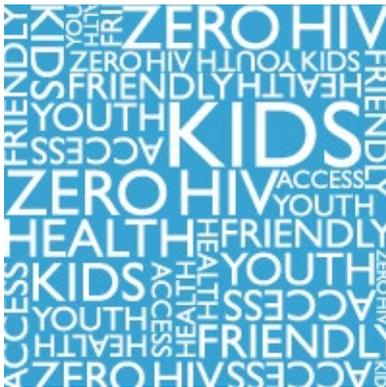
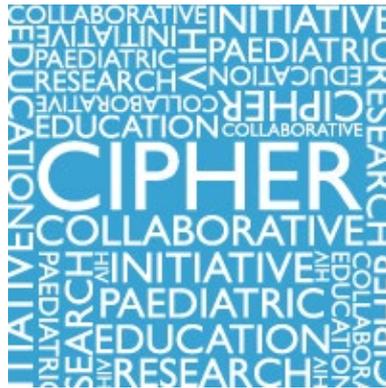


Prioritizing Paediatric HIV Annual Report 2014



The Collaborative Initiative for Paediatric HIV Education and Research (CIPHER)

Acknowledgements

Project Team

Marissa Vicari	Manager, CIPHER, International AIDS Society, Switzerland
Tamara Torri	Project Manager, CIPHER, International AIDS Society, Switzerland
Carina Sørensen	Junior Coordinator, Research Promotion, International AIDS Society, Switzerland
Bruce MacArthur	Executive Assistant, International AIDS Society, Switzerland
Anouk Chevalier Plante	Inter, CIPHER, International AIDS Society, Switzerland
Sine Gyruup	Intern, CIPHER, International AIDS Society, Switzerland

Special thanks to Lochan Shah, Boston University Intern, for help on preparation of this report.

CIPHER Scientific and Technical Advisory Committee

Annette Sohn	TREAT Asia/amfAR, Thailand
Celia Christie-Samuels	University of West Indies, Jamaica
Chewe Luo	UNICEF, USA
Diana Gibb	MRC Clinical Trials Unit, UK
François Dabis	INSERM, Université Victor Segalen Bordeaux, France
Laura Guay	Elizabeth Glaser Pediatric AIDS Foundation / George Washington University, USA
Linda-Gail Bekker	Desmond Tutu HIV Centre, University of Cape Town, South Africa
Lynne Mofenson	Elizabeth Glaser Pediatric AIDS Foundation, USA
Mark Cotton	Stellenbosch Children's Hospital, South Africa
Martina Penazzato	World Health Organization, Switzerland
Rohan Hazra	US National Institutes of Health, NICHD, USA
Shaffiq Essajee	World Health Organization, Switzerland

Support



Copyright

International AIDS Society, Switzerland

Produced by



Stronger Together Against HIV

Avenue de France 23
CH-1202 Geneva
Switzerland
Tel: +41 22 710 08 00
Fax: +41 22 710 08 99
info@iasociety.org
www.iasociety.org

Photo disclaimer: The photographs used in this publication are for illustrative purposes only; they do not imply HIV status, or any particular attitudes, behaviours or actions on the part of any person who appears in the photographs.

Executive Summary

Despite notable progress in reducing vertical transmission of HIV, the paediatric population remains significantly disadvantaged regarding access to treatment. Only 23% of children in need received treatment compared with 37% of adults in need in 2013. As the HIV epidemic matures, there is a growing population of adolescents living with HIV; in recent years, this particularly vulnerable group has seen a 50% increase in AIDS-related mortality compared with a decrease of 30% in the global population. These young people face unique challenges, which the Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) is committed to placing firmly on the global public health agenda.

