Guide to the RD-Connect Registry & Biobank Finder

for managers of biobanks and patient registries

In this guide

What is the RD-Connect Registry & Biobank Finder?

Registry & Biobank Finder is a comprehensive and searchable global directory of rare disease biobanks and patient registries, created by the RD-Connect project.

The purpose of biobanks and registries is to collect and share biosamples and clinical information from rare disease patients, but it is often difficult for researchers to find out what each resource contains and how to access it. Registry & Biobank Finder allows finding biobanks and registries with data and samples on a particular rare disease, including the numbers of cases and contact information.

Why sign up to the RD-Connect Registry & Biobank Finder directory?

Joining Registry & Biobank Finder is an excellent way to increase the impact of your biobank/registry and to encourage researchers and the rare disease community to use your collections.

Being part of Registry & Biobank Finder:

- lets researchers see a detailed overview of what samples/data you have and how to contact you
- helps you get more involved in research and innovative data-sharing mechanisms
- keeps your data up-to-date in other catalogues like the Orphanet system.

In the system, each biobank/registry has its own "ID-card" that provides a summary of the diseases you cover, the number of cases, and other important information about your resource.

Each ID-card is organised into five sections:

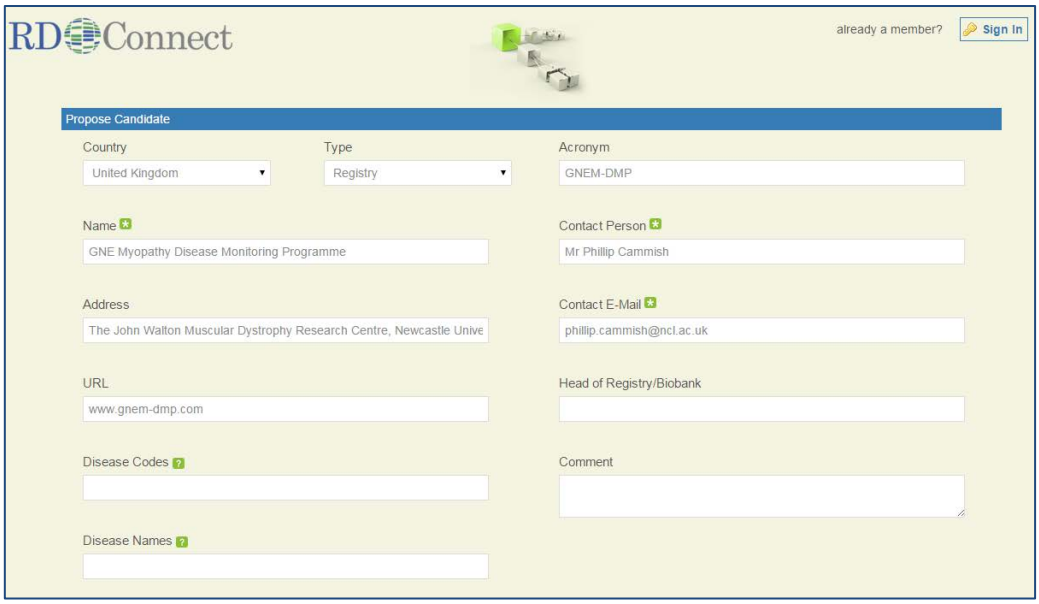
1. **General overview and organisation**
2. **Diseases collected**
3. **Standards and procedures**
4. **Accessibility of data**
5. **Study documents e.g. study protocol, case report form, informed consent template and data access agreement.**

Getting started

Visit http://catalogue.rd-connect.eu/ to access the Registry & Biobank Finder homepage. If you are new to the RD-Connect online catalogue, select the **Propose** button to get started (marked with the red arrow).

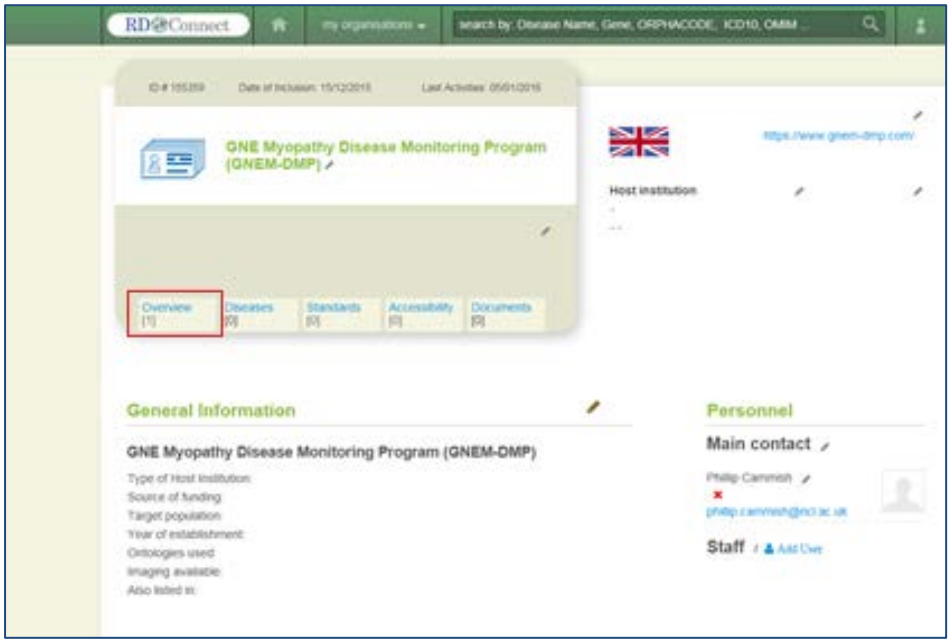
To create an ID card for your biobank/registry you need to enter data for your basic profile:

