



## BIOBANKING PROJECT

In scientific research on rare syndromes, the funds availability is not the only problem. To study these diseases, researchers need well-phenotyped clinical data and high-quality biological samples. Biosamples of people affected by Ring14 were not available to the scientific community before the Ring14 Association and the "Network Telethon Genetic Biobanks" (TNGB) started an important scientific collaboration. Biobanks are facilities authorized to collect and preserve biological material of patients and to make them available to researchers around the world.

After careful consideration, the Association focused on services promoted by the Telethon Network of Genetic Biobanks (TNGB, <http://biobanknetwork.telethon.it>) and, in particular, the Biobank located at Galliera Hospital in Genoa <http://ggb.galliera.it/>

In December 2009, the Association Ring 14 signed an agreement with the TNGB for taking custody of samples of blood and skin fibroblasts of their patients and to share these samples with the international scientific community.

The TNGB samples are available to all interested researchers involved in developing new research and scientific projects on Ring14. To gain access to samples, researchers must submit a specific request to the TNGB, according to access parameters and rules defined by TNGB in order to guarantee the privacy of patients.

Currently, you can find an updated list of all the samples collected from our families, composed of DNA, cell lines and fibroblasts at the following links:

<http://ggb.galliera.it/samplelist.php?ID> = 466 patient samples

<http://ggb.galliera.it/samplelist.php?ID> = 467 samples of family members.

Samples collected and stored in the Biobank are available to researchers worldwide and may request them at this link: <http://biobanknetwork.telethon.it/Pages/View/Instructions>

Together with blood samples, the association has collected clinical data which are compiled in own database available upon formal request at: <http://www.ring14.org/ita/115/database/>

Aware of the expenses and effort involved in collecting samples, and in order to maximize the size of our databank, the Association covers all operational and other relative costs.

Families who have not yet participated in our biobank project are kindly invited to do it now.

To receive the collection kit and protocol instructions SENDING SAMPLES write to [azzali.stefania@ring14.org](mailto:azzali.stefania@ring14.org)

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