

8,500 AIDS DEATHS WORLDWIDE EVERY DAY



# VISION

To ensure longer, healthier,  
and more productive lives  
for all people living with HIV

# MISSION

To enable communities in need  
to access HIV treatment



We are proud to present ITPC's first global annual report, highlighting the many achievements and challenges of 2013, our 10<sup>th</sup> anniversary year. We are at a crossroads in the global response to HIV: better treatment is available, more people are on treatment globally and some gains have been made to address the human rights of all people, including those who are the most disenfranchised. At the same time, we see less long-term commitment by the global community to keep AIDS on the international policy agenda and we still observe mind-boggling gaps in the availability, affordability, accessibility and quality of treatment in many countries. We are still a long way off from all people everywhere in the world fully realizing their right to health.

While the rhetoric about the importance of community engagement in the HIV response continues, the reality on the ground reveals communities are still not an integral part of treatment provision. At ITPC, we know that authentic grassroots-driven responses are complex, complicated and challenging. But we also know that we need communities to hold their governments accountable; to provide peer driven services that link patients to testing, treatment and care; and to stand up for the human rights of those who are marginalised.

The real-world solutions needed to overcome the unique obstacles people living with HIV in the Global South face in accessing treatment must come from the ground up. They must be designed and executed by community activists in the field – activists who know why drugs go missing in Ukraine; why doctors keep patients waiting in The Gambia; and how intellectual property rights are raising treatment prices in Morocco. ITPC helps these activists and their organisations develop and deploy the advocacy tools they need to increase treatment access for their communities. And, after a decade of experience, ITPC is uniquely poised to lead the HIV movement forward to secure treatment for the 25.9 million people who are eligible.

This report highlights the specifics of how ITPC, as a global network, harnesses the efforts of our nine Regional Networks to increase treatment access for those in need. You'll learn how research we are spearheading is being transformed into provocative advocacy actions that are reducing drug prices, challenging corrupted practices, stamping out stigma and discrimination and, most importantly, saving lives. You'll learn how many of these accomplishments were made possible because of the significant organisational improvements we've implemented and continue to explore; including new leadership and independent registration of ITPC's Global Secretariat and Regional Networks.

We are, in fact, a true coalition – one comprised of economically, politically and culturally diverse people from across the Global South. Though the fight for access to HIV treatment is what connects us, HIV is not what defines us. Rather, we are defined by the fight we are waging – and winning – to achieve the right to health that all people need and deserve.

'Rolake Odetoynbo  
*Chair*  
ITPC Global Advisory Board

Christine Stegling  
*Executive Director*  
ITPC Global Secretariat

# OUR ROLE: A GRASSROOTS MOVEMENT FOR TREATMENT ACCESS

ITPC was born in 2003 when a group of 125 treatment activists from around the world, including 65 countries of the Global South, gathered in Cape Town, South Africa to demand a rapid and community-driven increase in access to HIV treatment for the millions in need. One decade later, ITPC continues to be comprised of engaged grassroots community members working to expand access to HIV treatment and other essential medicines globally.

ITPC is driven and led by those most impacted by the pandemic. ITPC's Regional Networks have cultivated the leadership of gay and other men who have sex with men, women, people who use drugs, sex workers, young people and other marginalised groups, many of whom also guide ITPC's global advocacy. With investment and support from ITPC, activists around the world have documented unmet needs, delivered health services and advocated for more responsive health systems.

ITPC's community advocacy remains vital in the face of today's challenges. Despite new and improved treatments that have transformed HIV infection from a near-certain death sentence to a chronic condition that can be managed, pharmaceutical shortages, or drug stock-outs, make it impossible for many to begin and maintain treatment regimens. Globally, fifty percent of people living with HIV are unaware of their HIV status; and stigma and human rights violations prevent people living with HIV from accessing quality healthcare. The treatment coverage gap is as high as 85% in the Middle East and North

**“What makes ITPC unique is that the network brings together science-informed and politically savvy, community activists around the most important issue in the HIV response – making sure that everyone living with HIV has access to treatment if they need it regardless of where they live.”**

**BEN PLUMLEY**  
GLOBAL ADVISORY BOARD MEMBER

Africa, 75% in Eastern Europe and Central Asia, 54% in Asia and the Pacific and 44% in sub-Saharan Africa.

These numbers are inexcusable, especially since treatment is available, but not accessible. In addition, the release of the 2013 World Health Organization Consolidated Guidelines on Antiretroviral Drugs for Treating and Preventing HIV Infection (WHO Guidelines) estimates 25.9 million people are now eligible for treatment. Yet implementing this “public health approach” to treatment and prevention will require radical re-thinking of how treatment is currently delivered in most countries, where even those medically in need of treatment cannot access it. The WHO Guidelines present a significant challenge and opportunity – WHO estimates as many as three million AIDS-related deaths and three and a half million new HIV infections

could be prevented between now and 2025 if the Guidelines are implemented successfully.

In the pages that follow, which detail our achievements throughout 2013, you'll learn the specifics of how ITPC's Global Secretariat and nine Regional Networks continue to build a vibrant treatment advocacy movement. You'll learn how we are implementing unique community-level research and supporting communities to transform research into national advocacy. You'll learn how we are investing deeply in the capacity building of community treatment activists through hands-on treatment education trainings. You'll learn how all of these accomplishments were made possible because of the significant organisational improvements we've implemented and continue to explore; including new leadership and the independent registration of ITPC's Global Secretariat and Regional Networks, serious efforts to address the sustainability of our work, improvements in our communications, and a frank, forward-looking organisation-wide assessment of the diverse challenges we must overcome. Most importantly, you'll learn how ITPC's efforts continue to solidify our niche as an international HIV treatment activist network.

**“Through our programming in 2013, you can see that grassroots communities are at the center of our work. ITPC is my home because the organisation stands up for the needs of the voiceless.”**

**ROSE KABERIA**  
ITPC EASTERN AFRICA REGIONAL DIRECTOR

## GLOBAL IMPACT FROM THE GROUND UP

ITPC is more than the sum of its parts: it is a global entity directed by nine Regional Networks of grassroots activists that articulate the needs of their communities. Most networks are governed by boards composed primarily of people living with and/or affected by HIV. The ITPC Global Secretariat is the hub that brings these regional networks together into a coalition of mobilised actors.

