COLLABORATIVE INITIATIVE FOR PAEDIATRIC HIV EDUCATION AND RESEARCH

2016 ANNUAL REPORT
ACKNOWLEDGEMENTS

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MISSION AND GOALS

CIPHER aims to optimize clinical management and delivery of services to infants, children and adolescents affected by HIV in resource-limited settings through advocacy and research promotion.

Specifically, CIPHER works to fulfil the following key objectives:

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

CIPHER complements existing global initiatives and creates new partnerships to maximize investment in paediatric HIV research and improve paediatric health outcomes. CIPHER’s scientific and programmatic foundation is informed by a comprehensive needs assessment. The initiative is guided by a world-class Scientific Technical and Advisory Committee (STAC) of experts in paediatric HIV convened by the IAS.

The 2016 annual report illustrates how CIPHER has led in the field of paediatric HIV to address priority knowledge gaps for evidence-informed policy, programmatic and clinical decision making, and ultimately for better outcomes for children and adolescents affected by HIV. This is in line with the Operational Plan of the IAS HIV Programmes, which focuses on influencing policy, inspiring research and instigating action to remove structural barriers.

POLICY: INFLUENCE GLOBAL AND NATIONAL HIV POLICY AND BRIDGE GAPS BETWEEN THE HIV RESPONSE AND THE BROADER INTEGRATED HEALTH LANDSCAPE.

RESEARCH: INSPIRE HIV RESEARCH TARGETING SCIENTIFIC GAPS THAT LINK RESEARCH TO STRATEGIC PROGRAMME PRIORITIES.

STRUCTURAL BARRIERS: INSTIGATE ACTION TO REMOVE STRUCTURAL BARRIERS AND ADDRESS HUMAN RIGHTS VIOLATIONS THAT INHIBIT ACCESS TO AND UPTAKE OF COMPREHENSIVE HIV SERVICES FOR SELECTED POPULATIONS AND COMMUNITIES.

“CIPHER supports cutting-edge research that brings us closer to closing the gaps between global responses to HIV among adults and paediatric populations.”
- Chris Beyer, IAS President

“The impact of CIPHER research grants goes beyond the individual findings they generate…These grants support research that influence national and international policy, unlocking important additional funding for paediatric research to ultimately impact the lives of infants, children, and adolescents worldwide who are disproportionately impacted by HIV. That’s the kind of bold action we need and the reason we are proud to support the IAS and CIPHER in this investment to reduce the global burden of paediatric HIV.”
- Helen McDowell, Global Access and Positive Action Director of CIPHER Founding Sponsor ViiV Healthcare

“It is opportunities like these to work alongside people of such high calibre that are the game-changing moments CIPHER is creating.”
- Amy Slogrove, CIPHER Cohort Collaboration post-doctoral grantee

“Great heterogeneity both within and across countries made it clear that there will not be one approach that fits all.”
- Quote from an attendee of the 2nd Adolescent Transition Workshop
POLICY

Global research agendas for amplified impact

With fast-track targets to end paediatric and adolescent AIDS by 2030, evidence is needed to inform global policy change and ensure better outcomes for infants, children and adolescents living with and affected by HIV. Towards this, CIPHER and WHO launched a process, based on the Child Health and Nutrition Research Initiative (CHNRI) methodology for setting priorities in health research, to develop global research agendas on HIV testing, treatment and care and support for paediatric and adolescent populations. The aim of the agendas is to provide comprehensive and clear goals to streamline research in these fields and maximize available research resources.

Access to better treatment for kids, faster

A prominent stakeholder in paediatric drug optimization, in 2016 CIPHER actively worked to help advance global thinking and discussions on how to get better drugs to children faster. In March, the concept of a Global Accelerator for Paediatric formulations (GAP-f) to reduce the 8-10 year gap between development of optimal adult and paediatric drug formulation was launched at the ILF/CIPHER Thematic Roundtable on Paediatric ARVs: Stimulating Development of the Most Needed Formulations. A revised version of the GAP-f concept was presented to stakeholders for further feedback at AIDS 2016 at the CTA/IAS Consultation on Accelerating Development of Most NEEDED Paediatric ARVs (see meeting report here).

RESEARCH

The CIPHER Grant Programme: answering targeted research gaps in resource-limited settings while growing the next generation of investigators

CIPHER awarded its largest round of grants to date, US$1.2 million, in an official award ceremony at the 21st International AIDS Conference (AIDS 2016) in Durban, South Africa (see press release). Once again the programme saw a huge response, underlining the need for funding opportunities for early stage researchers in paediatric HIV. After a rigorous review process, seven projects were selected, spanning the CIPHER priority research topics.

We are delighted to welcome the seven researchers to the CIPHER Grant Programme and look forward to following their progress over the coming years.

- **Amara Ezeamama** of Nigeria, with the Michigan State University, Dept. of Psychiatry
  Chronic HIV, executive function, psychosocial adjustment and quality of life in Ugandan school-aged children – A study of long-term functional survival with perinatal HIV infection and exposure.

- **Dorina Onoya** of South Africa, with the Wits Health Consortium
  Understanding predictors of early antenatal care initiation and patterns of postpartum maternal mobility in relation to paediatric HIV diagnosis and linkage to HIV care in Gauteng province, South Africa.

- **Gabriel Loni Ekali** of Cameroon, with the Biotechnology Center
  Impact of in utero and breastfeeding exposure to TDF on renal function in HIV exposed uninfected children in Cameroon.

- **Latoya Small** of the United States, with the University of North Carolina at Chapel Hill
  VUKA EKHAYA: A take home family intervention to improve adherence and reduce behavioural risk among perinatally HIV infected youth.

- **Louis-Marie Yindom** of Cameroon, with The Chancellor, Masters and Scholars of the University of Oxford, UK
  HIV associated chronic lung disease (CLD) in older vertically infected children and adolescents: studies of aetiology and predictive biomarkers.

- **McNeil Ngongondo** of Malawi, with the UNC Project
  A pharmacokinetic evaluation of TDF and ATV exposure in HIV exposed breastfeeding infants of mothers taking TDF/3TC/ATV/r.

- **Watsamon Jantarabenjakul** of Thailand, with the Chulalongkorn University
  Neurodevelopmental and neuroanatomical outcomes in early antiretroviral treated young children with perinatally acquired HIV infection (PHIV) compared to age matched perinatally HIV exposed uninfected children (PHEU).

CIPHER Global Cohort Collaboration: the largest paediatric and adolescent observational cohort collaboration to date

This was a watershed year for the CIPHER Global Cohort Collaboration, which brings together the largest observational paediatric and adolescent observational cohorts worldwide to study two priority questions of public health importance:
• The durability of first-line antiretroviral treatment (ART) in children in resource-limited settings;
• The global epidemiology of adolescents living with HIV since birth.

Results from both projects were accepted for oral presentation at international scientific meetings throughout the year, including the Conference on Retroviruses and Opportunistic Infections (CROI), the International Workshop on HIV Observational Databases (IWHOD), the 8th International Paediatrics Workshop and AIDS 2016. Additional studies on the duration of second-line treatment in children and sub-Saharan adolescent growth analysis were also launched.

This reflects the success of this major global collaboration in bringing together disparate data sources to provide a global picture on these two topics for the first time. The research highlights major challenges to health worldwide, and suggests that in many countries, health outcomes consistently lag behind high income countries, especially in terms of mortality. Results from these studies have already informed the Paediatric ARV Drug Optimisation meetings and other policy related fora. Data from the collaboration has also been shared with UNAIDS to help inform the 2016 Spectrum global estimates.

STRUCTURAL BARRIERS

CIPHER focuses on two major structural barriers to wellbeing for adolescents living with HIV: transition of adolescents from paediatric to adult care and access to treatment for adolescents.

Adolescent Transition Workshop
Ensuring adolescents are retained in care as they transition to adulthood

In collaboration with the International epidemiologic Databases to Evaluate AIDS (IeDEA) Network Coordinating Centre (INCC), CIPHER held the 2nd Adolescent Transition Workshop, Budapest, Hungary, 6 April 2016. This abstract-driven workshop built on the baseline of knowledge and roadmap developed in first edition, to bridge the gap between paediatric and adult populations and help ensure that HIV-infected adolescents and young adults are retained in care. The scope included transition in the broad sense, keeping in mind that there are different types of transition that vary by setting, available health care infrastructure, age and emotional development. A total of 52 abstracts were submitted, underlining the increase in research now being done on this important topic.

Adolescent HIV Treatment Coalition

IAS/CIPHER are proud to host the Adolescent HIV Treatment Coalition (ATC). The ATC is a diverse community including youth networks, UN agencies, NGOs, researchers and other stakeholders united in advocacy to make quality treatment and care available for all adolescents living with HIV. It provide a collective voice promoting accountability in the HIV response to the realities of adolescent lives. For more information, see the ATC website.