



# Research Literacy Networking Zone

In 2016, the fields of HIV prevention, treatment and cure research are at an exciting juncture but the specifics of research and new HIV interventions can be difficult to understand, and more so, to articulate for advocacy purposes.

The Research Literacy Networking Zone is a space where delegates and local community members can come together to network and discuss current and future HIV research, as well as rollout of new interventions. It will provide a platform for dialogue among advocates and a space for engagement with researchers and conference presenters.

Some exciting features of the RLNZ include:

- **Help Desk**—Heard something at a session that you want to know more about or get resources on, stop by the Help Desk!
- **Recharging Area**—Need to sit for a minute to rest and maybe get a little more charge into your phone or laptop? Visit our Recharging Area!
- **Resource Library**—Spend a few minutes browsing the Zone’s extensive resource library, pick up materials to take home with you—and while you’re in the Zone don’t forget to look up and check out the learning panels that will be on display throughout the conference.
- **Sessions!** Read on for a robust schedule of events at the Zone. The daily schedule features a range of sessions organized by contributors from around the globe—check it out below!

**VISIT US!**  
BOOTH 606 IN THE GLOBAL VILLAGE

Brought to you by AVAC, IRMA, NHVAS, TAG, WACI Health and WRHI.

## MONDAY JULY 18

### Communicating Complex Science Clearly

**Time:** 10:00-11:00

**Organizer:** *WRHI*

**Speakers:** Deborah Baron, *WRHI*

Have you ever had difficulty explaining the information you learned at conferences or meetings to your coworkers, friends or community? This interactive workshop will provide capacity building strategies on how to break down difficult concepts and messages into the key information that needs to be shared with the community. This session is a can't miss for community educators and advocates attending the conference!

### One Woman, Many Choices: Hormonal Contraception and HIV Communication and Action in the Context of Uncertainty

**Time:** 11:15-12:15

**Organizer:** *AVAC, ICW-EA, WRHI*

**Speaker:** Emily Bass, *AVAC*; Chelsea Polis, *Guttmacher Institute*

To build understanding of the current state of the research, policy, communications and advocacy regarding hormonal contraception and HIV, including: (1) an update on the current state of the science regarding DMPA (Depo Provera) and other progestogen-only contraceptives and risk of HIV acquisition, and specific methods and interactions with ART in women living with HIV; (2) a review of the Strategic Framework for Communication on hormonal contraception and HIV (developed by USAID, piloted in Malawi and Swaziland); (3) a report on advocacy/coalition building for action in the context of uncertainty from the co-chair of the HC-HIV Advocacy Working Group; (4) update on the status of research, including the ECHO trial.

### Stories in Sisterhood: Using Digital Storytelling to Enhance Knowledge and Intent to Use PrEP

**Time:** 12:30-13:30

**Organizer:** *Texas Woman's University*

**Speakers:** Kimberly A. Parker PhD, Kristin L. Wiginton PhD and Dominique Guinn of *Texas Southern University*; Atlantis Narcisse, Community Stakeholder and Project Manager

Self-identified women of color are at an even greater risk for HIV/AIDS and other health related issues. Digital storytelling can serve as an effective health education strategy to increase knowledge and awareness about shared experience of marginalized groups by providing them the opportunity to serve as content experts through the use of personal narratives. Digital storytelling is a form of community based participatory research that combines narratives, images, videos and sound to create a short narrative about one's personal experience for a specific topic. The "Be PrEPared!" Digital Storytelling Project used digital stories related to the marginalized experience of cis and transwomen of color to inform intervention development of the "Be PrEPared!" Increasing Knowledge & Awareness about HIV Prevention and PrEP. Utilizing a Comprehensive Women's Health Approach health education curriculum. This presentation will highlight the methods and process for developing digital stories with eight cis and transwomen from the US (Texas) during a three-day training workshop to share knowledge and increase intent to use PrEP, and advocating for PrEP within a comprehensive women's health approach.

## **Understanding HIV Cure Research**

**Time:** 14:00-15:30

**Organizer:** IAS

**Speakers:** Giuio Maria Corbelli, *EATG*; Sharon Lewin, *Doherty Institute at the University of Melbourne*; Judith Auerbach, *UCSF*; Jerome Singh, *Nelson R. Mandela School of Medicine*; Gus Cairns, *NAM*; Anna Laura Ross, *IAS*

This workshop will aim to clarify the current context, provide information on the social and behavioral questions around the possibility of an HIV cure, debunk common myths and give guidance on how to interpret media reports, and give guidance on where the field is moving and what gaps are still to be addressed.

