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on Women and AIDS**



Salamander Trust
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Women in Europe and Central Asia Regions

Launch of the Young Women's Leadership Initiative at the 6th IAS HIV Pathogenesis, Treatment and Prevention Conference

Rome 17-20 July 2011

GCWA, ATHENA, Salamander Trust, WeCare+

Report

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Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
CSO	Civil Society Organization
GCWA	Global Coalition on Women and AIDS
HIV	Human Immunodeficiency Virus
IAS	International AIDS Society
ICASA	International Conference on AIDS and STIs in Africa
MDG	Millennium Development Goal
MMC	Medical Male Circumcision for HIV Prevention
NPT	New Prevention Technologies
PrEP	Pre Exposure Prophylaxis
SRHR	Sexual and Reproductive Health and Rights
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	UN General Assembly Special Session on HIV/AIDS
WNZ	Women's Networking Zone

Executive summary

In every region of the world, incidence of HIV among women, especially young women, is increasing. The 2011 Political Declaration on HIV/AIDS acknowledges that women are disproportionately affected by HIV in the global context and must be given priority in the response. According to a report by UNAIDS¹, “Securing the future today”, young women account for 64% of new HIV cases of among young people ages 15 to 24 worldwide. In the most affected countries, three young women are infected for every young man.

Although it is widely known that women are disproportionately affected by HIV, their needs are often under-recognized and their voices under-represented as research and action agendas are created in the HIV response. This is especially true of young women, who have unique social and health aspirations and needs, but who are rarely invited to the scientific and policy arenas. In light of this, the Global Coalition on Women and AIDS (GCWA) and the ATHENA Network created a Young Women’s Leadership Initiative. The Initiative was launched in July of 2011 in concert with the 6th International AIDS Society 2011 HIV Pathogenesis, Treatment and Prevention Conference in Rome.

The overarching goals of the Young Women’s Leadership Initiative are to:

- Develop the leadership of young women around HIV, women’s rights and gender equality to strengthen advocacy at the local, national, regional and global levels
- Increase the visibility and advocacy of young women, particularly enabling young women living with HIV to lead and participate in country level advocacy on policies and practices that impact and impair their quality of life, including in relation to gender-based violence and sexual and reproductive health and rights

The objectives of the launch of the Young Women’s Leadership Initiative at the 2011 IAS Conference in Rome were to:

- Expose participating young women to the scientific research agenda and strengthen their knowledge, awareness, and ability to engage with this agenda/forum
- Provide opportunities for engagement with and mentorship between young women and more experienced women leaders
- Provide opportunities for building a community of practice and the development of a shared long term agenda, including action plans for ICASA 2011 and related forums such as the upcoming International AIDS Conference 2012

GCWA and the ATHENA Network, in collaboration with a broad consortium of partners including the World AIDS Campaign, Salamander Trust, WECARE+ and ICW Global, supported the launch of the Young Women’s Leadership Initiative by leading a delegation of young women to participate in the International AIDS Society’s 2011 6th HIV Pathogenesis, Treatment and Prevention (IAS) Conference².

¹ UNAIDS July 2011. Securing the future today: *Synthesis of strategic information on HIV and young people*

² The Young Women’s Leadership Initiative has a global scope, and the delegation included women from around the world, however with a particular emphasis on Eastern Europe due to the location of the conference; young women were supported to come to Rome from: Argentina, Armenia, Estonia, Ethiopia, India, Namibia, Russia, Romania, South Africa, Southern Sudan, Tajikistan, UK, Ukraine, and

The presence of the Young Women’s Leadership Initiative delegation at the IAS Conference was the first of a continuum of international skills-building and advocacy activities designed to strengthen the engagement, capacity and skills of young women, including some young women living with HIV, in the HIV response.

It has to be said, also, that none of this would have been possible without the active work of local or national groups supporting the many issues faced by women with HIV in several of the countries from which the young women travelled. These local organizations have done so much, often with very limited funding, to support the young women to get to this point of the journey. It is important therefore to highlight here the role of these organisations and to ensure that this critical work is also acknowledged and adequately funded.

As the first activity of the Young Women’s Leadership Initiative, the IAS Conference provided the opportunity for the delegation of young women to develop a salient understanding of the HIV prevention landscape, the advances of new prevention technology (NPT) and to make the correlation between bio-medical research and sexual and reproductive health and rights (SRHR). Each day, there was a series of coordinated activities including group debriefings, skills-building sessions in the Women’s Networking Zone (WNZ), individual peer mentorship and shadowing with research advocates living with HIV and “Meet the Expert” informal dialogues in the WNZ. This concerted development time helped the young women to digest the complex research data, develop their understanding of HIV prevention research, pose critical questions to the researcher community on gender in prevention and construct key messages around women, research, sexual and reproductive health, and gender-sensitive budgeting to promote in their level regional and country-level advocacy.