Country	*Enter the country where biobank/registry is based.*
Type	*Select one of: Registry, Biobank, Biobank/registry – select registry if you only hold data and no samples, biobank if you are primarily a resource for sample banking and distribution, and biobank/registry if you not only hold samples but also clinical data about the patient the sample came from.*
Acronym	*If your resource is known by a project acronym or other short name, enter it here.*
Name	*Name of Biobank/registry - Mandatory Field*
Address	*Enter the address that someone wanting to contact you should use - Mandatory Field*
Contact Person/ Email	*Main point of contact for enquiries via catalogue - Mandatory Field*
URL	*Biobank/registry website address*
Head of Registry/ Biobank	*If different from person creating catalogue profile*
Disease Codes	*If possible enter at least one disease code for each disease your resource deals with. You can enter multiple disease codes separated by a semicolon (;) and can use ORPHA number, ICD10, OMIM, UMLS, MESH, MEDDRA, SNOMEDCT)*
Disease Names	*You can enter multiple diseases separated by a semicolon (;) – if possible please use the disease name as it appears in the Orphanet Rare Disease Ontology.*



Once you select **Propose** you will have completed your initial registration. You will then receive an email from catalogue@rd-connect.eu containing your username and password. This will allow you to log in. Follow the hyperlink within the email in order to log in for the first time. At this stage you will also be asked to change your password to one you set for yourself. If you do not receive your log in details within 24 hours, please contact rd-connect.wp2@iss.it to request them.

When logging in from the Registry & Biobank Finder homepage , use the **Sign in** button located in the top right hand side of the screen. Upon logging in to the catalogue for the first time you are taken to your **Overview** section, where you are able to see all of the basic information about your biobank/registry that was entered upon registration (as shown below).



Editing Your Biobank/Registry Information

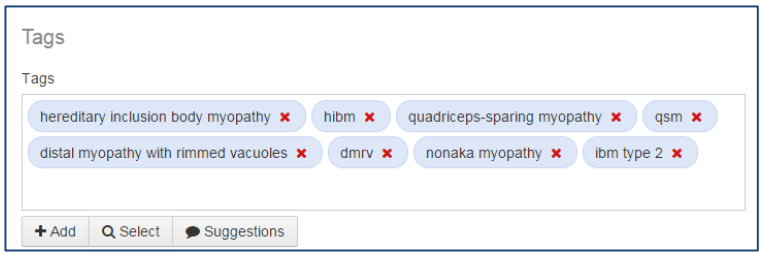
The next stage of the process is to add further relevant information about your biobank/registry.

The **edit buttons** on the Overview page let you edit and provide additional information to be displayed. The following categories can be edited:

Edit Organization

Organization Information:
Change the biobank/registry's name in the **Details** area and add your logo (as shown on the picture).

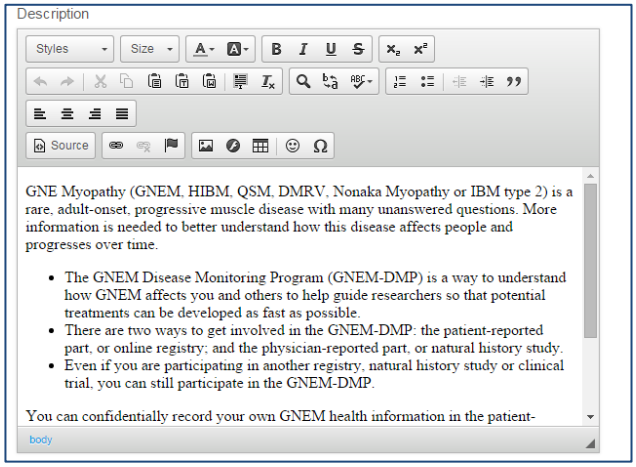
Categorization:
Add Tags (words or phrases) that will make your biobank/ registry easier to find via the "Search" tool (similar to keywords that are used on websites). You can add as many tags as you like.



Identification:
In this area, add your address, phone number(s), additional email addresses, website links as well as services (opening times). This information will appear on your **Overview** page.

