The International AIDS Society

Educational Fund meeting
5 April 2017
Rio de Janeiro, Brazil

“Science and community in the response to HIV in Latin America and the Caribbean”
Scientific and Community Responses to HIV in Latin America and the Caribbean

Background

On April 5, 2017, the International AIDS Society (IAS) brought together 46 scientists and community representatives from Latin America and the Caribbean for a one-day workshop in Rio de Janeiro, Brazil. The meeting was co-chaired by the President of IAS, Linda-Gail Bekker, Deputy Director and Professor at the Desmond Tutu HIV Center, Institute of Infectious Disease and Molecular Medicine, Faculty of Health Sciences, University of Cape Town, and Mauro Schechter, the Latin America representative on the IAS Governing Council and Titular Professor for Infectious Diseases at the Department of Preventive Medicine, Federal University of Rio de Janeiro. The meeting was held before the HIV and Hepatitis in the Americas Congress and the Americas Congress, and was conducted in Portuguese, Spanish, and English, with simultaneous translation in all three languages.

The views expressed in the report do not necessarily reflect the views of the International AIDS Society.

Welcome and Opening Remarks

Prof. Linda-Gail Bekker, IAS, South Africa
Prof. Mauro Schechter, Federal University of Rio de Janeiro, Brazil

The meeting began with an introduction by Prof. Mauro Schechter, who explained the purpose of the workshop organized by the IAS. What is the perspective of civil society on what needs to be done? How can the medical community influence civil society and governments in the struggle to provide access to health care to individuals with HIV? Over the last few years, the struggle has lost ground, both politically and in society. The IAS is looking for representatives from Latin America from other sectors, not just the health sector, who wish to become involved in these important questions.

Prof. Schechter also made the point that collaboration between scientists and community representatives was necessary. The workshop, which was made possible by resources donated by a pharmaceutical company, is an example of the need to bring together different interests which share the struggle for the right to life for people living with HIV. It is an IAS priority to mobilize society to acquire the resources needed for the fight against the HIV/AIDS pandemic. Not just the fight to reduce and eliminate the stigma, but also for greater integration between communities around the world.

Workshop participants then explained their reasons for attending. Prof. Schechter commented on the presentations and reinforced the importance of a closer relationship between civil society and the scientific community. The reason for the meeting was the same as the mission of the IAS: to seek ways of reconciling the interests of the pharmaceutical industry, scientists, and the community, which must benefit from scientific advances. How can we help these different areas speak to each other? Prof. Schechter commented on the importance of moving on from the “guinea pig” model to that of “research volunteer”. The role of the IAS was that of a catalyst, helping the various players communicate and work together. Prof. Schechter emphasized that all these issues are very important to the new IAS governing body.

Prof. Linda-Gail Bekker introduced herself and spoke of the importance of concentrating forces and
ideas to achieve a global solution. The current need was to find solutions to deal with the epidemic. According to Prof. Bekker, the time had arrived, more than ever, to rewrite the narrative and ensure that everyone was heard so that we could deal together with HIV. According to Prof. Bekker, the IAS had defined a strategy which could be summarized in three words:

- **Science** - science has the obligation to ensure that nobody is excluded.
- **People** - the epidemic cannot be fought without considering those who are dealing directly with the virus, both researchers and patients. We must not lose sight of those who are living and working with HIV.
- **Progress** - the IAS needs people to act together. Education is needed, as well as integration, so that all contribute to innovation.

**Improvements to Antiretroviral Therapy: 4, 3, 2, 1 and less!**

*Dr. Anton Pozniak, Kobler Clinic, Chelsea and Westminster Hospital NHS, United Kingdom*

Dr. Pozniak began his presentation questioning the reason for reducing the number of pills given to patients at the beginning of their treatment for HIV. Dr. Pozniak argued that if it was possible for the patient to take fewer pills, this meant less cost, less drug products to be manufactured and stored, a reduced likelihood of side effects, and fewer pills to be taken.