The delegation of young women that participated in the inaugural delegation of the Young Women’s Leadership Initiative at the IAS Conference in Rome emerged with:

- Enhanced knowledge of current research and advocacy affecting women living with HIV across the globe
- Increased understanding of leadership that is participatory, transformational, and gender sensitive
- New working relations with each other and with more experienced women working for women’s rights and gender equity in the HIV response
- Collaborative activities for group sustainability and outreach to local constituencies through the use of social networking media and other mechanisms
- Joint plans for further action to organize toward ICASA 2011 (Addis Ababa) and the 2012 International AIDS Conference (Washington, D.C.)

Zimbabwe. Young women from Jamaica, Nigeria, Nepal, Uganda and the USA were invited, but unable to attend due to competing commitments or visa issues.

Launch of the Young Women's Leadership Initiative at the 6th IAS HIV Pathogenesis, Treatment and Prevention Conference

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1. Introduction

The Young Women's Leadership Initiative builds on the principles which underpinned the "In Women's Words" Action Agenda of the 2011 High Level Meeting on AIDS (HLM). "In Women's Words" was a key advocacy tool and process which resulted from a virtual consultation led by the GCWA and the ATHENA Network in preparation for the 2011 High Level Meeting on AIDS³. It was defined by 5 principles:

- 1) Inclusion of women and girls in decision-making, including the **democratization of global processes**;
- 2) Importance of women, girls, and **gender equality**;
- 3) Centrality of **women's rights** to the success of the AIDS response; and,
- 4) Political opportunity to **define actions and address women, girls, and gender equality in the context of HIV and AIDS**;
- 5) Urgency of all the **Millennium Development Goals** to the well-being of all women and girls.

The Virtual Consultation and *In Women's Words* Action Agenda presented 5 priority items, which serve as the foundation for the Young Women's Leadership Initiative and expanded and Universal Access for women and girls globally:

- 1) ***Ensure comprehensive and inclusive HIV services that address the visions, life-long needs, and rights of women and girls in all our diversity.***
- 2) ***Eliminate stigma and discrimination, and ensure full protection of the human rights of all women and girls, including our sexual and reproductive rights.***
- 3) ***Strengthen, invest in, and champion our leadership and equality, to ensure the full and meaningful participation of women and girls, in particular those of us living with and affected by HIV, in the HIV response.***
- 4) ***Empower us to be catalysts of social justice and positive change, and eliminate all forms of violence against us.***
- 5) ***Ensure full access to information and education, including comprehensive sexuality education for all women and girls.***

³ UNAIDS, The Global Coalition on Women and AIDS, ATHENA Network, and UN Women, July 2011, *In Women's Words: HIV Priorities for Positive Change*, <http://www.unaids.org/en/resources/presscentre/featurestories/2011/june/20110607fwomanun/>

2. Goals and Objectives of the Young Women's Leadership Initiative

The overarching goals of the Young Women's Leadership Initiative are to:

- Develop the leadership of young women around HIV, women's rights and gender equality to strengthen advocacy at the local, national, regional and global levels
- Increase the visibility and advocacy of young women, enabling them all, including those young women in the group who are living with HIV, to lead and participate in country level advocacy on policies and practices that impact and impair their quality of life, including in relation to gender-based violence and sexual and reproductive health and rights

2.1 Specific objectives and activities undertaken:

- Expose participating young women to the scientific research agenda and strengthen their knowledge, awareness, and ability to engage with this agenda/forum. Key activities included:
 - ✓ Attendance of daily conference plenary sessions, followed by debrief and group discussion of issues raised;
 - ✓ Involvement in Satellite "Prevention Technologies – Gender and GIPA – Complement or Collision" convened by GCWA, Salamander Trust, ATHENA Network, ICW Global, Positive Women's Network, WECARE+, and NPS Italia;
 - ✓ Involvement in Town Hall session "Achieving Sexual and Reproductive Health and Rights for Women and Girls through the HIV Response", convened by GCWA, Salamander Trust, ATHENA Network, ICW Global, Positive Women's Network, WECARE+, and NPS Italia;
 - ✓ Participation and input into six critical dialogues held in the Women's Networking Zone booth addressing issues of: treatment access for all women; treatment as prevention; vertical transmission and sexual and reproductive health and rights; violence against women; harmful legal practices; and, involvement of women on the research agenda;
 - ✓ Participation in press conference and rally "Where the hell is the gel?"
- Provide opportunities for engagement with and mentorship between young women and more experienced women leaders
 - ✓ Pre-conference briefing session led by Louise Binder of ICW Global on 'How to Approach an International AIDS Society conference'
 - ✓ Allocation of dedicated 'Guardian Angels', drawn from more experienced women activists attending the conference, to each of the young women for support and guidance as needed;
 - ✓ Opportunities to work one-to-one with more experienced women activists to input into Critical Dialogue discussions;
 - ✓ 'Womanizing the booth' – all members of the team were scheduled to be in attendance at the booth for a period of three hours, in addition to ongoing participation at the booth. This provided opportunities for engagement with

