



**University of
Zurich** ^{UZH}



Call for Papers

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

Ethics-Conference

Caring for the orphans: Ethical issues in the context of rare diseases
15–17 June 2023, University of Zurich (Switzerland)

Despite their name, rare diseases are not uncommon: An estimated 400 million people worldwide suffer from about 7,000 distinct rare conditions. Rare diseases are often debilitating and require expensive therapies, causing high financial and social burdens for patients, their families and the healthcare system.

Rare diseases have become an important target of healthcare activities which raises a range of ethical, social and political questions. For example, how should health care resources for rare diseases be allocated? Considering that rare diseases are often chronic and life-shortening, what does it mean for patients and their families to live with a rare condition? Since most rare diseases are genetic, should genome sequencing be applied to detect gene mutations that (might) lead to rare diseases? And how can research on rare diseases be conducted in an ethically responsible way, given the special vulnerability of patients, often children?

The conference brings together international scholars from medical ethics, philosophy, medicine and the social sciences to discuss these and further issues. It aims to promote ELSI research in the field of rare diseases, in order to advance discussions in society and to contribute to the development of healthcare policies.

The conference is part of the University Research Priority Program (URPP) ITINERARE (Innovative Therapies in Rare Diseases) at the University of Zurich. ITINERARE integrates three major axes on gene therapy, molecular therapies, and ethics, legal and social innovations (ELSI). It engages in multi-disciplinary collaboration and training on all aspects associated with basic research into rare diseases and the translation of cutting-edge therapies into clinical practice. ITINERARE aims to develop novel molecular and gene therapies for selected genetic disorders and to establish a broad ethical-legal and educational framework of multidisciplinary expertise to address societal issues associated with novel therapies.

Keynote Speakers: Havi Carel, Niklas Juth, Rachel Grob, Bernice Elger, Heiner Fangerau, Deborah Mascalzoni, Eva Winkler, Dana Mahr.

We welcome paper proposals which focus on the following (non-exhaustive) list of possible topics regarding ethics of research and therapies of rare diseases:

- Justice, priority-setting, solidarity
- Good life
- (Whole) genome sequencing
- Newborn screening
- Research ethics
- Diagnostic odyssey
- Disease concepts
- Patients' experiences
- ...

The presentations are scheduled for 30 minutes (20 min presentation, 10 min discussion).

Please provide:

- A title and an abstract of max. 200 words
- Your name(s), institutional affiliation(s) and contact details

The deadline for submission is January 15, 2023.

Please send your abstracts by email to Dr. Nina Streeck, nina.streeck@uzh.ch.

You should expect notification about your paper by end of February 2023.

Conference and travel costs will be covered by URPP ITINERARE.

For any inquiries, please contact Dr. Nina Streeck, nina.streeck@uzh.ch.

For more information: <https://www.itinerare.uzh.ch/en/ITINERARE-Ethics-Conference.html>