This was a pivotal year for CIPHER as it went from being a two-year research promotion initiative to a priority programme of the International AIDS Society (IAS). In 2014, CIPHER focused on:

- Addressing the research gap associated with challenges in treatment and adherence for young people, especially adolescents
- Strengthening and guiding the largest collaboration of paediatric HIV cohorts to date on the first data-sharing projects – antiretroviral therapy (ART) in children and global epidemiology of perinatally HIV-infected adolescents – while exploring how the group can also support normative guideline development and help accelerate the availability of optimal paediatric antiretrovirals (ARVs)
- Extending the research grant programme with two awards in 2014 and the launch of a new round that will award US\$750,000 in 2015
- Convening key stakeholders to address challenges associated with paediatric ARVs.

CIPHER also organized a special issue in the Journal of the International AIDS Society (JIAS), “[HIV and adolescents: focus on young key populations](#)”, which was published in early 2015.

Throughout the 20th International AIDS Conference (AIDS 2014), CIPHER hosted and contributed to several events. Throughout the year, CIPHER also participated as a key stakeholder in paediatric HIV in relevant international initiatives, working groups and consultations.

For 2015, CIPHER will continue to promote the paediatric HIV research agenda by building on the solid core programme developed in this initial phase and extend its activities in paediatric HIV with an advocacy component. Widening the scope of CIPHER stakeholders to include additional partners and sponsors is part of this strategy.

Background

Much progress has been made in scaling up prevention of mother-to-child transmission (PMTCT), with a record 67% or 970,000 pregnant women receiving ART for PMTCT in 2013¹. An estimated 900,000 new HIV infections among children have been prevented since 2009². Despite this progress, globally, 3.2 million children were living with HIV in 2013 and 190,000 died from AIDS-related causes³. UNAIDS reported 240,000 new infections in children in 2013 – this is one new infection every two minutes⁴. The paediatric population also remains significantly disadvantaged regarding access to treatment. In 2013, only 23% of children in need received treatment compared with 37% of adults in need⁵.

Access to timely and reliable early infant diagnosis remains only one of many key challenges that paediatric populations face in resource-limited settings. With increasing implementation of PMTCT and expanding ART coverage, studies examining the long-term impact of early and extended ARV exposure on the growth and development of HIV-infected and uninfected children are needed. Data are also lacking on optimal ART initiation and management, paediatric formulations (first-line, second-line and salvage therapy) and interactions between ARVs and drugs to treat co-morbidities.

There is a growing population of adolescents living with HIV, and this is being called “the perfect storm”. In recent years, this particularly vulnerable group has seen a 50% increase in AIDS-related mortality compared with a decrease of 30% in the global population. More information is needed on optimal clinical management of these youth, including retention in care, treatment adherence and transition to adult ART programmes, as well as disclosure, psychosocial support and HIV/sexually transmitted infection prevention.

Increased efforts to bridge these identified research gaps are needed to support evidence-based policies and improve the treatment and care of infants, children and adolescents living with HIV.

The IAS launched CIPHER in 2012 with support from the founding sponsor, ViiV Healthcare, to start addressing outstanding research gaps related to clinical management and delivery of services to infants, children and adolescents affected by HIV in resource-limited settings. CIPHER is guided by a world-class Scientific and Technical Advisory Committee (STAC) of experts in paediatric HIV convened by the IAS.

The key objectives of CIPHER are:

- Promoting and investing in targeted research to address priority knowledge gaps in paediatric HIV
- Establishing collaboration mechanisms to strengthen communication, knowledge transfer and exchange among paediatric HIV cohorts
- Carrying out advocacy and outreach to support evidence-informed clinical, policy and programmatic decision making.

In 2012/13, CIPHER developed a comprehensive research agenda in paediatric HIV in collaboration with key stakeholders and experts and started promoting this agenda through a core programme of activities. By the end of 2013, paediatrics became one of three IAS programme priorities largely due to increased awareness and the overall success of CIPHER. In 2014, CIPHER strengthened its established its core programme while expanding its advocacy component and participating as a stakeholder in relevant initiatives and working groups in the paediatric space.

