

# International Community of Women Living with HIV NORTH AMERICA



**2020/2021 Annual Report**





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**Kneeshe R. Parkinson**  
Co-Chair USA



**Chantal Mukandoli**  
Co-Chair Canada

## MESSAGE FROM CO-CHAIRS

### Greetings to our Sisters Living with HIV, our Peers, our Partners, and our Allies

We are excited to share the International Community of Women Living with HIV – North America (ICW-NA) Annual Report. Guided by a new strategic plan, this report shares the transformative work we completed in 2020 and 2021 to secure and improve quality of life for women living with HIV in Canada and the United States. With an eye to the future, the report also shares our vision for building on these successes.

In our roles as 2020-2021 co-chairs, we have had the honor to lead our organization during a time of rebuilding. Over the last two years, we have focused internally, intentionally restructuring our team, investing in our infrastructure, and relaunching our organization. This work was not without challenges and growing pains; however, we are now positioned to strategically grow and unite women living with HIV across North America for years to come. While much of our focus was inward, we continued our efforts to mobilize, organize, advocate, mentor, and raise consciousness about the issues and policies that directly impact our lives and the lives of all women living with HIV. As you will see in this report, we led strategic and collaborative efforts to amplify and center the voices of women living with HIV, ensuring that we have a voice where decisions related to research, policy, and funding are made. We focused on the meaningful involvement of people living with HIV in federal HIV policy, ensuring that women are not left behind in the U=U movement, and led calls to respect the autonomy of women living with HIV to make sexual and reproductive health decisions for their families. We continued to grow our membership and build community among women living with HIV, creating spaces where we can support each other through our collective wisdom. We remained nimble, rapidly responding to the COVID-19 pandemic by providing direct aid, virtual support groups, and educational information. We implemented trauma-informed care programming, providing a safe place to heal and build collective power through story telling.

Despite internal change and global challenges, we achieved our goals and have much to celebrate. We are ready to catalyze these successes to grow our reach and increase our impact, building a world where all women living with HIV live free of gender oppression, realizing and claiming our full rights inclusive of sexual, reproductive, legal, social, economic and health rights. We will continue to conduct our work with a commitment to social justice, transparency, integrity, critical reflection, and accountability. As always, you, your voices, your presence, and your multiple identities are welcome.





## VISION

**ICW-NA envisions a world where all women living with HIV live free of gender oppression, realizing and claiming our full rights inclusive of sexual, reproductive, legal, social, economic and health rights.**

## MISSION

**ICW-NA exists to lead efforts to secure and improve the quality of life for women living with HIV in Canada and the United States. We do this by mobilizing, organizing, advocating, mentoring and raising consciousness on the issues and policies that directly impact our lives.**

# Core Values and Principles



## **Accountability**

We answer to the members of our network and the women living with HIV whose interests we serve



## **Self Determination and Emancipation**

We promote and practice the principles of GIPA/MEWA (Greater Involvement of People with AIDS/Meaningful Engagement of Women with HIV and AIDS)



## **Integrity and Critical Reflection**

We are committed to working in a way that is transparent to our members and that builds our capacity to put the needs of women living with HIV above individual interests



## **Feminism and Gender Equality**

We work to support the ability of all women living with HIV to define, establish and achieve equal political, economic, cultural, personal and social rights



## **Social Justice**

We recognize that as with all people, we share a common humanity and therefore a right to equitable treatment, support for our human rights, and a fair allocation of community resources.



