

Towards Genomic Newborn Screening in Germany

Risks, Opportunities, Challenges | March 18/19, 2024 | Heidelberg University

Day 1 (Monday March 18, 2024)

08:00 - 08:30	Arrival & Coffee
08:30 - 08:40	Welcome & Introduction Eva C. Winkler (Heidelberg University)
08:40 – 09:40	Sequencing healthy newborns is not yet ready for prime-time Lainie Friedman Ross (University of Rochester)
09:40 – 10:40	Strategies to reduce uncertainty (and harm) caused by recent and future NBS programmes James Bonham (Sheffield Children’s NHS Foundation Trust)
10:40 – 11:10	Coffee
11:10 – 11:40	Revising the Wilson-Jungner criteria for (genomic) newborn screening: Lessons from the German NBS program Elena Schnabel (Heidelberg University)
11:40 – 12:10	Genome Sequencing Pilot Study: Evaluating feasibility and scalability for genome-wide newborn screening Heiko Brennenstuhl (Heidelberg University)
12:10 - 13:30	Lunch
13:30 – 14:30	Genomic newborn screening: Which findings from 20,000 genes should we report? – Some strategic considerations Christian Schaaf, Nicola Dikow (Heidelberg University)
14:30 – 15:30	How longitudinal observational studies can guide a screening strategy for rare diseases: Implications of genomic screening Stefan Kölker, Ulrike Mütze (Heidelberg University)
15:30 – 16:00	Coffee
16:00 – 17:00	The BabySeq Project: A randomized trial of genomic sequencing in newborns Ingrid Holm (Harvard Medical School, Boston Children’s Hospital)
17:30 – 19:00	Keynote Lecture at Heidelberg Academy of Sciences & Humanities Newborn Screening, diagnosis, and precision medicine by genome sequencing and AI Stephen Kingsmore (Rady Children’s Hospital)
19:00	Dinner at <i>Kulturbrauerei</i> (Speakers only)

Day 2 (Tuesday March 19, 2024)

08:00 - 08:30	Arrival & Coffee
08:30 - 08:40	Welcome & Introduction Eva C. Winkler (Heidelberg University)
08:40 – 09:40	Implementing genomic newborn screening: Challenges in the German legal context Ralf Müller-Terpitz, Hannah Straub (Mannheim University)
09:40 – 10:40	Genomic newborn screening: Consent and privacy related concerns Mahsa Shabani (University of Amsterdam)
10:40 – 11:00	Coffee
11:00 – 11:30	Genomic newborn screening for adult actionable conditions – Why not?! Karla Alex, Eva C. Winkler (Heidelberg University)
11:30 – 12:00	Medicalization risks in genomic newborn screening Sascha Settegast (University of Halle-Wittenberg) Eva C. Winkler (Heidelberg University)
12:00 - 13:00	Lunch
13:00 – 14:00	The impact of genomic newborn screening on the family Stacey Pereira (Baylor College of Medicine)
14:00 – 15:00	Psychosocial determinants of familial decision-making in genomic newborn screening Beate Ditzen, Julia Mahal, Elena Doll, Carlotta Mayer (Heidelberg University)
15:00 – 15:30	Coffee
15:30 – 16:30	Genomic newborn screening: Principles and strategies for parental counselling Maja Hempel, Stefan Bär, Sebastian Sailer (Heidelberg University)
16:30 – 18:00	Roundtable discussion with patient representatives
18:00	Dinner

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Organization Contact	Dr. Sascha Settegast, Dr. Heiko Brennenstuhl sascha.settegast@phil.uni-halle.de
Conference Venues	International Academic Forum Heidelberg (IWH), <i>Hauptstraße 242</i> Heidelberg Academy of Sciences & Humanities, <i>Karlstraße 4</i>
Dinner March 18	Restaurant “Kulturbrauerei“ at <i>Leyergasse 6</i>
Acknowledgments	We would like to thank the <i>Fritz Thyssen Foundation</i> for its generous financial support and the <i>International Academic Forum Heidelberg (IWH)</i> for generously allowing us the use of its premises.

List of Speakers

Karla Alex

Section of Translational Medical Ethics, National Center for Tumor Diseases, Heidelberg University

PD Dr. rer. pol. Stefan Bär

Max Weber Institute of Sociology, Heidelberg University.

Prof. James Bonham, PhD, MBE

Sheffield Children's NHS Foundation Trust. President of *International Society of Neonatal Screening*.

Dr. med. Heiko Brennenstuhl, MBA

Institute of Human Genetics, Heidelberg University.

Dr. med. Nicola Dikow

Institute of Human Genetics, Heidelberg University.

Prof. Dr. phil. Beate Ditzen

Director of the Institute of Medical Psychology, Heidelberg University.

Elena Sophia Doll, M.Sc. Psych.

Institute of Medical Psychology, Heidelberg University.

Tobias Hagedorn (patient representative)

DIG PKU e.V.

Prof. Dr. med. Maja Hempel

Director of Genetic Clinic, Heidelberg University Hospital.

Prof. Ingrid Holm, MD, MPH

Professor of Pediatrics at Harvard Medical School; Harvard Medical School Center for Bioethics; Division of Genetics and Genomics, Boston Children's Hospital.

Prof. Stephen Kingsmore, MD, DSc

President/CEO Rady Children's Institute for Genomic Medicine, Rady Children's Hospital San Diego.

Prof. Dr. med. Stefan Kölker

Head of the Section for Neuropediatrics and Metabolic Medicine, Center for Pediatrics and Adolescent Medicine, Heidelberg University Hospital.

Dr. phil. Julia Mahal

Institute of Medical Psychology, Heidelberg University.

Carlotta Mayer, M.Sc. Psych.

Institute of Medical Psychology, Heidelberg University.

Prof. Dr. iur. Ralf Müller-Terpitz

Chair of Public Law, Law of Economic Regulation and Media. Director of the Institute for German, European and International Medical Law, Health Law and Bioethics (IMGB), Mannheim University.

Dr. med. Christine Mundlos (patient representative)

ACHSE e.V.

PD Dr. med. Ulrike Mütze

Section for Neuropediatrics and Metabolic Medicine, Center for Pediatrics and Adolescent Medicine, Heidelberg University Hospital.

Prof. Stacey Pereira, PhD

Center for Medical Ethics and Health Policy, Baylor College of Medicine.

Prof. Lainie Friedman Ross, MD, PhD

Dean's Professor and Chair, Department of Health Humanities & Bioethics; Director, Paul M. Schuyve MD Center for Bioethics; University of Rochester School of Medicine.

Dr. med. Sebastian Sailer

Institute of Human Genetics, Genetic Clinic, Heidelberg University.

Prof. Dr. med. Christian Schaaf

Director of the Institute of Human Genetics, Heidelberg University.

Dr. med. Elena Schnabel

Section for Neuropediatrics and Metabolic Medicine, Center for Pediatrics and Adolescent Medicine, Heidelberg University Hospital.

Dr. phil. Sascha Settegast

Department of Philosophy, Martin-Luther-University of Halle-Wittenberg.

Prof. Mahsa Shabani, PhD

Associate Professor in Health Law and Digital Citizenship, Law Centre for Health and Life, University of Amsterdam.

Claudia Sproedt (patient representative)

Cystinose e.V.

Hannah Straub, Maître en Droit

Department of Law, Mannheim University.

Prof. Dr. med. Dr. phil. Eva C. Winkler

Head of the Section of Translational Medical Ethics, National Center for Tumor Diseases, Heidelberg University.