## ADDRESSING HUMAN RIGHTS BARRIERS TO ACCESSING TREATMENT

In 2013, ITPC continued to play a critical role in advancing the *Bridging the Gaps* program. Formed in 2011, Bridging the Gaps is a groundbreaking global program that aims to achieve universal access to the prevention of HIV and sexually transmitted infections and treatment, care and support for sex workers; lesbian, gay, bisexual and transgender people; and people who use drugs. The program is a partnership between five Dutch-based organisations, four global key

population networks and more than 70 grassroots organisations. As a core global network partner, ITPC continued to implement initiatives in East Africa, Eastern Europe and Central Asia, South America and South Asia designed to tackle the human rights obstacles that key populations face in accessing HIV health services. ITPC issued small grants for community-led activism, provided trainings on treatment access

issues and conducted global advocacy based on input from Bridging the Gaps partners on the ground.

Natalia Isaleva, a former sex worker and chief executive officer of the Kirovograd regional branch of LEGALIFE in Ukraine, used a small ITPC grant through Bridging the Gaps to connect her community to mobile and rapid CD4 testing, providing a cheaper and more accurate CD4 count

## 2013 IMPACT AT A GLANCE

- **72,693** people referred to health services including the prevention, care and treatment of HIV, opportunistic infections, Tuberculosis and sexually transmitted infections.
- **72,693** people referred to health services including the prevention, care and treatment of HIV; opportunistic infections; Tuberculosis; and sexually transmitted infections.
- **173** significant policy changes achieved, including the implementation of transportation concession cards for people living with HIV in Goa, West India; the commitment to secure CD4 count machines in six cities across Bangladesh; improved HIV testing and outreach for men who have sex with men by the Belize Ministry of Health; and the insertion of an article into the Administrative Code of the Republic of Moldova that prosecutes persons who violate the privacy of people living with HIV.
- **72,300** people participated in **8,586** advocacy activities including meetings with government officials, the dissemination of official advocacy letters, the organisation of advocacy rallies and the formation of new coalitions.
- **59,697** people received education to improve their knowledge on HIV transmission and prevention, antiretroviral treatment, prevention of vertical transmission, Hepatitis, treatment adherence and sexual and reproductive health and rights.
- **658,408** HIV information-related materials distributed including booklets, flyers, CDs, posters, t-shirts and videos.
- **22,910** people were counseled on social aspects of HIV treatment-related issues, including stigma and discrimination and relationship concerns.

to people living with HIV living outside of urban areas. Natalia's efforts have put LEGALIFE and other community activists in negotiations with rapid testing manufacturers, HIV service organisations, the head of the national reference laboratory and the Ministry of Health. Through LEGALIFE's lobbying efforts, Ukraine's national Clinical Antiretroviral Therapy Guidelines are now considering including this technology.

An ITPC Bridging the Gaps small grant resulted in similar success for the Uganda Harmonised Rights Alliance (UHRA). UHRA used their grant to conduct trainings for health workers on providing appropriate and rights-based care to local sex workers, which resulted in improved quality of services at the local health care facilities. UHRA also organised treatment literacy workshops for sex workers. One workshop participant, Jane, a sex worker from Kawempe, reported attending the workshop after a failed suicide attempt. She said that she didn't know where to get HIV medicine, or how to make the right food choices to maintain her health. During the workshop, she learned about friendly health workers she could contact to discuss her health needs. Since connecting with medical and peer support, Jane is no longer isolated. Jane said that this has "given her a reason to live" and that she "no longer contemplate[s] suicide."

Around the world, severe stigma and discrimination continue to impede the ability of women living with HIV to access treatment. In 2013, ITPC, in partnership with other global organisations, began investigating the current barriers that exist for women as a result of a perceived HIV diagnosis. The partnership between ITPC and the Coalition of



Organisations of Women Living with HIV in Cote d'Ivoire resulted in the publication "Experiences of Stigma and Discrimination Against Pregnant Women and Mothers Living with HIV in Cote d'Ivoire". This report, which includes anecdotal data from more than 20 women speaking openly about the issues they confront in realizing their sexual and reproductive health, provides heart-breaking proof that the indifference of healthcare workers, the self-stigma that can accompany an HIV-positive diagnosis and the isolation from confused and/or outraged family members all seriously impact HIV positive women's ability to live healthy and happy lives.

Also in 2013, ITPC developed an initiative entitled *Leadership for Life*, in partnership with the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV, that looks to remedy the lack of involvement that women living with HIV have around the decision-making that affects their health and the health of their children. This partnership resulted in

two pilot rapid situation assessments that included one-on-one interviews and focus groups involving hundreds of women (and in some cases, their partners) on how to better involve women living with HIV in health-related decision-making.

**GLOBAL AND REGIONAL ADVOCACY FOR THE RIGHT TO HEALTH**

ITPC was among the first to respond to the new WHO Guidelines issued in June 2013, releasing a press statement that we were heartened that the Guidelines were a "step-in-the-right-direction" but dismayed that they did not specify the unique role communities play in supporting access to HIV testing and linkages to treatment and care and in not demanding that governments' commitment to reducing stigma and discrimination be reflected in actual law.

In response to the Guidelines' release, ITPC developed plans in 2013 for global monitoring of the Guidelines implementation from a community perspective. In 2014, ITPC Regional Networks will conduct live monitoring of the Guidelines' implementation in over 18 countries. In each of these countries, patients, clinicians and policymakers will provide standardised and verifiable feedback. ITPC will release the results of this community-led research at the July 2014 International AIDS Conference, along with a campaign to support country-level advocacy for the Guidelines' implementation and community involvement.

Another core area of our work in 2013 was increasing knowledge among civil society, government officials and other decision-makers to catalyse

further debate about intellectual property rights and public health. Throughout 2013, ITPC has emerged as a leader uniquely positioned to tackle intellectual property issues from a community perspective, to build the capacity of community members to engage in this highly technical arena and to support national-level coalitions to pressure governments to avoid taking actions that would compromise access to essential medicines for people living with HIV.