## **Commitment to Advocacy**

We are committed to improving health and social policies that increase fairness and access for all women living with HIV



## **Self-Care**

In doing our work with its many demands, we commit to care for ourselves as we offer care and support to each other



## **Diversity and Inclusion**

We recognize women in all of their diversity, and are actively inclusive of all women living with HIV, regardless of race, ethnicity, sexual identity, gender conformity, socioeconomic status, educational background, marital or parental status, housing status, employment status, and substance use



# ICW-NA Board Members



Carla Martinez, Orillia,  
Ontario, Treasurer



Kneeshe Parkinson, Saint  
Louis, Missouri, Co-Chair



Alecia Tramel, Miami,  
Florida



Melanie A. Reese,  
Baltimore, Maryland



Monisola Ajiboye, Nigeria  
and Canada



Chantal Mukandoli, Toronto,  
Ontario, Co-Chair Canada



SaVanna Wanzer, Petworth,  
Washington



Helen Zimba, Dallas, Texas,  
Secretary

# ICW-NA Key Achievements 2020-2021



## Strategic Goal 1:

Build an institutionally strong ICW-NA Secretariat

### **We developed our 2020-2024 Strategic Plan with input from WLWH and allies.**

ICW-NA's founding strategic plan covered the years of 2016-2019. In 2020, we finalized a new strategic plan covering the period of 2020-2024. This new strategy is designed to guide ICW-NA through its next stage of growth. We developed our plan in a participatory manner: starting in 2019 and continuing in 2020, we spoke with women living with HIV (WLHIV), our supporters, and our allies across North America. We first engaged our Board of Directors and staff to develop an initial strategy. Then we conducted a survey, open to all WLWH in North America.

Knowing that WLWH may face access related barriers to completing an online survey, we conducted five focus groups, intentionally seeking out perspectives may have been underrepresented in survey responses. Through the survey and focus groups, we heard from over 90 WLWH. We also conducted phone and email consultation with key stakeholders from organizations and agencies doing related work. This collective feedback helped us to refine and validate the strategic plan, which was approved in December 2020.

The strategic planning process was not without challenges. The COVID-19 pandemic delayed our initial timeline to finalize the strategy. The process of developing the strategy also revealed areas where we needed to invest in our organizational infrastructure. Despite these challenges, the strategy and the development process, prepared us to grow as an organization. The strategic plan is our road map: it focuses on concrete action we will take to assure institutional capacity, strengthen our connection and engagement with ICW-NA members, and amplify the voices of WLWH across the continent.





# ICW-NA Key Achievements 2020-2021

## **We restructured and grew our Board of Directors and staff.**

Our 2018-2019 Annual Report spoke of leadership transitions within ICW-NA. On the other side of those transitions, 2020-2021 was a period of restructuring. We recruited a new Board of Directors, convening a diverse, skilled, and passionate Board who are representative of the diversity of WLWH. ICW-NA's representative, working Board, is guided by two co-chairs, Kneeshe R. Parkinson, and Chantal Mukandoli, each serving a three-year term. We also restructured and grew our staff. In late 2020, Martha Cameron assumed the role of Executive Director, after previously serving as the Board Treasurer and then the Regional Coordinator. In spring 2021, Heather O'Connor joined the team as a Communications Specialist. Martha, Heather, and the Board bring a range of experience to their roles and are positioned to lead ICW-NA into the future.

## **We invested in our secretariat infrastructure to ensure the soundness of operations.**

With a restructured Board and staff, we are positioned for our next stage of strategic growth. However, there is a learning curve for a new team. During 2020-2021, we intentionally invested in our infrastructure and governance capacity. Our Board and Executive Director participated in a series of trainings for the Center for Nonprofit Advancement. This six-part course provided an overview of a board member's role, expectations, and responsibilities. The course covered topics including Executive Director evaluations, strategic leadership, risk management, diversity and inclusion, fiscal management, and fundraising. In addition, collaboratively with our funders and other stakeholders, we trained our Board of Directors on Greater/Meaningful Involvement of People living with HIV (GIPA/MIPA) principles and transgender advocacy.

# ICW-NA Key Achievements 2020-2021

In addition to strengthening the capacity of our team, we developed internal policies, procedures, and systems that will allow us to effectively manage our organization. We identified and began working with a Fiscal Sponsor, who provides financial oversight and administrative support, allowing us to meet the expectations of funders in the North American context. We implemented a new accounting software, developed policies and procedures to guide our financial operations, and continued to conduct our annual financial audits, a key component of our fiscal oversight. We also developed and implemented a conflict resolution policy, which provides a clear process that we will utilize when navigating conflict in the future.



