# Orphanet

How Can International Classification of Rare Diseases,
International Encyclopedias and Resource Listings Enhance Research and
Clinical Excellence?

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A Committee of **CoNGO**

CoNGO
The Conference of NGOs
in Consultative Relationship
with the United Nations

# Orphanet
# at the crossroads of the RD world

* Between countries : an international, multi-stakeholder consortium

* Between languages:  a multi-lingual service

* Between domains: health, research, disability, patients, industry, policy…

* For all audiences, globally

**Orphanet consortium**

■ Orphanet member
□ Orphanet contact point
□ Orphanet observer

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**orphanet**
*The Orphanet Consortium*

NGO COMMITTEE FOR
**RARE DISEASES**

# Information and awareness

* Working with experts around the globe to develop multi-lingual information and to produce data
    * Healthcare professionals
    * Researchers
    * Patient representatives
    * Professionals from the medical social sector
* To serve the needs of a global audience

Users from 217 countries
www.orpha.net

NGO COMMITTEE FOR
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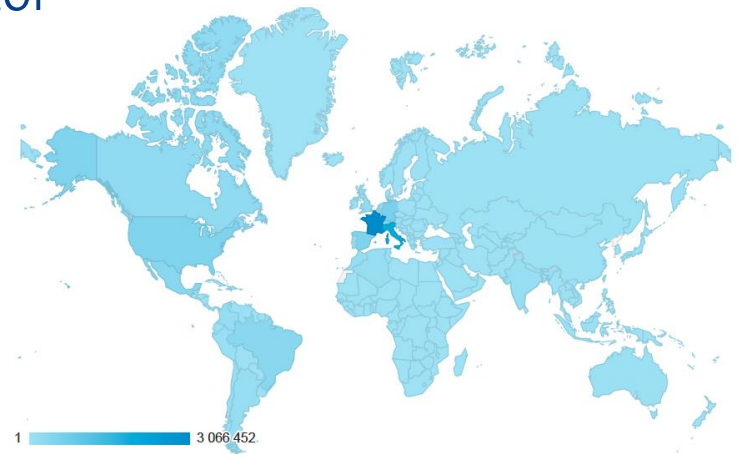
# Visibility

* In a global community, we need to understand each other, although we may not speak the same language

  * Unique, specific, multi-lingual nomenclature for rare diseases: ORPHA codes as a standard

* Rare diseases patients are scattered…as are rare diseases experts.

  * Directory of resources in 40 countries: a tool for networking, tackling isolation and fostering appropriate referrals

# Knowledge

* Integration pieces of a puzzling knowledge
  * Around the Orphanet nomenclature and classification
* Providing integrated, re-usable data
  * Orphanet Rare Disease Ontology (ORDO)
* Promoting interoperability
  * Bridging health and research
* Networking and partnering

# Data for policy and research

* Provide compiled data to inform policy decisions

  * State of the Art of RD Policies

  * State of Play of RD Research

  * Orphanet in EU recommendations

* Supporting national level policies in Orphanet countries

  * Orphanet in national plans

* Provide re-usable data for research

global utilisation of data
www.orphadata.org
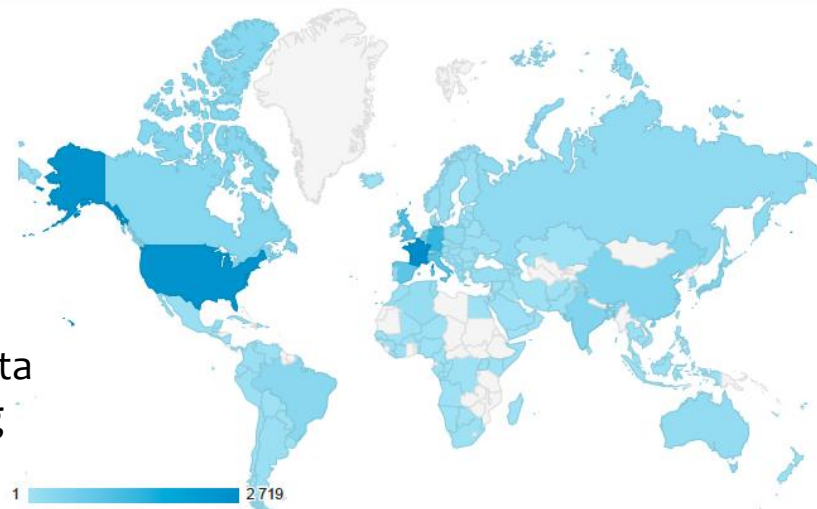
# Orphanet commitment for a global approach

* *« The Orphanet Consortium supports the work of the NGO Committee for Rare Diseases, and will, to the best of its ability, support the endeavour to improve the recognition and inclusion of rare diseases into the UN Sustainable Development Goals, and to strengthen the voice of research and medical institutions in all subsequent UN policy discussions around rare diseases. »*

**The Orphanet Consortium**

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**RARE DISEASES**

# Thank you

for your attention