In June 2013, Othoman Mellouk, the regional coordinator of ITPC MENA and the leader of ITPC's global advocacy for equitable trade and intellectual property policy, represented ITPC at a meeting on intellectual property and access to HIV treatment in middle-income countries that was organised by UNAIDS, UNITAID, WHO and the Brazilian government. This meeting, held in Brasilia, Brazil was both a direct outcome of ITPC's advocacy work and a milestone in achieving consensus around the impact of intellectual property barriers on access to treatment.

In November 2013, ITPC released a joint policy brief with Global Network of People Living with HIV (GNP+), the Global Forum on MSM & HIV, the International Network of People Who Use Drugs, and the Global Network of Sex Work Projects entitled "Access Challenges for HIV Treatment Among People Living with HIV and Key Populations in the Middle-Income Countries." The brief documents how access to essential medicines in middle-income countries – including improved antiretrovirals – is in jeopardy due to pricing and patent constraints, intellectual property regimes, the broader regulatory environment and lack of investment in science and technology.

ITPC also occupies an important position on the UNAIDS Programme Coordinating Board Non-Governmental Delegation, which influences UNAIDS Board decision-making. At the UNAIDS Programme Coordinating Board meeting in December 2013, ITPC and allies succeeded in securing intellectual property issues as a topic of serious discussion for the Board's meeting in June 2014, which will raise intellectual property concerns among governments and HIV decision-makers.

One of ITPC's core initiatives is the *Missing the Target* series of reports that, for the past decade, has been critical in helping community activists hold governments and global institutions accountable to their commitments to guarantee access to treatment. ITPC's Missing the Target model is unique in empowering communities affected by HIV to both understand research methodology and undertake

community-led research. This research often reveals overlooked challenges, the solutions to which are then the focus of strategic advocacy actions. To date, Missing the Target has supported communities affected by HIV in more than 30 countries to expose, document and resolve challenges to treatment access through lasting policy change. As result of the Missing the Target Cycle 10 research, community-level advocacy resulted in significant wins.

ITPC Central Africa is now recognized as a go-to source for information around treatment access on the ground. Subsequently, activists in the region are now invited more frequently to attend meetings where HIV treatment policy decisions are made and to participate in ongoing treatment debates. ITPC's Russia network, ITPCru, undertook advocacy actions that persuaded local Ministries of Health across Russia to initiate





a disheartening number of complex barriers that continue to hinder access to treatment. ITPC looks forward to reporting on the continued advocacy wins generated by Missing the Target 10 and Missing the Target 11 in the months to come.

## **BUILDING THE CAPACITY OF COMMUNITY TREATMENT ACTIVISTS**

ITPC's efforts to build the capacity of treatment activists in 2013 continued to be a collaborative process between the ITPC Global Secretariat and the Regional Networks. ITPC Global Secretariat staff and consultants continuously support the Regional Network staff through technical assistance, monitoring and evaluation, preparation for key regional and global advocacy meetings, curriculum development, development of regional boards and the administration of grantmaking, resource development and finance and human resources. One highlight of this work has been regional trainings for activists – another critical component of Bridging the Gaps – held in Anglophone Africa, Eastern Europe and Central Asia, South and Southeast Asia and Latin America. In each of these regions we also provided grants to support community-driven advocacy projects and held capacity-building workshops for grantees prior to the implementation of their funded projects. Yet another highlight of 2013, has been research trainings with our Missing the Target 11 country teams from Kenya and Uganda.

the development of a price reduction strategy for antiretrovirals that includes direct involvement of community activists.

In India, ITPC South Asia's campaign to demand phase out of the toxic antiretroviral drug stavudine (d4T) catalysed India's National AIDS Control Organisation to officially endorse, and initiate, a phase out of d4T and replacement with more optimal antiretrovirals.

Concurrent with the advocacy actions for Missing the Target 10, community-level research was conducted for the 11th report in the series, released in early 2014. Missing the Target 11 examines the challenges faced by sex workers in the Majengo district of Nairobi, Kenya and orphans

and vulnerable children affected by HIV in the Buyende District, Uganda. The research has revealed



**“With Christine, ITPC has found not only a strong proponent of community activism, but also a seasoned advocate and strategist. Under her leadership, we look forward to further expanding the key role ITPC plays in ensuring that the needs of people living with HIV remain paramount.”**

**‘ROLAKE ODETOYINBO**  
**ITPC GLOBAL ADVISORY BOARD CHAIR**

## **LEADERSHIP AND INDEPENDENT REGISTRATION**

In May 2013, the ITPC Global Advisory Board successfully concluded an extensive international search that led to the appointment of Christine Stegling as executive director of the global network. Ms. Stegling started her work in the field of HIV and human rights in the late 1990s in Botswana, initially working for the Ministry of Health, then as a lecturer at the University of Botswana, and for eight years as the executive director of the Botswana Network on Ethics, Law, and HIV/AIDS (BONELA). During her time in Botswana, Ms. Stegling was an active member of the National AIDS Council and the Botswana Country Coordinating Mechanism for the Global Fund to Fight AIDS, Tuberculosis, and Malaria. Under her

leadership BONELA became a leading HIV organisation in the country and was a founding member of the AIDS Rights Alliance of Southern Africa (ARASA). Ms. Stegling chaired the ARASA board from 2004 to 2009 and remains an active board trustee. Prior to joining ITPC, Ms. Stegling was the associate director of the HIV Best Practice Unit at the International HIV/AIDS Alliance in the United Kingdom and in this capacity served as a member of the senior management team.

Christine's appointment subsequently drew the attention of Open Society Foundations, resulting in ITPC receiving an inaugural New Executives Fund grant in 2013. The prestigious grant, which was established to provide financial assistance to nonprofits around the world that are working to promote social change, allowed Christine to hit



**“The Global Secretariat will relocate from the U.S. to South Africa and ITPC will be registered as an independent entity. The Global Secretariat will move to South Africa because of: South Africa's HIV and TB burden, with six million people living with HIV; the values enshrined in the South African Constitution and the work of ITPC’s Southern African partners; and ITPC was born in South Africa in 2003 and is coming back to the place of its birth.”**

RESOLVED BY THE GLOBAL ADVISORY BOARD, OCTOBER 2013

the ground running and to quickly put her ideas into action. Specifically, resources from this grant supported an ITPC global strategy meeting, held over a five-day period in October 2013 in Johannesburg, South Africa. The meeting brought together representatives from all nine of ITPC’s Regional Networks, the Global Secretariat, and the Global Advisory Board together to proactively address big picture questions about ITPC’s

role as a global network, as well as improving ITPC’s global advocacy and communications approaches.

