Each one of these women on that day had these horrific stories of how they might not have been homeless, but living where they were was a nightmare," Dixon Diallo remembers. So in 1992, SisterLove opened a transitional housing program to give women with HIV an option providing dignity, safety and support—and where they could bring their children.

It was the first program of its kind in the U.S. South. It began in a condo donated by a client; at its peak, the program operated two houses, one of which remains the group's headquarters.

"They made it a homey place," comments Phyllis Malone. The housing program was how she first encountered the organization. Malone, a mother of four, tested HIV positive in 1996. In 1998, she

was released from prison and, when she could no longer abide staying with her mother, moved into the LoveHouse, as it is still called, with her young son and daughter.

The program offered self-help groups, case management, kids' activities, spirited holiday celebrations and more. Malone and her kids stayed until 2001. "I loved staying there," Malone recalls. "We had somebody who cared about us."

For years after leaving the LoveHouse, Malone struggled with substance use, but she always remained connected with SisterLove, attending meetings and remaining friendly with a staff member who had gotten to know her family. When she stopped doing drugs, "I had a lot of time on my hands," she says, so she began volunteering with SisterLove, then worked with the group on projects as a paid contractor.

In 2013, she was told she could no longer be a contractor. "They wanted me to be on staff," Malone says. She has been SisterLove's prevention specialist ever since. She was inducted into LWS in 2016 and attends the gala each year as an alumna and a SisterLove staffer. "SisterLove made me who I am today," says Malone. "I found my voice."

***

The human right to parent one's children in a safe, sustainable community—of which the transitional housing program is one very literal example—is a key pillar of the reproductive justice (RJ) framework that SisterLove helped to articulate and continues to uphold.

This, alongside the other basic pillars—the right to bodily autonomy, to have or not have children—link reproductive rights to struggles against race and class bias, violence, criminalization, environmental injustice and other social issues negatively impacting communities of color. The framework was formed and named at a gathering of Black feminists in 1994, Dixon Diallo among them.

"Though there are almost as many interpretations and co-optations of the term [sexual and reproductive justice] as there are people using it," wrote Dixon Diallo in a 2017 Georgia Voice op-ed, "I work with the idea that sexual and reproductive justice exists when all people have the social, political and economic power and resources to make healthy decisions about our gender, bodies, sexuality and families for ourselves and our communities."

Loretta Ross, one of the "midwives" who birthed the RJ movement and a visiting associate professor at Smith College, attended the LWS gala. She is also a close friend of Dixon Diallo. Ross has spent nearly five decades launching or managing nonprofit feminist organizations, organizing historic marches and conventions, publishing books and inspiring generations of activists.

She and Dixon Diallo met in the mid-1980s. Onstage at the gala, Ross affectionately reminisced about a young Dixon Diallo's spiked haircut and irrepressible energy.

Loretta RossKaty Beltran

“Dázon has done the best work in the world of knitting together the RJ and the HIV/AIDS movements,” Ross says. “I remember getting involved in conversations about women with a diagnosis being discouraged from having sex, having children, doctors attempting to force women with [HIV to be sterilized].” These forms of reproductive oppression are similar to those experienced by women of color in general, she adds. “Dázon has been at the front lines of pointing this out.”

Ribbon Consulting’s Johnson, who also cofounded Positive Women’s Network–USA, the first and largest national advocacy network of women with HIV, noted that this was true in HIV as well. “Pushing the community to embrace sexual and reproductive health” is also among SisterLove’s contributions, she says. “From the perspective of the South and Black women, [it was] SisterLove that really made us pay attention to that body of work.”

LaDonna PerkinsKaty Beltran

In the 1980s, as the HIV movement grew with a narrow focus on white gay men, so, too, did a reproductive health movement centered on white, largely middle-class women's concerns. For nearly six years during that period, beginning when she was an undergraduate at Spelman College, Dixon Diallo worked at FWHC in Atlanta.

She recalls that when she first learned about HIV and its impact on Black women, she tried to start the program that would become SisterLove at FWHC. However, antiabortion forces were also gaining ground, and resources to respond to that onslaught took precedence over an HIV program.

"It was already very clear to me the immediate connection between access to choice around reproductive health options and access to information and options for preventing HIV and [sexually transmitted infections]," Dixon Diallo said in a 2009 interview with Ross for an oral history. "Those things weren't readily available in the same place."

Dixon Diallo was also part of the National Black Women's Health Project (NBWHP, now Black Women's Health Imperative). In fact, she had attended the group's seminal founding meeting, convened by veteran Black women's health activist Byllye Avery at Spelman College in 1983. Both that gathering and NBWHP have shaped Dixon Diallo's work ever since.

"[Avery] is the reason I do what I am doing now," Dixon Diallo says. As Ross and coauthors write in the book Undivided Rights, NBWHP pioneered the self-help approach to the promotion of Black

women's health, a method grounded in the power of telling personal stories to address trauma, connect women to one another across lines of difference and move women to take an active role in individual and community healing. This model inspired a movement of health organizations by and for women of color, including SisterLove.

In 1997, SisterLove leaders, including Williams and Dixon Diallo, convened SisterSong Women of Color Reproductive Justice Collective as a multiethnic, multi-issue national network. To this day, SisterLove shares space with SisterSong at Atlanta's MotherHouse, also the original home of NBWHP.

When SisterLove became an independent group, after three years of fiscal sponsorship by AID Atlanta (under the directorship of Sandra Thurman, who became the AIDS czar for President Bill Clinton), its staff worked from the MotherHouse's screened porch. SisterLove now owns that house.

"We always considered NBWHP as an incubator organization" for women's endeavors against the grain of mainstream Black communities, Avery says, "so I was just really glad to have folks come forth to work on HIV/AIDS. Half of Black folks were scared of people with AIDS [at that time], so this was welcome news to me."

