

RE(ACT)^x Switzerland: We Care for Rare

Translational Science in rare diseases, toward the creation of a Swiss Center for rare diseases

Campus Biotech 10 November 2016 (9am - 17pm)

09:00-09:30 Registrations

09:30-09:45 Welcome message:

Pr. Patrick Aebischer (EPFL) and Dr. Olivier Menzel ([BLACKSWAN Foundation](#))

Introduction: Anne-Françoise Auberson (President de [ProRaris](#), Swiss Rare Disease Alliance)

09:45-10:15 Patient's view:

Mrs. Sharon S. Lagas, Board President, [Alport Syndrome Foundation](#); USA: "The need to accelerate development of new treatments for rare diseases illustrated through a family's journey with Alport Syndrome"

10:15-10:45 Researchers' view:

Dr. Olivier Dorchies (UNIGE), CH: "Pre-clinical evaluation of disease modifiers: Example of nutraceuticals and repurposed drugs for severe myopathies"

Pr. Gisou van der Goot (EPFL), CH: "Hyaline Fibromatosis Syndrome: in depth mechanistic understanding"

10:45-11:15 Institution's view:

Pr. Kay Davies (Director of the MRC functional genetics unit, governor of the Wellcome Trust and director of the Oxford Centre for Gene Function); UK: "Rare Disease Consortium at Oxford: from patient to drug screens to therapy"

11:15-11:45 Break

11:45-12:15

Dr. Rashmi Gopal-Srivastava (Director Extramural Research Program, Office of Rare Diseases Research, [National Center for Advancing Translational Sciences, NCATS](#) at the National Institutes of Health, NIH); USA: "Rare Diseases Clinical Research Network (RDCRN) Program: A Model for Collaboration with Patient Advocacy Groups & Research Resources/Initiatives at NCATS, NIH"

12:15-12:45 Pharma success story:

Dr. Rudolf Hausmann (VP Technical Development & Operations at [Santhera](#)), CH: "Learnings from challenges in orphan drug development: The Santhera story"

12:45-14:00 Lunch

14:15-14:45 Therapeutic discovery center in other countries: The experience, the sustainability:

Dr. Michael Foley (Director of [Tri-Institutional Therapeutics Discovery Institute](#))

14:45-16:30 Round table

Presentation of the Swiss Center for Therapeutic Discovery, Pr. Leonardo Scapozza; CH

Round table with committed people and the audience (moderators Dr. Prunotto and Pr. Scapozza on behalf of the Medicine Discovery and Delivery Health2030 group)

16.30-16.45

Conclusion remarks

16.45 Networking and farewell cocktail

Organized and hosted by BLACKSWAN Foundation

Under the patronage of ProRaris - Swiss Rare Disease Alliance