#RAREVOLUTION: THE USE OF DIGITAL COMMUNICATION TO SUPPORT RARE DISEASE RESEARCH

Chiara Ciriminna – Project Coordinator
#RAREvolution

Stand up for scientific research

International program for rare and orphan diseases
Promoting the recognition of rare diseases as an international public health and research priority
Vision

Public Health & Research Priority

ADVOCACY & AWARENESS
- Petitions
- Ambassadors
- KOLs

SUPPORT FOR RESEARCH
- Treatments
- Diagnostics

RE(ACT) INITIATIVE
- Knowledge sharing
- Collaborations

Cure more people!
SAVE LIVES

BLACKSWAN® FOUNDATION

RE(ACT) Congress 2018
#RAREvolution: Awareness

8% of global population is affected by Rare Disease

75% are children

30% of children do not survive the 5th birthday

35% of children die in first year of life
#RAREvolution: Awareness

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475 MIO / 7.052 MIO

RARE Diseases

228 MIO / 7.052 MIO

AIDS + Malaria

1338
612
968

1156
897
766
Human rights based approach to assure non-discrimination, equity and justice. Rare diseases must be part of the 2030 Agenda for Sustainable Development to meet the goals and “Leave no one behind”.

Work on the commitment of the new WHO Director General Tedros Ghebreyesus during the policy event.
Petition: “Help us to increase support for rare diseases research”
Center for Therapeutics Discovery

Creation of a discovery and clinical research incubator dedicated to translational science on rare diseases. The center will combine academic expertise and technologies with industry know-how in drug discovery.
RE(ACT) Congress
7-10 March 2018
Bologna, Italy
#RARE-VOLUTION
GOAL: act as a game changer in the scientific field, spreading the voice about the urgency of investing in rare and orphan disease research.
The RE(ACT) Community promotes information exchange among researchers and encourages patients to share their health experiences. It supports acting as a game changer in the scientific field, spreading the voice about the urgency of investing in rare and orphan disease research.

Researchers can submit their projects and raise funds starting a crowdfunding campaign. Donations to the RE(ACT) Community help keep the whole platform running.

The RE(ACT) Community encourages both researchers to publish scientific information/new findings and patients to share their personal health experiences.

RE(ACT) Members can receive information on relevant studies, conferences, meetings, grants, and other related news.

RE(ACT) is a digital platform connecting all the researchers and allowskiing them to start new collaborations.

www.react-community.org
The RE(ACT) Community promotes information exchange among researchers and encourages patients to share their health experiences.

RE(ACT) Community helps connecting researchers and all of them to start new collaborations.

Connecting an international network in order to support rare and orphan disease scientific research.

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The RE(ACT) Community is a digital platform for rare and orphan disease scientific research. We are the RAREvolutionary People. We are about rare diseases support, scientific knowledge sharing, involving different types of stakeholders in campaigns and concrete actions in support of research engaging all those who want to support the advancement of scientific research and speed up the development of new therapies for patients with rare diseases.
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A Glimpse of Hope for FOXG1

WHAT IS FOXG1?
FOXG1 is a rare genetic mutation of the FOXG1 gene that impacts brain development and function. This severe neurological condition is characterized by seizures, inability to control body movements, and lack of speech.

While the spectrum of abilities is quite broad depending on the exact genetic mutation, many of the children cannot walk or talk, and they struggle to communicate their most basic daily needs. It is possible for parents to be carriers, but most cases of FOXG1 are non-inherited and have no family history.

ENGLISH (Francophones, vous trouverez la version en français ci-dessous)
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