THE 2018 ICASO ANNUAL REPORT

# DRIVING CHANGE



Together We Are

> Juntos Somos

Ensemble Nous Sommes



## **ABOUT ICASO**

The International Council of AIDS Service Organizations (ICASO) brings community perspectives into all levels of strategic decision-making in the global response to HIV. ICASO is a Canadian not-for-profit organization with a worldwide constituency, including partnerships that span Africa, the Asia-Pacific, Eastern Europe, and Latin America and the Caribbean. ICASO draws upon and takes direction from a large and diverse network of community experts in the HIV response, particularly members of key populations and community-based activists, implementers and policy-makers.

ICASO's work is guided by the following vision and mission:

ICASO's vision is an end to the HIV epidemic with strong contributions by communities in all their diversity to achieving universal access to HIV prevention, treatment, care and support, and to defending and promoting human rights.

ICASO's mission is to mobilize and support diverse community organizations and networks to create and sustain effective responses to HIV.

Since its founding in 1991, ICASO has been strongly focused on advocating for human rights and gender equality, holding governments and international institutions accountable for their HIV-related obligations, and promoting community sector participation and community- and rights-based initiatives. ICASO is well known for bringing together stakeholders from within and outside of the community HIV sector to build consensus and develop plans for collaborative action on issues of common concern.

ICASO has long participated in the UNAIDS Programme Coordinating Board, providing a vehicle for community priorities to be presented to this influential decision-making body. ICASO serves as a permanent partner on the Conference Coordinating Committee of the International AIDS Conference. ICASO also facilitates community engagement in high-level United Nations General Assembly meetings relating to HIV, health and development, as well as engaging in other key global and regional processes that shape the HIV response.

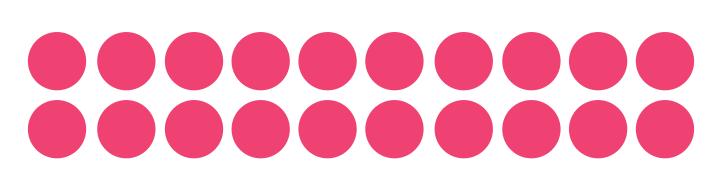
ICASO is governed by a board whose 10 members reflect an appropriate gender and regional balance and strong participation by people living with HIV, women and key populations, including sex workers, people who use drugs, youth, indigenous people, and men who have sex with men. ICASO's work is carried out by a small group of core staff based in Toronto, Canada, with support from a team of skilled staff and consultants based in four countries across three continents.

## **MESSAGE FROM ICASO**

The HIV epidemic, far from being over, urgently requires an intensified response. According to UNAIDS, there were 37.9 million people living with HIV in 2018, 21% of whom did not know their HIV status. An estimated 1.7 million people became infected with HIV in 2018, and 770,000 people died from AIDS-related illnesses. After increasing year on year since 2015, both domestic and international resources for HIV responses in low- and middle-income countries shrank in 2018 – together by US\$900 million. In spite of a global HIV funding decline, some countries continued to surge toward the ambitious UNAIDS "90-90" targets for HIV diagnosis, treatment coverage and viral suppression. However, other countries were far off-track, and 38% of people living with HIV worldwide did not have access to treatment in 2018.

While reports of progress against HIV in various settings are welcome, it is always important to ask *progress for whom*? Time and again, we see that key populations are being left behind. As a 2018 editorial in a leading HIV journal described the situation:

Globally, sex workers, [men who have sex with men] and [people who inject drugs] are 10, 24 and 24 times more likely, respectively, to acquire HIV compared with the general population ages 15 years and older. Transgender women are 49 times more likely to be living with HIV and prisoners are five times more likely to be living with HIV compared to other adults.... The limited population-based data that are available show that [HIV] testing and treatment coverage among key populations remains disproportionately low with no key population group close to achieving 90-90-90 targets.<sup>1</sup>



million people living with HIV in 2018 Furthermore, HIV prevention and treatment services for both the general population and key populations are not sufficiently taking into account women's needs and priorities in many settings. Human rights-related barriers also persist; in 26 countries with recent population-based survey data, more than half of respondents expressed discriminatory attitudes towards people living with HIV.<sup>2</sup>