Edit Core

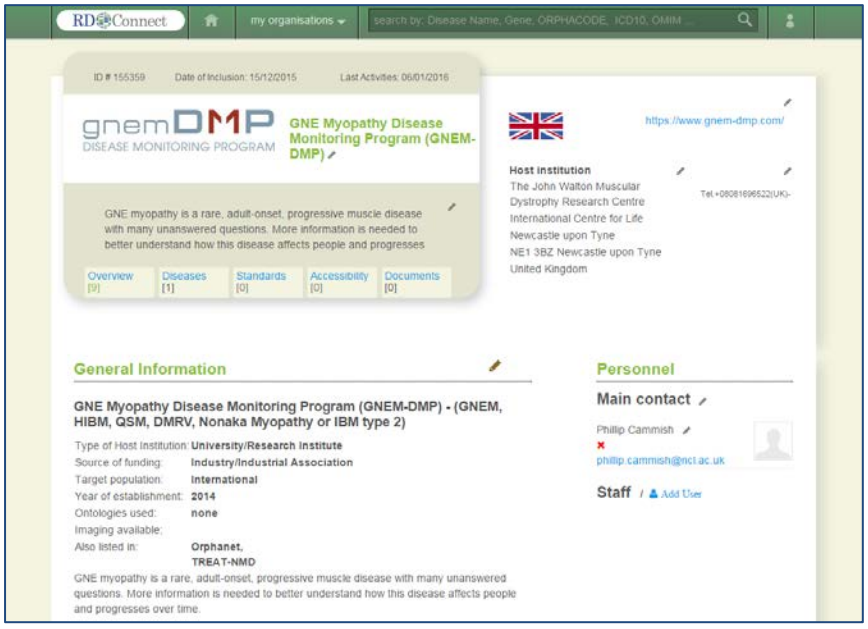
Description - Add information about your biobank /registry that will appear under the general information section on your homepage. You can use editing tools to alter the style and format of text in this area. You can also add **Acronyms** if appropriate that will appear next to the biobank/registry title.



Within the **Edit Core** section, you can also enter further information if applicable. It will appear under the biobank/registry title on your homepage:

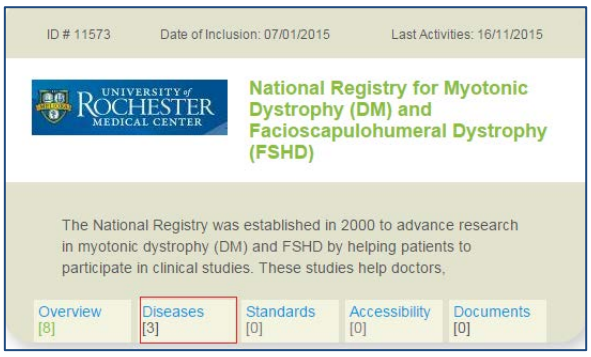
- **Type of host institution**
- **Source of funding**
- **Target Country**
- **Target population of the registry**
- **Year of establishment**
- **Ontologies**
- **Additional Ontologies**
- **Associated data available**
- **Additional Associated data available**
- **Imaging available**
- **Additional Imaging available**
- **The registry is listed in other inventories/networks**
- **Additional networks/inventories**

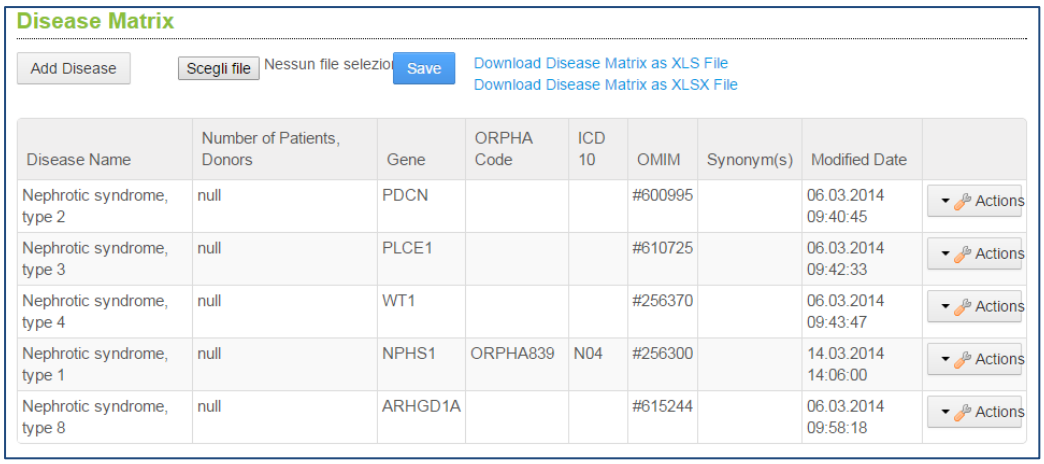
A number of options shown above let you select multiple options from the pre-populated list. To do this, hold the **Ctrl** button on your keyboard and use your mouse cursor to select the multiple options. Once you have finished the amendments to the **Edit Core** section, select **Save**. Your Overview page will look similar to the one shown below:



Diseases

Within this area you can edit the **Disease Matrix**. The Disease Name, Number of Patients/Donors, Gene, ORPHA Code, ICD10, OMIM, Synonym(s) can all be added to this area. If the registry or biobank that you are editing has more than one disease associated with it, you are able to add multiple entries using the **Add Disease** button.