To support our ongoing work and develop additional resources to support ICW-NA's mission, we also collaborated with a fundraising consultant, Spark Point. Working with this consultant, we developed a comprehensive fundraising plan, including developing a list of potential funders whose priorities align with ICW-NA's mission and a development workplan and calendar to guide our efforts.



# ICW-NA Key Achievements 2020-2021

## **We strengthened our communications capacity.**

As mentioned above, ICW-NA hired our first Communications Specialist in 2021. This increased capacity allowed us to more effectively pivot to conduct our work virtually due to the COVID-19 pandemic. We were able to leverage virtual platforms to maintain connection among our members, advance our policy priorities, and amplify the voices of WLWH, even during a time of increased isolation. Since bringing on the Communications Specialist, ICWNA has had a 394.1% increase in page reach on Facebook, our most utilized social media platform, for a total of 41,933 reaches. On Instagram, ICWNA has secured 321 follows, and on Twitter, 181. Through the use of social media, ICWNA has been able to secure more registrants to virtual webinars for a total of over 500 registrants since securing a Communications Specialist. We also utilize our communications platforms to recognize awareness days, including National Women and Girls HIV Awareness Day, National Transgender HIV Testing Day, National HIV/AIDS and Aging Awareness Day, among others.

## **Looking Ahead**

During 2020-2021, we laid the foundation for our strategic growth and future work. As we move in to 2022, we plan to continue to invest in our infrastructure, identifying and providing additional trainings for our Board of Directors, implementing our fundraising plan, and developing a MIPA/GIPA policy to guide our work.



# ICW-NA Key Achievements 2020-2021



## Strategic Goal 2:

Build and activate a robust membership

### **We grew our membership and maintained connections.**

Initially, we planned to grow our membership in 2020-2021. While we have continued to grow, gaining more members from North America and the Caribbean, the COVID-19 pandemic and our focus on internal restructuring and capacity building limited implementation of our plans. However, we pivoted and focused on increasing connection to and engagement with our existing members. We re-invigorated our I am ICW and Where Do You Fit In? campaigns. During the COVID-19 pandemic, this campaign included an hour-long webinar, providing information about ICW-NA and sharing stories of the diverse women who are a part of the organization, aiming to fight isolation, improve mental health, and to find ways to help and advocate for each other. Our co-chair, Kneeshe R Parkinson reflects on the value of the campaign sharing “ICW members have an intentional space for women living with HIV in North America. ICW-NA provides education and healing that intersect for women to know their life outside of a diagnosis. Women are being empowered by the work lead by ICW-NA.”





# ICW-NA Key Achievements 2020-2021



*The Healing Together/Common Threads program was an incredible opportunity. I have heard of trauma informed care for years but did not understand or participate in a training or educational opportunity... Being with other women, living with HIV, and sharing our common experiences was life changing. There is something special that happens when women living with HIV get together to inspire and heal with each other.*



Healing Together / Common Threads Participant



## **We collaboratively implemented programming to address the impact of trauma.**

During the Sixteen Days of Activism Against Gender Based Violence, ICW-NA collaborated with ICW- Caribbean (ICW-C) to host a webinar entitled, Healing Together: HIV and Trauma. This webinar launched virtual support groups, which fostered supportive connections between women, and led ICW-NA and ICW-C to partner to provide additional trauma-informed programming to WLWH. We worked with Vanessa Johnson of Ribbon to implement Common Threads, an integrated HIV trauma-informed, stigma-reduction intervention that enhances the ability of WLWH to powerfully share their lived experiences with each other and others of their choice. We adapted Common Threads for the virtual environment and the needs of ICW-NA and ICW-C's members; this adapted version is named Healing Together. The adapted intervention was implemented between March - May 2021 with the goals of decreasing the impact of internalized stigma and trauma, increasing opportunities for community engagement, and increasing conversations about quality health to improve engagement and retention in HIV services among WLWH. Over 25 WLWH participated in Common Threads/Healing Together. Feedback from these women indicates that the intervention created connection, community, and a safe and supportive space to process complex experiences.