- other members of the team and conference participants, as well as to share the work of their respective organizations and networks;
 - ✓ 2 networking dinners were arranged by WECARe+ to foster engagement between the young women and a larger delegation of other women activists from among the various organizations and networks attending the conference;* Participation and input into WECARe+ meeting. Some of the young women from the UK did a formal PowerPoint presentation in front of 50 advocates from 12 European countries in order to share good practice of working with young women through a peer lead model
- Provide opportunities for building a community of practice and the development of a shared long term agenda, including action plans for ICASA 2011 and related forums such as the upcoming International AIDS Conference 2012
 - ✓ End of conference de-brief, to review, evaluate and assess the young women's experience
 - ✓ Participation of some of the young women in an AIDS 2012 strategising meeting convened by ATHENA, the Global Coalition on Women and AIDS, and ICW Global
 - ✓ Introduction of young women to Francoise Barre Sinoussi, in-coming President of the IAS, at the WNZ booth
 - ✓ Establishment of an email group and Facebook page for continued discussion and engagement

3. Key Areas of Engagement at the 6th IAS Pathogenesis Conference

3.1 Satellite session: "Prevention technologies: Gender and GIPA - Complement or Collision?"

A satellite session entitled "*Prevention technologies: Gender and GIPA - Complement or Collision?*" was organised by GCWA, ATHENA Network, WECARe+ and Salamander Trust. It examined the HIV prevention agenda with a focus on women, particularly women living with HIV, in the context of new prevention technologies. The session addressed issues including the intersections between HIV New Prevention Technologies (NPT's), social action and political momentum to increase the health, human rights and sexual and reproductive health for women and girls beyond the context of HIV. It also highlighted the development and human impact on NPT's, such as: microbicides, MMC, PrEP, Treatment as Prevention, an increased demand for and availability of the female condoms, what medical male circumcision means for women, and the HPTN 052 study with regards to treatment as prevention and its potential to reduce HIV transmission, increase the health of people living with HIV, repeal criminalization and punitive laws and increase the sexual and reproductive health of people living with HIV. For video footage of this session please click here: <http://vimeo.com/album/1669467>



The panel featured a diverse cadre of researchers, UN Leadership, a women's rights advocate and Mariliza Toban, a member of the young women delegation from Southern Sudan. As a young woman, she particularly highlighted the:

- Lack of sexual and reproductive health education linked to medical male circumcision
- Female partners are often not included in the process of education on the risk, benefits and post-procedure care issues for medical male circumcision
- Men may not wait to heal before initiating sex and put partners at increased risk
- There is still a need for condom use to prevent Sexually Transmitted Infections, reduce HIV transmission and prevent unplanned pregnancy
- Women have an even harder time advocating for condom use when male partners believe that because of medical male circumcision they "CANNOT" contract or transmit HIV
- Medical Male Circumcision services need to include positive messages about the sexual and reproductive rights of women and joint responsibilities around HIV prevention, pregnancy prevention and RESPECTING the RIGHT TO CHOICE!

3.2 Town Hall Meeting: "Achieving Sexual and Reproductive Health and Rights for Women and Girls through the HIV Response"

The Global Coalition on Women and AIDS (GCWA), ATHENA, Salamander Trust, WECARe+ and Network Persone Seropositive convened a Town Hall meeting "Achieving the Sexual and Reproductive Health and Rights through the HIV Response" to link the community of advocates in Rome with the discussions and debates that were occurring within the formal conference setting – and to create space to champion community leadership and innovation. The Town Hall was the platform to launch "*Community Innovation: Achieving sexual and reproductive health and rights for women and girls through the HIV response*"⁴. Developed by UNAIDS and the ATHENA Network, the report presents case studies pioneering community undertakings to advance women's sexual and reproductive health and rights through the HIV response and vice-versa, from different community perspectives. This report recognizes that women face unique challenges to access and fulfill their sexual and reproductive health and rights, including gender-based violence, and therefore have less access to HIV prevention, care and support services.

