RE(ACT) Congress

7-10 March 2018
Bologna, Italy

#RARE-VOLUTION
RE(ACT) Community

is a digital platform

research on orphan and rare diseases support

crowdfunding

scientific knowledge sharing

connecting an international network in order to support the rare and orphan diseases scientific research
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
#RAREvolution

Stand up for scientific research

International program for rare and orphan diseases
Promoting a global and comprehensive strategy to recognise rare diseases as an international public health and research priority
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

475 MIO / 7'052 MIO
RARE Diseases

228 MIO / 7'052 MIO
AIDS + Malaria

1338
612
968

1156
897
766
#RAREvolution: Advocacy

Coordination of the Working Group Research: Dr Olivier Menzel

Co-organisation of the International Policy event in Geneva (10th Feb. 2017)

change.org Petition: “Help us to increase support for rare diseases research”
Where and how do we go forward?

HOW:

• 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”
• Common voice towards the international community

WHERE:

• Work on the commitment of the new WHO Director General Tedros Ghebreyesus during the policy event
• Innovation, research and access
• Learn from others (HIV/AIDS, Albinism, Mental Health...)
• UN Resolution