



17th Annual Chiva Conference

Growing up, growing older and living well with HIV



Friday 17 March, Woburn House, London (& online)

WELCOME FROM THE CHIVA CHAIR



I would like to extend a very warm welcome to the 17th annual Chiva conference: Growing up, growing older and living well with HIV. We are very pleased to be back to a primarily in-person conference, although we still welcome some of our attendees online.

Today, we will be looking across the lifespan of what it means to grow up, grow older and achieve the best possible quality of life with HIV. We are delighted to welcome our eminent speakers, giving a UK and international perspective about clinical care, strategy and research.

We will be hearing about vertical transmission and infant feeding, from youth mentors and what their support can mean in clinics, and about ageing with HIV. We will also hear from the fantastic Chiva Youth Committee, who will play an extract of their recent podcast recording about the mental health challenges of growing up with HIV. There will also be a symposium this afternoon dedicated to all the ways young people with HIV are meaningfully involved in Chiva, as well as some of our partner organisations.

This year is Chiva's 21st year and it is an exciting time. As the young people we work with grow older, we are looking towards the future to see how we can work to support children living with HIV and their families, and also young adults, some of whom now have families of their own. I am grateful to Chiva staff and associates, the steering group, the Chiva Youth Committee, trustees and volunteers, who are shaping and delivering this work, and of course to Chiva members. It's important we continue to work together as a medical and social care community, especially in supporting the transition of young people who have grown up with HIV into adult care.

We hope you enjoy the day and find it educational and fun.

Dr Amanda Williams
Chiva Chair

WELCOME FROM THE CHIVA YOUTH COMMITTEE

A warm welcome to the conference from all of us and thank you to everyone who attends our session. This is an exciting opportunity and we are all delighted to share with you all our experiences, perspectives and the work we have done alongside Chiva. As a collective, a lot of work has been put into our session and we are open to any questions or queries you may have afterwards.

Chiva Youth Committee (CYC)

JOIN THE CONVERSATION ONLINE



Share your day and join the conversation online with **#ChivaConference**

Follow **@ChivaProjects** on Twitter, Instagram and Facebook.



Follow us on our new LinkedIn page as we build an online community of health and social care professionals working with children and young adults who've grown up living with HIV.

We'll also be using Mentimeter for online polls and to submit questions during talks. Look out for this and the WiFi password on the screen and signage around the venue, or in your email inbox. Online attendees can also submit questions through Zoom.

SPONSORS



We would like to thank our sponsors, Gilead Sciences and ViiV Healthcare Ltd, who have provided sponsorship towards the meeting but have had no input into or influence over the agenda, content or selection of speakers.

RCPCH Accreditation

RCPCH has approved this activity for CPD in accordance with the current RCPCH CPD Guidelines.

Positive Advice: A new podcast brought to you by Chiva



As part of Positively Spoken, our project to find and record the stories of those growing up with HIV, we stationed ourselves at the International AIDS Conference in Montreal last summer, asking eligible attendees to get involved.

We have mixed their life stories with thoughts from invited guests, who explore the topics further, creating the 'Positive Advice' podcast. Look out for it where you usually get your podcasts or check out our social media channels.

17th Annual Chiva Conference:

Growing up, growing older and living well with HIV

17 March 2023

09:30 - 9:55

Registration and coffee

9:55 - 10:05

Conference welcome

Dr Amanda Williams, Chiva chair

Aiming for U=U in vertical transmission?

Session chairs

Dr Amanda Williams, Dr Marthe Le Prevost & Dr Bala Subramaniam
Chiva Steering Group Members

10:05 - 10:30

Vertical transmission: Where are we now in the UK?