It was noted that, learning from these community case studies, there is an opportunity to enhance the HIV response, in light of the Millennium Development Goals and the 2011 Political Declaration on HIV/AIDS. The case studies indicate that for responses to be effective they must include the empowerment and inclusion of women in all our diversity, dedicate attention to sexual and reproductive health, including improvements in maternal and child health, and address the socio-cultural practices underlying gender inequality. The young women participated energetically, recognizing that improving the health and rights of women in all our diversity, including young women living with HIV, is essential to an effective HIV response.

During the Town Hall Meeting, UNAIDS Deputy Executive Programme Director, Dr Paul De Lay championed women in his comments stating, "*Women and girls at every level and throughout different stages of their lives must be supported to demand quality services that meet their needs*

⁴ Available at:

http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/07/20110719_Community%20innovation.pdf

and those of their community.” Speakers on the panel called on policy-makers, country leaders and the research community to marry progress in technology with policy reform, gender equality and on the ground medical processes that will really facilitate women’s access to exciting bio-medical interventions and, as such, be life-changing for women.

As one young women noted, ***“The issues are common issues across countries and these new findings and different contexts of treatment and prevention are community related and need to be approached in a holistic manner.”***

3.3 Women’s Networking Zone:

The Women’s Networking Zone (WNZ) booth, coordinated by the GCWA and the ATHENA Network and characterized by the WNZ signature panty line, is a space designated primarily to building and strengthening partnerships among conference participants, especially women’s organizations and networks of women living with HIV. The booth was well supported and ‘womaned’ by the young women on a shared roster basis.

The WNZ booth hosted a number of ***Critical Dialogues*** where experts discussed the topics of vertical transmission and SRHR, treatment as prevention, treatment for all women and girls, violence against women, harmful legal practices, and putting women on the research agenda. These dialogues were a great way to immerse the young women’s delegation into the conference in a more intimate and safe space with community delegates, researchers, thought leaders and fellow global advocates. During dialogues, which can be viewed here (<http://vimeo.com/album/1669467>), members of the young women’s delegation shared country contexts, community realities, best practices, personal experiences and innovative solutions to bridge young women and women living with HIV into the prevention, treatment, care and support landscape. The WNZ provided opportunities for group discussions and reflections around critical issues affecting women and girls. Additionally, it served as a communal space where questions were raised about the often dense and highly technical sessions of the conference and emerging research. It proved to be an excellent point of cross-community education and exchange.



The Women’s Networking Zone as well as the process overall, provided an important space for the young women to connect with some of the more experienced women’s activists working towards gender equity in the HIV response.

“It was good to see experiences from different countries – young and older women can be involved in different stages of activism... I was surprised to see so many women across age groups, some living with HIV for many years – it gives me hope to be an activist.”

This opportunity to connect with some of the more experienced activists allowed the young women to tap into knowledge around the history of women’s HIV activism, but also opened up new conversations, especially around how young women are organising themselves and how the HIV response itself is transforming. One issue that remains a concern to young, emerging women

activists is the limiting impact of stigma and discrimination in relation to their passion to lead in the HIV response.

“Each of us is very unique because of our backgrounds and we are brought together by the same issues but it’s important to know what activism and visibility can mean for different people and in different contexts.”

3.4 “Where the hell is the gel?” Rally and Press Conference

The delegation participating in the Young Women’s Leadership Initiative, along with other advocates, led a demonstration on female controlled prevention methods, chanting, *“Where the hell is the gel?”* and also called for meaningful engagement of women. This peaceful demonstration was revolutionary at a scientific conference. The young women also made their voices heard at the press conference, that called for strengthened support for the HIV related needs, rights and equality of all women, including those living with HIV. The young women were joined in the press conference by researchers, advocacy organizations and fellow advocates, where they firmly asserted that HIV research is not only about bio-medical development, but also a revolution of women’s rights.



4. The Impact of the Young Women’s Initiative

The young women attached great importance to being able to voice issues pertaining to young women living with and affected by HIV to a global audience, and to ***“collectively be able to show the scientific community that women advocates are capable of engaging in this conference.”***

Also, there was a great thirst for knowledge to be gained from each other and from the broader conference delegates, both regarding specific issues affecting them locally, nationally and regionally, and also to gain different perspectives on HIV and women from around the world. As one of the young women expressed:

“I want to share ideas about best practices and policy and how to implement; to learn about projects that work; to learn about the women’s movement worldwide – to come together and share experiences – learn about issues relevant to our lives and how we can change and improve the lives of women living with HIV worldwide.”

