

#RAREvolution – Stand up for Scientific Research on Rare Diseases

2018 is an important year for the BLACKSWAN Foundation (<http://www.blackswanfoundation.ch>) and for the research community to advocate for more research on rare diseases (RDs).

The BLACKSWAN Foundation believes that a stronger engagement at international level is fundamental to attract more resources, create new incentives for research, and develop therapies for millions of patients. For this reason, the Foundation started the #RAREvolution program that combines the work and experience developed in the last years through the RE(ACT) Initiative (RE(ACT) Congress [<http://www.react-congress.org/>] and RE(ACT) Community [<http://react-community.org/>]) with new interventions aimed at integrating its international action.

One of the main objectives of the #RAREvolution is to increase the awareness of RDs. Furthermore, it is pivotal to improve the understanding of RDs among the public, policy-makers, health professionals, researchers, and academics. The BLACKSWAN Foundation is promoting an online action using digital channels named “#RAREvolution: Stand up for Scientific Research” on the importance of advancing RD research and providing patients with more and better treatments. At the same time, the Foundation launched an online petition, which provides guidance to institutions and international organizations for the establishment of policies on RD research. The petition is available online at <http://www.blackswanfoundation.ch/en/petition/>. Please sign it and share it with your contacts.

The RE(ACT) Initiative is part of the #RAREvolution Program and promotes international cooperation in scientific research on RDs. Existing research efforts are in fact still scattered, and fragmented research is being performed with little coordination between research laboratories. This lack of coordination is particularly detrimental when it comes to increasing knowledge on RDs, especially in this field where resources are very limited and the patient population is small.

Through the RE(ACT) Initiative, the BLACKSWAN Foundation builds a community of researchers revealing the needs in this field, showing public institutions the important results achieved, and gaining stronger political leverage to ask for more support.

This year's 4th RE(ACT) Congress taking place in Bologna, Italy, from the 7th to 10th of March 2018 is organized by the BLACKSWAN Foundation and E-RARE, the ERA-Net for Research Programs on RDs. The Congress focuses on: opportunities in RDs around the world, next-generation sequencing (NGS) technology and undiagnosed RDs, pathophysiology, gene and cell therapy as well as neurological diseases. The unique feature of the RE(ACT) Congress is that specialists from different fields of research come together to address RDs and treatments across the boundaries of their own disciplines. Two parallel workshops, including the Undiagnosed Diseases Network International (UDNI) and the European Reference Networks (ERNs) are going to highlight the work and importance of international collaborations.

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