

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

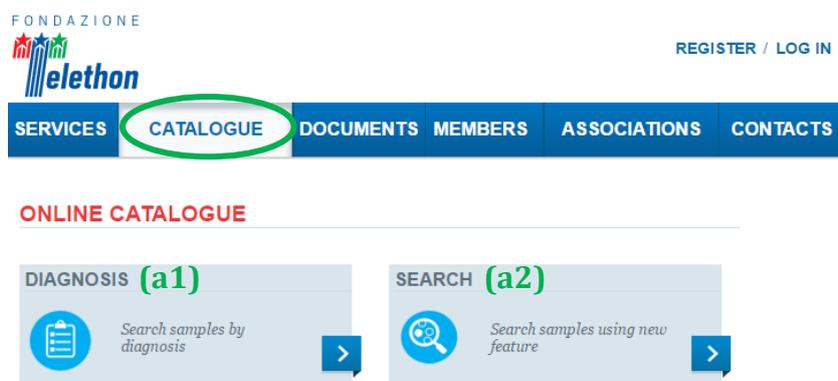
<b>Document ID: #02</b>			
<b>Document title: TNGB Standard Operating Procedure: User guide for sample access</b>			
<b>Rev. no.</b>	<b>Date</b>	<b>Author(s)</b>	<b>Approval</b>
00	July 2017	<b>L. Casareto</b>	Network Board
01	August 2020	<b>L. Casareto</b>	Coordination
02	September 2022	<b>L. Casareto</b>	Coordination

## 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>



FONDAZIONE  
**telethon**

REGISTER / LOG IN

SERVICES **CATALOGUE** DOCUMENTS MEMBERS ASSOCIATIONS CONTACTS

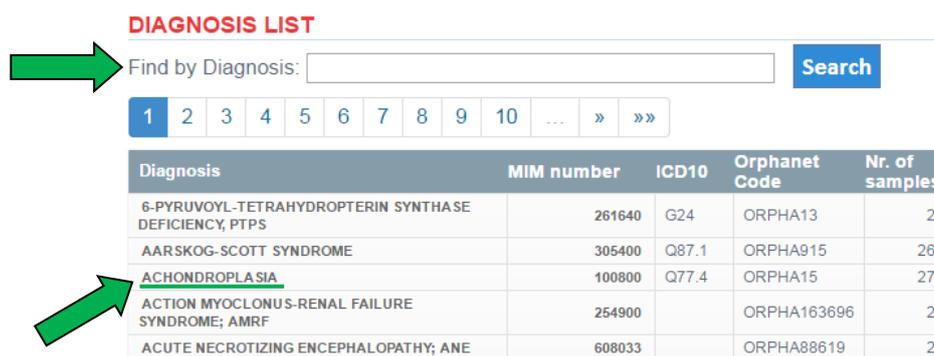
**ONLINE CATALOGUE**

**DIAGNOSIS (a1)**  
Search samples by diagnosis

**SEARCH (a2)**  
Search samples using new feature

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.



**DIAGNOSIS LIST**

Find by Diagnosis:  **Search**

1 2 3 4 5 6 7 8 9 10 ... » »»

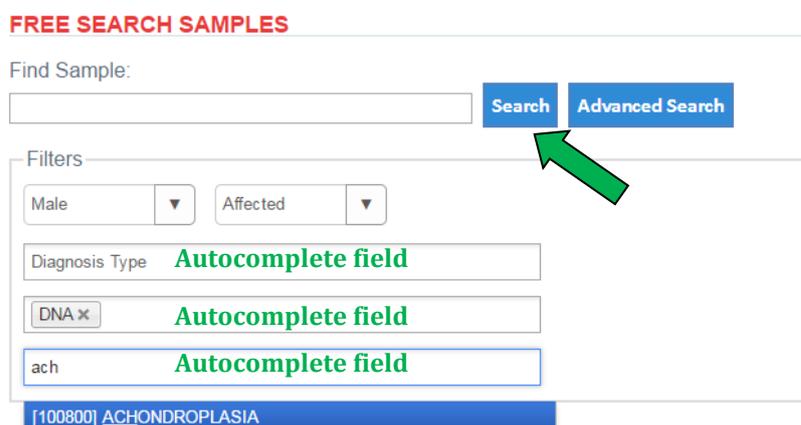
Diagnosis	MIM number	ICD10	Orphanet Code	Nr. of samples
6-PYRUVOYL-TETRAHYDROPTERIN SYNTHASE DEFICIENCY, PTPS	261640	G24	ORPHA13	2
AARSKOG-SCOTT SYNDROME	305400	Q87.1	ORPHA915	26
<b>ACHONDROPLASIA</b>	100800	Q77.4	ORPHA15	27
ACTION MYOCLONUS-RENAL FAILURE SYNDROME; AMRF	254900		ORPHA163696	2
ACUTE NECROTIZING ENCEPHALOPATHY; ANE	608033		ORPHA88619	2

**(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:  **Search** **Advanced Search**



**FREE SEARCH SAMPLES**

Find Sample:  **Search** **Advanced Search**

Filters

Male  Affected

Diagnosis Type **Autocomplete field**

**Autocomplete field**

ach **Autocomplete field**

[100800] ACHONDROPLASIA

(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:




Filters

Male  Affected

Diagnosis Type

DNA x

[100800] ACHONDROPLASIA x



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 \*  
Academic

Host institution \*

Address \*

City \*

ZIP Code (C.A.P.) \*

State or Province \*

Country \*  
Andorra

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

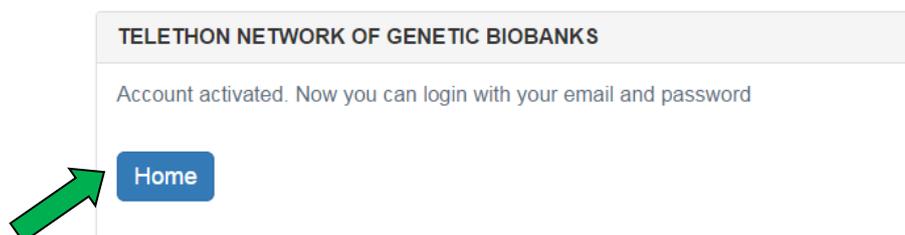
[Home](#)

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

#### Registration Confirmation

Dear Ms [redacted], new account created successfully. To activate your account please click on the link below: <http://biobanknetwork.telethon.it/Account/ActiveAccount/CUgxSHKcyaDJinX-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	
	<b>Biobank</b>	<b>Last Update</b>	<b>Status</b>
	C - IGG-GB	04-05-2017 14:49	CLOSED
71	10-11-2015	PENDING	
	<b>Biobank</b>	<b>Last Update</b>	<b>Status</b>
	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	<a href="#">View</a>	<a href="#">Add To Request</a>
20404	DNA	1995	<a href="#">View</a>	<a href="#">Add To Request</a>

[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

\* Required Fields

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

Project Title \*

Specify the research grant under which the project is conducted

Research Grant

e.g., EU Research Framework Programme

Research Sponsor \*

e.g., European Commission

**MANDATORY FIELD**  
Specify the research sponsor financially supporting the project

Project Number (if available)

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

Period of Funding

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

Brief project description (max 1000 char) \*

**MANDATORY FIELD**  
Select the most appropriate

Ethics Committee Approval \*

[select Ethics Committee approval] ▼

**MANDATORY FIELD**  
Select the most appropriate from the dropdown list

Request reason

Research  Diagnostic

Note or Previous Agreements

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

**SAMPLES SELECTED**

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

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

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

---

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.

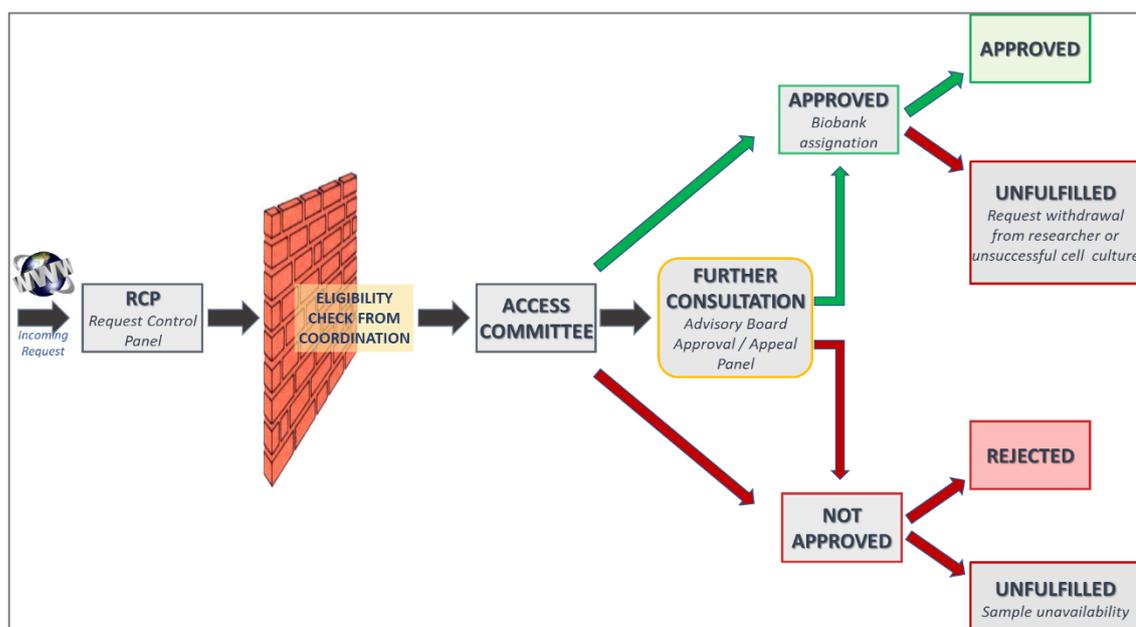


Figure 1: Request evaluation process by the Telethon Network of Genetic Biobanks  
(from Iacomussi et al., 2021. doi: [10.1089/bio.2021.0057](https://doi.org/10.1089/bio.2021.0057))

## General info

- General questions can be addressed to the Network coordination Office at [biobanknetwork@telethon.it](mailto:biobanknetwork@telethon.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](mailto: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>