



University of
Zurich^{UZH}

URPP ITINERARE - Innovative Therapies in Rare Diseases



ITINERARE *Symposium*

December 1st, 2022
University of Zurich
14:00 – 18:00



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RAA-G-01 Aula klein | 14:00 – 18:00

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We are very pleased to invite you to the ITINERARE Symposium 2022.

ITINERARE - Innovative Therapies in Rare Diseases – is a University Research Priority Program (URPP) of the University of Zurich. Through an interdisciplinary network of researchers and clinicians, the URPP ITINERARE fosters excellent translational research on rare diseases at the University Children's Hospital Zurich, the University Hospital Zurich, and the University of Zurich. The URPP 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 associated societal issues.

Join our ITINERARE Symposium to get an insight into cutting-edge research and social innovation aspects in rare diseases through the contributions of invited international speakers and our project leaders.

We look forward to welcoming you at the University of Zurich!

The URPP ITINERARE Directorate

Director

Prof. Janine Reichenbach, Institute for Regenerative Medicine
University of Zurich

Co-directors

Prof. Olivier Devuyst, Institute of Physiology
University of Zurich

Prof. Matthias Baumgartner, Division of Metabolic Diseases
University Children's Hospital Zurich

Deputy-directors

Prof. Brigitte Tag, Faculty of Law

Prof. Nikola Biller-Andorno, Institute of Biomedical Ethics and History of Medicine
University of Zurich

Program

- 14:00** **Opening**
Prof. Janine Reichenbach, IREM, University of Zurich
Prof. Elisabeth Stark, Vice President Research, University of Zurich
- Chair:* *Prof. Olivier Devuyst, Institute of Physiology, University of Zurich*
- 14:10** **Gene therapies for rare disease: development and access challenges from a Primary Immunodeficiency (PID) perspective**
Leire Solis, International Patient Organisation for Primary Immunodeficiencies (IPOPI), UK
- 14:40** **Advances in the gene therapy of blood cell diseases**
Dr. Juan Bueren, Biomedical Innovation Unit, CIEMAT, Spain
- 15:10** **From genetic to auto-immune predisposition to life-threatening COVID 19**
Dr. Paul Bastard, Imagine Institute Paris, France
- 15:40** **Coffee Break**
- Chair:* *Prof. Matthias Baumgartner, Division of Metabolic Diseases, University Children's Hospital Zurich*
- 16:10** **Access and development of orphan drugs: the role of academia**
Prof. Carla Hollak, University Medical Center Amsterdam, The Netherlands
- 16:40** **Hopes, privileges and money - Orphan drug pricing in Germany**
Dr. Thomas Kapitzka, M&E Ethics Lab, IBME, University of Zurich
- 17:00** **Panel Discussion:
Innovative therapies for rare diseases: what are fair prices?**
- Panelists:* Prof. Michael Coors - Institute of Social Ethics, University of Zurich;
Shayesteh Fürst-Ladani - Rare Disease Action Forum (RDAF);
Dr. Ursula Schafroth - Schweizerische Gesellschaft der Vertrauens- und
Versicherungsärzte (SGV)
- Moderator:* Prof. Nikola Biller-Andorno, IBME, University of Zurich
- 17:50** **Networking Apéro**

More information here



www.itinerare.uzh.ch

Registration deadline: 20th November 2022