And four drugs? When more drugs are given, four instead of three, does that prevent more deaths? According to Dr. Pozniak, studies show that prescribing four rather than three drugs at the beginning of treatment does not lead to better results. And when only two drugs are prescribed, instead of three? Fewer drugs, cheaper, and fewer side effects. Dr. Pozniak presented studies which show that starting treatment with three drugs is better than with two, that more benefits are obtained. And what happens when only two drugs are used? Once the virus is undetectable, it is possible to change to using only two drugs, but it is not known if this is beneficial to the patient in the long-term. And what about changing to long-acting injectable drugs? According to Dr. Pozniak, the results so far are good. The results are not worse than when the drugs are taken orally. But for some people who only inject them every 8 weeks, their virus may become resistant to the drugs.

Dr. Pozniak also spoke about pregnancy and hepatitis and then returned to the issue of optimizing drug use. Regarding the use of only one drug, Dr. Pozniak presented studies that show that the result is worse. He said that doctors should not treat patients with a single drug, since many patients develop resistance to monotherapy.

**Taking on the Challenges of Vaccines and a Cure**

*Dr. Luis Soto-Ramirez, INCMNSZ, Brazil*

Cure or vaccine? According to Dr. Luis Soto-Ramirez, there is a widespread desire for a vaccine. He started by speaking of those individuals who suspended their treatment after they thought they were cured. The virus returns when treatment is suspended. In the light of that situation, he began his talk explaining about virus reservoirs.

How can the infection be cured if we cannot find the virus reservoirs? Reservoirs appear when the virus becomes part of the genetic material of the cell. Everywhere where Lymphoid cells are to be found, the virus will be hidden there. Dr. Soto-Ramirez described where the main reservoirs are to be found and the reasons for the virus returning when treatment is suspended. He also explained why the size of the reservoirs is unknown. So, he asked, how can we cure the infection if we do not know where the reservoirs are?

Dr. Soto-Ramirez said that, when we think of a cure, there are two possibilities. One is a sterile cure, where we eliminate the virus entirely. The other is a functional cure, where a person lives with the virus but does not require any treatment. An example of this is the elite controllers, a group of patients who, thanks to specific genetic characteristics, manage to control the virus. Dr. Soto-Ramirez also described a group of patients treated at the very beginning of the infection and who, after discontinuing treatment, were able to control the infection.
What can be done to eliminate these reservoirs of virus? How can we remove or limit these reservoirs? Dr. Soto-Ramirez spoke about the possibilities of a vaccine for HIV being produced. He explained that it would be difficult to persuade people to be vaccinated and then expose themselves to the virus. He finished his presentation saying that it may be possible for AIDS to be eradicated by 2030. He posed the question, however, of even if there were a vaccine and a possible cure, how do we ensure that everyone takes it? What would be the economic cost of vaccinating everybody in the world? And how could everyone have access? How can we pay for a vaccine that would have to be produced on such a large scale? He also spoke about the ethical aspects. How to deal with the stigma? How to remove the stigma from those who have been cured, and in cases where people are cured and have unprotected sex, but became reinfected, contract syphilis, etc.? How can we produce a cure that will actually be available to all, and what would be the conditions set to gain access this cure? Dr. Soto-Ramirez finished by saying that the desire for a cure is only part of the story, since the main focus would be prevention.

Human Rights and Structural Barriers
Veriano Terto Jr., ABIA, Brazil

Mr. Veriano Terto Jr. spoke of human rights issues and structural barriers in responding to the HIV/AIDS pandemic. Mr. Terto Jr. began by sharing his belief in dialog between civil society and academia. He said that he believed that the epidemic should always be viewed in an interdisciplinary way. He believed that AIDS should be viewed as a whole, given that all social crises affect the whole of society. And so HIV/AIDS should be seen as a synergistic epidemic, a group of factors in synergy with other physical and clinical ailments, as HIV is never found alone. Other cultural and social factors contribute to the illness.

According to Mr. Terto Jr., AIDS should be seen as three epidemics, with stigma, prejudice, and discrimination constantly interacting with the infection and illness. Social oppression factors that are integral to societies, such as racism, gender discrimination, urban violence, homophobia, criminalization, and discrimination against HIV carriers make it difficult to provide care to individuals and control the epidemic. So the answer must be an integrated approach to the individual, social and programmatic dimensions.