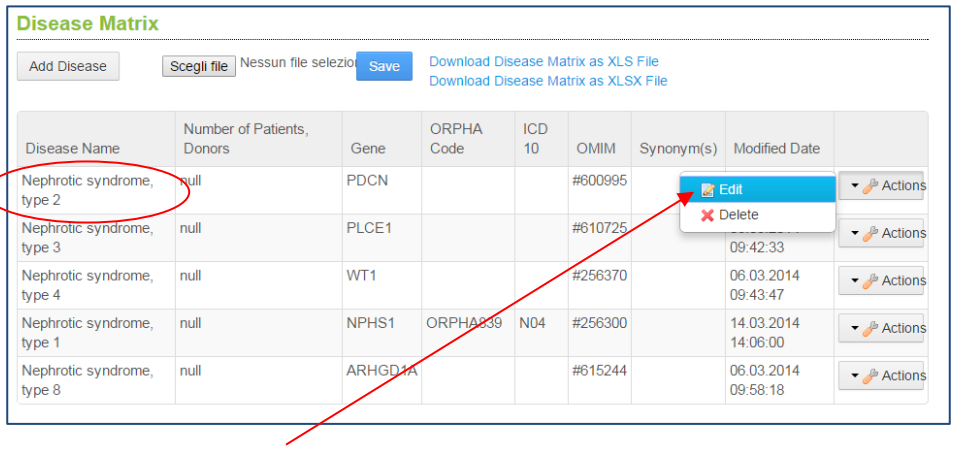




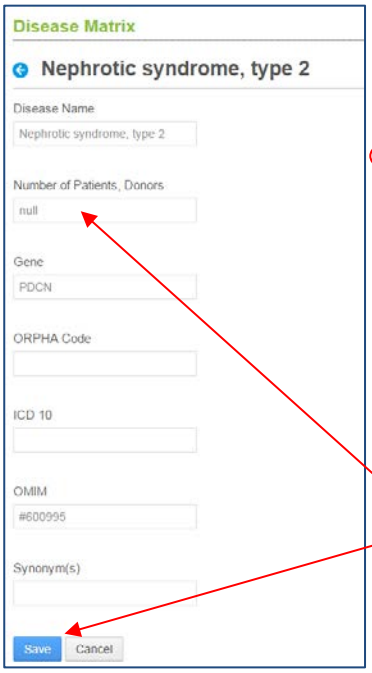
Within the **Disease Matrix** section you can also import/export data, e.g. export the matrix in an excel file, where you can change existing disease information and import it back to the system (using the **Choose File** button and then **Save**). A **Modified Date** section appears on the right hand side of the matrix and will update each time the information for each disease has been edited.

How to edit your disease matrix – method 1

Click "Diseases"

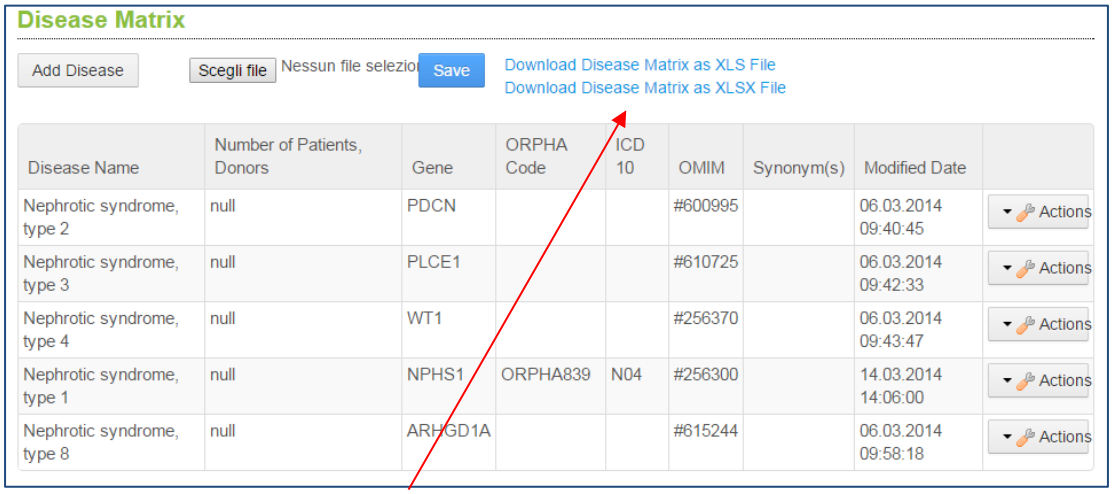


Select "Actions" and then "Edit"