Under Ms. Stegling’s leadership, one of the priorities of ITPC’s Global Secretariat is to transition away from our current fiscal sponsor, the Tides Center, and to register independently. Independent registration will help meet four organisational needs: improved structure; increased transparency and accountability to affected communities; and community ownership leading to strengthened organisational sustainability. Accordingly in 2013, ITPC’s Global Advisory Board resolved that the ITPC Global Secretariat should register in, and relocate our headquarters to, South Africa. Several reasons helped make this determination, including agreement that the future of ITPC should be both ideologically and physically rooted in the Global South and our reinvigorated partnership with ARASA, generously funded by the Robert Carr Civil Society Networks Fund.

COMMUNICATING MORE STRATEGICALLY

During 2013, ITPC reinvigorated our communications strategy to increase the role communications plays in advancing an advocacy agenda. For example, the Missing the Target 11 process of documenting treatment gaps on the ground was expanded in 2013 to include an advocacy and communications component; several regional websites were developed, such as those of ITPC Latin America which includes a mechanism through which community members can report drug stock-outs as they occur; and ITPCru developed hard-hitting videos and

cultivated their regional listserv in Russian.

At its global meeting in Johannesburg, the ITPC collective also made a number of commitments to improve external communications mechanisms, to ensure ITPC’s work is disseminated effectively and new members are engaged in the movement. ITPC’s internal communications continue to be cost-effective; in addition to hosting staff and board meetings online, ITPC began hosting monthly calls to discuss urgent treatment advocacy issues with Regional Networks and partners worldwide.

RETHINKING OUR ROLE AS A GLOBAL NETWORK

In 2013, we assessed our network’s strengths and weaknesses, and have begun implementing a series of internal changes to ensure ITPC remains relevant in the global health landscape. ITPC – like other global networks tackling structural issues – faces challenges in meaningfully measuring our impact. Change is often slow and does not occur within short time periods. However, ITPC is committed in 2014 to improving our evaluation model so we can more clearly track, monitor, and understand the impact of our work. At the same time ITPC is putting in place measures to ensure the increased financial sustainability of our Regional Networks, including through supporting them with more regional-based fundraising. In 2014, ITPC will also embark on a new strategic plan for the following three years, and this process will include critical input from a range of diverse actors from within

and outside of ITPC’s networks.

From ITPC’s reflections so far, a few things are clear. ITPC welcomes the global consensus that governments must assume ownership of their health systems and HIV responses, ensuring resources are allocated appropriately at the national level. However, many countries lack the political will to provide adequate funding for health, and mobilising adequate resources for authentic community activism is increasingly difficult, especially in an environment of decreasing resources for middle-income countries. These countries comprise a growing share of the global HIV burden, but have lower rates of antiretroviral treatment coverage compared to low-income countries. While it is estimated that 57% of people living with HIV were in middle-income countries in 2010, it is projected that 70% of people living with HIV will be in middle-income countries in 2020. The gap in treatment coverage is also expected to grow, with one analysis estimating that only 33% of eligible patients will be receiving antiretroviral treatment.

As some governments anticipate increasing HIV treatment for millions of people in the context of preventing new infections, continued inequity gaps emerge in each country and for specific communities. At the same time, other countries continue to violate the human rights of people living with or affected by HIV through laws and policies that impede the HIV response and make treatment scale-up impossible. It is in this context that ITPC continues to play a crucial role to enable all communities to demand full realisation of the right to

health. This can only be done through strengthening local coalitions to address gaps at the national level, and through leveraging cross-regional collaborations to tackle the systemic barriers preventing access.

While HIV treatment remains our focus, ITPC recognizes it cannot be addressed in isolation. Twelve years after the World Trade Organisation’s “Doha Declaration on the Trade-Related Intellectual Property Rights Agreement and Public Health” – which allowed countries to ignore patent protections and issue compulsory licenses to ensure lifesaving medications reach people in need – few countries have utilized these flexibilities. Free trade agreements on the horizon may further hinder the ability of people living with HIV to access affordable drugs. Moving forward, ITPC will seek innovative collaborations to ensure communities mobilize around access to all essential medicines – such as new Hepatitis C drugs that are entering the market at exorbitant prices. Only through addressing intellectual property barriers within a broader, more inclusive coalition can we realize a world where all people have access to the medicines they need.

**“There is no other HIV organisation that occupies decision-making positions at the global level, the regional level, and the country level like ITPC.”**

JOHN ROCK  
GLOBAL ADVISORY BOARD MEMBER

ITPC REGIONAL NETWORKS

ITPC’s Regional Networks, originally conceived to oversee community-driven grantmaking, have now grown to also assume leadership and advocacy roles, putting community members at the same decision-making table with HIV treatment policy makers. In the pages that follow, you will read about real-world advances – achieved in 2013 through nurturing community activism with more than 30 active grantees, using grants totaling \$635,000 – that include increasing access to life-saving HIV treatment, game-changing policy initiatives and international-level negotiations that have transformed HIV treatment policy.

- ITPC CARIBBEAN
- ITPC LATIN AMERICA
- ITPC MIDDLE EAST-NORTH AFRICA
- ITPC WEST AFRICA
- ITPC CENTRAL AFRICA
- ITPC EASTERN AFRICA
- ITPCRU
- ITPC CHINA
- ITPC SOUTH ASIA

On the following pages...



**ITPC CARIBBEAN'S efforts throughout 2013 resulted in significant growth of the organisation's influence at the community and international levels. In 2013, ITPC funded five organisations that successfully connected nearly 4,000 men and women to services that include prevention, care and treatment for HIV, sexually transmitted diseases and opportunistic infections. Additionally, ITPC Caribbean has mobilized more than 1,200 people for targeted advocacy group work. In addition to supporting local grassroots organisations to connect people living with HIV to treatment, ITPC Caribbean worked to address the structural barriers impeding treatment access, achieving several specific wins in 2013:**

ITPC Caribbean hosted a meeting in the Dominican Republic that resulted in a coalition of seven organisations united in an effort to revise the existing "Law on HIV and AIDS." The coalition, led by ITPC Caribbean, submitted an injunction to modify articles in the national law that criminalise HIV transmission. ITPC Caribbean presented at the 33rd

UNAIDS Programme Coordinating Board meeting, where they delivered an intervention on the treatment gaps for adolescents living with HIV, as well as the potential impact of Free Trade Agreements on access to medicines. As a result of this advocacy, the board adopted a decision-point to "ensure that national programs effectively address the barriers to HIV testing and treatment faced by children and adolescents."