¹ AIDS.gov Global HIV/AIDS Overview

² AVERT: Children, HIV and AIDS

³ UNAIDS: Global Report: UNAIDS Report on the Global AIDS Epidemic 2013

⁴ UNAIDS: Gap Report 2013

⁵ WHO Data & Statistics: HIV/AIDS

Research Promotion

Research Grant Programme

The CIPHER Grant Programme is specifically designed to attract early-stage investigators to paediatric HIV research in order to cultivate a new generation of scientists dedicated to the field and to foster innovative ideas and evidence-based approaches and interventions. All projects funded must address one of the 12 clinical and operational priority research questions (see Annex 1) identified by the [2012 needs assessment](#). The grants are for up to US\$150,000 (up to US\$75,000 for up to two years) each; 80% of direct costs of the grant must be spent in resource-limited settings.

In the first round of the grant programme, seven grantees were awarded a total of US\$1 million at the 7th IAS Conference on HIV Pathogenesis, Treatment and Prevention (IAS 2013) in Kuala Lumpur, Malaysia.

To maximize the impact of CIPHER in 2014, two additional grantees were selected from the pool of short-listed applicants for the 2013 round. The 2014 Grantees were awarded at the 20th International AIDS Conference (AIDS 2014) in Melbourne, Australia.

A major accomplishment this year was the continuation of this much-needed opportunity for young investigators with the launch of a new round of grants at AIDS 2014, worth US\$750,000. The call for letters of intent (LOIs) opened in October 2014: 101 LOIs were received, 80 of which were eligible. By the end of the year, 24 applicants were short-listed to submit a full proposal. Following peer review and selection in early 2015, the winners will be announced at the 8th IAS Conference on HIV Pathogenesis, Treatment and Prevention (IAS 2015) in Vancouver, Canada.

Box 1: 2014 CIPHER Grantees

Eric McCollum, The Johns Hopkins University, School of Medicine, USA

For research in Malawi, on *Bubble continuous positive airway pressure (bCPAP) treatment in hospitalized African infants failing standard pneumonia care in a high HIV prevalence country*. Pneumonia is the most common cause of death in children <5 years old worldwide. Pneumonia mortality rates in Africa are high and increased further in HIV-infected children. Treatment innovations are needed. bCPAP is an innovative, effective, low-cost, simple, non-invasive ventilation approach to treat severe paediatric respiratory illnesses. This study will assess bCPAP effects on mortality and physiology in children failing standard pneumonia treatment to inform current care and potential refinements to bCPAP technology.

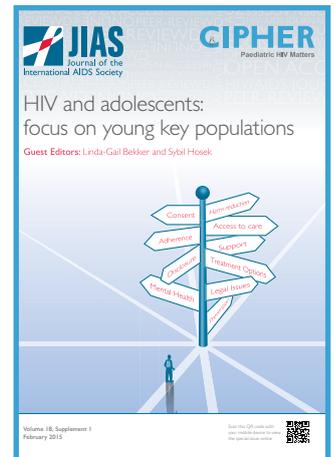
Tavitiya Sudjaritruk, Research Institute for Health Sciences, Chang Mai University, Thailand

For research in Thailand, on *Liver injury and long-term metabolic complications among perinatally HIV-infected children and adolescents receiving antiretroviral therapy*. This study focuses on the long-term complications of HIV infection and ART among perinatally HIV-infected children and adolescents. The specific aim is to determine the prevalence of non-alcoholic fatty liver disease (NAFLD) in perinatally HIV-infected youths in a resource-limited setting.

JIAS Special Issue: HIV and Adolescents

While a decrease in HIV deaths has been observed in other age groups, HIV deaths continue to increase dramatically in adolescents. Young key populations (YKPs) in particular have been identified as bearing a disproportionate burden of HIV. These include young men who have sex with men, transgender youth, young people who sell sex, young women and young people who inject drugs, as well as various combinations of these. YKPs also encounter high levels of stigma and discrimination, posing additional barriers for getting tested for HIV, accessing services and adhering to treatment.