# ICW-NA Key Achievements 2020-2021

## **We provided rapid COVID-19 relief.**

The COVID-19 pandemic has been a difficult and re-traumatizing time for many WLWH. ICW-NA stepped in and provided support for individuals who had nowhere else to turn. International citizens visiting the United States (US) found themselves unable to return to their homes due to COVID-related travel restrictions. Some had only a few weeks' worth of medication. While we do not provide direct services, we worked tirelessly to connect individuals with trusted organizations. We also used COVID-19 relief funding to support the most marginalized communities we work with, including sex workers and women of trans experience. We created virtual support groups where WLWH could process their collective trauma in a safe space, with 76 women participating in our two groups.



## **Looking Ahead**

We will continue to find new ways to build connections among WLWH. With our strengthened infrastructure and restructured team, we will renew our efforts to grow our membership, while also finding new and creative ways to deepen our engagement with our existing members. We also aim to grow our trauma-informed care programming. We hope to build on our success implementing Common Threads/Healing Together, tailoring an adaptation to transgender women. We also aim to develop a train the trainers' program, investing in WLWH so that they can in turn share this impactful program in their communities. In addition, we will explore how the Common Threads/Healing Together program can seamlessly lead into our Feminist Movement Building Program, using storytelling to help women change their own narrative, build power, create healing, and foster resiliency.

# ICW-NA Key Achievements 2020-2021



## Strategic Goal 3:

Amplify, prioritize, and advocate for WLHIV across North America

### **We implemented a U=U: Not Without Women campaign.**

U=U has changed the lives of people living with (PWLH); however, the movement has fallen short in acknowledging the structural barriers women face becoming undetectable, both in terms of research and the wider dialogue. In 2020, we developed the U=U: Don't Forget Women campaign as a call to action for the HIV movement to use science and research to better understand the impacts of being undetectable in women's bodies in relation to their access to sexual and reproductive health and rights, body autonomy, pregnancy, and breast/chest feeding. Events leading up to AIDS 2020, including our U=U + Women: Minding the Gaps webinar and U=U: Not Without Women Tweetathon reinforced and garnered additional awareness of the campaign and its core message. As our co-chair Kneeshe R Parkinson shares, "The campaign resonated with WLWH knowing they can't transmit HIV to their sexual partners. Reducing stigma and raising awareness matters."

# NOT WITHOUT WOMEN



[WWW.ICWNORTHAMERICA.ORG](http://WWW.ICWNORTHAMERICA.ORG)

# ICW-NA Key Achievements 2020-2021

## **We developed an Expert Consensus Statement on Breast/Chest feeding.**

With the focus of our U=U on campaign on breast/chest feeding for WLWH, we partnered with The Well Project to develop additional resources advocating for the autonomy of WLWH to breast/chest feed. The result is an Expert Consensus Statement on Breastfeeding and HIV in the United States and Canada, which calls for parents living with HIV to have access to the information, support, and tools they need to make informed infant-feeding decisions. We convened 21 multi-disciplinary, multi-sectoral experts to author the statement and stakeholders across HIV and intersectional movements signed on.

This consensus statement kicked off a multi-year campaign around HIV, pregnancy, and infant-feeding. Our campaign includes a resource for individual parents and children seeking support, including an online peer support group, Milky Mamas +, which provides expert resources and community to parents living with HIV who are interested in breast/chest feeding. The response to the campaign and related resources was incredible: the most popular post on ICWNA's Facebook page, an advertisement for the virtual webinar "Mama Knows Breast" covering the topic of HIV and breast/chest feeding, reached 27.7K followers, obtained 254 likes, 51 comments, and 36 shares.





