

# RE(ACT) CONGRESS

9-12 March 2016 BARCELONA

## **Collaboration is the key towards success in rare diseases research #RAREvolution**

The third edition of the RE(ACT) Congress – International Congress on Research of Rare and Orphan Diseases, organized by the BLACKSWAN Foundation (<http://www.blackswanfoundation.ch/en/>) in collaboration with E-Rare (<http://www.erare.eu/>) has been held at the Crowne Plaza in Barcelona, from 9th to 12th March 2016. The Congress supported by IRDiRC, Eurordis and CIBERER presented some of the most innovative and outstanding research on rare diseases on topics like drug repositioning and personalized medicine, NGS, pathophysiology and gene therapies.

The event involved more than 200 attendees: researchers, doctors, organizations, patients, sponsors and other international stakeholders. World-class speakers like Alex MacKenzie, Gert Matthijs, Olaf Horst Riess, Danilo Tagle and many others, shared their studies during the four days conference and were the protagonists of a successful edition of the RE(ACT) Congress 2016. The full list of the speakers is available on: <http://www.react-congress.org/speakers/>.

Speaking at the opening ceremony, Christopher P. Austin, Director of the National Center for Advancing Translational Sciences (NCATS) at the U.S. National Institutes of Health (NIH) underlined the importance of collaboration in rare diseases to catalyze the innovative methods and technologies for the development, testing and implementation of diagnostics and therapeutics.

Patients were represented at the Congress by the presence of Yann Le Cam, Chief Executive Officer of the European Organization for Rare Diseases – EURORDIS, who stressed the importance of building bridges between patients and the scientific community and as part of this objective announced a new collaboration with the BLACKSWAN Foundation.

The RE(ACT) Congress gathered not only the attendees interest, but also a wide online popularity. In fact, more than 350 contents were shared on the social networks with the official hashtags #REACTCongress, #RAREvolution, #REACTCommunity.

The RE(ACT)Congress 2016 has been chosen by the BLACKSWAN Foundation for launching the restyling of the RE(ACT) Community, (<http://react-community.org/>), the digital platform created in 2014. The graphic restyling went hand in hand with the definition of its overall mission, summarized in the claim: “We are the RAREvolutionary people. Stand up for Scientific Research”. The idea behind the Community is to provide a space where researchers and patient can learn from each other and support rare diseases projects through crowdfunding. The goal is to improve knowledge and involve different types of stakeholders in campaigns and concrete actions.

During the Congress opening, the BLACKSWAN Foundation also launched an online international petition to advocate for research on rare and orphan diseases. The Petition includes the most strategic points that deserve the attention of institutions and international organizations and provides guidance for the establishment of policies on rare diseases research. World leading researchers attending the Congress welcomed the initiative and endorsed the petition. If you also want to support the petition you can sign and share it:

<http://www.blackswanfoundation.ch/en/petition/>.

Lausanne, 17<sup>th</sup> March 2016

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Pictures from the congress: <https://flic.kr/s/aHskt6hiiN>

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