In 2014, CIPHER organized a special issue in JIAS, "HIV and adolescents: focus on young key populations", with guest editors Linda-Gail Bekker (Desmond Tutu HIV Centre, South Africa) and Sybil Hosek (John H. Stroger, Jr. Hospital, USA). The articles in this supplement are aimed at identifying the current gaps in understanding the HIV-related issues faced by YKPs while calling for innovative and comprehensive approaches to linking YKPs to HIV prevention and treatment cascades. Articles look at tailoring combination prevention packages to the needs of YKPs, facilitating access to HIV testing and health services, enabling adherence to treatment, and addressing and providing support for the specific mental health needs of YKPs while also addressing the legal and policy frameworks that directly impact on their health.



Supporting Cohort Collaboration

Global Cohort Collaboration

The [CIPHER Global Cohort Collaboration](#) reached a major milestone in 2014 with its first data merge starting in December. This is the largest collaboration of paediatric HIV observational cohorts to date, representing 250,000 infants, children and adolescents affected by HIV, or 20% of children on antiretroviral treatment worldwide. The collaboration is currently running studies on two critical research gaps in paediatric HIV:

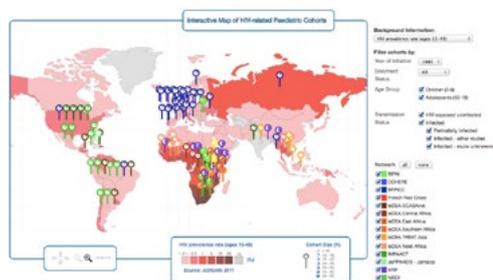
- The durability of first-line ART in children
- The global epidemiology of perinatally HIV-infected adolescents.

On 3 March 2014, CIPHER held its annual meeting in Boston, USA, with more than 60 participants; a follow-up technical meeting was held in Sitges, Spain (27 March). At the ILF/CIPHER thematic roundtable in Melbourne at AIDS 2014, the group explored how it can support normative guideline development and help accelerate the availability of optimal paediatric ARVs.

The collaboration is governed by an Executive Committee (IAS and CIPHER) and a Steering Committee with representatives of participating cohorts. Data management is led by a collaboration of three major data centres on three continents and the Project Oversight Team.

CIPHER Online Database

The CIPHER [online paediatric HIV cohort database](#) is an open-access platform for investigators, funders and policy makers designed to support cohort collaboration and research. It features an interactive map, detailed cohort profiles and the number of participants in each cohort disaggregated by age group, sex and route of HIV transmission.



In 2014, CIPHER continued mapping out paediatric cohorts worldwide. Beyond supporting cohort collaboration, the World Health Organization (WHO) used the database to help survey work on adolescent treatment; CIPHER used it to help develop the first workshop on adolescent transition. New search and information viewing functions were designed, and will be released in 2015.

Outreach and Advocacy

With CIPHER positioned as the paediatric priority of the IAS in early 2014, all IAS paediatrics activities were brought under the umbrella of CIPHER, including participation in relevant international committees and working groups:

- Inter-Agency Task Team for Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and Children Child Survival Working Group (IATT CSWG)
- Paediatric ARV Procurement Working Group (PAPWG)
- Paediatric ARV Working Group (PAWG)
- Paediatric HIV Treatment Initiative of UNITAD, DNDi and the Medicines Patent Pool
- Adolescent Treatment Coalition.

The advocacy and outreach component places the IAS/CIPHER at the table as a stakeholder in paediatric HIV, and allows us to identify synergies, engage with other partners, avoid overlap and identify potential sources of funding. It also leverages the IAS's strength as a third-party convener, bringing together stakeholders to identify key barriers and ways of moving forward. This both creates stakeholder engagement and helps identify strategic activities where our resources can be most effective and have the most impact.