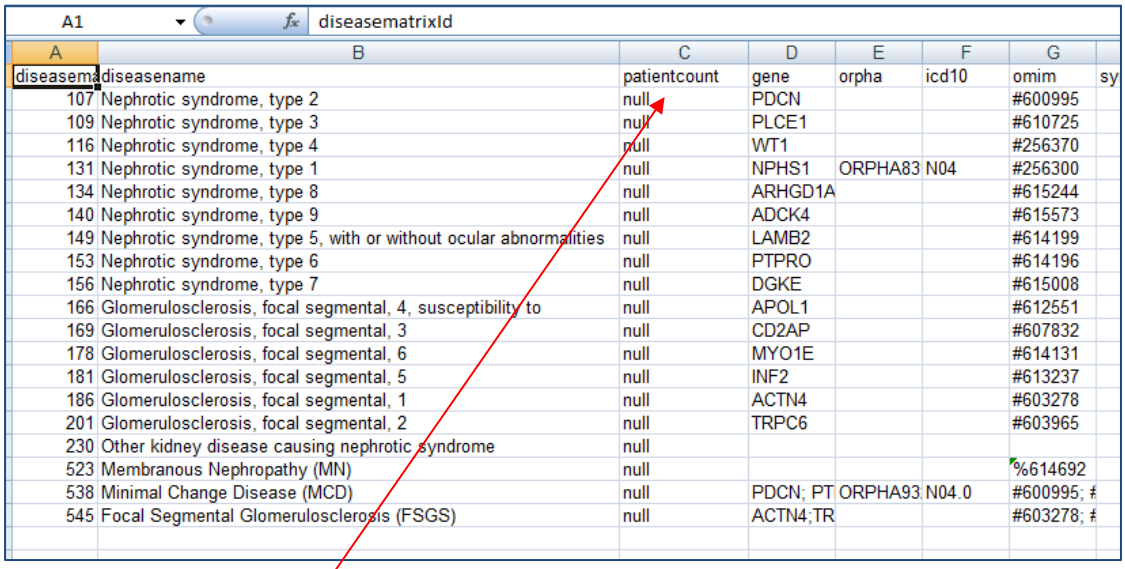


Add the number of patients/donors with the diagnosis and click "Save"

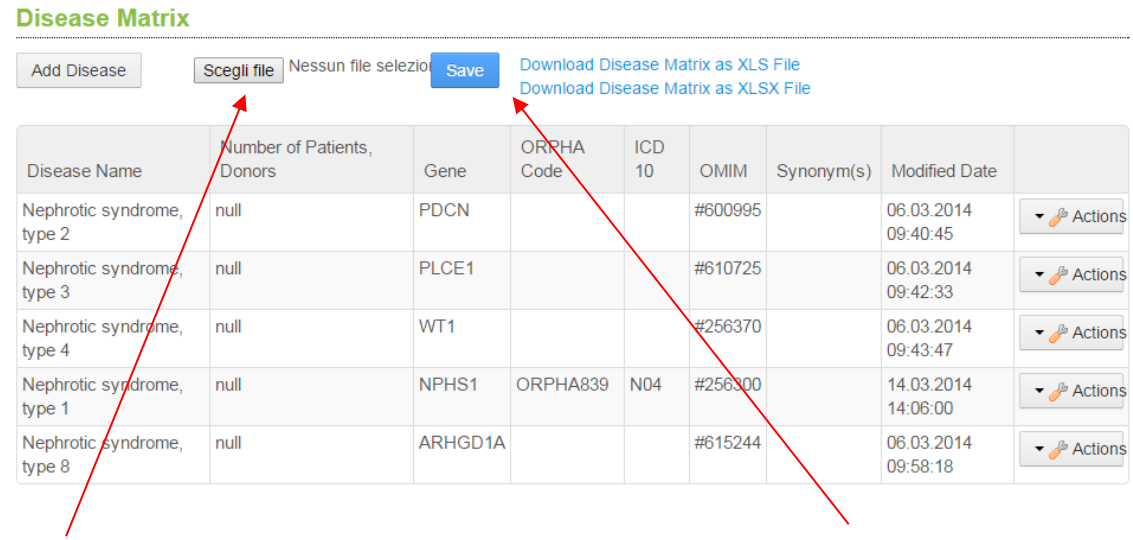
How to edit your disease matrix – method 2



download the disease matrix as xls file



fill in the field "patientcount" with the no. of registered cases for each disease, save your file



upload your modified excel file (here, in Italian “Scegli file”) and click "Save"

Standards

This area contains 8 fields to complete as appropriate:

- **Accreditation/certification program**
- **If yes, specify (ISO standards,…)**
- **Standardized case inclusion and exclusion criteria**
- **If yes, specify**
- **Standard Operating Procedures (SOPs) available for data management**
- **Quality control external audits**
- **If yes, frequency of audits**
- **Training program for the registering activities**

As your biobank/registry progresses through different stages you are able to edit this area as appropriate. The system will store **versions** of each set of Standards that you have saved over time, for you to reference in the future if required.

Accessibility

Complete the fields below as appropriate using a series of drop down and free text boxes:

- **Kind of Personal Data Collected**
- **Kind of data made available outside the registry**
- **Procedure to access data**
- **Other, please specify**
- **Has the registry a Data Access Committee?**
- **If yes, please provide the Data Access Committee webpage**
- **Do you use a Data Access Agreement?**
- **Data Access Agreement**
- **Are patient's data linked to other resources?**
- **Other, please specify**
- **Is informed consent mandatory as per your country's regulations?**
- **What kind of consent is obtained from patients/donors?**
- **Is an ethics board decision available for the use of data in research?**

As your biobank/registry progresses through different stages you are able to edit this area as appropriate. The system will store **versions** of each set of Standards that you have saved over time, for you to reference in the future if required.

Documents

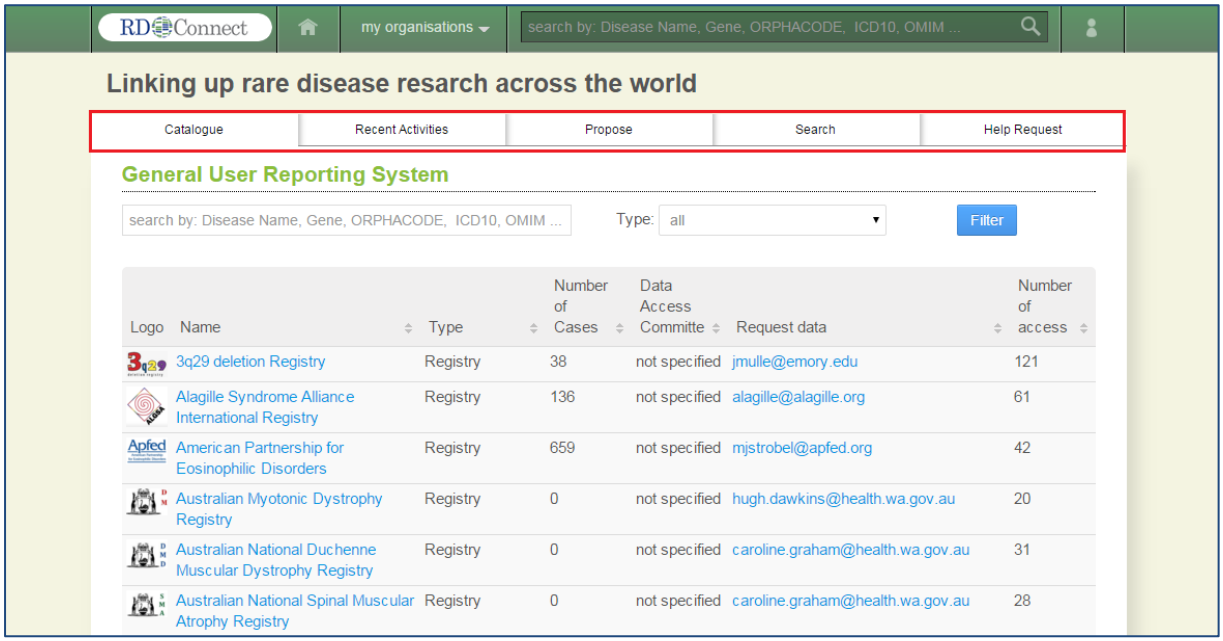
Upload any appropriate documents (basic document, contract, marketing banner, online training, and sales presentations) to this area, to make available to anybody viewing your biobank/registry area on the Registry & Biobank Finder directory.

(Please note that if you do not add any information to the Standards, Accessibility or Documents area of the catalogue, these tabs will not appear on the live website. They only appear if an area contains information that has been entered).

Using the Registry & Biobank Finder directory

As well as adding your own biobank/registry to Registry & Biobank Finder, you are also able to view all other registries and biobanks that have been added. The catalogue homepage has five sections:

- **Catalogue**
- **Recent Activities**
- **Propose**
- **Search**
- **Help Request**



