

## Registry & Biobank Finder

The RD-Connect Registry & Biobank Finder is a searchable online directory of existing rare disease patient registries and peer-reviewed biobanks around the world.



**A tool to find rare disease patient registries and biobanks in just few clicks.**

The Registry & Biobank Finder is a free online directory that will let you easily find the rare disease patient registries and high quality biobanks that store data or biosamples from the patients with your rare disease of interest. The tool provides databases' contact information and the exact numbers of registered cases for each disease in the patient registry or biobank, regularly updated by the database curators.


Users can search the directory by disease name and its synonyms, OMIM- and ORPHA-codes and other keywords, such as the country or contact name. The system also provides access to documents such as databases' study protocols, case report forms, informed consent templates and data access agreements.



RD Connect


search by: Disease Name, Gene, ORPHACODE, ICD10, OMIM

ID # 11825    Date of Inclusion: 07/01/2015    Last Activities: 31/01/2018

 **Italian National Rare Disease Registry**

The RNMR has been established at the National Institute of Health by Ministerial Decree (MD) in 2001 as part of the measures devoted to improve health care for RD patients.

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 <http://www.iss.it/cnmr>

**Host institution**  
Istituto Superiore di Sanità  
Viale Regina Elena 299  
00161 Roma  
Italy

*The Registry & Biobank Finder interface.*



### Disease Matrix

Disease Name	Number of Patients, Donors	Gene	ORPHA Code	ICD 10	OMIM
Retinitis pigmentosa	4		ORPHA731	H35.5	#180100 #180104 #180105 #180210 #268000 #268025 #268060
Retinoblastoma	1023	RB1	ORPHA730	C89.2	#180200
X-linked retinoschisis	100	RS1	ORPHA732	Q14.1	#312700
Reft syndrome	1159	MECP2, CDKL5, FOXC1	ORPHA778	F84.2	#312750
Rothmund-Thomson syndrome	2		ORPHA2309	Q82.8	#268400








Funded by the European Union



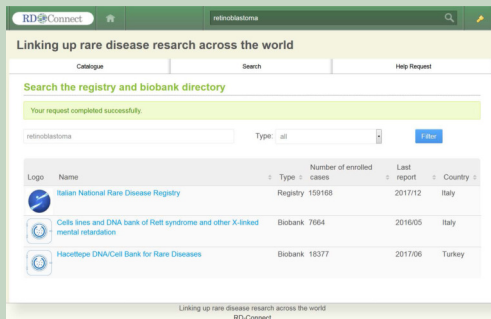
## Interoperable registries

The Registry & Biobank Finder also supports creating new rare diseases patient registries. The RD-Connect Linked Data And Ontology Task Force helps registry managers set up their patient registry in a way that allows standardization, interoperability and linking up with other registries, according to FAIR data standards (Findable, Accessible, Interoperable, Reusable).

## What are the benefits?

-  Access to information about hundreds of rare disease patient registries and biobanks around the world.
-  Find exact numbers of patients or donors in each registry or biobank for each disease.
-  Database regularly updated by registries' and biobanks' data curators.
-  Direct link to biobank's sample collections in the RD-Connect Sample Catalogue.
-  For registries and biobanks: increase your visibility in the rare disease field.
-  Map the rare disease databases and patient numbers for clinical trial preparation and feasibility studies.
-  Access free of charge and no registration needed.

[rd-connect.eu](http://rd-connect.eu)



*The Registry & Biobank Finder searching interface allows searching by disease name as well as OMIM- and ORPHA codes and sort them by country, number of cases or the date of the last update.*

## Biobank registration

For biobanks, registration in the Registry & Biobank Finder is the first step towards publishing their sample collections in the RD-Connect Sample Catalogue.

## Further information

If you have questions or would be interested in collaboration, please send an e-mail to:


[info@rd-connect.eu](mailto:info@rd-connect.eu)



[rd-connect.eu](http://rd-connect.eu)



[catalogue.rd-connect.eu](http://catalogue.rd-connect.eu)

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**Read more:** Gainotti et al. *The RD-Connect Registry & Biobank Finder: a tool for sharing aggregated data and metadata among rare disease researchers.* Eur J Hum Genet (2018) 26:631–643.

[catalogue.rd-connect.eu](http://catalogue.rd-connect.eu)