CIPHER at AIDS 2014

At AIDS 2014, CIPHER organized and participated in many activities, leveraging the convening power of the International AIDS Conference to promote its objectives, raise awareness about the initiative and engage with stakeholders.

6th Virology Education International Workshop on HIV Pediatrics

Friday 18 July, 08:00-17:30; Saturday 19 July, 08:00-17:30

During the workshop, CIPHER engaged in the following activities:

- Nelleke Langerak and Rebecca Hodes (2013 Grantees) and Tavitiya Sudjaritruk and Eric McCollum (2014 Grantees) presented their research projects on an LCD screen during the breaks. This was a great opportunity for these early-stage investigators to engage with colleagues in the field, demonstrate preliminary findings from their research, and present their new granted projects.
- Degu Jerene Dare (2013 Grantee) had an oral abstract accepted for the programme: "The Effect of Antiretroviral Therapy on Tuberculosis Incidence Rate among Adolescents and Younger Children Living with HIV in Ethiopia".
- CIPHER introduced the 2014 Grantees and announced the launch of a [new round of grants for 2015](#).
- Virology Education granted free workshop registration to all CIPHER Grantees.

ILF/CIPHER Thematic Roundtable on Paediatric HIV

Saturday 19 July, 18:00-21:00

In collaboration with the IAS's Industry Liaison Forum (ILF), CIPHER held the ILF/CIPHER Thematic Roundtable on Paediatric HIV. This meeting was a follow up to the first of this series, on [paediatric ARVs](#), which was held in Geneva, Switzerland, on 27 November 2013, gathering together representatives of 13 ARV manufacturers and 12 international organizations to identify challenges specific to paediatric ARVs and discuss multi-stakeholder approaches to addressing those challenges.

The aim of the Melbourne roundtable was to widen the scope of the discussion to include investigators from the largest paediatric HIV cohorts worldwide, as well as regulators. The objective was to identify key challenges in optimizing paediatric HIV care and treatment and approaches for multi-stakeholder collaboration. The contributions from cohorts, industry and regulators fostered innovative ideas on how to move forward. The discussions included reflections on how the IAS and CIPHER in particular could play a key role in addressing these challenges. Meeting report, agenda and slides available [here](#).

CIPHER Stakeholder Meeting

Sunday 20 July, 14:00-15:30

The CIPHER Stakeholder Meeting provided an update on CIPHER's achievements and progress to key stakeholders. The CIPHER Scientific Technical and Advisory Committee (STAC), cohort representatives, grantees and key stakeholders were invited to the meeting. The objective was to review CIPHER's programme, discuss the year's developments and next steps, and network.

- New directions on developing CIPHER as the IAS paediatric priority were presented and updates were given on projects underway.

- The 2014 Grantees, [Tavitiya Sudjaritruk](#) and [Eric McCollum](#), presented their projects. [Rebecca Hodes](#) and [Nelleke Langerak](#) (2013 Grantees) shared preliminary findings from their CIPHER projects. STAC members provided feedback on the presentations to guide the early-stage investigators.
- Finally, participants were updated on the [ILF/CIPHER Thematic Roundtable on Paediatric HIV](#), which was held the previous day.

Reaching Young Key Populations: Scaling Up Approaches

Monday 21 July, 18:30-20:30

As a co-organizer of this WHO [satellite session](#), CIPHER was pleased to provide support for the official launch of the technical briefs on HIV and young key populations produced by the Interagency Working Group on Key Populations. The briefs came alive with thorough presentations mixed with interviews/dialogue and a panel discussion with questions from the audience. The purpose was to bring together young activists, government and UN and research institutions to make a passionate call to action for creative and sustainable development and scaling up of programmes for young key populations at higher risk of HIV infection. Besides introducing the briefs, participants presented the lived experiences of young key populations and showcased best practice in responding to the specific needs of these populations.