Dr Hermione Lyall, Imperial College Healthcare NHS Trust

10:30 - 11:05

Infants exposed to HIV

Prof Andrew Prendergast, Queen Mary University of London

11:05 - 11:40

An international perspective on vertical transmission

Dr Elaine Abrams, Columbia University

11:40 - 12:05

Coffee break

12:05 - 12:20

Nourish-UK: A study on feeding your baby while living with HIV

Bakita Kasadha & Dr Tanvi Rai, University of Oxford

12:20 - 12:30

HIV and infant feeding: A BHIVA Guidelines perspective

Dr Shema Tariq, University College London

12:30 - 13:00

Panel discussion on breastfeeding

13:00 - 14:00

Lunch

Youth involvement and adolescent services

Session chairs

Katie Warburton & Djamel Hamadache
Chiva Steering Group Members & CYC Member

14:00 – 14:25	Chiva Youth Committee symposium Chiva Youth Committee
14:25 - 14:40	Youth peer mentors in clinics Eli Fitzgerald & Michelle Bockor, Positively UK
14:40 - 14:55	Youth participation in clinical trials and research Mercy Shibemba, Penta
14:55 - 15:15	Adolescent specialist sexual health services Jane Ashby, Central and North West London NHS Foundation Trust, BASHH invited Speaker
15:15 - 15:30	Panel discussion on youth involvement and youth-friendly clinics
15:30 - 15:55	Break and poster viewing
Session chairs	Dr Srin Bandi, Susanna Keiderling & Sharon Peters Chiva Steering Group Members
15:55 - 16:30	Oral abstract presentations: <ul style="list-style-type: none"> 1. High-risk HPV prevalence and serostatus in women living with perinatally acquired HIV (the SHiP study), Dr Merle Henderson, Imperial College London 2. Population-level paediatric HIV surveillance in England: The current picture, Gabriela Toledo, Children's HIV and AIDS Reporting System 3. Infant Postnatal Prophylaxis (PNP) following maternal viraemia during breastfeeding, Dr Emily Lees, University of Oxford

Antiretrovirals and long-term outcomes

16:30 - 16:50	Update on antiretrovirals Dr Alasdair Bamford, Great Ormond Street Hospital
16:50 - 17:20	HIV and ageing: What does this mean for young people? Prof Alan Winston, Imperial College London, BHIVA invited speaker
17:20 - 17:30	Awards and conference close
17:30 - 18:30	Drinks reception

SPEAKER BIOGRAPHIES



Dr Hermione Lyall is a consultant in paediatric infectious diseases at Imperial College Healthcare NHS Trust and Professor of Practice at Imperial College. She runs both HIV and congenital infection clinics at St Mary's Hospital in London and is a ward-attending consultant for paediatric infectious diseases three months per year. She's also a member of the Paediatric European Infection Network (Penta ID) and participates in HIV treatment and prevention trials for children. She has been actively involved in the development of international courses for education for paediatric infections for many years, working with Penta and the European Society for Paediatric Infectious Diseases (ESPID). From 2018-2021, she was a member of the board of ESPID and is now a Trustee on the board of the ESPID Foundation.

In 2020, with colleagues from around Europe, she set up CCMVNET, an international network built around a registry of children with congenital CMV and is currently a chair of the network. Their aim is to learn as much as possible about this condition and promote collaboration for research into prevention and treatment.

"Fundamentally, I am a frontline clinician who can bring people together – children, families and peer supporters, clinicians, laboratory scientists, epidemiologists, virologists, pharmacologists, and trialists – the team that we will need to change the future for children with congenital infections."



Professor Andrew Prendergast is a Wellcome Senior Clinical Fellow, and Professor of Paediatric Infection and Immunology at Queen Mary University of London. He trained in paediatric infectious diseases, HIV immunology and clinical trials in the UK, and has spent the past 11 years in Zimbabwe, where he is Director of the Zvitambo Institute for Maternal and Child Health Research in Harare.

Zvitambo has been at the forefront of HIV research over the past two decades as the HIV epidemic has evolved in Zimbabwe, and has generated some of the first data reporting adverse health outcomes among children who are HIV-exposed and uninfected. Zvitambo's current research focuses on interventions to ensure that children have a healthy start, by promoting healthy birth, growth and development, especially among children born to women living with HIV.