ITPC Caribbean regional coordinator, Carlo Oliveras, became the steering committee chair of the HIV Young Leaders Fund – a resource mechanism modeled on ITPC's signature community-driven

approach to grantmaking and advocacy – that is both led by, and designed to engage, youth affected by HIV. Carlo's leadership of the Fund will help ensure new voices enter the treatment advocacy movement, as well as strengthen ITPC's ability to respond to the needs of young people living with HIV.

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## ITPC CARIBBEAN IN BRIEF

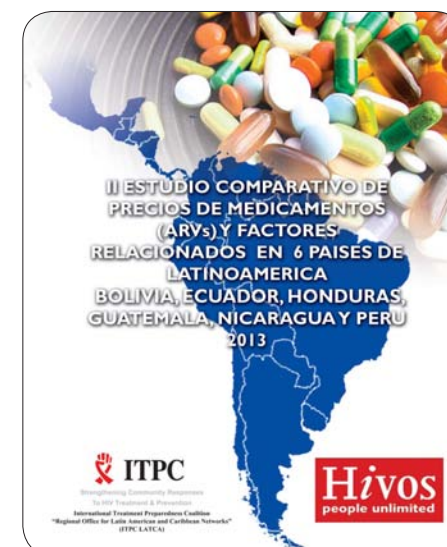
ITPC Caribbean is a coalition of activists that hail from countries that include Antigua/Barbuda, Aruba, Bahamas, Belize, Dominica, Dominican Republic, Grenada, Guyana, Haiti, Jamaica, Puerto Rico, St. Lucia, Suriname and Trinidad & Tobago. Since 2005, ITPC Caribbean has distributed more than \$1.1 million in grants to 86 community-based organisations. ITPC Caribbean's main goal is to increase access to HIV treatment, particularly among marginalised communities, and has been successful in drawing attention to the unique treatment needs affecting adolescents and young people living with HIV. ITPC Caribbean is part of the fiscal and administrative hub, ITPC Latin America and the Caribbean, and is headquartered in Guatemala City, Guatemala.

**ITPC LATIN AMERICA'S strategy unites regional, national and local networks of HIV activists to collaborate, give consensus and generate synergy across activist movements. In 2013, ITPC Latin America funded four organisations that successfully connected 1,238 men and women to services like counseling and treatment for HIV and opportunistic infections. In addition:**

ITPC Latin America developed an important tool in the "Study of Prices of ARVs and Factors Related to Six Latin American Countries: Bolivia, Ecuador, Honduras, Guatemala, Nicaragua, and Peru". This study transformed data into real advocacy actions that have ignited ongoing community mobilization to guarantee access to HIV treatment.

ITPC Latin America mobilised more than 50,000 people for advocacy activities. ITPC Latin America's advocacy helped secure an increase of the annual national HIV budget from \$40 million to \$98 million in Guatemala.

ITPC Latin America activists successfully called for the addition of third-line



## ITPC LATIN AMERICA IN BRIEF

ITPC latin america is a coalition of activists currently operating in Argentina, Bolivia, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru, Uruguay and Venezuela. Since 2005, ITPC Latin America has distributed more than \$1.1 million to 89 organisations. Their efforts focus on guaranteeing access to quality HIV treatment. In the past year, ITPC Latin America has prioritized sustaining the financial resources required to meet the needs of communities impacted by HIV and training activists to overcome the barriers posed by pharmaceutical patents. ITPC Latin America is part of the fiscal and administrative hub, ITPC Latin America and the Caribbean, and is headquartered in Guatemala City, Guatemala.

treatment into the new treatment guidelines of some countries in the region. Without third-line treatment, people living with HIV who experienced treatment failure had no other options. New antiretrovirals like darunavir, etravirine, raltegravir, saquinavir and atazanavir have now been made available as part of third-line antiretroviral treatment regimens. ITPC Latin America also advocated for the implementation of the 2013 World Health

Organisation Consolidated Guidelines on Antiretroviral Drugs for Treating and Preventing HIV Infection.

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**I**N 2013, ITPC MENA focused on regional and international advocacy. Activists participated in critical global consultations and conferences as well as at the board meetings of key global health institutions like the Global Fund to Fight AIDS, Tuberculosis, and Malaria, UNAIDS and UNITAID. Specifically, in 2013:

ITPC MENA hosted a five-day training for ten judges from Morocco and Tunisia on intellectual property rights and public health. In order to familiarize participants with the dynamics of the issue, the course used real-world scenarios from the community to shed light on the regional pharmaceutical sector as well as certain trends and practices. The training greatly enhanced the participants' ability to use the public health-related aspects of intellectual property rights flexibilities in the interpretation and application of their own national laws towards local generic pharmaceutical production and

## ITPC MENA IN BRIEF

ITPC Middle East and North Africa (MENA) is headquartered in Marrakech, Morocco and is the only network in the region of people living with HIV and allies focused on treatment. Community activists host capacity-building workshops and online webinars, adapt and translate treatment information and produce HIV-related publications. The network documents critical issues in a region – which includes Algeria, Egypt, Lebanon, Libya, Mauritania, Morocco, Tunisia and will extend to Jordan, Lebanon, Sudan, and Yemen in 2014 – where the majority of people in need of treatment do not receive it. Community-level data collection helps ITPC MENA track the progress of treatment delivery and identify treatment access barriers, which they then disseminate through reports and video testimonies.

to promote access to medicines in their countries.

ITPC MENA published the first comprehensive manual on antiretroviral treatment in an Arabic language. The groundbreaking manual fills an enormous void in resources on the treatment of people living with HIV in the region. It contains up-to-date information, including the new 2013 World Health Organisation Consolidated Guidelines on Antiretroviral Drugs for Treating and Preventing HIV Infection.