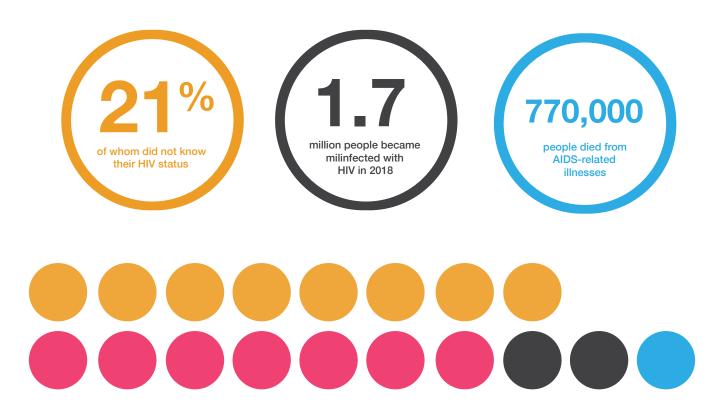
ICASO's response to this unacceptable situation is to continue working to fundamentally change the architecture of the HIV response – at the global level, country level and community level. We do this by collaborating with a large and diverse network of partners to bring civil society and community experts into key decision-making processes, and to insist that their voices be heard. We are grateful to the many partners, collaborators, funders and allies who have entrusted ICASO with this role, from our 1991 founding to the present day. We look forward to continuing to work with you until together we have ended the HIV epidemic.

#### Ben Plumley

Chair of the Board of Directors

#### Mary Ann Torres

**Executive Director** 



<sup>1.</sup> Wolf RC, Bingham T, Millett G, Wilcher R. Building the evidence base to optimize the impact of key population programming across the HIV cascade. Journal of the International AIDS Society 2018 Jul;21 Suppl 5:e25146.

## **ICASO IN 2018**

ICASO'S MISSION IS TO MOBILIZE AND SUPPORT DIVERSE COMMUNITY ORGANIZATIONS AND NETWORKS TO CREATE AND SUSTAIN EFFECTIVE RESPONSES TO HIV.

#### New York

In 2018, ICASO harnessed its good practice and lessons learned from UN High Level Meetings on HIV, to influence the first ever TB Political Declaration.

**GREAT BRITAIN** 

UKR/

TUNISIA

• OTTAWA • TORONTO

**WASHINGTON DC** 

• MEXICO

·JAMAICA

• HONDURAS

COLOMBIA ·

#### Amsterdam In 2018, ICASO

created platforms for community participation at the International AIDS Conference in Amsterdam.

• BRAZIL

· CÔTE D'IVOIRE

RWANDA

PERU •

BOLIVIA

#### Venezuela

In 2018, ICASO worked with ACCSI to create greater transparency on the HIV, TB and malaria epidemics in Venezuela, calling for international action.

PARAGUAY

ARGENTINA

GUYANA

Bolivia, Guyana, Honduras, Jamaica, Malawi, Tunisia In 2018, ICASO provided technical

assistance to civil society actors in six low- and middleincome countries

#### Geneva

In 2017 and 2018, ICASO influenced UNAIDS PCB discussions with interventions on HIV prevention and the Venezuela crisis.

• RUSSIA

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As the politics, funding and biomedical evidence base underpinning the response to HIV continued to change in 2018, ICASO maintained a clear course. Our work throughout the year fully embodied our mission: to mobilize and support diverse community organizations and networks to create and sustain effective responses to HIV.

This work took many forms and addressed many issues, including human rights- and genderrelated barriers, limited access to services for key populations, gaps in funding for national HIV responses, and the need for intensified community engagement in the United Nations High Level Meeting on Tuberculosis. Our outputs included reports, discussion papers, advocacy alerts, interventions in global policy fora, community training, and technical assistance to civil society organizations and community-led groups. ICASO championed community priorities and community capacity-strengthening in numerous activities associated with the 2018 International AIDS Conference, such as sponsoring the Robert Carr Research Award and Memorial Lecture, advising on the design of the Positive Lounge for conference delegates living with HIV, conducting a workshop on how "Undetectable=Untransmittable" can be translated into public health policy, organizing pop-up classes to disseminate key scientific information to community delegates, and presenting original research conducted with partners on HIV prevention funding gaps and on the humanitarian crisis in Venezuela. Additionally, ICASO staff engaged in extensive behind-thescenes negotiations throughout 2018 to facilitate cooperation and build consensus among a wide range of stakeholders in relation to key issues facing the global HIV community.

The impact of these efforts could be seen in more inclusive decision-making processes, more prominent roles for community-based actors in local and national HIV responses, and policy outcomes that reflect community priorities. Three of our major success stories are highlighted as case studies in the pages that follow.

Looking back at 2018, we celebrate these and other success stories of community-led change. We also celebrate new alliances beyond the HIV field and new ways of working to support the broader health and development agenda articulated in the Sustainable Development Goals.

#### CASE STUDY IN CHANGE

### EVIDENCE-INFORMED ADVOCACY IN HUMANITARIAN EMERGENCY CONTEXTS: VENEZUELA

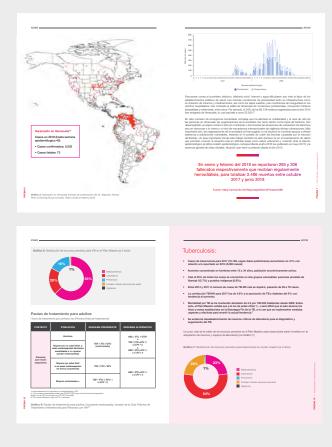
#### SITUATION

The collapse of the Venezuelan economy amid ongoing political instability has resulted in a complex humanitarian crisis. With the health system in ruins, progress against HIV has been rapidly reversed, and stock-outs of antiretroviral medicines are threatening the lives of tens of thousands of people living with HIV. In 2017, ICASO took urgent measures to support Venezuelan civil society organizations that are addressing this situation and to call attention to the impact of the crisis on Venezuela's epidemics of HIV, tuberculosis and malaria.

#### RESPONSE

In 2018, ICASO continued working to mobilize international support for health services in Venezuela, publishing two widely read updates to its December 2017 report, Triple Threat: Resurging Epidemics, a Broken Health System, and Global Indifference to Venezuela's Crisis. ICASO utilized the July 2018 International AIDS Conference, attended by more than 15,000 people, to cast a spotlight on the situation through a number of high-profile activities. ICASO and its allies worked behind the scenes throughout 2018 to encourage key health and development actors to recognize the HIV prevention and treatment needs of people in Venezuela as an important dimension of the humanitarian crisis. ICASO also publicized the advocacy and watchdog efforts of Venezuelan civil society organizations working on these issues, including the campaign to get antiretroviral medicines to people living with HIV whose treatment had been interrupted by widespread stock-outs.





#### RESULTS

ICASO's efforts helped to galvanize a much stronger response. In September 2018, the Global Fund to Fight AIDS, Tuberculosis and Malaria allocated US\$5 million in emergency assistance for Venezuela. The impact of ICASO's advocacy reached well beyond the HIV field, with other health and development actors recognizing that Venezuela's HIV epidemic, far from being under control, is one of numerous health issues that continue to require the urgent intervention of the international community. ICASO has continued to contribute to the on-the-ground response in Venezuela, with the focus shifting to monitoring the availability of drugs procured with the Global Fund donation. ICASO is also building on its success to bring about greater data transparency in relation to Venezuela's resurgent malaria epidemic.

#### CONCLUSION

Effectively addressing HIV in the midst of Venezuela's humanitarian crisis requires understanding the interplay between political instability, economic turmoil, poverty, immigration, foreign intervention and other complex factors. At a time when there are widespread calls for the global HIV response to become better integrated into the broader health and development landscape, ICASO's efforts to support the people of Venezuela demonstrate its readiness to lead in taking this approach.

There is a government policy to leave people with chronic health conditions without medicines in stock and then deliver them in exchange for votes during electoral periods.

Coalición de organizaciones por la defensa del derecho a la salud y a la vida (CODEVIDA)

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For more information on ICASO's work in Venezuela, please visit our website at http://icaso.org/venezuela/

#### Understanding U=U for women living with HIV ICASO Community Brief September 2018



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#### Pregnancy

Women\* living with HIV have the right to self-determination and the power over their own bodies and to support to make informed choices in regard to pregnancy and childbirth.

Research from over two decades ago demonstrated that when a woman living with HU is virally suppressed prior to contraception and remains undetectable throughout their pregnancy there is virtually <u>no vertical</u> <u>transmission</u> of HV from a mother to her infant.