Dr Elaine Abrams is a Professor of Epidemiology and Paediatrics at Columbia University with over 35 years of experience in the prevention and treatment of HIV infection and associated infectious diseases in pregnant women, children, and their families. As the Senior Director for Research at ICAP, she leads ICAP's large research agenda and is responsible for the development of technical assistance and service programs for paediatric and perinatal prevention initiatives for ICAP programs in sub-Saharan Africa and Asia.

Dr Abrams served three consecutive terms as Chair of the NIH-funded IMPAACT network HIV treatment scientific committee and currently guides the network scientific agenda as a member of the Senior Leadership Group. She chaired the WHO consolidated guidelines for the use of antiretroviral drugs, 2015-2019, introducing universal treatment, antiretrovirals for prevention, and optimized antiretroviral regimens with dolutegravir. She co-chaired the WHO Paediatric Antiretroviral Working Group and is currently co-chair of the WHO HIV, Hepatitis and STIs Pregnancy and Breastfeeding Therapeutics Working Group. Dr Abrams' research interests have focused on maternal-child health, vertical transmission, the natural history of paediatric HIV, and optimising therapies for infants, children, adolescents and pregnant and breastfeeding women.



Bakita Kasadha is an NIHR Fellow at the Nuffield Department of Primary Care Health Sciences (University of Oxford). She was the main researcher on the multi-award-winning HIV and infant feeding study, Nourish-UK.

In 2022, she co-edited a SAGE special collection of writing with Dr Shema Tariq (UCL) titled *HIV & Women: Where Are We Now?* She has held a range of national and international advisory and strategic roles including as the current chair of Glitch, a charity focused on digital safety. She is a member of the Sexual Health and HIV All East Research (SHARE) Collaborative Community Advisory Board at Queen Mary University of London.



Dr Tanvi Rai is a Senior Researcher in the Nuffield Department of Primary Care Health Sciences at the University of Oxford and Principal Investigator for the NOURISH-UK study. Her research focuses on the social determinants of health and health inequalities. Her expertise is in developing and conducting mixed methods research to understand how social and structural factors influence how people cope with different health conditions, and their experience of accessing and receiving healthcare services.

Pamela Morrison: (breastfeeding panel participant) Lactation Consultant.

International Board Certified Lactation Consultant, Retired (1990-2020). Pamela spent most of her life in East and Southern Africa, where breastfeeding is both the cultural norm and a cornerstone of child survival. Breastfeeding her own sons, including a set of twins, led to an interest in mother-to-mother support. After qualifying as the first International Board Certified Lactation Consultant in Zimbabwe in 1990, she worked in private practice in Harare while also serving on various national breastfeeding committees. Pamela left Africa in 2003 and worked for an international breastfeeding advocacy organisation until 2018. She now lives in England where she continues to advocate for safe breastfeeding in the context of HIV.



Dr Shema Tariq is a Senior Research Fellow at UCL's Institute for Global Health, and Consultant in HIV at the Mortimer Market Centre in London. Shema's main area of interest and expertise is the health and wellbeing of women living with HIV. She has been involved in a number of studies on HIV and pregnancy, and HIV and infant feeding. Shema is a former Vice-Chair of the BHIVA HIV and Pregnancy Guidelines Committee and is leading the writing of the updated HIV and infant feeding guidelines. She is Chair of the 4M Mentor Mother Network Steering Group, and a Trustee of Positively UK and Tommy's Baby Charity.



Since 2010, the **Chiva Youth Committee (CYC)** has been working alongside the Chiva staff team, Trustee Board and Steering Group to:

- Give a voice to children and young people growing up with HIV in the work of Chiva and in the public domain.
- Tackle HIV stigma and support campaigns by working with the media, policy makers and the public.
- Develop Chiva resources and ensure youth voices are represented.