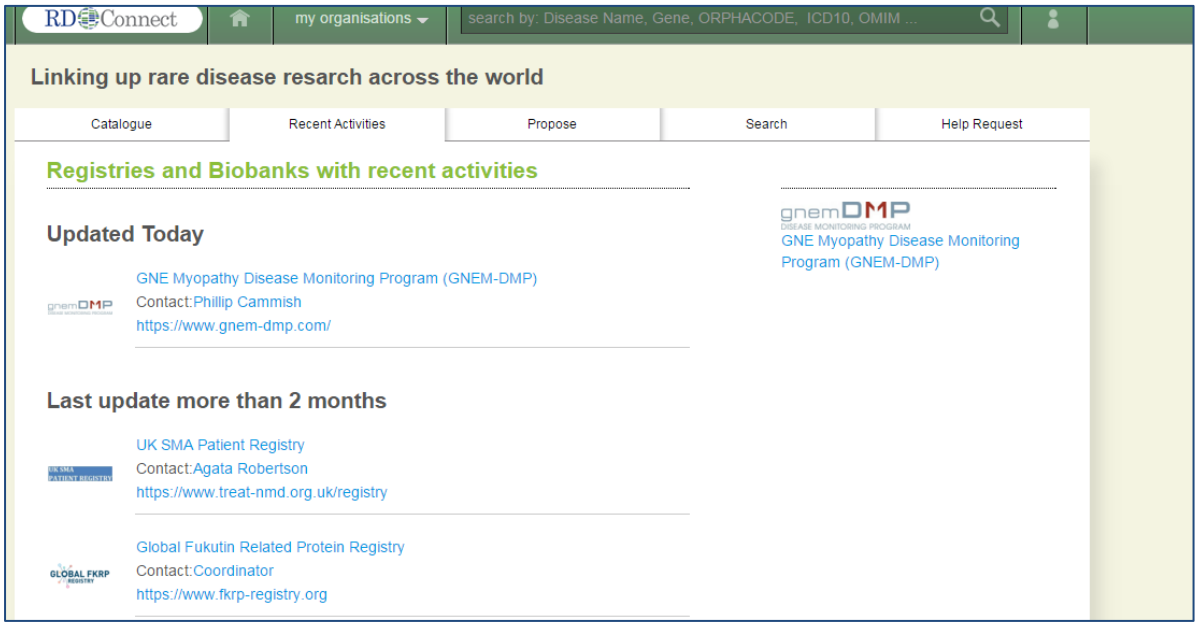
Catalogue

The catalogue tab lists all registries/biobanks that have been added by other members of RD-Connect, which you and external visitors to the catalogue can view. On the **General User Reporting System** page you can use the search box to enter information to find the correct biobank/registry that you would like to view. You can search by: the Disease Name, Gene, ORPHA Code, ICD10 or OMIM (information that was added to the Disease Matrix).

If your search term brings back a large number of search results, you can filter them by the type (biobank or registry) using the "Type" drop-down menu.

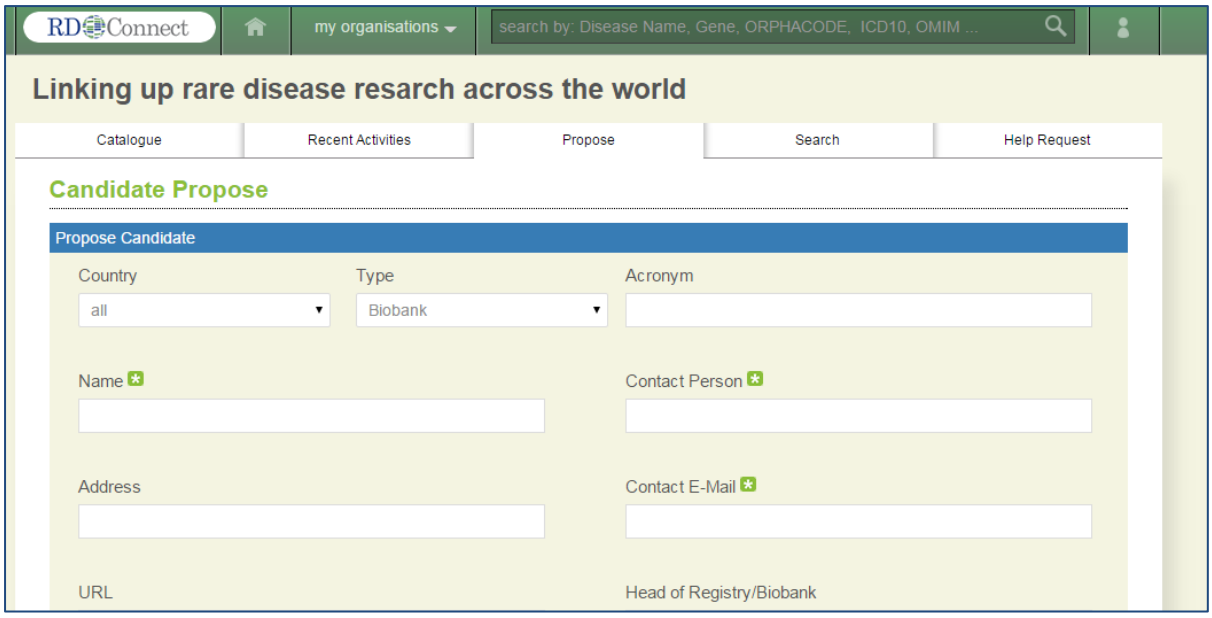
Recent Activities

The “Recent Activities” tab shows in chronological order, the registries and biobanks that have been recently edited within Registry & Biobank Finder.



