

Services

The **Rare Disease Biobank** at the Rare Diseases Research Institute (*Instituto de Investigación de Enfermedades Raras*) offers the following services:

- ◆ Processing of biological samples
- ◆ Storage of samples and data associated with the National Registry of Rare Diseases
- ◆ Storage of samples and data associated with the Registry of Autism Spectrum Disorders
- ◆ Provision of samples for research projects by investigators
- ◆ Access to sample collections of Eurobiobank www.eurobiobank.org/
- ◆ Access to sample collections of other European biobanks



Management of Rare Disease Biobank is made with Bio-e-Bank, a comprehensive management system for biobanks. Improvements in security, traceability and integrity of processes provided by this system facilitates compliance with the Biomedical Research Act and the Organic Law on Data Protection.



Instituto de Investigación
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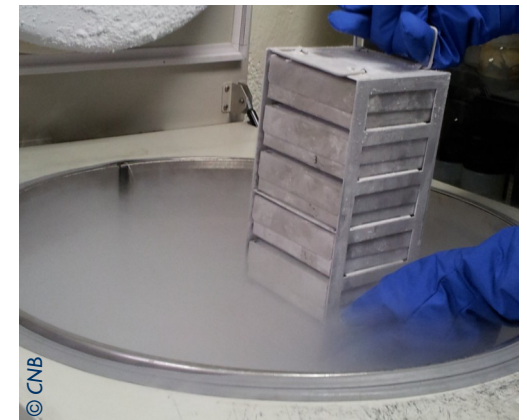
Spain

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Instituto de Investigación
de Enfermedades Raras

Rare Disease Biobank



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Membership:



Red Biobancos
Instituto de Salud Carlos III

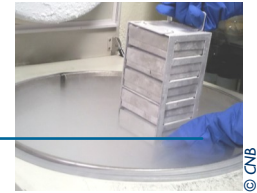


Biospecimens
Office of Rare Diseases
Research/NIH

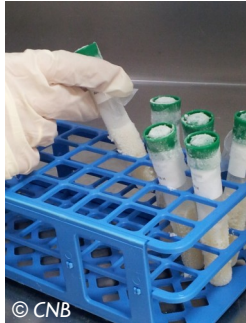
RDConnect



Rare Disease Biobank



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Biobanking is an important activity for research on rare diseases. The rarity and diversity of these diseases and their associated biomaterials present challenges and opportunities specific to biobanking that call for transnational collaboration and harmonization.

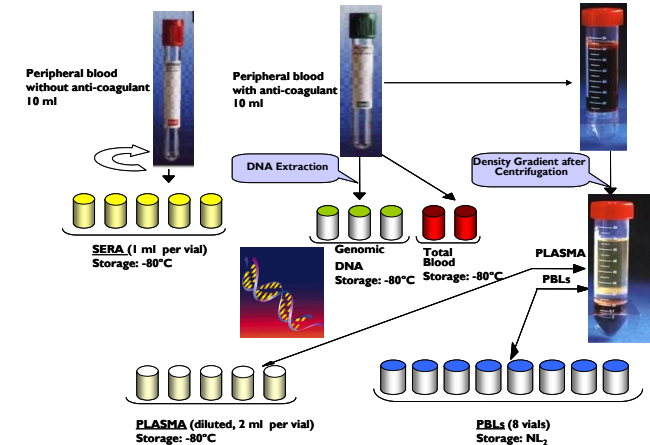
The Rare Disease Biobank (RDB) at the Rare Diseases Research Institute (*Instituto de Investigación de Enfermedades Raras-IIER*) is a **pioneering initiative in the RD field in Spain**. It houses biological samples of persons with rare diseases and also samples of persons with autism spectrum disorders.

The RDB is linked to the **National Registry of Rare Diseases**, a joint infrastructure that combines the registration of patients with rare diseases and the donation of biological samples for research. Since 2010 the RDB is a member of RetBIOH, the network of biobanks of the Institute of Health Carlos III (*Instituto de Salud Carlos III-ISCIII*).

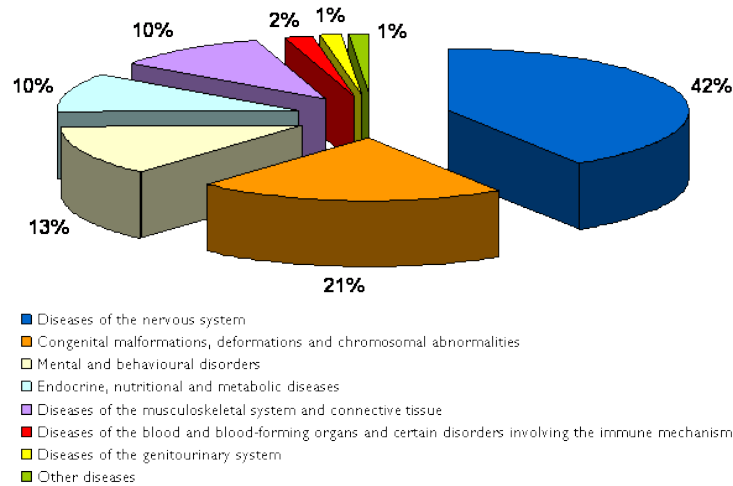
BIOBANK IN FIGURES

The **Rare Disease Biobank (RDB)** has biological samples for over 120 different rare diseases. These samples are aliquoted DNA, plasma, serum and cells. The total amounts to 911 donors. 10 per cent of these donors are family controls with rare disease.

In addition, the RDB includes biological samples from more than 3,000 donors affected by the toxic oil syndrome.



Outline of processing blood samples
Source: B. Cárdbaba, S. Gallardo / Dpto. Inmunología IIS-FJD



Distribution of donors according rare WHO ICD-10 chapters
Source: ISCIII / Instituto de Investigación de Enfermedades Raras

INTERNATIONAL SCENE

The **Rare Disease Biobank** is a founding partner of the consortium Eurobiobank. This European collaboration provides access to 440,000 biological samples from patients.

RDB is also involved in SpainRDR, Spanish Rare Diseases Registries Research Network, an initiative of the International Rare Diseases Research Consortium (IRDIRC).

It collaborates in the European project RD-Connect and the RD-HUB of the NH in the United States, as well.