All CYC members are aged 14–17 years old and living with HIV. The group has recently expanded to 20 members, including an elected Chair and Deputy Chair. Committee members hold their roles for two to three years. The CYC achieves its aims by: reviewing Chiva's work and influencing developments at CYC meetings 3–4 times a year; working with Chiva's partner organisations to tackle issues, strengthen campaigns and speak at conferences; and getting involved in projects they feel will work towards creating a better awareness and understanding of HIV.

Abi Carter is the Chiva Participation Manager who supports the CYC along with a wider team of associates and peer workers who have also grown up with HIV. The CYC is excited that six members of its group will be representing them at the conference today.



Eli Fitzgerald and **Michelle Bockor** work with the Positively UK Youth Project, which supports young adults living with HIV by providing peer support in multiple HIV clinics based in London. They co-create group workshops so young people feel less isolated, form connections, grow their knowledge around HIV and have fun.



Mercy Shibemba works on youth engagement and participation across paediatric clinical trials and research at Penta. She is also a health journalist sharing information about HIV.



Darren Tippetts has over 30 years' experience in the NHS and the voluntary sector, which has included working for NHS trusts, two national helplines, an HIV charity, The Alzheimer's Society and The Princess Royal Trust for Carers. He is currently a Safeguarding Lead for Integrated Sexual Health and HIV at Central and North London NHS Trust and a member of BASHH Adolescent Special Interest Group. CNWL have sexual health clinics in four London boroughs and across Surrey, and the safeguarding team provide advice, support and training for all staff working in sexual health and HIV.



Gabriela Toledo works as a Surveillance Officer for the NHS Integrated Screening Outcomes Surveillance Service (ISOSS) and the Children's HIV and AIDS Reporting System (CHARS) based at UCL Great Ormond Street Institute of Child Health. In her role, she contributes to the active surveillance of health outcomes and quality of care services for children living with HIV in England. Gabriela is also a PhD candidate at the Institute of Child Health and focuses her research on the health risks and outcomes of children who are HIV-exposed and uninfected in Malawi. She is passionate about maternal and child health in the context of infectious diseases and plans to continue her research in paediatric HIV following the completion of her PhD.



Dr Emily Lees is Clinical Lecturer in Paediatrics at the University of Oxford, having completed her Paediatric clinical training in the field of Infectious Diseases and Immunology. She completed an Academic Clinical Fellowship at the University of Liverpool during her first 3 years of Paediatric training. Following this, she undertook a PhD looking at the interactions of *Salmonellae* with the human host, in the form of hiPSC-derived gut organoids and macrophages at the Wellcome Trust Sanger Institute / Fitzwilliam College with the Dougan group from 2016-2019. She returned to Fitzwilliam as a Research fellow in 2021 in order to complete further work on this topic, supported by a starter grant from the Academy of Medical Sciences, and currently split her time between the University of Oxford and Fitzwilliam College, Cambridge.



Dr Alasdair Bamford is a Paediatric Infectious Diseases Consultant and Specialty Lead at Great Ormond Street Hospital and an Honorary Associate Professor at UCL GOSH Institute of Child Health, London, UK. He also works with the MRC-CTU as clinical advisor to paediatric infection trials and cohort studies and also for Penta on the faculty for international HIV training courses and lead for HIV treatment guidelines. He is also secretary of the British Paediatric Allergy Infection and Immunity Group (BPAIIG).



Dr Alan Winston is a professor of HIV and Genitourinary Medicine at Imperial College and Consultant Physician at St. Mary's Hospital, London. He has an MD in antiretroviral clinical pharmacology and his research focuses on non-infectious co-morbidities associated with HIV-disease in the modern antiretroviral era, with a strong focus on central nervous system complications.

Dr Alan Winston qualified from Glasgow University and undertook training in general medicine and HIV medicine in the UK and Australia. He leads the HIV and GU clinical trials unit at St. Mary's Hospital, which runs over 20 studies at one time. He is the principal clinical investigator on the POPPY study, a cohort study describing the incidence and nature of co-morbidities in HIV.

