

**A Framework for Genomic Newborn Screening**  
*Symposium on Final Results of the NEW\_LIVES Project ("Genomic **NEW**born  
Screening Programs – Legal Implications, Value, Ethics and Society")*

**11:00–12:00 Part I. Why Are We Discussing Genomic Newborn Screening?**

Chair: Prof. Dr. Dr. Eva Winkler, Institute for Medical and Data Ethics, Heidelberg Univ.

11:00–11:15 Welcome and Introductory Notes

11:15–11:40 (incl. 10 min. discussion) **Newborn Screening and Genomic  
Newborn Screening (gNBS) – Introduction and Current Research on  
Potential Medical Gains of gNBS**

Prof. Dr. Ulrike Mütze, Division for Neuropediatrics and Metabolic Medicine,  
Pediatric Clinic I, Heidelberg University

Dr. Heiko Brennenstuhl, Institute of Human Genetics, Heidelberg University

11:40–12:00 (incl. 5 min. discussion) **Role of Patient Representation in the  
Research Project NEW\_LIVES**

Tobias Hagedorn, Deutsche Interessengemeinschaft Phenylketonurie und  
verwandte angeborene Stoffwechselstörungen, DIG PKU e.V.

12:00–12:10 Short break

**12:10–13:00 Part II. Societal Perspectives – Results of Socio-Empirical Studies in  
the NEW\_LIVES Project**

Chair: Prof. Dr. Beate Ditzen, Institute of Medical Psychology, Heidelberg University

12:10–12:15 Brief Introduction to Parts II and III – ELSI of gNBS

12:15–13:00 (incl. 15 min. discussion) **Empirical Work in NEW\_LIVES on  
German Population and Parental Attitudes Towards gNBS**

Elena Doll and Dr. Julia Mahal, Institute of Medical Psychology, Heidelberg  
University

13:00–14:00 Lunch break

**14:00–15:30 Part III. Ethical and Legal Grounds of Genomic Newborn Screening**

Chair: Prof. Dr. Ralf Müller-Terpitz, Department of Law, University of Mannheim

14:00–14:25 (incl. 10 min. discussion) **Current Legal Regulation of Genomic  
Newborn Screening**

Hannah Straub, Department of Law, University of Mannheim

14:25–14:50 (incl. 10 min. discussion) **Ethical Framework for a Genomic  
Newborn Screening Program**

Karla Alex, Lars Neth, and Prof. Dr. Dr. Eva Winkler, Institute for Medical and  
Data Ethics, Heidelberg University

14:50–15:30 min (incl. 15 min. discussion) **Genomic Newborn Screening from an International ELSI Perspective**

Dr. Amicia Phillips, University of Exeter Medical School

15:30–16:00 Coffee break

**16:00–17:20 Part IV. Recommendations for a Genomic Newborn Screening Program of the NEW\_LIVES Project Group**

Chair: Prof. Dr. Stefan Kölker, Division for Neuropediatrics and Metabolic Medicine, Pediatric Clinic I, Heidelberg University

16:00–16:45 (incl. 15 min. discussion) **Criteria for the Selection of Target Diseases**

Karla Alex, Institute for Medical and Data Ethics, Heidelberg University, Dr. Elena Schnabel-Besson, Division for Neuropediatrics and Metabolic Medicine, Pediatric Clinic I, Heidelberg University, and Dr. Nicola Dikow, Institute of Human Genetics, Heidelberg University

16:45–17:20 (incl. 15 min. discussion) **Criteria for Program Management & Recommendations for Legal Reform**

Elena Doll, Institute of Medical Psychology, Heidelberg University  
Hannah Straub, Department of Law, University of Mannheim

17:20–18:00 Break

**18:00–19:00 Panel Discussion on Genomic Newborn Screening – Status Quo and Next Steps**

Moderator: Dr. Jens Foell

Panellists:

Prof. Dr. Beate Ditzen

Institute of Medical Psychology, Heidelberg University

Tobias Hagedorn

DIG PKU e.V. (patient representative NEW\_LIVES)

Prof. Dr. Georg Hoffmann

Department of General Pediatrics, Neuropediatrics, Metabolism, Gastroenterology, Nephrology, Heidelberg University (advisory board NEW\_LIVES)

Dr. Amicia Phillips

University of Exeter Medical School

Prof. Dr. Christian Schaaf

Institute of Human Genetics, Heidelberg University

Prof. Dr. Dr. Eva Winkler

Institute for Medical and Data Ethics, Heidelberg University

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