According to Mr. Terto Jr., the three dimensions (individual, social and programmatic) must be considered together so that we can deal with all the factors that contribute to the disease. The response must always be integrated, never in isolation. Mr. Terto Jr. then spoke about the key populations, which are more vulnerable to HIV infection. What would be the correct terminology to use, which is inclusive of all citizens? What discourse would facilitate a more integrated response, where human rights are more effectively incorporated in the response, considering not only controlling the risk associated with bodies living with HIV but, above all, quality of life?

Questions and Answers #1

The meeting was then opened to questions and debate. The themes discussed were:

- When will we arrive at the situation where citizens are not just treated as bodies, but as carriers of a virus? This was followed by a lively debate about the moral interpretations of right and wrong in HIV exposure. What would be "put at risk"?
- Also discussed was prevention for individuals who do not have a “structure” or “life plan”, as well as the need to target the excluded and the marginalized in a different way. The question was raised about using different strategies when speaking about prevention, depending on the scenario, population and practices.
- The transsexual community was also discussed, which does not benefit from either legal or social protection. The link made by society between female transsexuals and prostitution was discussed. With regard to male transsexuals, the consequences of their almost complete social, medical and scientific invisibility were discussed.
- Questions were asked about how long it will take to find a cure and the reasons for different
estimates.

- The question of whether drugs under development address the needs of older patients, carriers of virus strains resistant to multiple drugs, was discussed.
- The meeting also discussed prevention for people who are already HIV positive.
- The question of integrated care was discussed. Many consider that patient care is based on a narrow view of people, and does not consider the social and cultural dimensions of their lives. There was harsh criticism of health care professionals who only consider their patients’ viral load, restricting them to a bio-medical vision.

**HIV in Latin America: The Prevention of HIV infection in transsexual women and in men who have sex with men: lessons learned, successes and challenges**

*Dr. Alfonso Silva-Santisteban, UPCH, Peru*

In his talk, Dr. Alfonso Silva-Santisteban began by talking about the limitations in the services offered to key populations. The non-inclusion of transsexual women and the effects it has on this marginalized and excluded population. As a parallel culture, the transsexual population is deprived of both health services and access to prevention services.

Another major problem is the lack of knowledge of self-diagnosis, as many do not know they are infected. Interventions, according to Dr. Silva-Santisteban, need to be organized, since the entire system is deficient in serving this population. The services which support the LGBT population need to be modified to make them more appropriate to the community supported. One of the options is for mobile services to be offered in areas where the community gathers, with a rapid turnaround on test results.

Dr. Silva-Santisteban also spoke about the lessons learned from his research. He underscored the need to understand the epidemiological, social and local contexts to adjust the operations, with improved integration between the health sector and other sectors to establish social programs. He concluded with the point that training and building awareness amongst health workers are the keys to improving the provision of services.

**HIV in the Caribbean**

*Dr. Anton Best, Ministry of Health, Barbados*

Dr. Anton Best began by reporting on the current situation regarding the epidemic in the Caribbean. In 2015, there were 13,000 deaths related to HIV/AIDS. He also gave details of the high rates of infection amongst sex workers. He spoke about the funding of research in the Caribbean and also about the situation of men who have sex with men.

Cuba was the first country to eliminate the transmission of the virus from mothers to their children. However, it is estimated that 5.4% of children born in Haiti in 2015 are infected with HIV.

According to Dr. Best, Caribbean countries in general have some of the worst laws and policies for the prevention of HIV infection in key populations. For example, consensual sex between adults of the same sex is criminalized and there are laws that prevent access to sexual and reproductive health policies. He finished by questioning how it would be possible to treat HIV more effectively given the legal and political situation in the region.