COMMUNITY STALL HOLDERS



The Integrated Screening Outcomes Surveillance Service (ISOSS) is part of the NHS Infectious Diseases in Pregnancy Screening Programme. Based at UCL Great Ormond Street Institute of Child Health, ISOSS carry out the national monitoring of HIV, syphilis and hepatitis B in pregnant women and children. Long-term paediatric HIV surveillance is carried out by the **Children's HIV and AIDS Reporting System (CHARS)**, which runs alongside ISOSS, and is commissioned by NHS England and NHS Improvement.



The Food Chain exists to ensure people living with HIV in London can access the nutrition they need. We deliver meals and groceries, offer cookery and nutrition classes, and host communal eating opportunities to help people get well, stay well and lead healthy independent lives.



4M Network of Mentor Mothers

4M stands for My Health, My Choice, My Child, My Life. A unique perinatal peer mentoring project led by and working with mentor mothers living with HIV. We train women living with HIV as Mentor Mothers to provide psycho-social support to peers in their pregnancy journey and beyond. Our approach seeks to ensure that our voices and priorities are heard in all discussions about issues affecting women living with HIV pre, during and beyond the pregnancy journey. We are guided by a Steering Group made up of healthcare providers.



Positively UK is the lead charity for peer support, run by and for people living with HIV. Our peer caseworkers can support you at your clinic, over the phone or online. You can join our confidential groups, meet other people like you and chat about anything HIV-related and beyond. Through our support, people are able to move from isolation to involvement, find new friends and explore how to live their best life with HIV. We also train people with HIV to become peer mentors and support others, and we advocate for system change so policy makers take decisions informed by those living with HIV.



The National HIV Nurses Association (NHIVNA) is the leading UK professional association representing nurses in HIV care. We are committed to promoting excellence in the nursing care of those living with and affected by HIV through advocacy, education, leadership and research and by disseminating innovative practice widely to the nursing profession. We work with individuals and organisations that share our desire for excellence in care and provide a voice for nurses working in the field.



We are **ViiV Healthcare**: a specialist pharmaceutical company 100% dedicated to HIV medicines and research, and completely focused on people living with HIV and AIDS. In the last 30 years, the world of science and the HIV and AIDS community have worked together to control the HIV epidemic. Right now, we face a new wave of challenges, still... we have to keep going. We are here until HIV and AIDS aren't.



Gilead Sciences, Inc. is a biopharmaceutical company that has pursued and achieved breakthroughs in medicine for more than three decades, with the goal of creating a healthier world for all people. The company is committed to advancing innovative medicines to prevent and treat life-threatening diseases, including HIV, viral hepatitis and cancer. Gilead operates in more than 35 countries worldwide, with headquarters in Foster City, California.

For more than 30 years, Gilead has been a leading innovator in the field of HIV, driving advances in treatment, prevention, testing and linkage to care, and cure research. Today, millions of people living with HIV globally receive antiretroviral therapy provided by Gilead or one of the company's manufacturing partners.

ORAL ABSTRACTS PRESENTED

1) High-risk HPV prevalence and serostatus in women living with perinatally acquired HIV (the SHiP study)

Merle Henderson^{1,2*}, Tamara Elliott^{1,2*}, Ellie Crook², Sara Ayres², Simon Beddows³, Kavita Panwar³, Corrina Wright^{4,5}, Deirdre Lyons², Miranda Cowen², Hasit Patel⁵, David Smith⁵, Sarah Fidler^{1,2}, Caroline Foster²

¹Department of Infection, Imperial College London, ²Imperial College Healthcare NHS Trust, ³HPV Unit, UK Health Security Agency, ⁴North West London Pathology, ⁵Cervical Screening London, Health Service Laboratories
*joint first author