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**ITPC West Africa's efforts throughout 2013 were focused primarily on the elimination of HIV vertical transmission. Specifically, the Regional Network supported a new coalition of women living with HIV that resulted in extensive community discussions around International Women's Day, community research around the stigma and discrimination women experience and a pilot project that aimed to strengthen the leadership of women living with HIV. Additionally, in 2013, ITPC West Africa achieved:**

ITPC West Africa hosted, as part of the Leadership for Life initiative, a rapid situation assessment in Kenya and Cote d'Ivoire. The assessment revealed challenges specific to women's access to HIV treatment and explored ways in which to support their development and leadership. It was concluded that community involvement regarding the prevention of vertical transmission should be combined with efforts to improve service delivery within health infrastructures. As a result, advocacy work

## ITPC WEST AFRICA IN BRIEF

ITPC West Africa focuses on countries that include Benin, Burkina Faso, The Gambia, Guinea Bissau, Guinea Conakry, Cote d'Ivoire, Liberia, Mali, Niger, Nigeria, Senegal, Sierra Leone and Togo. A strong coalition of activists that span the region, ITPC West Africa primarily addresses issues of treatment access and stigma and discrimination, while simultaneously building the leadership of women and young people living with HIV, enabling them to participate in decisions that affect them. Since its inception, ITPC West Africa has distributed nearly \$700,000 to 74 organisations. Those grants have successfully connected 9,429 men and women to services like counseling and treatment for HIV, opportunistic infections and the prevention of vertical transmission. Additionally, ITPC West Africa has mobilised more than 4,900 people for advocacy activities. ITPC West Africa is headquartered in Abidjan, Cote d'Ivoire.

was taken up by community members to join national technical working groups on the prevention of vertical transmission. ITPC West Africa was a strong presence at the International Conference on AIDS and Sexually Transmitted Infections in Africa in Cape Town, South Africa in December 2013. A booth, hosted by ITPC West Africa, featured the message: Community Involvement in Implementing New Antiretroviral Guidelines: End Stigma Now!, which was derived from previous civil society campaigns. The booth

created a forum for discussion among key stakeholders from the WHO, UNICEF and the International HIV/AIDS Alliance.

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**2013 was a banner year for ITPC Central Africa, witnessing numerous steps toward creating a replicable model of HIV treatment access advocacy across the region that addresses issues of pharmaceutical stock-outs, health funding and the accountability of healthcare providers. In 2013:**

ITPC Central Africa, through intense advocacy actions, convinced the Permanent Secretary of the National AIDS Control Committee and the Minister of Public Health in Cameroon to recognize the escalating problem of stock-outs of critical HIV medication.

ITPC Central Africa, after lengthy efforts by local activists, persuaded the President of the Republic of Cameroon to add an additional \$10 million to the amount of domestic health funding earmarked for the purchase of antiretroviral treatments. ITPC Central Africa, with the assistance of legal counsel, mobilised community

members in Cameroon to identify two healthcare providers engaged in subpar behavior that included absenteeism and outright discrimination against people living with HIV. As a result of that mobilisation, the two healthcare providers were replaced with two far more qualified staff members appropriately concerned with the well-being of their patients. ITPC Central Africa mobilised community members in the Democratic Republic of Congo in order to include the priorities

of people living with HIV in the country concept note submitted to the Global Fund to Fight AIDS, Tuberculosis and Malaria.

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## ITPC CENTRAL AFRICA IN BRIEF

ITPC Central Africa distributed its first grants in 2005 and has, since that time, distributed nearly \$600,000 to 64 organisations in countries that include Burundi, Cameroon, Central African Republic, Chad, Democratic Republic of Congo, Gabon, Republic of the Congo, Rwanda and Sao Tome & Principe. The work of these grantees, which has connected 8,448 men and women to services like up-to-date HIV treatment information and counseling for opportunistic infections and sexually transmitted diseases, has transformed the community response to the epidemic in this region. Additionally, ITPC Central Africa has mobilised nearly 1,100 people for targeted advocacy activities. ITPC Central Africa is independently registered and headquartered in Messa, Cameroon.

**In 2013, ITPC Eastern Africa was instrumental in continuing the ongoing fight for access to optimal HIV treatment throughout the region through advocating for the improvement of national healthcare policy. Through their highly successful efforts, people living with HIV have a growing voice at the policy-making table at all levels of government. In 2013:**

ITPC Eastern Africa continued to be a key member of the Coalition on Access to Medicines – which has worked to amend the articles currently in the Kenya Anti-Counterfeit Act that threaten to block access to generic medicines production. The coalition launched its campaign by releasing a five-chapter position paper outlining its proposals and a call to action so that community members continue to push for adoption of the amendments. ITPC Eastern Africa litigated, and continues to litigate, along with a number of other stakeholders, to clarify a recent ruling by a magistrate that the government must include members of communities impacted by HIV in the critical Economic Partnership Agreement with the European Union. This inclusion is essential to

## ITPC EASTERN AFRICA IN BRIEF

ITPC Eastern Africa is a powerful presence in Djibouti, Ethiopia, Kenya, South Sudan, Tanzania (including Zanzibar) and Uganda. Since 2005, ITPC has distributed more than \$1 million in grants to 86 organisations. In 2013, ITPC Eastern Africa funded seven organisations that successfully connected 16,500 men and women to services like counseling and treatment for HIV, Tuberculosis and reproductive health. ITPC Eastern Africa also mobilised nearly 8,500 people for advocacy work.

ITPC Eastern Africa was independently registered in 2008 and is headquartered in Nairobi, Kenya. ITPC Eastern Africa provides financial support through small grants, capacity building through grantee training workshops and technical assistance on project implementation through hands-on site visits. As a result, many of these organisations have grown from loosely affiliated groups of people living with HIV to independently registered non-governmental organisations conducting their own grantmaking, research and advocacy.

ensuring the interests of people living with HIV are appropriately represented in such forums and that policy outcomes take their needs into account.

ITPC Eastern Africa under Missing the Target 11 provided training, mentoring and financial support to community-based organisations to conduct community-based research on barriers to HIV treatment faced by sex workers in the Majengo slum in Nairobi, Kenya; and by orphans and vulnerable children in the Buyende District of Uganda. As a result,

ITPC Eastern Africa documented frequent shortages and stock-outs of drugs and supplies; stigma and discrimination from healthcare providers towards sex workers; and lack of youth-friendly treatment services.

