IRDiRC

INTERNATIONAL
RARE
DISEASES
RESEARCH
CONSORTIUM

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- Australia
  - Western Australian Department of Health
- Canada
  - CIHR
  - Genome Canada
- China
  - Beijing Genomics Institute
- EU
  - European Commission
- France
  - French Association against Myopathies
  - Agence National de la Recherche
  - Lysogene
- Germany
  - Federal Ministry of Education and Research
- Italy
  - Italian Higher Institute of Health
  - Telethon Foundation
- International Consortium
  - E-RARE 2 Consortium
- Netherlands
  - The Netherlands Organization for Health Research and Development
  - Prosensa
- Spain
  - National Institute of Health Carlos III
- UK
  - National Institute for Health Research
- USA
  - Food and Drug Administration Orphan Products Grants Program
  - National Human Genome Research Institute (NIH)
  - National Center for Advancing Translational Sciences(NIH)
  - National Cancer Institute (NIH)
  - National Eye Institute (NIH)
  - National Institute of Neurological Disorders and Stroke (NIH)
  - National Institute of Arthritis and Muscoloskeletal and Skin Diseases (NIH)
  - National Institute of Child Health and Human Development (NIH)
  - National Eye Institute (NIH)
  - NKT Therapeutics
  - Office of Rare Diseases (NIH)
  - PTC Therapeutics
  - Sanford Research Institute
  - Shire

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More members wanted!

- Many countries remain unrepresented.
- Some public-sector funders who are active in the rare disease area are absent.
- *Many* companies are missing.

To join:

- Demonstrated commitment of $10M USD for research in rare diseases in the next 5 years.
- Agreement with IRDiRC policies and guidelines, now ratified.

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IRDiRC Scientific Secretariat

- In place in Paris, at the Rare Disease Platform
- Management of the network / assistance to scientific committees and working groups
- Launch of the website:

WWW.IRDIRC.ORG

IRDiRC | International Rare Dise...

www.irdirc.org

Google

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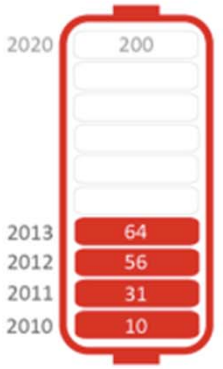
NEW THERAPIES



Objective 2020: 200 new therapies

Disclaimer: the numbers do not reflect IRDiRC initiatives only

NEW DIAGNOSTICS

MORE ARTICLES

Firefox automatically sends some data to Mozilla so that we can improve your experience.

Choose What I Share

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Analysis of the research landscape

- Collection of research projects funded since 2010 in all participating countries to be released on Orphanet (www.orpha.net)
- Analysis of overlaps and of areas for possible collaboration
- Identification of trends / emerging fields to be supported in the future

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Indicators of output

- Research activity
  - No. of IRDiRC members / allocated budget
- For diagnostics
  - No. of new causative genes discovered / No. of clinical tests of diagnostics/ No. of diseases with available test / by country and by region
- For therapeutics
  - No. of designations / No. of clinical trials / Attrition rate / No. of diseases covered/ Type of products
  - No. of disease registries / sources of clinical data

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Goals of IRDiRC

200 new therapies for rare diseases by 2020

Means to diagnose most rare diseases by 2020

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200 new therapies, diagnostics for nearly all rare diseases

- Are these goals sufficient?
- How will you help? What is your personal goal?

  –Tell us at contact@irdirc.org !