**Questions and Answers #2**

The meeting was then opened to questions. The debate began with a discussion of the role of IAS in reducing the stigma associated with people who live with HIV. Prof. Bekker spoke about IAS and how it is building a dialog with different groups and taking part in various health programs to tackle the stigmatization of people with HIV. Prof. Schechter spoke of the new situation at IAS, which was returning to its origins, with activism having a central place in the search for programs that seek solutions.
The following issues were then debated:

- How to establish social inclusion practices which address the health of the transsexual population?
- How to prioritize and allocate resources to contain the epidemic?
- Where are the transsexual men, who are not included in social debates and agendas?
- What will be the situation over the next few years in Brazil, given that the financial support to HIV/AIDS programs is being reduced?

**Where is the HCV?**  
*Carlos Varaldo, World Hepatitis Alliance, Brazil*

Mr. Carlos Varaldo spoke about the enormous disparities between the estimates of the number of people infected by the hepatitis C virus made by various institutions such as the World Health Organization, the Centers for Disease Control and Prevention (CDC, USA), various Ministries of Health, and independent researchers. Mr. Varaldo pointed out that these estimates can differ by more than 100%. That is why, he believes, the first step to combat the epidemic is to know its real size. Mr. Varaldo made some basic proposals, based on experience that, according to him, could contribute to improved mapping of the hepatitis C epidemic.

Mr. Varaldo also spoke about the difficulty of accessing treatment in Brazil. He argued that, despite the most modern drugs being available free in the public health service, the bureaucratic barriers are enormous and, in practice, restrict access to treatment.

**Community Participation: Challenges and progress**  
*Jana Villayzán, IRGT: A Global Network of Trans Women, Peru*

Ms. Jana Villayzán began her presentation by contextualizing community participation, its advances and current challenges. She spoke of the importance of a global network that connects transsexual women. She asked where the transsexual women were. According to her, the exercise of human rights is fundamental for the implementation and enforcement of protection policies for those who live daily in situations of vulnerability.

As far as transparency and sustainability are concerned, Ms. Villayzán said that she believed that the two are fundamental for governmental policies, so that governments can distribute free medicines to all in the most vulnerable populations, which are not protected by the law. She also spoke about inequality in everyday life and the lack of community spaces for transgender people and how all these issues should also be the responsibility of community organizations.

According to her, the transsexual and gay populations do not have political power, the movement remains fragmented, which makes everything more difficult, including the struggles and movements in favor of their lives.

**Questions and Answers #3**

The meeting was then opened up to the third round of questions and debate. The topics debated were:

- The importance of carrying out and participating in biomedical research.
- Who are the people who participate in HIV/AIDS research?
- The ethical issues surrounding payments to volunteers in research programs.
- What are the policies for supporting research that is inclusive of all sectors of the population?
- The low participation of transsexual women and men in research projects.
- The invisibility of the transsexual population and the lack of inclusion of middle class transsexual people, who end up not being included in the studies.
- The majority of transgender people are living in poverty and, therefore, how should the
The AIDS situation in Venezuela
Dr. Martin Carballo, AIDS Unit, Caracas University Hospital, Venezuela

Dr. Martin Carballo spoke about the recognition of diversity and about how to include all individuals and not exclude populations. He also spoke about the HIV/AIDS situation in Venezuela and the lack of access to antiretroviral therapies.

He then described the situation of the epidemic amongst the indigenous population. According to Dr. Carballo, up to 10% of this population is infected. There are major cultural, geographical and economic barriers which make it difficult to treat these individuals. In addition, there are language barriers, since many of the native populations do not speak Spanish.

Haiti: Providing services to AIDS patients during a crisis
Prof. Jean William Pape, GHESKIO, Haiti

How to deal with the AIDS epidemic during a crisis? How to prepare for disasters? After describing the natural disasters that hit Haiti, and his group’s response, Prof. Jean William Pape listed the essential precautions that should be taken, including stocks of drug supplies sufficient to meet at least three weeks demand, stockpiles of drugs in specific, protected locations in the cities, lists of patients in each district, and clinical and medical centers which inform their patients about travel options and other care centers around the country. It is important to set up multidisciplinary groups that live in the same district as the patients to facilitate the organization of services and transport, and radio and communications systems that are available 24 hours a day. Contingency plans should be constantly updated and improved following disasters.

