ITINERARE
Innovative Therapies in Rare Diseases
University Research Program of the University of Zurich

Caring for the orphans: Ethical issues in the context of rare diseases

June 15-16, 2023
University of Zurich (Switzerland)

Thursday, 15 June

12:00 Arrival & Lunch Bag

12:30 Welcome & Introduction

12:45 **Havi Carel** (University of Bristol)
Rare diseases, epistemic injustice and the good life

13:45 **Heiner Fangerau** (University of Duesseldorf)
Diagnoses and historical concepts of disease – is the end of a diagnostic odyssey a useful fiction?

14:45 Coffee Break

Parallel sessions

15:15	**Sebastian Wäscher** (University of Zurich) The burden of rare diseases. Patient narratives on managing their disease	**Kathryn Tabb** (Bard College) Individualized genetic therapies as a treatment-research hybris	**Susanne Wehrli** (University of Zurich) Access to healthcare among Swiss adults with rare diseases – the influence of facilitating and inhibiting individual factors
16:00	**Lainie Friedman Ross** (University of Rochester) Thinking zebras not horses when the herd runs past: Atypical Diabetes Mellitus	**Urte Laukaityte** (UC Berkeley) Rare diseases in the context of effective altruism	**Jacopo Morelli** (University of Modena-Reggio) Kantian constructivism applied to rare diseases

16:45 Coffee Break

17:00 **Rachel Grob** (University of Wisconsin)
Diagnostic information and uncertainty in the newborn period: qualitative dimensions of families' experiences with novel technologies

18:00 **Bernice Elger** (University of Basel)
Genetic testing of children: Child welfare versus parental autonomy

19:00 End

19:30 Dinner

Friday, 16 June

9:00 **Dana Mahr** (University of Geneva)
Citizen science and biomedical research: the experiential knowledge of a lived genome

10:00 **Marcello Ienca** (Technical University of Munich and Ecole Polytechnique Fédérale de Lausanne EPFL)
Patient-engagement in rare disease research. The case study of rare neurological diseases

11:00 Break

Parallel sessions

11:30	**Lucie Perillat** (University of Toronto) Rare diseases: a universal priority	**Francesca Greco** (Insubria University) Understanding orphan drugs: roles and perspectives regarding orphan drugs for rare diseases
12:15	**Nina Streeck (**University of Zurich) The vulnerable orphans: Does vulnerability constitute a right to solidarity?	**Rebeca Méndez-Veras** (Universidad Mariano Gálvez de Guatemala) Ethical issues regarding clinical exome and targeted gene sequencing. A Guatemalan experience

13:00 Lunch Break

14:00 **Deborah Mascalzoni** (Uppsala University)
Respecting the rights of children with rare disease in research within their lifespan: challenges and perspectives

15:00 **Eva Winkler** (University of Heidelberg)
Data use for research in rare disease. Ethical considerations on the governance of data initiatives

16:00 Coffee Break

17:00 **Niklas Juth** (Uppsala University and Karolinska Institutet)
Prioritization of orphan drugs: considerations of ethics and justice

18:00 End