RE(ACT) CONGRESS AMERICA

8-10 May 2019 TORONTO

We amplify collective action for research on rare diseases #RAREvolution

The fifth edition, and the first one held in North America, of the RE(ACT) Congress – International Congress of Research on Rare and Orphan Diseases – was held at the Sheraton Centre Toronto Hotel in Toronto, Canada, from 8-10 May 2019. It was organized by the <u>BLACKSWAN Foundation</u> in collaboration with the Office of Rare Diseases Research (ORDR) within the <u>National Center for Advancing Translational Sciences (NCATS)</u> at the National Institutes of Health (NIH) and the <u>Children's Hospital of Eastern Ontario (CHEO)</u>, in partnership with the <u>Canadian Organization for Rare Disorders (CORD)</u>, the <u>Canadian Institutes of Health Research (CIHR)</u> and <u>Genome Canada</u>. The Congress also benefited from the support of IRDiRC, Rare Diseases International, Eurordis and Genome Canada.

The event attracted around 150 attendees, including scientists, physicians, patient organizations, pharmaceutical industry representatives and start-ups, patients, and other international stakeholders. During the three-day conference these world-class speakers and participants shared their experiences and presented their innovative and outstanding scientific research on rare diseases. The full list of speakers is available at: http://www.react-congress.org/speakers/.

In his opening speech, Dr. Christopher Austin, Director of NCATS at the NIH, highlighted the importance and unique focus of the Congress which, aligned with the BLACKSWAN Foundation's mission, aims to amplify the collective efforts and voices in rare diseases research.

Topics discussed at the congress involved, among others, new developments in stem cells, regenerative medicine, and gene and cell therapies for rare diseases, new methods and tools to study these diseases, insights and lessons gained from indigenous populations, and a joint collaborative session with CORD concluded the RE(ACT) Congress. In this session, patients and family members recounted their experiences and success stories in progressing towards the treatment of their specific diseases. Over the course of the meeting, two dedicated workshops on multi-national clinical trials/registries and generalizable therapeutic approaches for rare diseases provided an overview of collaborative projects dedicated to the scientific community.

Lausanne, 15th May 2019

Contact information: contact@react-congress.org

Pictures from the congress: http://bit.ly/REACT2019



SCHWEIZERISCHE STIFTUNG FÜR DIE FORSCHUNG SEILENER KRANKHEITEN FONDATION SUISSE POUR LA RECHERCHE SUR LES MALADIES ORPHELINES FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALATTIE ORFANE