Dominican Republic: The nation’s response to HIV
Dr. Mónica Thormann, Department of Infectious Diseases, Doctor Salvador Bienvenido Gautier Hospital, Dominican Republic

Dr. Mónica Thormann began by estimating the percentage of the population of the Dominican Republic with HIV in 2015, and the financial resources the government provides for drugs and other supplies. During her presentation, Dr. Mónica Thormann spoke of the general situation in the Dominican Republic and of the people who live with HIV, as well as the government’s budget estimates. She presented data and information on the situation in 2015.

Response to HIV during an outbreak of Zika in Brazil
Dr. Adele Schwartz Benzaken, Ministry of Health, Brazil

Dr. Adele Schwartz Benzaken spoke about Zika in the context of HIV. The Zika virus outbreak began in 2015, the major impact being microcephalias. At the national level, the Ministry of Labor set up a multi-sector task force. One of the main focuses is the young population. The Brazilian government’s actions to control the Zika virus included controlling the vector, caring for patients, educational programs, and technical research and development. Dr. Benzaken emphasized the importance of their being internal discussions between educators and civil society when responding to the results of the research.

Retention in care
Prof. Mauro Schechter, Federal University of Rio de Janeiro, Brazil

Prof. Mauro Schechter spoke about retention in care and about when to start it. According to Prof. Schechter, the life expectancy of people living with HIV has changed enormously. According to him, demographic projections in the UK show that people living with HIV have a life expectancy greater than that of the general population. In other words, the treatment works.
Prof. Schechter presented data that shows that around 50% of individuals leave follow-up programs after three years of treatment. This phenomenon is world wide. According to Prof. Schechter, it is not enough to have an undetectable viral load, it needs to be undetectable for a long time. He said that there is a phenomenon known as pill fatigue, which leads to patients stopping taking their medicines. This has consequences for both the individual and the epidemic, given that 60% of new infections are acquired from individuals who know they are HIV-positive and interrupt their treatment. One consequence is an increase in the prevalence of resistance to antiretroviral drugs among people receiving treatment for the first time.

Prof. Schechter wondered what needed to be done to increase retention and adherence to treatment. What should the priorities be? How to ensure that patients remain in treatment for many years, for decades?

**PrEP and new options for the prevention of HIV infection**  
*Prof. Beatriz Grinsztejn, Fiocruz, Brazil*

Prof. Grinsztejn spoke about the prevention of HIV infection and its prevalence in men who have sex with men. She said that a recent epidemiological study showed that the prevalence of HIV in transvestites and transsexuals is more than 30% in Rio de Janeiro. According to Prof. Grinsztejn, there is a need for a thorough discussion of the issues that affect these populations, as well as combating stigma, prejudice, and criminalization. Studies in the USA which assessed the survival rates of minorities by the districts where they lived, showed that mortality through violence and suicide is higher in districts where there is greater stigmatism.

Prof. Grinsztejn also spoke about pre-exposure prophylaxis in Brazil, as well as the possibility of its implementation in the Unified Health System (SUS).

Lastly, she spoke about how to combine prevention with health policies that address HIV in young people, gays, transsexual women, and sex workers. The work needs to be cross-sector, in movements that have a broader reach than government and NGO programs. Finally, she said that the fight against stigma continues to be important and that science has a significant responsibility in removing it, that science needs to work together with the community to meet social needs.

**HIV among young people**  
*Adolfo Ruiz, SOMOSGAY, Paraguay*

Dr. Adolfo Ruiz presented data on HIV infection rates among young people. He also spoke on the stigma and subjective views of populations in this age group living with the virus.

**Questions and Answers #4**

The meeting was then opened to questions and debate. The main issues discussed were:

- The government policies adopted in Brazil in 2013 without public debate, which was challenged by the representative of the Brazil National AIDS Program.
- The mechanisms for young people to access health care. The role of social networks, their importance as a means of communication to young people of messages on the prevention of HIV infection, the search for new languages to reach them.
- Activism among young people, stimulating new young leaders, the role of youth leaders as they become adults.