## **Regulatory Pathway for HIV Prevention Products: The Dapivirine Vaginal Ring as a New Drug Application**

**Time:** 16:00-17:30

**Speakers:** Robert Moraba, *IPM 032 Open Label Extension Study*; Nomfundo Eland, Advocate and Community Mobiliser; Annalene Nel, *International Partnership for Microbicides*; Duduzile Lembethe, *MatCH Research*

**Moderators:** Holly Seltzer and Leonard Solai

The HIV prevention field welcomed the results from two pivotal phase III studies that showed that the dapivirine vaginal ring is both safe and effective as an HIV prevention tool that women may use. This result changed the vaginal microbicide landscape as it is the first time that two studies demonstrated statistical significance for product efficacy. Results from these studies have been communicated to key stakeholders in Africa and also globally. The product developer and regulatory sponsor, The International Partnership for Microbicides (IPM), will move forward with submitting a dossier of studies to medicines regulatory authorities for licensing the product for public use.

Four key areas will be addressed:

- Regulatory pathway for the dapivirine ring as a new drug application – what the process involves
- What advocates need to know and how they could assist in the meanwhile
- Implementing dapivirine ring Open Label studies – what needs to be done differently and does adherence matter
- Post results: Managing expectations in study communities who have seen both futile and efficacious study results

## TUESDAY JULY 19

### Understanding HIV Prevention Research and Clinical Trial Processes

**Time:** 11:00-11:45

**Organizer:** *WRHI*

A foundational session on the basic of HIV research. This session covers the essential topics, from clinical trial design to understanding basic terms in research literacy. Participants new and old to HIV prevention research will build capacity around the essential knowledge of HIV research.

## **Breaking Down Silos: Community Engagement Across Diseases and Donors**

**Time:** 11:45-12:45

**Organizer:** AVAC, WRHI

The Good Participatory Practice guidelines (GPP) are a set of recommendations for including a broad set of individuals and groups who have influence over a trial into the research process. This workshop will examine various models of GPP implementation across research phases, diseases and donor requirements. Participants will be able to use or adapt models of GPP for use within their own programs or contexts and hear/share successes and challenges of GPP implementation in real-world settings.

## **CUREiculum Presentation: Promoting Community Dialogue Around HIV Cure Research**

**Time:** 13:00-14:00

**Organizer:** MDC Collaboratory Community Advisory Board/UNC-Chapel Hill

**Speakers:** David Evans, *Project Inform*; Laurie Sylla, *defeatHIV Community Advisory Board*; Jeff Taylor, *Collaboratory of AIDS Researchers for Eradication (CARE) Community Advisory Board*; Richard Jefferys, *Treatment Action Group*

**Moderators:** Jessica Salzwedel, AVAC; Karine Dubé, UNC-Chapel Hill

The HIV cure research training curriculum team will provide a basic foundation in the science of HIV cure research. The team will explain the importance of stakeholder and community engagement in HIV cure research focusing on specific topics like early treatment, pediatrics and ethical challenges of the research. Community educators and advocates will leave with a deeper understanding of the issues facing the HIV cure field and strategies to enter the global dialogue surrounding the research.

## **Ask the Researchers: Talking About the Use of Antibodies for HIV Prevention**

**Time:** 14:45-15:45

**Organizer:** HIV Vaccine Trials Network

**Speakers:** Jim Maynard, Nandi Luthuli and Dr. Simba Takuva of the *HIV Vaccine Trials Network*; Danielle Campbell MPH, *PxROAR*

**Moderators:** Gail Broder, *HIV Vaccine Trails Network*

This will be an open forum for discussion and Q&A, with a short presentation to introduce the HIV prevention and antibody research. Presenters will also introduce the AMP Studies (HVTN 703/HPTN 081 in sub-Saharan Africa, HVTN 704/HPTN 085 in the Americas) being conducted globally.

