

## MEDIA RELEASE

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### **RE(ACT)x Switzerland: We Care for Rare - Symposium devoted to Swiss Translational Science on Rare Diseases**

Geneva - On 10 November 2016, the "RE(ACT)x Switzerland: We Care for Rare" brought together a group of motivated researchers and patients advocates to discuss about the creation of a Swiss Center for Therapeutics Discovery (SCTD) focused on rare diseases (RD). The symposium organized by the BLACKSWAN Foundation on behalf of "Medicine Discovery & Delivery" Health2030 workgroup, will be probably remembered as the turning point for translational research on rare diseases in Switzerland and in Europe. The event was organized at Campus Biotech in Geneva under the patronage of ProRaris, the Swiss alliance of rare disease patients.

Prof. Patrick Aebischer (EPFL) addressed a welcome message to the more than 100 people representing the Swiss and international research community. The President of EPFL emphasized the importance of building an ecosystem for rare diseases such as the successful one developed by EPFL for the Innovation Park. He also welcomed the commitment of the people who started the SCTD project and offered his full support to make it a reality.

Welcoming the participants, Dr. Olivier Menzel, President and founder of the BLACKSWAN Foundation, illustrated the unmet medical needs for rare diseases and explained how the creation of a Swiss Center for Therapeutics Discovery was a unique opportunity to provide hope for patients and position Switzerland as a pioneer of drug discovery for rare diseases in Europe.

The first part of the day was dedicated to listening to patients' voices reporting on the unmet medical needs, to researchers working in that domain showing the advances that science can bring but also the difficulties experienced in translating scientific knowledge into cure to patients and to learn from successful projects that made it from the bench to the bedside. Keynote speakers included Mrs. Anne-Françoise Auberson, President of ProRaris, Swiss Rare Disease Alliance; Mrs. Sharon S. Lagas, Board President, Alport Syndrome Foundation, USA; Dr. Olivier Dorchies University of Geneva, Switzerland; Prof. Gisou van der Goot, Dean of the School of Live Science at EPFL and Dr. Rudolf Hausmann, VP Technical Development & Operations at Santhera, Switzerland.

Pr. Kay Davies and Dr. Rashmi Gopal-Srivastava provided institutional examples of rare diseases translational centers and exiting inputs for thoughts to the participants. Professor Davies, Director of the MRC functional genetics unit, governor of the Wellcome Trust and director of the Oxford Centre for Gene Function in the UK brought the model of the Oxford Rare Disease Initiative and suggested to build a taskforce benefiting from clinical and patient

networks as well as academic and industrial resources. Through the experience gained by the National Center for Advancing Translational Science (NCATS) at NIH, in the United States, Dr. Rashmi Gopal-Srivastava Director of Extramural Research Program offered an overview of the Rare Diseases Clinical Research Network (RDCRN) Program.

Thanks to Dr. Michael Foley's presentation on the Tri-Institutional Therapeutics Discovery Institute in the US, the audience had excellent points of discussion for the second part of the RE(ACT)x symposium. Prof. Leonardo Scapozza, representing the Medicine Discovery and Delivery Health2030 group, presented the project for the creation of a Swiss Center for Therapeutics Discovery and exchanged with the public audience. He received an enthusiastic feedback, excellent ideas for the implementation phase and advices to avoid possible bottlenecks.

The event was a major milestone in the creation process of the Swiss Center for Therapeutics Discovery focused on rare diseases. The interest and commitment from the vast majority of the participants demonstrated the viability of the project and confirmed that the main and probably only difficulty lie on the raising of funds for the kickoff. However, promising signs already came from Swiss academic institutions, the federal government and from private donors bringing hope for the establishment of a public-private partnership in favor of the SCTD. In the coming months, the BLACKSWAN Foundation is going to raise funding for the creation of this unique center which will give hope and treatments to millions of patients.

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