The participants then divided into three groups, in accordance with their language preference (Portuguese, Spanish, and English). Each group debated a chosen theme and presented its conclusions to the other groups.
First Group -

The first group discussed retention in care, including personal, mental, structural and clinical issues.

According to the group, adherence to treatment depends on the quality of the clinical treatment that is available. Treatment care policies need to recognize the stigma experienced by those who access treatment. They spoke of the difficulties experienced by sex workers and other marginalized groups in following treatment programs that require them to go to clinics that are not set up to handle their needs, and to overcome the stigma.

The group also spoke about the health care systems in each country and how each system determines its policies, care models, and access to medicines. There was a discussion about whether to fight for improvements to the health care system as a whole and, in that way, improve the care of people living with HIV or, in contrast, focus on improving the care to people living with HIV which, as a secondary benefit, would benefit the general population.

The group also discussed the monitoring of patients, the ease of navigating through the health care system, and the possibility of changing clinics in case of need or from personal choice.

They concluded that a decentralized health care system should be introduced. The group also discussed therapy regimens for patients which did not require them to take the drugs at weekends, when to start treatment, and how to ensure access to treatment.

They also concluded that training for all health professionals who deal with patients is urgently required. Not only doctors and nurses, but the whole team, given that the lack of a caring environment makes it harder for patients to seek treatment.

Second Group -

The second group discussed the details of the introduction of pre-exposure prophylaxis (PrEP) in Brazil's public health system, in particular the measures needed to include adolescents. The lack of information available to the population in general and to health professionals has become clear in studies of pre-exposure prophylaxis. The Ministry of Health plans to start by opening a center for the distribution of pre-exposure prophylaxis in each state capital.

The importance of the centers being open outside business hours was emphasized. As for those individuals who start PrEP and then stop, it was emphasized that the testing phase should be used to inform the population of its rights, to encourage a view of citizenship and the rights of the individual.

The group also discussed the question of drug users having access to PrEP and whether the service should be available in other health centers. There was a lively debate about the lack of studies involving adolescents and children. In particular, the legal, ethical and moral issues involved in treating or providing PrEP to adolescents without parental consent were discussed.

Third Group -

The third group discussed where we are now and where we want to go regarding the issue of young people. According to the group, many speak of young people but do not know what to do with the communities affected. Young people are the focus at present.

There are many unresolved questions. How should we work with gender identity laws? How should we work with the most vulnerable and least studied, such as minors who are carriers of HIV/AIDS?

How, with young people becoming sexually active ever earlier, can public policies not remain blind to the reality of the situation? Where, how and when, and at what moment, should we work with
young people? From what age? At what age should we start to discuss primary prevention, positive prevention?

The lack of spaces for young women living with HIV to participate was emphasized. It was also emphasized that many young people cease to be activists regarding HIV for lack of money and resources to support this militancy. The need for greater technical and financial support for groups of young people was reaffirmed, in order to leverage the influence of these groups on their networks and communities.

The third group also discussed where and when to take action, emphasizing the importance of multiplying acquired knowledge and of working together.

The role of the education sector was extensively discussed. In several countries, Ministries of Education and Health may not disseminate educational materials in schools on account of reactionary forces, which prevents the establishment of an effective sex education policy. Without a partnership with the education sector, it is impossible to work with the younger generation. The group finished by saying it is necessary to widen the debate about combined prevention and not restrict it to only the use of condoms.

Conclusion

At the end of the workshop, Prof. Linda-Gail Bekker and Prof. Mauro Schechter thanked everyone for their presence and reiterated that IAS is totally committed to working with the younger generation, encouraging them and creating opportunities like this workshop for them to interact with other young people to create their own activist networks. They also said that the IAS does not believe that the end is in sight for the epidemic, that there is still a long road ahead of us and that, if we are to succeed, it is essential for there to be ongoing communication between the community and scientists. The role of workshops such as this one is to encourage activists and professionals who are not physicians and biological scientists to join the IAS, become active members, and stand for its Governing Council.