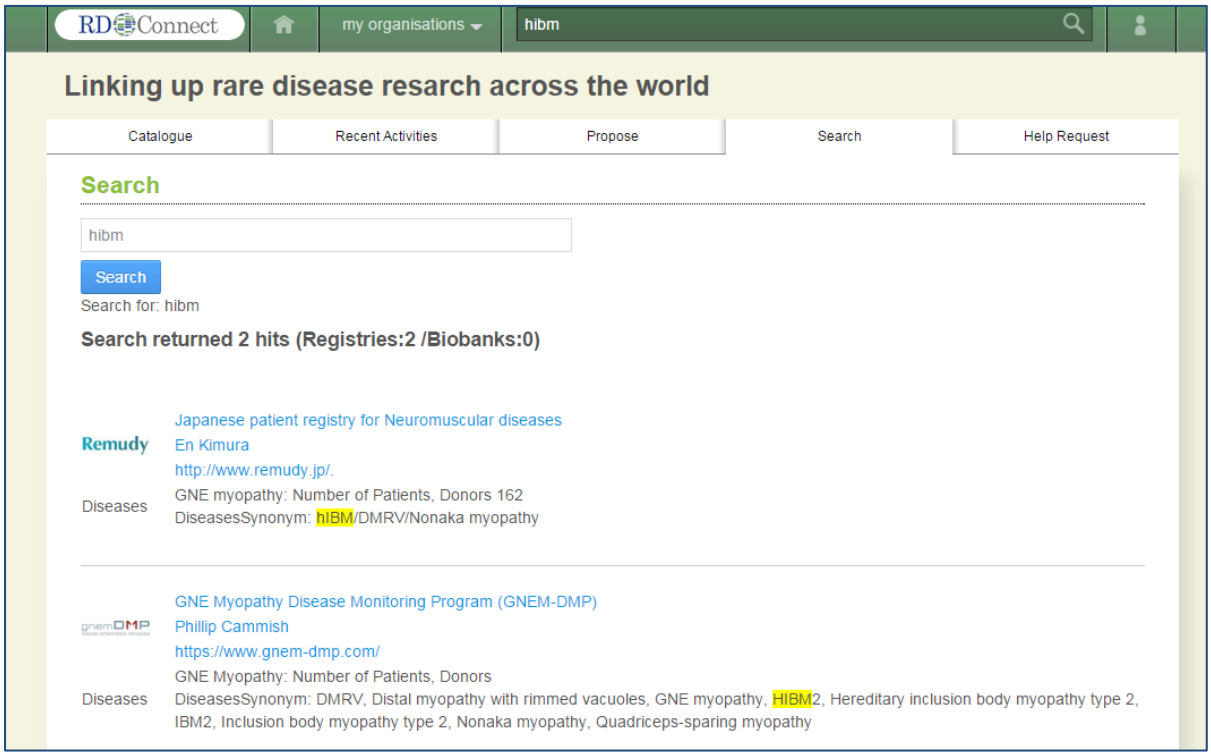
Propose

While logged in to Registry & Biobank Finder, you can create an additional registry or biobank using the **Propose** tab. This is the exact same process as used when registering for the first time– with the exception that the Submitter fields are automatically filled with your name and email address.



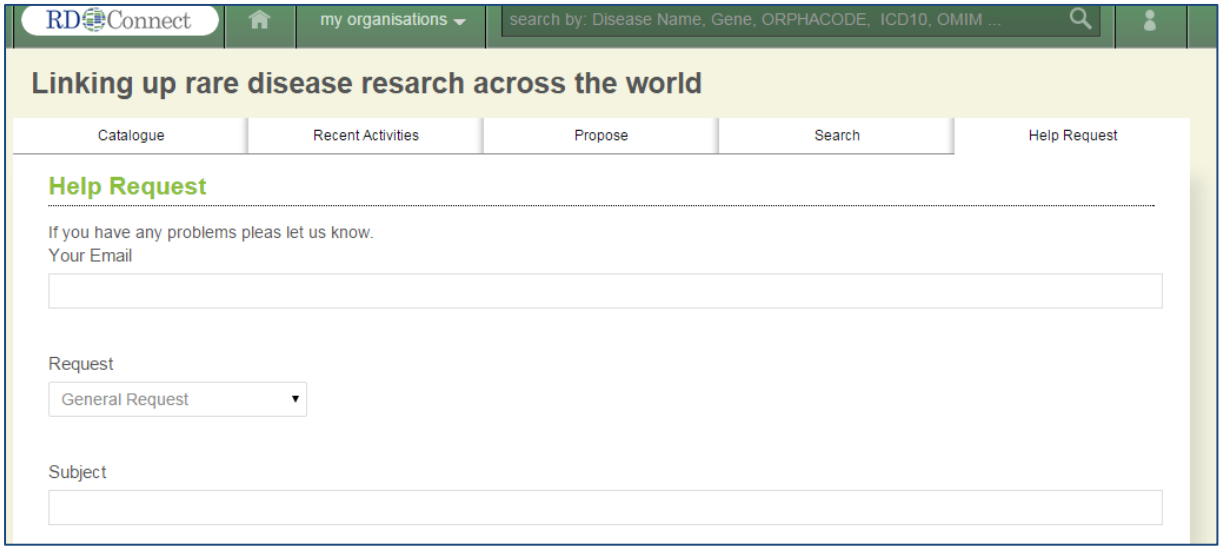
Search

The "Search" tab allows you to search for biobanks/registries based upon the **search terms** that were entered in the Disease Synonym area, as shown below:



Help Request

Use the "Help Request" tab to contact the system administrator if you have questions about using Registry & Biobank Finder, or experience other problems.



To contact the administrator directly, please email: *rd-connect.wp2@iss.it*