

Conference on

## Progress and challenges implementing genomics into practice and society

Wellcome Trust Lecture Hall The Royal Society 6-9 Carlton House Terrace, London SW1Y 5AG on Wednesday 16<sup>th</sup> October, 2024

Admission is **FREE**, but strictly by ticket, available from: <u>www.eventbrite.co.uk</u> or the General Secretary Adelphi Genetics Forum 19 Northfields Prospect, London SW18 1PE <u>executiveoffice@adelphigenetics.org</u> <u>www.adelphigenetics.org</u>

## **Speakers and Chairs**

Dian Donnai CBE FRCP FRCOG FMedSci	Emerita Professor of Medical Genetics, Manchester Centre for Genomic Medicine, University of Manchester and Adelphi Genetics Forum
Anne Ferguson-Smith CBE FRS FMedSc	Arthur Balfour Professor of Genetics, the University of Cambridge Executive Chair – BBSRC (from 1.7.24.)
Shirley Hodgson BSc BM BCh DM FRCP FRBS	Professor Emerita, St George's University of London and Adelphi Genetics Forum
Anneke Lucassen DPhil(Oxon) FRCP FRCGP(Hon)	Professor of Genomic Medicine and Director of the Centre for Personalised Medicine, University of Oxford; and Adelphi Genetics Forum
Helen Middleton-Price PhD FRCPath	Adelphi Genetics Forum
Bill Newman MA FRCP PhD	Professor of Translational Genomic Medicine, Clinical Director Northwest Genomic Medicine Service Alliance and Honorary Consultant, Manchester University NHS Foundation Trust
Michael Parker BEd MA PhD	Professor of Bioethics and Director of the Ethox Centre at the University of Oxford
Andrew Read PhD FRCPath FMedSci	Emeritus Professor of Human Genetics, Manchester Centre for Genomic Medicine, University of Manchester and Adelphi Genetics Forum
Fergus Shanahan MD DSc	Emeritus Professor of Medicine, University College Cork and APC Microbiome Ireland
Steven Sturdy MA PhD	Professor of the Sociology of Medical Knowledge the University of Edinburgh
Clare Turnbull MD PhD FRCP FRCPath FFPH	Professor of Translational Cancer Genetics, Division of Genetics and Epidemiology, Institute of Cancer Research and Honorary Consultant in Clinical Cancer Genetics, Royal Marsden NHS Foundation Trust
Nicholas Wood PhD FRCP FMedSci	Professor of Clinical Neurogenetics, Institute of Neurology, UCL (University College London) and President of Adelphi Genetics Forum
Sarah Wynn BSc MSc MS PhD	CEO at Unique – Rare Chromosome Disorder Support Group

**Conference organisers:** Helen Middleton-Price, Shirley Hodgson, Anneke Lucassen

## Progress and challenges implementing genomics into practice and society

09 55 - 10 00	Welcome: Nicholas Wood, President of Adelphi Genetics Forum
10 00 - 10 40	Chair and Introduction: Helen Middleton-Price Andrew Read The Human Genome Project – 20 years on
10 40 - 11 10	Coffee
11 10 - 11 45	Chair: Anneke Lucassen Sarah Wynn The promise and challenges of genomics for patients and families affected by rare conditions
11 45 - 12 20	<b>Clare Turnbull</b> Genomics in population screening for cancer: opportunities, challenges and cautions
12 20 - 12 55	<b>Michael Parker</b> The changing moral life of genetics and genomics since the Human Genome Project
12 55 – 13 50	Lunch
13 50 - 14 25	Chair: Dian Donnai Bill Newman Implementing pharmacogenetics at scale in clinical practice
14 25 - 15 00	Anne Ferguson-Smith Epigenetic inheritance – models and mechanisms
15 00 - 15 35	<b>Chair</b> : <b>Shirley Hodgson</b> Fergus Shanahan <i>No stool left unturned-why our microbiomes differ</i>
15 35 -16 05	Теа
16 05 - 17 00	Chair: Nicholas Wood Adelphi Lecture Steven Sturdy The fortunes of medical genomics: a quarter-century of promise Presentation of the Adelphi Plate by Nicholas Wood

## Adelphi Genetics Forum – formerly the Galton Institute

In 2021 the Galton Institute's name was changed to the Adelphi Genetics Forum.

The Galton Institute was named after Sir Francis Galton who was a hugely important scientist working in the 19<sup>th</sup> and early 20<sup>th</sup> centuries. He was one of the founding fathers of the science of genetics as well as making foundational contributions to other fields, including statistics, meteorology and psychology.

However, some of Galton's views had darker implications: he held beliefs about race and social class which might have been acceptable then but are not now. Among these, he introduced and fostered the idea of eugenics, described by him as the scientific study of factors which affect the 'inborn qualities of humans and future generations', and which he developed to the 'breeding out' of so called 'undesirable' characteristics from the human population. It was these ideas that sparked the formation of the Eugenics Education Society, which later became the Galton Institute.

To be clear, the Adelphi Genetics Forum completely rejects his and all other eugenic and racist ideas as morally unacceptable and scientifically flawed, and nothing the current Forum does in any way supports or furthers such ideas. Furthermore, it is important to note that we have never benefitted financially from Francis Galton. Thus, whilst we recognise Galton's immense scientific achievements, it was decided it was time to change our name.

The name Adelphi Genetics Forum: Exploring Heredity and Society was chosen by our Trustees.

The literal translation of the Greek 'Adelphi' is 'brothers', but, as well as meaning brother or sibling, it means fraternity, with no gender implication, and friends with mutual respect. So, 'Adelphi' gives a sense of family, community and support. Hence, we are gesturing towards the future and how the Forum can continue to help educate, inform and foster debate about human heredity and society.