The conference was also perceived by the young women as a space to make new contacts and strengthen their own activism through feeling and being part of a bigger global movement. One of the young women saw her participation in the conference and in the initiative as having the following benefits:

“Meet new people. Establish new contacts; feel the spirit of different networks and orgs – forge close relationships; Feel empowerment and energy from our community to continue working in our country.”

Through facilitated group sessions as well as informal conversations, it became clear through the course of the conference that the participants valued the opportunity not only to engage with a conference of such scale and scope, but also that their participation specifically within a group of young women added depth and knowledge to their experiences. As one young woman reported, the opportunity gave her the feeling that this kind of conference makes women who participate wiser and more powerful. Another young woman said that she had learned about how to work with the political agenda at a large, international conference, as well as how she might use and share her new knowledge in her home country. In addition, some of the young women had profound personal experiences. For example, one young woman noted that engaging with the conference helped her to accept her own status as a woman living with HIV.

During the group’s final meeting, it became clear that making connections with more experienced women in the field was important and connected many of the participants to a wider network of both professional and personal support, particularly for those young women who are living with HIV. These connections also introduced the young women to different ways of thinking about and approaches to their work, particularly in the advocacy arena.

While learning from the more experienced women was a very positive experience for the participants, this work also brought to light the changing nature of advocacy and activism in the field. During the final debriefing meeting among themselves, the young women were particularly interested in the question of being open about one’s sero-positive HIV status, which has been a strong advocacy tool for the more experienced women, and to what extent this facilitates work in the field. Having this separate conversation only among the young women opened up a space to start thinking about the changing nature of the movement and how the needs of up and coming advocates might be met in a way that is both respectful and productive.

5. Challenges and Recommendations

Obtaining visas was one of the challenges which affected most of the participants due to extensive visa application processes and the short timeline available to secure visas. Despite this challenge, we were able to support 15 out of the 20 young women initially nominated, thanks to the dedication of the coordination team.

Participants also reported feeling as though there was a lack of clarity as to the clearly defined purpose of the group, and in particular that there was insufficient clarity in advance of the conference about the extent to which they would be asked to participate in public events such as press conferences. This was especially a concern for some of the young women who are living with

HIV, but who are not open about their HIV status at all, or not open about their HIV status in their own communities.

Since we believe that respecting the rights of all individuals, whether they describe themselves as activists or not, to maintain confidentiality around their HIV status is crucial, it is also recommended collectively with the young women, that the young women themselves draw up guidelines and criteria for future engagement, expectations for participation and respect for confidentiality prior to involvement of any young women in future initiatives.

In addition, organizers and facilitators should be aware of the potential for media exposure and be sure to inform participants ahead of time in case those who are not comfortable participating would like to opt out.

It has to be said, also, that none of this would have been possible without the active work of local or national groups supporting the many issues faced by women with HIV in each of the countries from which the young women travelled. These local organizations have done so much, often with very limited funding, to support the young women to get to this point of the journey. For example, Positively UK has done a lot of preparatory and follow-up work with the young women who travelled to the conference from the UK. It is important therefore to highlight here the role of these organisations and to ensure that this critical work is also acknowledged. We recommend therefore that the issues highlighted in the Policy Brief which has been signed by over sixty networks of women living with HIV and related organisations should also be highlighted, in order for this local and national support for these and other young women, as they develop their advocacy work, to continue⁵.

Finally, communication was a challenge within the group for reasons of language difference, which can only be addressed by ensuring greater availability of translation.

6. Conclusion

Young women are truly the leaders of today; they are committed, passionate and ready to voice the constraints affecting their right to health and justice in national, regional and global spaces. They are also ready to share with the world their achievements and skills. To enable them to do so, investment is needed to further their skills and capacity, as well as to open spaces for political participation.

Supporting young women at international platforms, ensuring that national realities drive international responses and that these are informed by young women's realities and rights, is paramount to achieving effective HIV responses. The need to build the leadership of young women

⁵ See the Policy Brief page of www.wecareplus.net

in the HIV response and to promote gender equality is clear. This work by GCWA, ATHENA, Salamander Trust and WECARe+, presents an opportunity for an emerging young women's leadership initiative with a venture to build new SRHR and HIV champions through a collection of expertise. To continue strengthening and expanding young women's engagement, the WNZ has been identified as one of the prospects to continue to support young women's representation and participation at International AIDS conferences. In order to mainstream and link the SRHR issues of women living with HIV, this process aims to expand and strengthen partnerships with youth initiatives, tying efforts to national, regional and global processes. Finally, there is an important component of continuing to connect emerging and young women leaders with more experienced women's activists with ongoing mentoring.