## **PrEP Preposition 4 Prevention: Who's Prepared 2 Know?**

**Time:** 16:45-17:45

**Organizer:** *APHA, WRHI*

**Speakers:** Brian Kanyemba, *Advocacy for Prevention of HIV and AIDS / Desmond Tutu HIV Foundation*; Millicent Atujuna, *Desmond Tutu HIV Foundation*; Oziel & Nompumelelo Mdletshe, *Uthando Lwethu Project*; Zukhanye Mgoqi, *Passionate Unlimited Peers in Action (PUPA)*

**Moderators:** Michelle Moorhouse, *Wits RHI* and Ntando Yola, *Advocacy for Prevention of HIV and AIDS / Desmond Tutu HIV Foundation*

Sub-Saharan Africa continues to be noticeably the axis of the HIV epidemic, with adolescent girls and young women aged 15 - 24 helplessly at risk of new HIV infections. Historically there has been over reliance to ABC which has clearly not worked for everyone. Currently, Truvada, which is used as a form of pre-exposure prophylaxis (PrEP) to prevent HIV, has been approved by a number of countries, including South Africa and Kenya in Africa. This session looks to engage participants in the basics of PrEP and its science including what and how advocates can get involved.

## **WEDNESDAY JULY 20**

### **Safer Conception for HIV-affected Individuals and Couples: Synopsis of Findings**

**Time:** 11:00-12:30

**Organizer:** *HIVE*

Globally, 19 million people living with or affected by HIV want a child. Men and women accept unnecessary HIV risks to meet their reproductive goals. Research has shown that safer conception strategies make it possible for HIV-affected individuals and couples to conceive while keeping partners and children HIV-free. This session will be an interactive workshop. Researchers, people living with/affected by HIV, clinicians, and advocates who are committed to empowering HIV-affected individuals and couples to access their desired reproductive and sexual choices will share what we know about safer conception strategies. Synopses of safer conception research studies and programs from around the world will be shared and discussed.

Participants will be able to:

- Describe three strategies for reducing HIV transmission during pregnancy attempts
- Identify guidelines & policies that support the rollout of safer conception strategies
- Share two online resources to support providers and patients in implementing safer conception

## **Addressing Known Causes of Poor Participation by Black MSM in HIV Prevention, Treatment and Research**

**Time:** 12:45-13:45

**Organizer:** *AIDS Project of the East Bay*

**Speakers:** Minister Rob Newells and “Mizrahi” Jackson of the *AIDS Project of the East Bay*

The most commonly cited causes of poor participation by African Americans in HIV prevention trials are mistrust or fear, stigma, and misinformation. These are also common causes of poor participation by Black MSM (BMSM) and Young Black MSM (YBMSM) in HIV prevention and treatment. This workshop will focus on strategies to improve engagement of BMSM/YBMSM in primary medical care, regular STI testing, PrEP uptake, and HIV prevention and treatment research studies. These strategies include investing in building the research literacy of local BMSM leaders; improving the health literacy of front-line staff and clients of community-based organizations; and providing community role model stories to increase PrEP use and research study participation. At APEB in Oakland, California, staff is working with UCSF to implement the STYLE (Strength Through Livin’ Empowered) intervention to improve retention in care for BMSM living with HIV. In addition, efforts to engage members of the Black Church and the House/Ball Community in HIV prevention and treatment

research will be discussed by a licensed Baptist minister and a Legendary House Father.

## **Advancing PrEP Advocacy: Opportunities and Challenges in Settings Where it Has Been Approved, and Where it Has Not**

**Time:** 14:00-15:00

**Organizer:** *International Rectal Microbicide Advocates*

**Speakers:** Brian Kanyemba, *Advocacy for Prevention of HIV and AIDS / Desmond Tutu HIV Foundation*; Will Nutland, *London School of Hygiene & Tropical Medicine*; Midnight Poonkasetwattana, *APCOM*; Yvette Raphael, *Advocacy for Prevention of HIV and AIDS*; Dr. Kevin Rebe, *Health4Men/ANOVA*; Ntando Yola, *Advocacy for Prevention of HIV and AIDS / Desmond Tutu HIV Foundation*

**Moderators:** Jim Pickett, *International Rectal Microbicide Advocates*

Discuss PrEP advocacy strategies, opportunities and challenges across the world with advocates working on the front lines. Share your own successes and struggles, and hear from others.

## **Hope vs. Hype in Reporting HIV Cure Research: Advice for Journalists, Bloggers and Concerned Consumers of the Media**

**Time:** 15:30-16:30

**Organizer:** *UNC-Chapel Hill & AVAC*

**Speakers:** Ida Jooste, *InterNews*; Kay Marshall, *AVAC*; Michael Louella, *defeatHIV Community Advisory Board*; Richard Jefferys, *Treatment Action Group*

**Moderators:** Karine Dubé, *UNC-Chapel Hill*

Given that an increasing number of HIV cure-related studies are conducted in resource-limited settings and the inherent complexity of HIV cure science, we propose to organize a literacy session dedicated for journalists, bloggers and concerned consumers of the media. We will base the discussion on actual media HIV cure coverage prior to the IAS 2016 conference, reviewing examples from Africa, America and European media.