Our bodies were the first testing grounds to demonstrate U=U (although not described as U=U at the time).

In 1996, women" living with HIV were the subjects of the <u>first research studies</u> that showed a 66% decrease in transmission when treatment was used as the prevention from mother to child.

as the prevention form mother to cikil. Providing vorome the backbone of a entry hereaftical Amberto Scilla Transmission (PMCT) prevention of Muharto Scilla Transmission (PMCT) prevention of Muharto Scilla Transmission (PMCT) commonly referred to as the Emmission to Muther to Child Transmission is the term that many community to Child Transmission (RMCT). However, Vertical Transmission is the term that many community common King skill who have or complete bits. Early commencement of Instanter has impacted women's first grant (An other and and and a signal bits in smit adds Chine automatic that a signal bits in smit adds Chine automatic that a signal bits in smit adds Chine automatic that a signal bits in smit adds Chine automatic that

O Understanding U-U for women living with HV ICASO Community Brief







Women' living with HW who are virally suppressed are often free to choose the method of delvey they desire. In some cases, they also have access to support programs that storogly recommend that women' living with HW have access to treatment prior to their pregnancy and after their child is form. This is based upon the body of research that clearly demonstrates that healty monthes have health plantiles.

There have been important strides for pregnant women living with HW that has resulted in a nearly O's chance of <u>vertical transmission</u> when a woman' has been on treatment before and during the birth of her baby. We encourage are expanded I-U-I disclogue that includes of the importance of applying the U-U message to the complexity of choices associated with pregnancy.

Without question, the U–U message has direct relevance to the very important life experience for women' globally who want to become pregnant and give birth. The U–U campaign has the volume to make our voices heard.

The misconception is that women' can have sex and have a baby and everything will be fine, this is both true and not. White babies are born without HV to women' bing with HV without treatment intervention, the dominant view is that women's 'bodies continue to be seen as the conduit of potential transmission to their children and our chickes about treatment commencement and interruptions are often taken away to the second and interruptions are often taken away and the second second treatment of the second second treatment of the second second second treatment of the second second treatment of the second seco

Women' living with HW are protoundly impacted by the HV stigma and discrimination that continues to exist across health care settings and communities in every nation. The U-J message provides a challenge to the undue, unnecessary and <u>contrast surveillance and correction</u> by health care workers of the bodies and choices of women' living with HW.

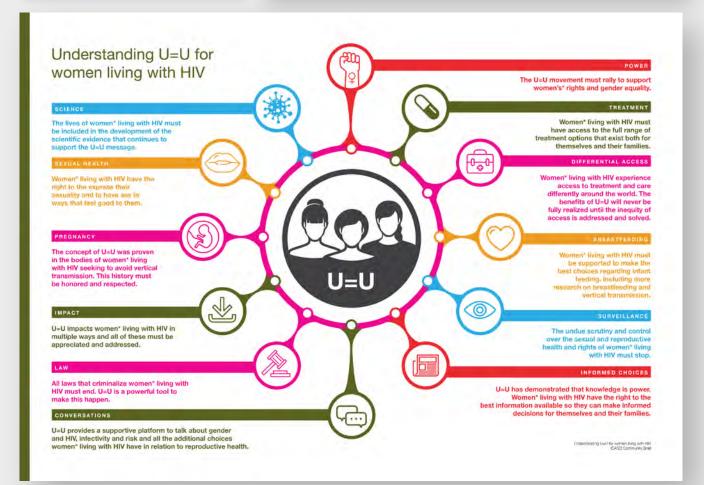






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#### CASE STUDY IN CHANGE

## **U=U FOR WOMEN**

#### SITUATION

In recent years, the community-driven U=U (undetectable equals untransmittable) movement has been hugely successful in publicizing the scientific finding that people living with HIV who are taking antiretroviral therapy and have undetectable viral loads are not at risk of sexually transmitting HIV to their partners. However, little attention has been given to how the current U=U messaging applies to women's experiences or how women's needs should inform U=U initiatives.

#### RESPONSE

ICASO spearheaded the development of a community brief, *Understanding U=U for Women Living with HIV*. A team of women living with HIV authored the brief with guidance from a global community advisory committee, also made up of women living with HIV. The brief drew on stories from more than 65 women living with HIV worldwide and on two community consultations held in conjunction with the 2018 International AIDS Conference in Amsterdam.