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**2013 was an extraordinary year that saw numerous accomplishments in the effort to achieve systemic changes in HIV treatment and care in Russia. All of these wins were, and/or will be shortly, realised entirely by the advocacy efforts of ITPCru and partner organisations. For example, in 2013:**

ITPCru designed and implemented a nation-wide system that gathers real-time data via the monitoring of drug procurement and provision and then translates that data into immediate advocacy actions addressing drug stock-outs, disrupted tenders and exorbitantly high prices. These actions have stifled potential corruption and, over time, will hopefully move Russian policy-makers to commit to centralised and simplified HIV treatment for all in need. One notable success was a local campaign in Khakassia, where there was an antiretroviral treatment shortage in November 2013 leaving 30 people without

## ITPCRU IN BRIEF

ITPCru, headquartered in St. Petersburg, Russia, unites HIV activists and organisations in the region towards a comprehensive treatment access agenda. ITPCru provides critical information platforms that are the main source of real-time information on HIV treatment, including a listserv with more than 1,100 subscribers and a popular YouTube channel with videos viewed more than 72,000 times. ITPCru also runs grassroots advocacy campaigns in several countries. ITPCru distributed its first grants in 2003 and was formally established in 2005. Since 2003, ITPCru has distributed more than \$1.4 million in funds to 107 grantees in countries including Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Moldova, Russia, Tajikistan, Ukraine and Uzbekistan. The efforts of these grantees, which have connected 3,681 men and women to services like care for the prevention of vertical transmission, HIV counseling and HIV treatment information, cannot be overstated. Additionally, ITPCru has mobilised nearly 200 people for advocacy work.

medicine. ITPCru began a campaign to address this shortage, including sending a petition letter to the government, and as a result, those in need started to receive medicines.

As recognized experts on HIV treatment, ITPCru, along with other civil society groups, was invited by government ministries to contribute chapters on

medications, stock-outs and other key issues to the National HIV Response Strategy. When finalised, the strategy will be considered in Parliament as the basis of the next National HIV Response. ITPCru's recommendations include universal antiretroviral treatment, stock-out prevention, and a focus on vulnerable groups that until now have gone unaddressed.

ITPCru helped achieve significant price reductions – as a result of sophisticated comparative monitoring of the cost of medications in various regions combined with strategic advocacy – of important drugs, like the six-fold price reduction of lamivudine/zidovudine and Hepatitis C therapies in St. Petersburg as well as other reductions elsewhere in the Russian Federation.

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**Throughout 2013, despite ITPC China's invaluable influence on new national treatment guidelines, system-wide change has been slow. For example, the new guidelines require the much-needed phasing out of the toxic medication, d4T. Regrettably, but understandably, many treatment disbursement sites have been reluctant to change patient regimens, due to a lack of training and the existence of an enormous remaining stockpile of the drug. To address this critical issue, in 2013:**

ITPC China advocacy activities directly resulted in only 2% of the entire drug procurement order for 2014 being comprised of d4T, a drastic decrease and an enormous victory. ITPC China activists are partnering with patients to advocate, individually and collectively, with healthcare providers on improving their treatment regimens. One of the notable results of this advocacy is in Yangjiang City of Guangdong Province, where ITPC China achieved a decline from roughly 30% to 3% in usage of d4T over a six-month period.

ITPC China supported a lawsuit, the threat of which successfully motivated healthcare providers to disregard – and in one case even return – some of the large quantities of d4T that remain in the country. ITPC China organised an action day on July 28th, World Hepatitis Day. Community-based organisations in Henan, Guangxi, Guangdong and Yunnan provinces collaborated with local infectious disease hospitals to run a free Hepatitis C testing and counseling day. As a result, hundreds

of people received counseling and testing. In Guangdong, after the action, there were three times as many people actively enrolled in treatment than in 2012.

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## ITPC CHINA IN BRIEF

ITPC China, headquartered in Guangzhou, has been a leading voice in the fight for antiretroviral treatment in China. Efforts by community activists were instrumental in steering the national treatment guidelines revision process to more closely reflect the new World Health Organisation's Consolidated Guidelines on the use of Antiretroviral Drugs for Treating and Preventing HIV Infection. ITPC China's close partner and fiscal sponsor is AIDS Care China. Since 2005, ITPC China has distributed more than \$1.1 million in funds to 137 grantee organisations. During the most recent grant cycle, which concluded in 2013, ITPC China supported 13 grantees through its small grants programme designed to support ARV optimisation advocacy and Hepatitis C awareness building. As a result of the grantees' collective work under this grantmaking cycle alone, 14,280 people living with HIV were served; 7,328 people received screening for, and 940 were diagnosed with, Hepatitis C; 186 people were referred to treatment; and 419 women living with HIV received cervical cancer screening.

**In the fight for equitable and optimal access to HIV treatment for everyone in need, ITPC South Asia made significant strides in clearing the path for generic pharmaceutical production in India, eliminating drug stock-outs, and securing the human rights of people living with HIV. In 2013:**

ITPC South Asia has mobilised nearly 2,500 people for targeted advocacy activities. ITPC South Asia organised widely-attended street protests in Delhi to voice opposition to the signing of the India-European Union Free Trade Agreement. As a result, the signing of that agreement has been delayed. With India serving as the pharmaceutical provider to much of the developing world, the agreement could potentially affect more than 80% of the antiretroviral treatment currently procured from Indian generic pharmaceutical companies. ITPC South Asia responded throughout the year to drug and diagnostic stock-outs by reporting the issues to the National AIDS Control Organisation and others. ITPC South Asia also organised a strategy meeting of civil society in 2013 to discuss



how to respond to stock-outs in a more systematic and coordinated way. ITPC South Asia revitalized efforts to pass the “The HIV AND AIDS (Prevention and Control) Bill” that had stagnated in the Indian parliament since 2006 and aims to protect the rights of people living with HIV. In partnership with DNP+, ITPC South Asia organised a protest in support of the bill and is now sensitising members of parliament on the need for the bill.

ITPC South Asia participated in the Bridging the Gaps program – an innovative partnership to address the health needs of key affected populations. Under this program, ITPC South Asia funded 14 community groups in Indonesia, Nepal, Pakistan, and Vietnam to enhance HIV treatment knowledge, collect treatment-access data and advocate for meaningful HIV policy improvements for key populations.