Inter-Agency Working Group on Key Populations technical briefs are available here:

- [HIV and young transgender people \(pdf, 179kb\)](#)
- [HIV and young people who sell sex \(pdf, 203kb\)](#)
- [HIV and young people who inject drugs \(pdf, 179kb\)](#)
- [HIV and young men who have sex with men \(pdf, 195kb\)](#)

IAS Industry Consultation

Tuesday 22 July, 18:30-20:30

CIPHER was on the agenda at the IAS Industry Consultation, an invitation-only meeting organized by the ILF. The IAS held its first high-level IAS Industry Consultation on 4 March 2014 in Boston, US, where the IAS presented its strategic priorities while getting insights from industry partners regarding their interest in fostering further collaboration.

Following this successful event, the Melbourne IAS Industry Consultation was an occasion to deepen the discussion started in March and get feedback from a range of companies. The meeting report is available on request from IAS-ILF Research Officer Sébastien Morin at sebastien.morin@iasociety.org.

IAS Members' Meeting

Wednesday 23 July, 12:45-14.15

IAS incoming President-Elect Linda-Gail Bekker introduced CIPHER at the [IAS Members' Meeting](#).

Oral Abstract Presentation: CIPHER Grantee Rebecca Hodes

Wednesday 23 July, 14:30-16:00

CIPHER 2013 Grantee Rebecca Hodes was invited to present preliminary findings from her project with an oral abstract, "Promoting adolescent antiretroviral adherence and sexual and reproductive health uptake: Interim findings from the Mzantsi Wakho study in Eastern Cape of South Africa", at a [plenary session](#).

Growing Tomorrow's Leaders in Paediatric HIV

Wednesday 23 July, 18:30-20:30

CIPHER was featured in a symposium organized by ViiV Healthcare to celebrate tomorrow's leaders in paediatric HIV. This symposium was aimed at exploring activities that will help us identify, grow and support leaders across all disciplines, from research to policy, so that the children infected with HIV today become leaders themselves in the future.

- Linda-Gail Bekker introduced CIPHER and told the story of how it has grown from a two-year initiative to become an IAS Priority.
- CIPHER 2013 Grantee Degu Jerene Dare spoke about his CIPHER grant and what it meant to him professionally.
- ViiV Healthcare generously put together a beautiful video introducing the [CIPHER 2013 Grantees](#).
- Finally, the CIPHER 2014 Grantees and the launch of a new round of grants for 2015 were announced.

To watch other videos from the symposium, please click on these links:

- [An AIDS Free Generation](#)
- [How to Dance](#)

CIPHER Press Conference

Thursday 24 July, 10:00-11:00

In collaboration with ViiV Healthcare, CIPHER organized a press conference on the topic, "Children are being left behind in the global effort to reduce HIV infections – how can we close the gap?"

- Panel speakers included: Linda-Gail Bekker, IAS President-Elect; Annette Sohn, amfAR Vice President and Director of TREAT Asia; Dominique Limet, ViiV Healthcare CEO; and Charles Lyons, President and CEO of the Elizabeth Glaser Paediatric AIDS Foundation.
- [ViiV Healthcare confirmed its continued support](#) of CIPHER and generously committed to providing CIPHER with an additional £1.5 million in funding for 2014/15.

CIPHER Grant Programme Official Awards Ceremony

Friday 25 July, 08:10-08:25

CIPHER was pleased to show the [CIPHER Grantees 2013](#) video created by ViiV Healthcare as an introduction to the CIPHER Grant Programme awards ceremony. Linda-Gail Bekker introduced the CIPHER Grant Programme and Françoise Barré-Sinoussi handed over the grants to the 2014 Grantees, Tavitiya Sudjaritruk and Eric McCollum.



From right: Linda-Gail Bekker, Tavitiya Sudjaritruk and Françoise Barré-Sinoussi