

**STANDARD OPERATING PROCEDURE:
USER GUIDE FOR SAMPLE ACCESS**

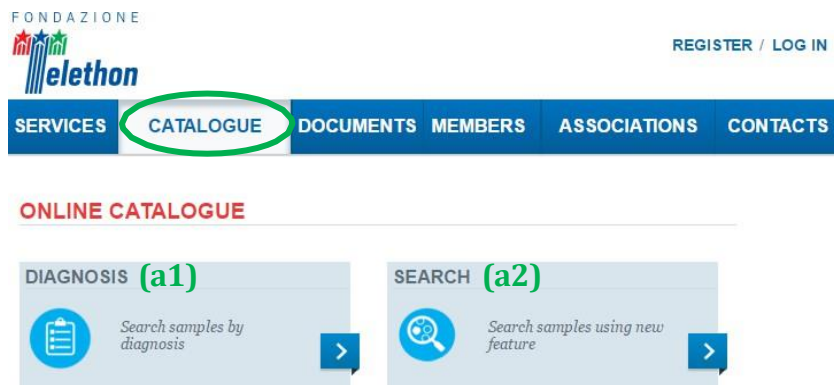
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Indexes

| | |
|-------------------------------|---|
| Browsing the sample catalogue | 3 |
| User registration | 5 |
| User management menu | 7 |
| New request submission | 8 |
| General info | 1 |
| 0 | |

Browsing the sample catalogue

TNGB sample catalogue is publicly accessible at <http://biobanknetwork.telethon.it/Pages/View/Catalogue>



Samples can be searched:

(a1) by “Diagnosis”, the disease name can be typed in the free text field or directly selected from the list. The related OMIM webpage will open by clicking on the MIM number.



(a2) through the advanced search tool, click on “Advanced search” to open the filter search box. Then, after having selected the filters, click on “Search” to obtain your search results

FREE SEARCH SAMPLES

Find Sample:

FREE SEARCH SAMPLES

Find Sample:

Filters

Male Affected

Diagnosis Type

(b) regardless the tool used to perform the search (a1) or (a2), the system will display the list of the search results

FREE SEARCH SAMPLES

Find Sample: [Search](#) [Advanced Search](#)

Filters

Male Affected

Diagnosis Type

DNA

[100800] ACHONDROPLASIA

| ID | Sample type | Gender | Phenotype | Diagnosis | Diagnosis type | |
|-------|-------------|--------|-----------|----------------|----------------|----------------------|
| 67772 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67773 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67774 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67775 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67782 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67783 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67785 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67787 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67789 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |
| 67790 | DNA | Male | Affected | ACHONDROPLASIA | Molecular | View |



Page 1 of 2

(c) from the list of the search results, click on “view” to access to the sample details. All available samples from the same individual are listed under “Patient samples”. If samples from patients’ relatives are also present in the catalogue, they are listed below the patients’ sample details, under “Relatives”.

PATIENT INDIVIDUAL

| | |
|--------------------|---------------|
| Gender | M |
| Type of diagnosis | Enzymatic |
| Diagnosis | GAUCHER 1 |
| MIM Number | 230800 |
| Clinical phenotype | Affected |
| Molecular analysis | Not available |

PATIENT SAMPLES

| ID | Sample type | Extraction Year | |
|-------|----------------------|-----------------|----------------------|
| 20415 | Fibroblast cell line | 1980 | View |
| 20416 | DNA | 2012 | View |

RELATIVES

Mother/Father

| | |
|--------------------|---------------|
| Gender | M |
| Type of diagnosis | Enzymatic |
| Diagnosis | GAUCHER 1 |
| MIM Number | 230800 |
| Clinical phenotype | Not Affected |
| Molecular analysis | Not available |

| ID | Sample type | Extraction Year | |
|-------|----------------------|-----------------|----------------------|
| 20417 | Fibroblast cell line | 1980 | View |
| 20418 | DNA | 2012 | View |

User registration

- (a) registration with the website <http://biobanknetwork.telethon.it/Account/Register>
- (b) filling in the user registration form (all fields are mandatory)

USER REGISTRATION

* Required Fields

Salutation *
(Mr., Mrs., Dr., Prof., etc.)

