BLACKSWAN® FOUNDATION

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASES
SCHWEIZERISCHE STIFTUNG FÜR DIE FORSCHUNG SELTENER KRANKHEITEN
FONDATION SUISSE POUR LA RECHERCHE SUR LES MALADIES ORPHELINES
FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALATTIE ORFANE

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

Chiara Ciriminna – Project Coordinator

RE(ACT) CONGRESS 2018

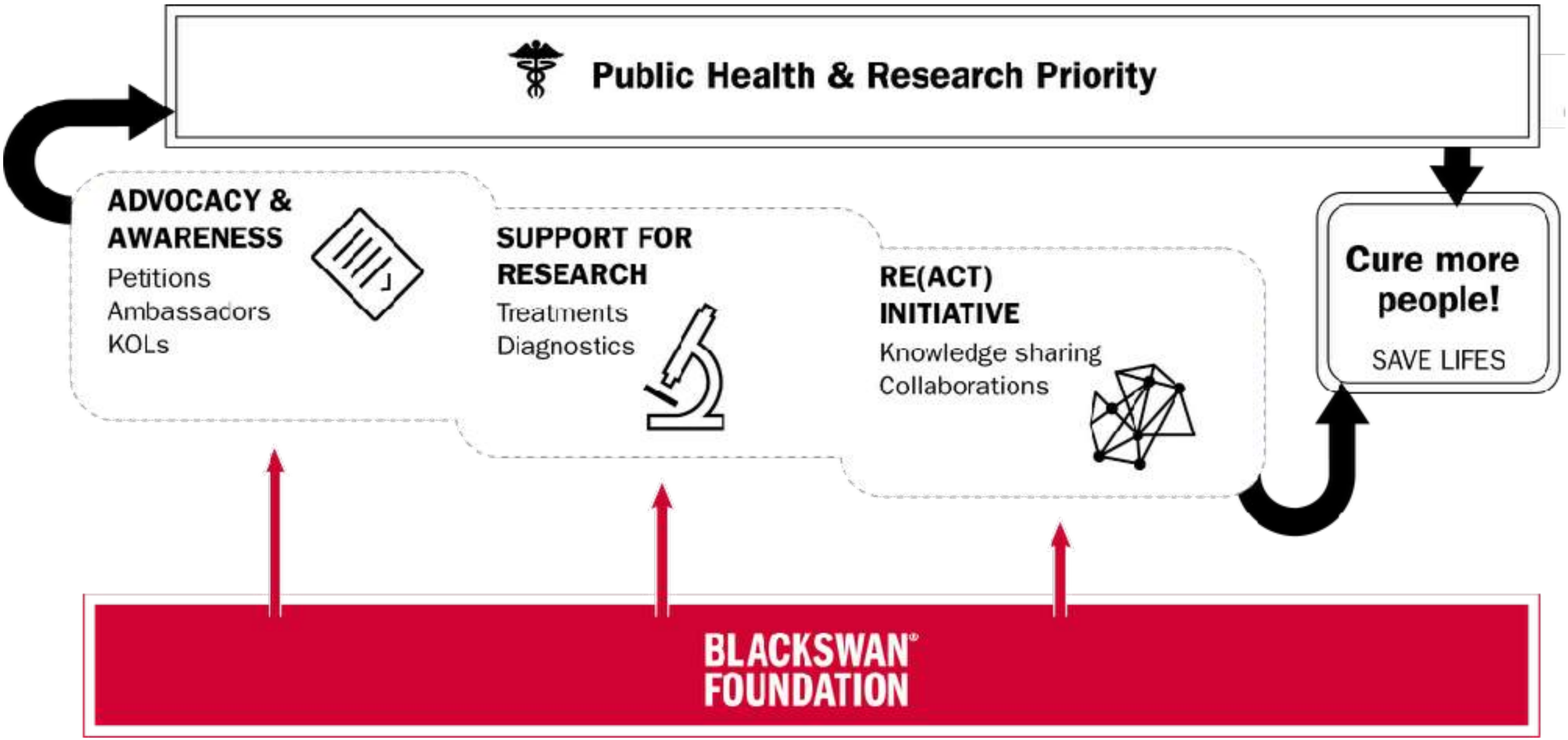
#RAREvolution

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 LIFES
BLACKSWAN® FOUNDATION

