

Frequently Asked Questions

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My question is not listed here, whom can I contact for help?

What type of human biospecimens are available from the Genizon Biobank?

Frozen DNA samples on 96-well plates unless specified otherwise. The DNA is of good quality as confirmed by an independent laboratory.

What is the access procedure and how long does it take?

The process is as follows:

- Following the initial discussion between the researcher and Génome Québec's Client Management Office (CMO), the researcher submits his application form.
- After a compliance review, which includes a copy of the researcher's institutional ethics review board approval letter, the CMO will send a Material Transfer Agreement (MTA) for signature.
- For biospecimen request: upon reception of the signed MTA, the selection of samples will be generated and transferred to the biobank manager for sample retrieval and to the biobank IT data manager for retrieval of the clinical data. The sample plates will be prepared and shipped to the researcher (~1-2 weeks for a typical request). The clinical data will be transferred encrypted.
- For a genotyping data request: upon reception of the signed MTA, the selection of samples will be generated and the associated data prepared and sent to the researcher.

What is the Genizon Biobank?

The Genizon Biobank is a collection of human biological samples, genotyping data and clinical data recovered from the company Genizon BioSciences Inc. They had collected over 44,000 human DNA samples from 26 complex diseases and one cohort of general controls from the Québec founder population. The Genizon Biobank is financially supported by Génome Québec to make this resource accessible to the research community.

Does the Genizon Biobank contain any genetic trios?

Genetic trios were collected for the majority of the diseases.

Which cohorts contain genotyping and statistical data?

Endometriosis, schizophrenia, ADHD, Alzheimer's disease, longevity, coronary heart diseases, Type 2 diabetes, psoriasis, rheumatoid arthritis and obesity. Approximately 12,000 cases.

What is the cost of the samples?

The cost of samples and data depends on the number of samples requested and the associated data. For an estimate, please contact Génome Québec's Client Management Office (infoservices@genomequebec.com; 514 398-7211).

If you are applying for funding for a research project, we can provide a non-binding pricing quotation and letter of support for your application.

What clinical information comes with the specimen?

The clinical information linked to the DNA samples varies depending on the disease studied. A list of the specific phenotypes can be provided during the initial discussion. Clinical experts have selected the list of phenotypes for each disease along with an intense review of the literature.

What happens if an original donor chooses to withdraw from the biobank program?

If a participant wishes to withdraw from the study and no longer wants his/her DNA and data retained by the Genizon Biobank, any remaining biospecimen will be destroyed by the laboratory. Data or samples that have already been distributed to researchers cannot be recalled. Data or samples that have been previously anonymized cannot be destroyed.

Is the resource available to academic investigators and commercial entities outside of Québec?

Yes.

Are there any control samples?

Yes, control samples have been collected for many cohorts. There is also a cohort of approximately 4000 DNA samples from general controls linked to self-declared health assessments.

Where are the samples physically located?

The samples are located at the Biobanque Génome Québec and CIUSSS Saguenay-Lac-Saint-Jean Biobank in Chicoutimi in the Province of Québec.

Which cohorts have not been anonymized?

The following cohorts have not been anonymized and would allow researchers to recontact the participants.

1. Rheumatoid arthritis
2. Osteoarthritis
3. Asthma
4. Type 2 Diabetes
5. Endometriosis
6. Longevity
7. Coronary Heart Disease
8. Chronic Obstructive Pulmonary Disease (COPD)
9. Migraine with aura
10. Obesity
11. Osteoporosis
12. Allergic Rhinitis
13. General controls
14. Panic disorder
15. Crohn's disease

Which cohorts have been anonymized?

The following cohorts have been anonymized.

1. Acne
2. Alzheimer's disease
3. Baldness
4. Macular degeneration
5. Major depression
6. Glaucoma
7. Psoriasis
8. Schizophrenia
9. Metabolic syndrome
10. Essential tremor
11. Attention deficit/hyperactivity disorder (ADHD)
12. Obsessive-compulsive disorder

After my study is completed, can I use the samples for another project?

No, you will have to destroy the samples and send a written confirmation of their destruction to the Genizon Biobank.

Will access be granted for purposes other than genetic research?

No.

How will you deal with limited amounts of sample?

The amount of DNA available from each participant is limited and could run out. Consequently, the Genizon Biobank will carefully review requests to maximize the use of the resource. In such cases, the Genizon Biobank may encourage collaboration between research groups in order to optimize the use of samples and may initiate contact between scientists working on similar research projects. If necessary, the McGill University and Génome Québec Innovation Centre could undertake the genomic analysis of samples and provide the results to the research team. After the research project has been completed, other scientists may be able to have access to the data that have been generated by these analyses.

How is patient privacy protected?

The Genizon Biobank has technical, administrative and physical safeguards in place to protect the participant's personal information. Modern security technologies and controls are used to protect the privacy and integrity of information during transfer, storage and use. Data is encrypted during transmission and stored on secured servers. The Genizon Biobank has extensive privacy and security policies in place that limit access and disclosure of data. These processes and procedures are reviewed by the IRB board of the Genizon Biobank.

Could participants be re-contacted?

As specified during the initial consent of the participants, some have agreed to be re-contacted again to seek new information. Participants are under no obligation to provide any further information and, if they choose, they can request no further contact.

Where the samples come from?

The biobank consists uniquely of subjects from the Québec Founder Population. Similar to DeCode Genetics in Iceland, the biobank has access to comprehensive genealogy information for the entire population, going back to the original founders. A comparison of disease-associated loci with the genealogy of a study cohort may help identify combinations of genes that predispose to the disease.

While the Icelandic population represents about 280,000 people, the Québec Founder Population is currently about 6 million people, providing a much larger source from which to recruit patients with well-defined phenotypes. The population descended from 2,600 founders, and its relative genetic homogeneity combined with Genizon's rigorous statistical analyses of genetic data and proprietary data mining techniques provides excellent sensitivity to detect and discover disease genes and pathways, and biomarkers.

Do you have the disease classify by categories?

Major disease categories are:

Autoimmune diseases	Crohn's disease Psoriasis Rheumatoid arthritis
Central Nervous System diseases	ADHD Alzheimer's disease Essential tremor Major depression Migraine Obsessive-compulsive disorder Panic disorder Schizophrenia
Eye diseases	Glaucoma Macular Degeneration
Cardio metabolic diseases	Coronary artery disease Type-2 Diabetes Obesity
Respiratory diseases	Asthma COPD
Women's health	Endometriosis Osteoporosis
Other diseases	Allergic rhinitis Acne Baldness Longevity Osteoarthritis

My question is not listed here, whom can I contact for help?

You may contact Génome Québec's Client Management Office at 514 398-7211 or send an e-mail to infoservices@genomequebec.com.