First Name *

Last Name *

Phone number *

Email address *

Password *

Confirm password *

User kind *

Host institution *

Address *

City *

ZIP Code (C.A.P.) *

State or Province *

Country *

I agree to the [Terms of Service and Privacy Policy](#)

Please select one among:

- **Academic:** users working for academic/public institution or no-profit organisations
- **Corporate:** users working for for-profit organisations
- **Private:** patient family members
- **Association:** users belonging to a patient organisation



Register

- (c) a pop-up window will notify that the registration has been successfully sent to the system and the new account needs to be activated by clicking on the link sent to the e-mail address given in the registration form

TELETHON NETWORK OF GENETIC BIOBANKS

To activate your account, please click the link in the activation email which has been sent to you

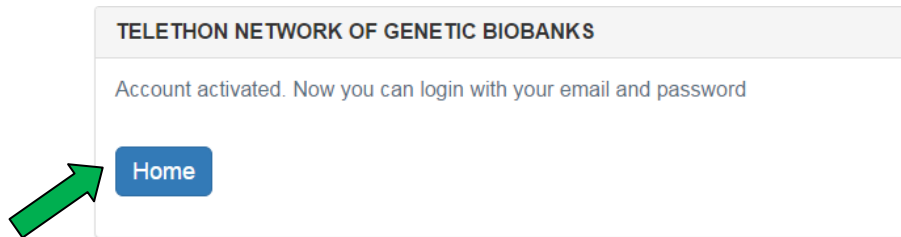
[Home](#)

- (d) click on the link received by email to activate your account

Registration Confirmation

Dear Ms , new account created successfully. To activate your account please click on the link below: <http://biobanknetwork.telethon.it/Account/ActiveAccount/CUgx8HKcyaDJinX-R1IadA2?>

(e) your account is now activated and you can log in



Telethon Network of Genetic Biobanks

Log In

* Required Fields

Your e-mail address: *

Enter your UserName

Your password: *

Enter your password

Remember me?

[Log In](#)

If you are a new user please [register here](#) .

[? Forgot your password?](#)

User management menu



By logging in you will have access to the user management menu (right side of the screen) which enables to manage your profile, check the status of already submitted requests and submit new ones.

Click on your email address to access the user management area and edit your profile

Hello, [email@domain.com](#) | [Log off](#)

List of all requests submitted to TNGB by the User

REQUEST MANAGEMENT

| Id | Request Date | Status | |
|-----|--------------|------------------|---|
| 404 | 04-05-2017 | CLOSED |  |
| | Biobank | Last Update | Status |
| | C - IGG-GB | 04-05-2017 14:49 | CLOSED |
| 71 | 10-11-2015 | PENDING |  |
| | Biobank | Last Update | Status |
| | C - IGG-GB | 26-02-2016 16:13 | REJECTED |

MANAGEMENT MENU

CURRENT REQUEST

0 item in your request

GENERAL

New sample request

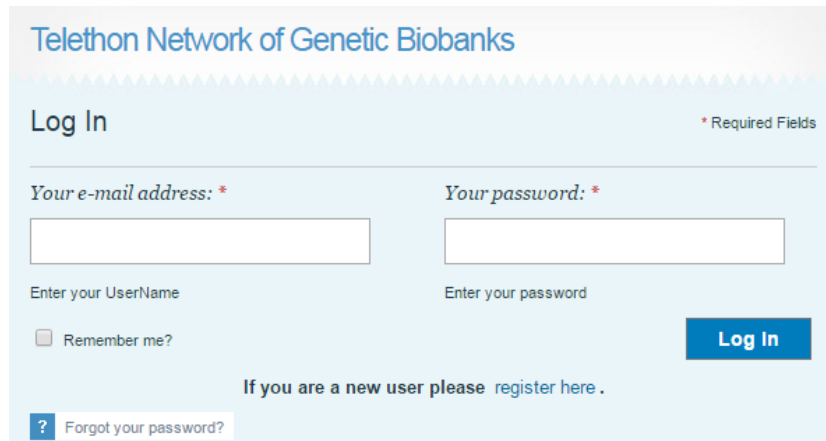
My Requests

List of selected samples, not ordered yet

New request submission form (without samples selection)

New request submission

- (a) log in at <http://biobanknetwork.telethon.it/Account/Login> using your credentials. If you are a new user, please click on “register here” and follow the procedure for User registration.



- (b) if you do not need to select specific samples (“open request”), please go to (c); otherwise, if you want to select the samples, start by Browsing the sample catalogue. After having accessed the sample details, click on “Add to request” button to add the sample(s) to your request. Repeat for all samples you would like to add to your request. Note that samples will remain selected in your request until the submission, even when you log out.

Back

PATIENT INDIVIDUAL

| | |
|--------------------|---------------|
| Gender | M |
| Type of diagnosis | Enzymatic |
| Diagnosis | GAUCHER 1 |
| MIM Number | 230800 |
| Clinical phenotype | Affected |
| Molecular analysis | Not available |

PATIENT SAMPLES ▼

| ID | Sample type | Extraction Year | | |
|-------|----------------------|-----------------|------|----------------|
| 20403 | Fibroblast cell line | 1980 | View | Add To Request |
| 20404 | DNA | 1995 | View | Add To Request |

Add all to Request

- (c) In the User management menu click on “New sample request”. A webpage will open displaying the sample request submission form to be filled in as follow.