#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

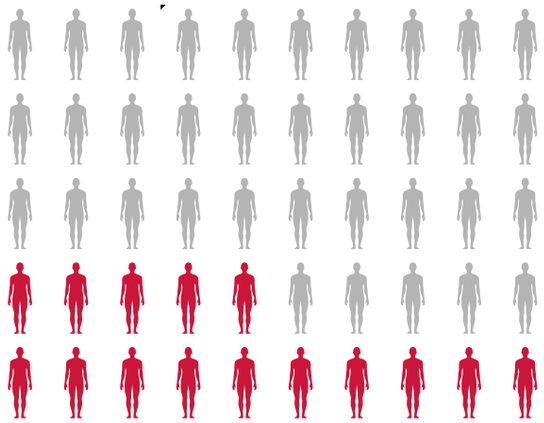
#RAREvolution: Awareness

8 %

of global population
is affected by Rare Disease

75 %

are children



30 %

of children do not survive
the 5th birthday

35 %

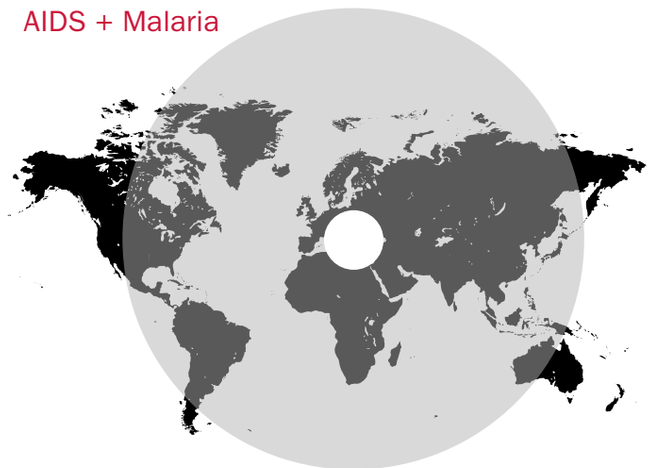
of children die
in first year of life

475 MIO/7'052 MIO

RARE Diseases

228 MIO/7'052 MIO

AIDS + Malaria



1 338 612 968 CHINA POPULATION

1 156 897 766 INDIA POPULATION

475 304 355 RARE DISEASE POPULATION

302 074 000 USA POPULATION

#RAREvolution: Advocacy

RARE DISEASES INTERNATIONAL

SUSTAINABLE DEVELOPMENT GOALS

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

change.org

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

www.react-congress.org

7-10 March 2018
Bologna, Italy

WE ARE
RAREVOLUTIONARY
PEOPLE.**Stand up for Scientific Research.**

GOAL: act as a game changer in the scientific field, spreading the voice about the urgency of investing in rare and orphan disease research

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 rare and orphan disease scientific research

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

involving different types of stakeholders in campaigns and concrete actions in support of research

RE(ACT)
Community

www.react-community.org

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

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

RE(ACT) Community

www.react-community.org

The RE(ACT) Community helps connecting researchers and allows them to start new collaborations

The RE(ACT) Community promotes information exchange among researchers and encourages patients to share their health experiences

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

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

RE(ACT) Community

The scientific knowledge sharing and crowdfunding platform for rare diseases

DONATE

HOME | HOW IT WORKS | DISEASES | PROJECTS | RESEARCHERS | ABOUT | FAQ

PROJECTS LIST

A Glimpse of Hope for FOXG1

€79351 PLEDGED

+ invite friends

DONATE

DAYS 13 | HRS 15 | MIN 43

by: A. Renieri

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, mild...

INTERNATIONAL FOXG1 FOUNDATION

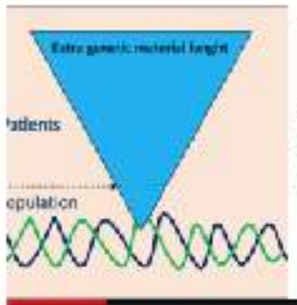
FUNDING € 79.352 MILESTONE GOAL 154k

How a better characterization of the genotype-phenotype r...

€ 141 PLEDGED

+ invite friends

BACK AND REACTIVATE ?



by: Gisela Nogales-gadea

Research project: How a better characterization of the genotype-phenotype relation will help in applying early symptomatic treatments for Steinert Myotonic Dystrophy patients OVER...

FUNDING € 1.141 MILESTONE GOAL 8.800

Building a national biobank and registry of large and g...

€ 46040 PLEDGED

A GLIMPSE OF HOPE FOR FOXG1

Atypical Rett syndrome

DESCRIPTION RESULTS 0 UPDATES 2 BACKERS 82 MILESTONES 1

Share

EDIT

WHAT'S 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)*

The project is Fully Funded

€ 154k

+ invite friends

A GLIMPSE OF HOPE FOR FOXG1

Atypical Rett syndrome

DESCRIPTION RESULTS 0 UPDATES 2 BACKERS 82 MILESTONES 1

Share

EDIT

The project is Fully Funded

€ 154k

+ invite friends

INTERNATIONAL FOXG1 FOUNDATION

WHAT'S 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)*

BLACKSWAN®
FOUNDATION

WEB
blackswanfoundation.ch
react-community.org
react-congress.org

SOCIAL
facebook.com/REACT.community.official
twitter.com/blackswanfound
linkedin.com/company/blackswan-foundation
instagram.com/blackswan_foundation/