## **Ask the Researchers: Talking About Preventive HIV Vaccine Research**

**Time:** 17:30-18:30

**Organizer:** *HIV Vaccine Trials Network*

**Speakers:** Jim Maynard, Nandi Luthuli and Dr. Simba Takuva of the *HIV Vaccine Trials Network*

**Moderators:** Gail Broder, *HIV Vaccine Trials Network*

This will be an open forum for discussion and Q&A, with a brief presentation to introduce the HIV preventive vaccine field. Presenters will also introduce the upcoming HVTN 702 study that will be starting in South Africa later this year.

## **THURSDAY JULY 21**

### **What is Health Research and Development (R&D) and Why Should Advocates Advocate for Increased Funding for Health R&D in South Africa?**

**Time:** 11:00 - 12:30

**Organizer:** *PATH*

**Speakers:** Yolanda Moyo and Dr Samukeliso Dube and Vanessa Msengezi of *PATH*; Daniel Molokele, *Aids Accountability International*

This workshop will provide health advocates a platform to share ideas on how to improve implementation of R&D policies, and streamline regulatory processes that support the development, introduction and scale of high-impact health technologies in South Africa. This session will focus on:

- Understanding policies that affect R&D and regulatory processes; existing health R&D platforms; R&D and regulatory decision-makers; health researchers; and R&D and regulatory advocates and advocacy networks
- Providing an analysis of the impact of R&D in HIV in the last decade
- Defining what health R&D is and what it means for South Africa
- Articulating, as a collective, the need for R&D advocacy in South Africa and how to enhance it
- Discussing the value and mutual benefits of establishing a coordinated advocacy network for access to health technologies across disease areas including HIV and TB

## How is that Rectal Revolution Coming? An Update on Global Rectal Microbicide Research and Advocacy

**Time:** 12:45 - 13:45

**Organizer:** *International Rectal Microbicide Advocates*

**Speaker:** Dr. Ian McGowan MD PhD, *University of Pittsburg*

**Moderator:** Jim Pickett, *International Rectal Microbicide Advocates*

So what's up with rectal microbicide research? Now that we have PrEP, do we even need a rectal microbicide for HIV prevention? What are the trials, issues, opportunities and challenges we should be paying attention to? Join us as we tackle these questions in a casual, conversational format. #RectalPride

## Engage Yourself: Responsible and Responsive Science

**Time:** 14:15 - 15:15

**Organizer:** *The Amsterdam Institute for Global Health and Development*

**Speakers:** Brandon O'Dell and Cate Hankins, *The Amsterdam Institute for Global Health and Development*

The role of the individual in science is changing rapidly as new technologies arrive. The European Union (EU) is articulating a way of working across a range of science stakeholders that is inclusive and responsive called Responsible Research and Innovation (RRI). RRI recognizes and values the competences of people who are not scientists but who hold important knowledge, opinions, desires, and ideas. The EU project, SPARKS, is an awareness-raising project to demonstrate involvement in science. Taking place over three-years, the project involves a network of science shops, centers, and museums across Europe mounting 29 exhibition sites and carrying out nearly 300 activities. With the goal of engaging citizens with the concept and practice of RRI through the topic of technology shifts in health and medicine, the exhibition explores six different stories of Europeans engaging in DIY (do-it-yourself) research. Sparks promotes RRI by inviting key stakeholders to actively question, experiment and play with science.

## Hypothesis, Design and Impact of the START Study

**Time:** 15:30 - 16:30

**Organizer:** *PINA Uganda*

**Speakers:** Asia Russel, *Health Gap*; Joshua Wamboga, *Unaso*

**Moderators:** Moses Supercharger and Asia Namusoke, *PINA Uganda*

This session will go over the results of the START study, a landmark trial about the impact of when treatment is initiated. This session aims to pass on the importance of the study and its results to community and discuss how the study impacts the treatment landscape in various African countries.

## The PROUD Study – A Video Documentary

**Time:** 17:00-18:00

**Organizer:** *georgetown media*

**Speakers:** Nicholas Feustel, *georgetown media*; Mitzy Gafos, *PROUD Study*; Sheena McCormack, *University College London*

Screening the official, 25 minute video documentary on the PROUD Study on PrEP, followed by a Q&A with the audience. Learn about the study design, outcomes, ethics, community engagement and participants' personal experiences of one of the major PrEP studies with gay men.

The Research Literacy Networking Zone is brought to you by:

