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The International AIDS Society’s CIPHER Initiative Launches Innovative Online Paediatric HIV Cohort Database and Grants US$500,000 to Start Global Paediatric HIV Cohort Collaboration

4 December 2013 (Geneva, Switzerland) — On the occasion of World AIDS Day 2013, the IAS’s Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) is launching an online Paediatric HIV Database and granting US$500,000 for a global paediatric HIV cohort collaboration.

The CIPHER database is intended to act as a dedicated platform and clearing house for cohort collaboration, and is aimed at facilitating communication, data collection, sharing and analysis between cohorts. This online resource provides centralized information and contact details on paediatric HIV cohorts worldwide.

At the XIX International AIDS Conference (AIDS 2012), CIPHER initiated dialogue with paediatric HIV cohort investigators on how to strengthen cohort collaboration and support the generation of more robust evidence to inform policy makers and programme implementers. It was identified that there was a need for a global forum for paediatric HIV investigators to come together and share results, ideas and experiences, as well as an online paediatric HIV cohort database to inform future research directions.

The CIPHER database features an interactive map of paediatric HIV cohorts. Detailed information about each cohort is available, and an interactive pivot table provides a breakdown of cohort participants by route of transmission, age and gender. Cohorts can register, modify and update their entries. The most recent information on the numbers and routes of transmission of subjects will also be included, adding an important epidemiologic tool to the database.

“We have made remarkable progress in prevention of new HIV infections amongst children, with a tremendous 54% drop in new infections from 2001 to 2012. Still, some 260,000 children became newly infected with HIV in 2012 and in the same year HIV treatment coverage for children remained half of coverage for adults,” said Bertrand Audoin, Executive Director of the IAS. “These data are unacceptable, and we think the new CIPHER online database will contribute to a better understanding of the complexities and the specificities of paediatric HIV by promoting collaboration and dialogue between researchers”.

There are many challenges facing paediatric cohort investigators; currently, there is a mix of cohort data, and it is often unclear how the results impact policy and/or clinical practice.

In May 2013, CIPHER convened a Paediatric HIV Cohort Investigator Consultation with investigators from major paediatric HIV cohorts worldwide. Notably, this meeting defined a research agenda of knowledge gaps that can be addressed by cohort collaboration and resulted in an agreement to collaborate on global data-sharing projects. The projects will look at two critical research gaps in paediatric HIV: the durability of first-line antiretroviral treatment (ART) in children in resource-limited settings; and the global epidemiology of adolescents living with HIV since birth.

These two projects aim to fill research gaps and support evidence-based policy decisions and optimize care and treatment of children and adolescents. For example, data on the durability of ART regimens is critical to inform clinicians, public health policy and programme planning, particularly in HIV-infected children under five years old who, according to the new 2013 WHO Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection, have been recommended to initiate immediate therapy and are likely to need life-long treatment. However, data on the probability of switch to second-line in children are limited, and definitions of what constitutes ‘second-line’ treatment vary. With increasing access to ART, HIV-infected children now live longer, making perinatally HIV-infected adolescents an emerging and growing population. In order to ensure optimal
health outcomes, there is a global need to better understand the characteristics of these adolescents and their ability to remain in paediatric care and transition to adult care.

CIPHER is providing a grant of USD$500,000 to fund these two important projects, the first to include such a broad range of participating paediatric cohorts. The grant will be given to three data centres that will be handling the data collection and analysis for the project. The principal investigator for the project is Dr. Mary-Ann Davies, with the Centre for Infectious Disease Epidemiology and Research, University of Cape Town, South Africa, in partnership with lead investigators Dr. Ali Judd, with the Medical Research Council Clinical Trials Unit at University College London, UK, and Dr. George Seage III, with the Paediatric HIV/AIDS Cohort Study Data and Operations Center, Harvard School of Public Health, USA. Findings of the studies will be published jointly under the CIPHER Cohort Collaboration.

In addition, the grant includes a capacity-building scholarship for a scholar from the University of Cape Town to study for two months with the HSPH data centre.

The planned partners for the projects are:

- A Prospective Surveillance Study of Long-term Outcomes in HIV-infected Infants, Children, and Adolescents (IMPAACT P1074)
- Baylor International Pediatric AIDS Initiative at Texas Children’s Hospital (BIPAI)
- Caribbean, Central and South America Network for HIV Research (CCASAnet)
- Collaborative HIV Paediatric Study (CHIPS)
- East African International Databases to Evaluate AIDS (EA-IeDEA)
- Identifying Optimal Models for Care in Africa (Optimal Models ICAP)
- International Epidemiologic Database to Evaluate AIDS Central Africa (CA-IeDEA)
- International Epidemiologic Database to Evaluate AIDS Southern Africa (IeDEA-SA)
- International Epidemiologic Database to Evaluate AIDS West Africa Collaboration (WADA and pWADA)
- Médecins Sans Frontières Pediatric Cohorts (MSF)
- Pediatric HIV/AIDS Cohort Study: Adolescent Master Protocol (PHACS AMP)
- Pediatric HIV/AIDS Cohort Study: Surveillance Monitoring for ART Toxicities Study (PHACS SMARTT)
- Pediatric Late Outcomes Protocol (PACTG/IMPAACT 219/219c)
- TREAT Asia Pediatric HIV Observational Database (TApHOD-IeDEA)
- Ukraine Paediatric HIV Cohort Study

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About CIPHER:
The Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) is a flagship paediatric research initiative of the International AIDS Society (IAS), aimed at addressing outstanding research gaps related to clinical management and delivery of services to infants, children and adolescents affected by HIV in resource-limited settings. Initiated in 2012, CIPHER is supported by an unrestricted grant from ViiV Healthcare’s Paediatric Innovation Seed Fund. The content and structure of the project is guided by paediatric experts convened by the IAS.

The main objectives of CIPHER are:

- Promoting and investing in targeted research to address knowledge gaps/priority questions to optimize service delivery and clinical management of infants and children in resource-limited settings.
- Convening stakeholders and establishing collaboration mechanisms to strengthen communication, knowledge transfer and exchange among paediatric HIV cohorts.

CIPHER is designed to complement existing global initiatives and create partnerships with other organizations to maximize investment in paediatric HIV research and improve paediatric health outcomes. The first phase of the project consisted of building a solid scientific and programmatic foundation. A comprehensive needs assessment was conducted, including a literature review and key
informant interviews with experts, which outlined a set of research priorities that has been used to inform and guide CIPHER.

About the IAS
The International AIDS Society (IAS) is the world’s leading independent association of HIV professionals, with over 16,000 members from more than 196 countries working at all levels of the global response to AIDS. The IAS members include researchers from all disciplines, clinicians, public health and community practitioners on the frontlines of the epidemic, as well as policy and programme planners.
The IAS is custodian of the biennial International AIDS Conference, which will be held in Melbourne, Australia, 20-25 July 2014 and lead organizer of the IAS Conference on HIV Pathogenesis, Treatment and Prevention, which will be held in Vancouver, British Columbia, Canada, 19-22 July 2015.

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