#### RESULTS

ICASO published the brief in September 2018 in partnership with the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine: Positive Women Victoria; and the National Association of People with HIV Australia. The brief was launched at the 2018 Australasian HIV and AIDS Conference and is available in English and Russian. It discusses how the U=U message and movement are significant to women in relation to sexuality, pregnancy, breastfeeding, access to health care, and other issues. ICASO and its large network of allied civil society organizations have extensively publicized and disseminated the brief. The brief sparked debate among civil society and community actors, creating an opportunity for ICASO to further emphasize the need for advocacy to be informed by the best available scientific evidence.

#### CONCLUSION

There is strong demand from women living with HIV and the organizations that serve them for the U=U movement to more explicitly take into account women's unique needs. The scientific and public health communities are failing to provide effective leadership on U=U for women, most notably in regard to the issue of whether women with undetectable HIV should breastfeed. As noted in the brief:

For many mothers living with HIV, there continues to be a disconnect between medical evidence, breastfeeding guidelines, cultural practices and public health approaches to the risks and harms in relation to breastfeeding. ... There is a fear on the part of women living with HIV that they will not receive all the information on breastfeeding, nor will they receive appropriate social or medical support if they express their desire to breastfeed. ... This prevents women living with HIV from having the information they require to make their own informed decisions and choices that may affect the future health of their children and families.

#### CASE STUDY IN CHANGE

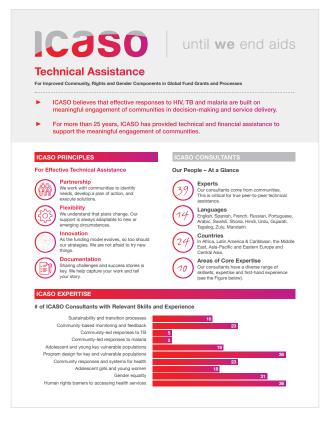
## STRENGTHENING CIVIL SOCIETY THROUGH TECHNICAL SUPPORT

#### SITUATION

The Global Fund to Fight AIDS, Tuberculosis and Malaria strongly encourages civil society actors to engage in the country-level processes that shape national HIV, tuberculosis and malaria programs. The complexity of the Global Fund's funding model can make it challenging for civil society actors to engage in ways that achieve results in line with community priorities. Meaningful community engagement in the design, implementation, and monitoring of Global Fund grants is essential for achieving results.

#### RESPONSE

With input from key civil society representatives, including ICASO, the Global Fund has developed several strong technical assistance programs. Through these programs, ICASO is a prequalified civil society technical assistance provider, deploying experienced consultants to work with organizations and coalitions that are seeking to engage in Global Fund-related processes. ICASO specializes in assignments related to human rights, sustainability, and the meaningful engagement of key populations. In 2018, ICASO provided technical assistance to civil society actors in six low- and middle-income countries.



A full version of the report can be downloaded here http://icaso.org/wp-content/uploads/2019/02/ICASO-TA-Overview-v5.pdf

#### RESULTS

In **Bolivia**, ICASO supported sustainability and transition processes by uniting HIV, tuberculosis and malaria activists and implementing activities in the civil society social dialogue work plan.

In **Guyana**, ICASO supported transgender communities working to identify and articulate their programmatic priorities.

In **Honduras** and **Jamaica**, ICASO was instrumental in ensuring strong baseline assessments for the Breaking Down Barriers initiative, reviewing current programs, and defining an optimal suite of interventions to take to scale. In both countries, ICASO led the convening of multi-stakeholder meetings and contributed to the development of national plans to address human rights-related barriers to accessing HIV services.

In **Malawi**, 2018 saw the fruition of efforts driven by three years of ICASO technical assistance. As documented in the December 2018 ICASO report, *No Such Accountability on the Ground,* communities credit ICASO's support with bringing about a major increase in the amount of Global Fund funding requested for key and vulnerable populations. The next step in ICASO's collaboration with the Malawian partners will be working to monitor grant implementation and ensure effective service delivery.

In **Tunisia**, ICASO contributed to the design of human rights programs proposed in Global Fund grants. This helped the country make effective use of the additional catalytic funding it was allocated to address human rights-related barriers to accessing HIV services.