2) Population-level paediatric HIV surveillance in England: The current picture

Gabriela Toledo¹; Kate Francis¹; Sally Cavanagh²; Anna Kafkalias²; Claire Thorne¹, Helen Peters¹

¹Children's HIV and AIDS Reporting System, UCL Great Ormond Street Institute of Child Health, London UK, ²NHS England

3) Infant Postnatal Prophylaxis (PNP) following maternal viraemia during breastfeeding

Dr Emily A Lees^{1&2}, Mr Neil Tickner³, Dr Hermione Lyall³, Dr Paddy McMaster⁴, Dr Birgitte Smith⁵, Dr Lucy Cliffe⁶, Dr Caroline Foster³

¹University of Oxford, Oxford Children's Hospital, Oxford, UK, ²Fitzwilliam College, University of Cambridge, Cambridge, UK, ³Imperial College Healthcare NHS Trust, St Mary's Hospital, London, UK, ⁴Manchester University NHS Foundation Trust, North Manchester General Hospital, Manchester, UK, ⁵Hvidovre Hospital, Copenhagen University Hospital, Hvidovre, Denmark, ⁶Nottingham University NHS Foundation Trust, Nottingham Children's Hospital, Nottingham, UK

POSTERS SUBMITTED

1) The HIV empowering adults' decisions to share – UK/Uganda project (HEADS-UP): Primary outcomes

Michael Evangeli

Royal Holloway University Of London

2) The HIV empowering adults' decisions to share – UK/Uganda project (HEADS-UP): A qualitative analysis of interviews with participants and therapists

Michael Evangeli

Royal Holloway University Of London

3) Metabolic health and bone density in youth living with perinatal HIV

Caroline Foster, Colette Smith, Merle Henderson, Moira Cheung, Sarah Fidler

Imperial College London

4) The BONDY Study: Bone density in youth living with perinatally acquired HIV

Merle Henderson^{1,2}, Colette Smith³, Sarah Fidler^{1,2}, Moira Cheung⁴, Caroline Foster^{2,5}

¹Department of Infectious Disease, Faculty of Medicine, St Mary's Campus, Imperial College London UK, ²Department of HIV and GU Medicine, St Mary's Hospital, Imperial College Healthcare NHS Trust, London UK, ³Department of Population Health Sciences UCL Institute for Global Health, London UK, ⁴Department of Paediatrics, Evelina London Children's Hospital, Guys and St Thomas' NHS Trust, London UK, ⁵Department of Paediatric Infectious Diseases, St. Mary's Hospital, Imperial College Healthcare NHS Trust, London UK

5) Eligibility for long acting cabotegravir/ rilpivirine in youth aged 12-25 living with perinatally-acquired HIV

Fionnuala Ryan¹, Nicola E Mackie², Hana Jayadel¹, Sara Ayers², Caroline Foster^{1,2}

¹Department of Paediatric Infectious Diseases, Imperial College Healthcare NHS Trust

²Department of GUM/HIV Medicine, Imperial College Healthcare NHS Trust

POSTERS SUBMITTED

6) Comparison of pregnancy outcomes for mothers living with perinatally acquired HIV, behaviourally acquired HIV, and those not living with HIV

S Shah, GP Taylor, EGH Lyall, C Foster

Imperial College Healthcare NHS Trust

7) Correlation of HIV-coinfection with severe malaria in children: A systematic review and meta-analysis

Ni Made Adnya Suasti

University of Oxford

8) HIV self-management among adolescents and young people living with HIV: Assessment of mHealth performance capacity

Dr Shola Adeyemi¹, Prof Eren Demir², Mr Benjamin Llesanmi¹, Dr Usame Yakutcan²

¹Bohemian Smartlytics Limited, United Kingdom, ²University of Hertfordshire, United Kingdom



Follow us on our new LinkedIn page as we build an online community of health and social care professionals working with children and young adults who've grown up living with HIV.



@chivaprojects

Join the conversation with:

#ChivaConference