RE(ACT)CONGRESS

7-10 March 2018 BOLOGNA

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

The fourth edition of the RE(ACT) Congress - International Congress of Research on 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 Rizzoli Institute – Istituto di ricerca Codivilla Putti in Bologna, Italy, from 7th to 10th March 2018.

The Congress supported by IRDiRC, Eurordis and Fondazione Telethon presented some of the most innovative and outstanding scientific research on rare diseases. The main topics discussed during the RE(ACT) Congress included NGS and undiagnosed rare diseases, pathophysiology, gene and cell therapies and neurological diseases.

Over the course of the meeting, a dedicated session on the opportunities in rare diseases research around the world provided to participants an overview of collaborative projects dedicated to the scientific community. Two workshops were also organized on the first day of the congress, one by the Undiagnosed Diseases Network International (UDNI) on undiagnosed diseases and the other one by the European Reference Network on Rare Bone Disorders (ERN-BOND) on European Reference Networks (ERNs).

The event involved more than 100 attendees: researchers, doctors, organizations, patients, sponsors and other international stakeholders and world-class speakers included Professor Silvio Garattini, Professor Harvey F. Lodish, Professor William Gahl, Professor Luigi Naldini, Professor Nicolas Lévy and many others. During the three days conference, they shared their studies and were the protagonists of a successful edition of the RE(ACT) Congress 2018. The full list of speakers is available at: http://www.react-congress.org/speakers/.

In his opening speech, Professor Silvio Garattini, founder and director of the Mario Negri Institute for Pharmacological Research highlighted three main reasons why rare diseases should be studied. He emphasized the right of patients to be cured independently from the type of their disease, the fact that rare diseases furnish information useful for common diseases, and the importance of rare diseases for the future since they pave the way to personalized medicine. He also opened a discussion on the importance of creating more incentives for ultra-rare diseases.

During the opening ceremony, Professor William Gahl, Senior investigator at the Intramural Research Program, National Institute of Health (NIH) underlined the importance of putting more effort on diagnosis within the international network.

The opening ceremony was closed by Harvey F. Lodish, Professor of Biology and Biological Engineering at the Massachusetts Institute of Technology (MIT) and Founding Member of the Whitehead and Broad Institute for Biomedical Research. Professor Lodish, who is the lead author of the textbook Molecular Cell Biology and the founder and Board member of several biopharmaceutical companies, provided a speech on Academic Entrepreneurs, New Technologies and Building Companies to Treat Rare Diseases. During his talk he emphasized the need for intense collaboration of different stakeholders to develop a cure for rare diseases. One of the take home messages of his presentation was on the importance of "geography" to push research forward and deliver new treatments, the importance of creating an ecosystem like the one the MIT and the Whitehead and Broad Institute for Biomedical Research have formed in Boston attracting biotech, pharmaceutical and venture capital firm to translate academic research into new therapies.

Lausanne, 19th March 2018

Contact information: contact@react-congress.org

Pictures from the congress: https://goo.gl/zdyYFv

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