# ICW-NA Key Achievements 2020-2021

## **We collaborated to develop and advocate for a HIV Federal Policy Agenda.**

We continue to be a leader in the policy and advocacy space, ensuring WLWH's voices are at policy decision making tables. Our executive director is the co-chair the Policy and Advocacy Committee of the US People Living with HIV (PLWH) Caucus. In 2021, the US PLWH Caucus, including representatives from the Global Network of People Living with AIDS – North America, ICW-NA, National Working Positive Coalition, Positively Trans, Positive Women's Network-USA, the Reunion Project, SERO Project, and THRIVE SS, collaborated to develop *Demanding Better: An HIV Federal Policy Agenda* by People Living with HIV. This document calls for increases in the meaningful involvement of people living with HIV and disproportionately impacted communities within the US federal HIV response by outlining a shared policy agenda. This policy agenda aims to ensure better care, treatment, and quality of life for people living with HIV through the federal HIV response. The agenda provides clear, concrete recommendations for federal agencies, the executive branch, congress, the HIV National Strategic Plan, and the Ending the HIV Epidemic Plan.

With our allies across networks of PLWH, ICW-NA contributed our knowledge, expertise, and skills, as well as the lived experiences of our team and the members we represent to formulating the agenda. We worked to incorporate the voices and experiences WLWH, in all of our diversity, in the agenda. This agenda provides recommendations span five issue areas which must be centered in the HIV response:

- 1 Concretely elevating the meaningful involvement of people living with HIV and disproportionately impacted communities in the HIV response;
- 2 Proactively creating an affirming human rights environment for people living with HIV by addressing stigma, eliminating HIV criminalization, and halting molecular HIV surveillance
- 3 Addressing inequities in the federal response by attending to racial and gender disparities;
- 4 Adding sex workers and immigrants living with HIV as priority populations throughout the federal response; and
- 5 Affirmatively committing to improving quality of life for people living with HIV

# ICW-NA Key Achievements 2020-2021

The agenda enables PLWH in the United States to speak with one voice, leveraging our collective power to demand change and concrete action. We also contributed to a social media campaign, developed to raise the visibility of the plan and the actions it recommends. ICW-NA continues to engage with our partner networks and policy makers to raise awareness of the plan and advocate for implementation of the recommended actions.



## **We represented WLWH in in local, national, and global Forums.**

We are active participants in a number of critical forums, ensuring that the voices of WLWH are heard and advocating for our needs in these spaces. We represent our members as part of the US PLHIV Caucus, District of Columbia Center for AIDS Research (DC CFAR), and AIDS Watch planning meetings. On an international scale, ICW-NA works with the global International Community of Women Living with HIV (ICW), including the International Steering Committee and Rebuilding Work Group, supporting program coordination, governance reform, communications, and advocacy. Our Co-Chair, Kneeshe Parkinson, was recently elected to the position of Vice Chair of the ICW International Steering Committee (ISC) where she will be advocating for WLWH at a global level. ICW-NA also participates in forums like the Global Network of People Living with HIV, UN Women, and the Global AIDS Policy Partnership. We also participate in key conferences and meetings, to raise the visibility of WLWH and ensure the issues that effect WLWH are included in these spaces. We participated in the 2020 Commission on the Status of Women session, presented by partners including the World Health Agency. Our executive director was a collaborating partner in a UNAIDS side event during that session.

## **Looking Ahead**

We will continue our advocacy work as a core part of our mission, amplifying the voices of WLWH in the places and spaces with the ability to create change and ensuring that WLWH are leading when decisions are made that affect our lives. We will continue our existing campaigns and work to develop additional campaigns focusing on PrEP, aging, and transgender advocacy.

# ICW-NA Key Achievements 2020-2021



## Strategic Goal 4:

Build capacity within the community of WLHIV across North America to engage, influence, and be active participants in defining research, funding and policy agendas, and advocate at local and national levels.

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## FINANCIAL STATEMENTS

- 2020 Financial Statement
- 2021 Financial Statement

## FINANCIAL STATEMENTS

Thank you to our funders Robert Car Networks Fund, AIDS United – People Organizing Positively, and The Sero Project for making this work possible.