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TPC’s inaugural annual report represents a significant step towards further financial accountability to the communities that we serve and to the donors who make our work possible. At ITPC, a little bit goes a long way; and the achievements that you have read about are all the more extraordinary given the relatively modest financial means available to support them. In an era where sources of funding for community-driven HIV programming are limited, ITPC’s donors remain committed to our mission.

ITPC’s Global Secretariat has not yet registered independently. Instead, we have operated as a project of the Tides Center, a U.S.-based nonprofit organization that acts as our fiscal sponsor and recipient of grant funding. We expect to continue this arrangement in the interim period until our registration in South Africa, after which we will establish ITPC independently.

The Global Advisory Board’s decision to take this step reflects our commitment to increase our financial transparency, accountability and efficiency. After this has been accomplished, ITPC will undergo independent audits and make the results publicly available. In the interim period, ITPC’s finances are treated for accounting purposes as part of Tides. During the fiscal year ending December 31, 2013, ITPC’s program expenses constituted 71% of our total organisational budget; and 55% was invested directly in grassroots groups and regional networks of HIV treatment activists.

The generous donors listed below contributed ITPC’s revenue during this period. We treasure financial participation at all levels, and in this annual report we gratefully acknowledge the supporters whose financial gifts and commitments – of which the smallest was \$50 and the largest was a pledge of more than \$1.7 million over two years – made our work in 2013 possible.

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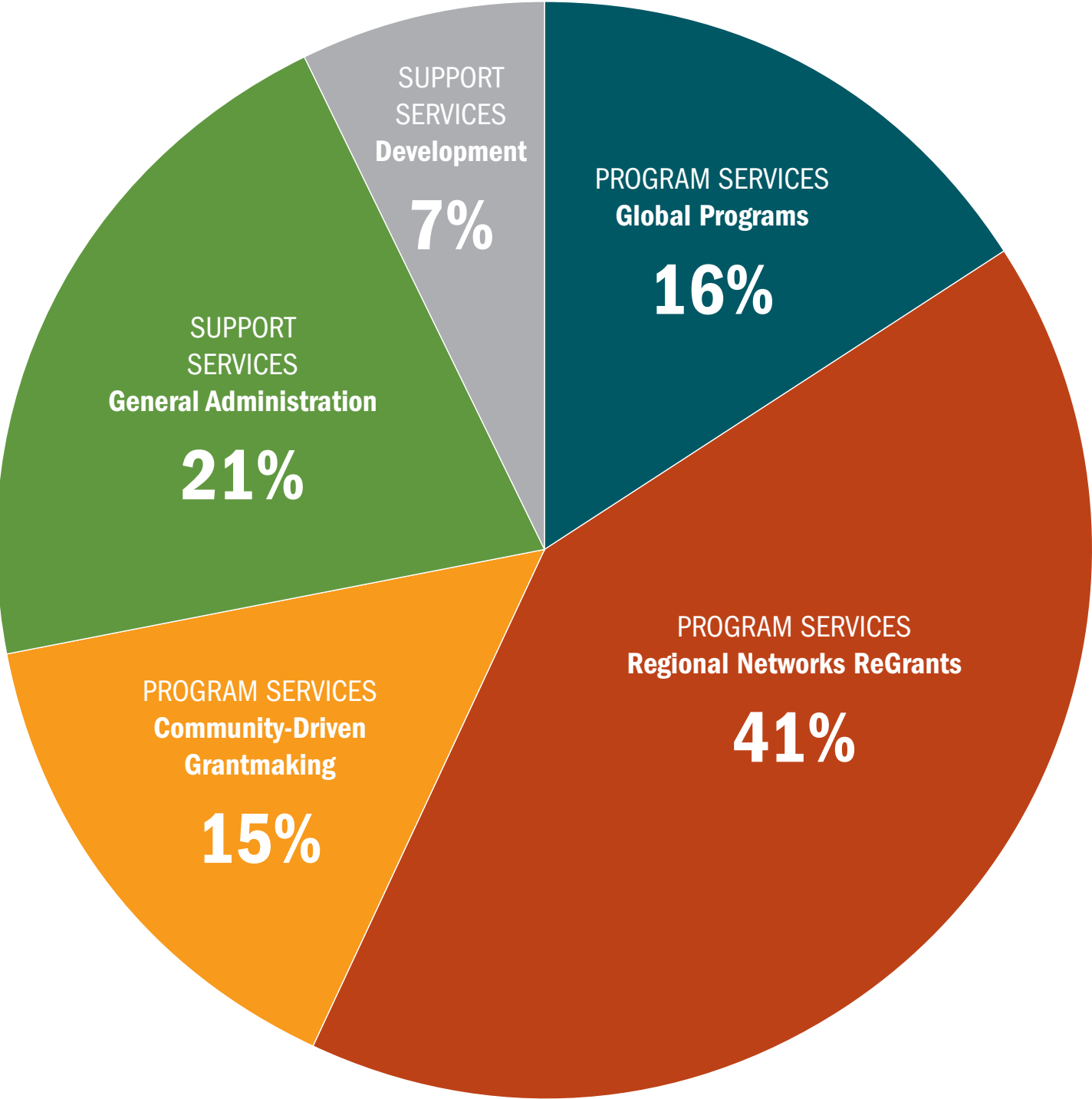
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## ITPC SOUTH ASIA IN BRIEF

Grantmaking by ITPC South Asia and the DNP+ has supported grassroots groups responding to HIV in Bangladesh, India, Nepal, Pakistan and Sri Lanka. Since 2005, nearly \$850,000 has been distributed to more than 78 organisations in the region. ITPC South Asia, long a leader in advocating for the treatment rights of people living with HIV, is fiscally sponsored by our regional partner the Delhi Network of Positive People (DNP+) and is headquartered in Delhi, India. The Delhi Network was recently honored with the prestigious UNAIDS Red Ribbon Award in the category of Advocacy and Human Rights.

Investments were made in the work of two grantees in Pakistan and Nepal. Together, they connected 7,198 men and women to life-changing services like counseling and treatment for HIV, opportunistic infections and Tuberculosis.

2013 EXPENSES \$2,430,943



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