CARING FOR THE ORPHANS

Ethical issues in the context of rare diseases

Despite their name, rare diseases are not uncommon, affecting approximately 400 million people worldwide with around 7,000 distinct conditions. These diseases can be debilitating and require expensive therapies, resulting in significant financial and social burdens for patients, families, and healthcare systems.

Rare diseases have become an important target of healthcare activities which has given rise to various ethical, social, and political questions. For example, how should health care systems address the challenge of resource allocation for rare diseases? What are the lived experiences of patients and their families dealing with rare diseases, considering their chronic and potentially life-shortening nature? What are the implications of utilizing genome sequencing to identify gene mutations associated with rare diseases, given their predominantly genetic basis? How can ethical research practices be established and implemented to ensure responsible investigation of rare diseases, considering the heightened vulnerability of patients, especially children?

To address these complex issues, the conference convenes scholars from diverse fields such as medical ethics, philosophy, medicine, and the social sciences. The primary objective of this conference is to foster discourse on the ethical, legal, and social implications (ELSI) of rare diseases. By advancing discussions within society and contributing to the development of healthcare policies, the conference seeks to promote ELSI research in the realm of rare diseases.

The conference is part of the University Research Priority Program (URPP) ITINERARE (Innovative Therapies in Rare Diseases) at the University of Zurich. ITINERARE encompasses three primary pillars: gene therapy, molecular therapies, and ethics, legal and social innovations (ELSI). Through multidisciplinary collaboration and comprehensive training, ITINERARE explores all facets associated with fundamental research into rare diseases and the translation of state-of-the-art therapies into clinical practice. The program endeavours to develop novel molecular and gene therapies for selected genetic disorders while concurrently establishing a broad ethical-legal and educational framework bolstered by multidisciplinary expertise to address the societal issues intertwined with novel therapies.

INFORMATION

FURTHER INFORMATION

www.itinerare.uzh.ch/en/ITINERARE-Ethics-Conference.html

REGISTRATION

www.itinerare.uzh.ch/en/ITINERARE-Ethics-Conference/Registration-form.html

PARTICIPATION IS FREE OF CHARGE

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University Research Priority Program
ITINERARE: Innovative Therapies in Rare Diseases

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15–16 JUNE 2023

THURSDAY 15 JUNE

12:00 ARRIVAL & LUNCH BAG

12:30 WELCOME & INTRODUCTION KOL-H-317

12:45 RACHEL GROB
University of Wisconsin
Diagnostic information and uncertainty in the newborn period: qualitative dimensions of families' experiences with novel technologies

13:45 BERNICE ELGER
University of Basel
Genetic testing of children: Child welfare versus parental autonomy

14:45 COFFEE BREAK

15:15 PARALLEL SESSIONS

SESSION A: SEBASTIAN WÄSCHER KOL-H-320
University of Zurich
„If you hear it from a doctor, you internalize it." Medical Gaslighting in the field of rare diseases – insights from a qualitative interview study

SESSION B: DANIELLE PACIA KOL-H-321
Hastings Center
Individualized genetic therapies as a treatment-research hybris

SESSION C: SUSANNE WEHRLI KOL-H-322
University of Zurich
Access to healthcare among Swiss adults with rare diseases – the influence of facilitating and inhibiting individual factors

16:00 SESSION A: LAINIE FRIEDMAN ROSS KOL-H-320
University of Rochester
Thinking zebras not horses when the herd runs past: Atypical Diabetes Mellitus

SESSION B: URTE LAUKAITYTE KOL-H-321
UC Berkeley
Rare diseases in the context of effective altruism

SESSION C: JACOPO MORELLI KOL-H-322
University of Modena-Reggio
Kantian constructivism applied to rare diseases

16:45 COFFEE BREAK

17:00 DEBORAH MASCALZONI
Uppsala University
Respecting the rights of children with rare disease in research within their lifespan: challenges and perspectives

18:00 EVA WINKLER
University of Heidelberg
Data use for research in rare disease. Ethical considerations on the governance of data initiatives

19:00 END

FRIDAY 16 JUNE

09:00 MARCELLO IENCA KOL-H-317
Technical University of Munich and École Polytechnique Fédérale de Lausanne EPFL
Patient-engagement in rare disease research. The case study of rare neurological diseases

10:00 DANA MAHR
University of Geneva
Citizen science and biomedical research: the experiential knowledge of a lived genome

11:00 BREAK

11:30 PARALLEL SESSIONS

SESSION A: LUCIE PERILLAT KOL-H-320
University of Toronto
Rare diseases: a universal priority

SESSION B: FRANCESCA GRECO KOL-H-321
Insubria University
Understanding orphan drugs: roles and perspectives regarding orphan drugs for rare diseases

12:15 SESSION A: NINA STREECK KOL-H-320
University of Zurich
The vulnerable orphans: Does vulnerability constitute a right to solidarity?

SESSION B: REBECA MÉNDEZ-VERAS KOL-H-321
Universidad Mariano Gálvez de Guatemala
Ethical issues regarding clinical exome and targeted gene sequencing. A Guatemalan experience

13:00 LUNCH BREAK

14:00 HAVI CAREL
University of Bristol
Rare diseases, epistemic injustice and the good life

15:00 HEINER FANGERAU
University of Duesseldorf
Diagnoses and historical concepts of disease – is the end of a diagnostic odyssey a useful fiction?

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