One of SisterLove's legendary programs is its education and prevention event, the Healthy Love Party. Conducted with groups of women already familiar with one another (sorority sisters, office mates) in their own environments, gatherings feature frank talk not just about HIV and other health conditions but also the things that make sex fun.

"It was the first time I heard anybody ever talk about sex in the context of women and HIV," Johnson says of Healthy Love Parties. It became the Healthy Love Workshop when, after several years of validation, it officially entered the Centers for Disease Control and Prevention's (CDC) compendium of evidence-based interventions.

"Dázon really modeled well that one can talk about sex. She teaches her staff that—they don't talk about it with hang-ups," Johnson says. "[Sexual and reproductive health is] a dialogue, along with all the techniques and skills. If we're not talking, that's not sexual and reproductive health."

SisterLove made me who I am today.

"Indigenous women, women of color and trans people have always fought for Reproductive Justice," begins the "Herstory" section of SisterSong's website. By that token, Nadine Ruff has been working to secure safety and justice for LGBT people and women, without necessarily calling it "RJ."

"I was trying to help everybody that was living with HIV," Ruff says. "When I started to realize that

there were a number of people that suffered more, like women of trans experience and women period, then I started focusing on that."

Ruff, a mother and grandmother, tested HIV positive in 1987. After finding peace through recovery from substance use and breaking a years-long cycle of homelessness and incarceration, she wanted to find ways to help her communities. She became a case manager and learned about the health disparities and discrimination faced by LGBT communities, issues she, too, had experienced throughout her life.

She took every route she could think of to deliver resources and support: going into prisons, working through her recovery community and through churches—or trying to—and earning a master's degree with honors in social work. She founded a support group for women of trans experience in New Haven, Connecticut, and coordinates the Aging Positively program at her agency. But it was LWS that first acknowledged the work she had been doing for over a decade.

"Being an honoree and being inducted was one of the highlights of my whole journey," she says. "Not until I got into the sisterhood is when I clearly heard 'Thank you'! It made it ever so worthwhile to continue to do the work."

Similarly, Kim Canady-Griffith didn't even realize she was looking for this kind of supportive network until she found it in LWS. "That's always been my goal, to link up with other women who were doing the work," she says, "not just solely focused on HIV but the intersections."

Canady-Griffith was born with HIV. Her first experience of being in community with other women living with HIV was the support group at a clinic when she was a teenager. She has been involved with youth programs and advocacy ever since.

Canady-Griffith says she was raised by a grandmother who was a pastor and has two older sisters who are social workers. With that background, she says, community work came naturally. She has always worked with teens. The depression, rebellion and trauma of her own youth inform the education and training work that she has done with young people for more than half her life, around all aspects of sexuality, including healthy relationships.

A friend who was part of LWS told her about it and nominated her in 2019. "I didn't realize so many women that I know and that I've worked with at different events are actually inducted," she remarks. "It kind of feels like a secret society." For her, it's been refreshing to see that "there are other women who are trying to uplift you and want you to succeed and not tear you down."

Angelisa Austin (center)Katy Beltran

“RJ is still required, because if we don’t keep it on the table, then [decision makers] forget that we exist,” says Lisa Diane White, SisterLove’s deputy director. She came to SisterLove through NBWHP, as a volunteer outreach worker and facilitator of a self-help group for women with HIV. “They forget that the world is not white men only…. People move through the world by the people that they see, and if they don’t see us, then they won’t think about us.”

This fact became apparent again in October 2019 when the drug Descovy was newly approved by the Food and Drug Administration (FDA) for HIV prevention through sex, excluding those who have receptive vaginal sex. Cisgender women and transgender men—whose HIV vulnerability is already largely misunderstood and ignored—were excluded from the clinical trials that confirmed Descovy as the second drug that people can use to remain HIV negative.

SisterLove now helps drive the push to correct this oversight—just as the group fought against the CDC’s exclusion of health conditions affecting women in its definition of AIDS roughly 25 years ago. The group has also been a driving force for women in building the field of biomedical HIV prevention, including pre-exposure prophylaxis (PrEP), from the worldwide uphill battle for an effective microbicide to convening the U.S. Women and PrEP Working Group to inform the rollout of Truvada, the first PrEP drug, in the early 2010s.

Dixon Diallo spoke of this history of struggle for inclusion at the gala—before a representative from Gilead, the maker of Descovy and Truvada, read a statement from the company stating its

intention to work with the FDA on “an innovative trial design to conduct a study evaluating PrEP medications in cisgender women and adolescent females.”

SisterLove will continue to hold Gilead—as well as other institutions—accountable to its promises. Never mind just a seat at the table, as Dixon Diallo coolly asserted from the stage, “We are setting the table.”

Katy Beltran

“I don’t have to be invited to a stage again,” comments Scruggs, regarding her decades of mentorship. “I have enough ladies out there [doing great work]. Leadership is also pushing up other people.” Likening those she has mentored to seeds, she says, “My fruit tree is full, and that feels incredible.”

LWS has become a nationwide network of dozens of women leaders with ready access to one another for support and growth. What comes next for this expanding circle? For many members of LWS, the power is in so many women sharing different versions of a common experience and different tactics to achieve a common goal.

“Being connected with SisterLove, I have people with like minds, that think like I do and want to help like I do,” says Ruff. “It’s more like a family.”

Canady-Griffith would like to see LWS become a collective voice in advocacy: “For all of us to say, [for example], ‘We want better health care,’ and we are the voices of it,” she says.

She agrees with Ruff on the importance of having a network of sisters: “It might not be the family you want, but it’s the family you need.”

For further conversations by four 2020 Leading Women Society honorees, click here.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/leading-women-sisterlove