#### "No Such Accountability is Available on the Ground"

A Rapid Appraisal of Community Engagement in Malawi's Global Fund Processes

rom the International Council f AIDS Service Organizations (IC, December 2018

> 'In recent years, evidence has shown Malawi to be a regional leader in fostering community

engagement

in Global Fund processes'

Executive Summary



Malawi is home to approximately 1 million people living with HIV, equating to a prevalence of 9.6% among adults age 15-49 years.



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#### CONCLUSION

In 2018, as in previous years, ICASO's technical support contributed to making Global Fund grants more efficient and effective, making national HIV responses more sustainable, and ensuring that HIV programs are informed by – and responsive to – the specific needs and priorities of communities.

## FINANCES

ICASO'S MISSION IS TO MOBILIZE AND SUPPORT DIVERSE COMMUNITY ORGANIZATIONS AND NETWORKS TO CREATE AND SUSTAIN EFFECTIVE RESPONSES TO HIV.

Statement of Financial Position As at December 31, 2018

	2018	2017
ASSETS		
CURRENT		
Cash	\$379,766	\$573,475
Short-term investments	\$980,250	\$1,415,298
Accounts receivable	\$45,783	\$23,678
Prepaid expenses and deposits	\$4,308	\$8,238
	\$1,410,107	\$2,020,689
CAPITAL ASSETS	\$5,568	\$6,470
	\$1,415,675	\$2,027,159
LIABILITIES		
Accounts payable and accrued liabilities	\$26,489	\$85,123
Funds held in trust	\$145,744	-
Deferred contributions	\$372,238	\$1,135,289
	\$544,471	\$1,220,412
NET ASSETS		
INDERTRICTER		
UNRESTRICTED	\$431,873	\$366,514
	\$431,873 \$433,763	\$366,514 \$433,763
UNRESTRICTED INTERNALLY RESTRICTED INVESTED IN CAPITAL ASSETS		
INTERNALLY RESTRICTED	\$433,763	\$433,763

#### COMMITMENTS

APPROVED ON BEHALF OF THE	BOARD
fundingly	Director
Ab Cade	Director
. )	

#### Statement of Operations Year Ended December 31, 2018

	2018	2017
REVENUES		
Grants and contributions	\$1,025,760	\$1,323,878
Foreign exchange gain	\$81,092	-
Interest	\$22,621	\$12,393
Event tickets	\$21,087	-
Other	\$10,470	\$7,646
	\$1,161,030	\$1,343,917
EXPENSES		
Salaries and benefits	\$515,499	\$464,172
Professional fees	\$276,909	\$208,579
Global, regional, and country technical support	\$104,891	\$420,966
Travel and accommodation	\$81,563	\$54,198
Travel - meetings held abroad	\$49,005	\$11,927
Occupancy	\$38,136	\$48,532
	<b>*</b>	<b>.</b>

	\$1,096,573	\$1,313,174
Foreign exchange loss	-	\$74,537
Amortization of capital assets	\$4,953	\$6,463
Office and general	\$25,617	\$23,800
Occupancy	\$38,136	\$48,532
Travel - meetings held abroad	\$49,005	\$11,927
Travel and accommodation	\$81,563	\$54,198
Global, regional, and country technical support	\$104,891	\$420,966
Professional lees	\$270,909	\$206,579

	\$1,096,573	\$1,313,174
EXCESS OF REVENUES OVER EXPENSES	\$64,457	\$30,743

## THE ICASO BOARD OF DIRECTORS 2018











**Olayide Akanni** 

Inni Jacqueline Coleman

Carlos Garcia De Leon

Marama Pala

**Tony Di Pede** 



Meena Saraswathi Seshu

**Alexander Pastoors** 

Ben Plumley



Phylesha Brown-Acton

#### Acknowledgements

None of the changes achieved by ICASO would be possible without the support of our funding partners. ICASO thanks the Bill and Melinda Gates Foundation, the International AIDS Society, International Civil Society Support, Aidsfonds, Open Society Foundations and Global Affairs Canada for their investments in communities.

The International Council of AIDS Service Organizations (ICASO) is a Canadian organization that acts as a global policy voice on HIV issues that impact diverse communities around the world. Our advocacy work champions the leadership of civil society and key populations in the effort to end AIDS. We do this through collaborative partnerships with people and organizations in all regions and various sectors, always with a view to serving and empowering communities. www.icaso.org

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