SUBMIT REQUEST

MANDATORY FIELD
Complete with the title of your project or the reason why you are requesting the sample(s)

Specify the research grant under which the project is conducted

MANDATORY FIELD
Specify the research sponsor financially supporting the project

Specify the number of the project and the period of funding (free text fields)

MANDATORY FIELD
Briefly describe your project, including aims, planned experiments and expected results

MANDATORY FIELD
Select the most appropriate

MANDATORY FIELD
Select the most appropriate from the dropdown list

Add any note and specify here if you had prior contacts with a specific Biobank

If you have submitted an open request, this field will be empty

* Required Fields

Project Title *

Research Grant
e.g., EU Research Framework Programme

Research Sponsor *
e.g., European Commission

Project Number (if available)

Period of Funding

Brief project description (max 1000 char) *

Ethics Committee Approval *
[select Ethics Committee approval] ▼

Request reason
 Research Diagnostic


Note or Previous Agreements

SAMPLES SELECTED

| ID | Description | |
|-------|----------------------|--------|
| 20403 | Fibroblast cell line | Remove |
| 67773 | DNA | Remove |
| 67776 | DNA | Remove |

Submit Request ←

- (d) After submitting your request, the system will notify through a pop-up and an e-mail message that it has been successfully sent.

 **Request sent successfully**
biobanknetwork [redacted]

Dear Ms [redacted], request sent successfully. You can track the progress by clicking on the following link:
<http://biobanknetwork.telethon.it/CP/ManageRequest?requestId=432>

- (e) The request is centrally received and evaluated by the Network Board (Fig. 1), after its approval the assigned biobank will directly contact you and send the appropriate MTA form which has to be filled in and signed by your Organisation.

From now on, contacts between the researcher and the biobank will be direct and occur through their own e-mail addresses. Researchers can check anytime the status of their request through the User management menu.

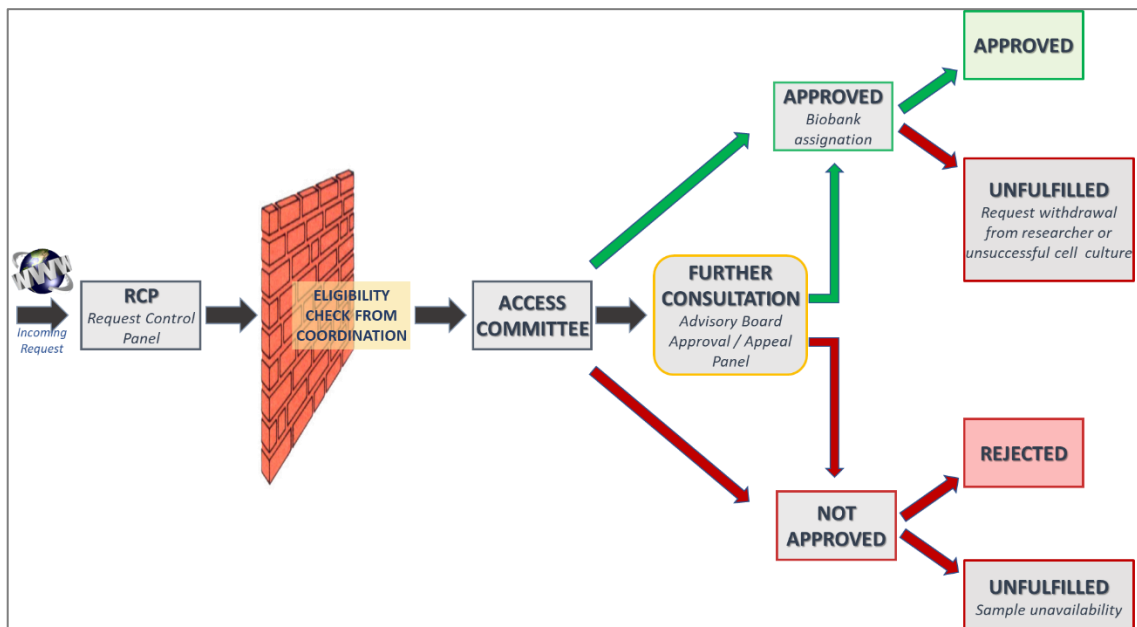


Figure 1: Request evaluation process by the Fondazione Telethon Network of Genetic Biobanks (from Iacomussi et al., 2021. doi: [10.1089/bio.2021.0057](https://doi.org/10.1089/bio.2021.0057))

General info

- General questions can be addressed to the Network coordination Office at biobanknetwork@fondazionetelethon.it
- Questions about the request status, the samples characteristics or the data associated to the samples should be addressed directly to the assigned biobank. Network contacts are managed by the Coordination office who does not have this type of information
- If any problem is met during any of the above described procedures, users can contact the Support Office at support@biobanknetwork.org
- Descriptions of the services provided by the Network, access rules and request approval procedure are available at <http://biobanknetwork.telethon.it/Pages/View/Services>
- A template of the Network documents (e.g., MTA and Informed consent) can be downloaded at <http://biobanknetwork.telethon.it/Pages/View/Documents>