



## CLINICAL DATABASE

For a scientist or a clinician interested in learning more about Ring14 syndrome, to access to clinical data correctly stored and regularly updated is of absolute importance. These data are used to encourage and develop genetic and transactional clinical research in order to improve the healthcare processes for patients.

Families from all over the world are already involved in our clinical database project by providing copies of their child's medical records to Ring14 International. We collect and keep them in compliance with current privacy legislation. Any record is transformed into a digital and anonymous format in our database.

The database is available online through an interface accessible via request to Ring14 Association ([info@ring14.org](mailto:info@ring14.org)).

To date, there are 54 patients in our database, which stores data divided into the following main areas:

- GENETICS
- GROWTH AND DEVELOPMENT
- NEUROPSYCHIATRY AND NEUROLOGY
- VARIOUS DISEASES AND MALFORMATIONS
- PHOTOS
- PHARMACOLOGICAL THERAPIES
- ADMISSIONS
- EXAMINATIONS AND TREATMENTS

Clinical data are digitalized and can be viewed and analyzed both singularly or in an aggregate format in order to produce statistics and provide results that can be visualized by applying specific filters and parameters by any approved user. The user can also view a complete medical history of each patient.

The platform also allows for the inclusion of attachments such as photos, videos, EEG, MRI and diagnostic reports as well as the management of "follow-up" clinical data in order to correlate the possible appearance or disappearance of symptoms at specific ages.

All data are placed under the supervision of a specifically trained physician to ensure the quality and accuracy of clinical and scientific information.

Families can, always through a personal password, access the profile of their child and print a complete medical report.

The database is owned by Ring14 Association and it is updated by Doctor Rinaldi Berardo.

### **Ring14 International Onlus**

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***info@ring14.org | www.ring14.org***



The clinical database, together with the Biobank of biological samples are stored at the [Biobank Galliera http://www.ring14.org/ita/336/biobanca/](http://www.ring14.org/ita/336/biobanca/) are important instruments placed at the disposal of the international scientific community in order to promote and develop new biomedical research projects on syndromes related to chromosome 14.

Based on its experience of the last few years in the development of the clinical database, Ring14 International has been invited to become a member of the IGC (<http://rd-connect.eu/platform/registries/core-implementation-group/>) of RD-Connect, a project financed by the European Community, which aims to develop new tools to be made available for research. This is an important opportunity to engaged international partners dealing with genetic diseases and is designed to make results quickly accessible to patients.

The families of the association who have not yet participated in our clinical database are kindly invited to do so to help advance knowledge on the syndromes of chromosome 14.

You can send a copy of your child's medical records (on paper or digital) with particular attention to EEG, MRI, genetic analysis, photos and clinical and cognitive development to the following address:

Ring14 International

Via Lusenti 1/1

42121 REGGIO EMILIA

ITALY

Otherwise you can send your documents by email to [info@ring14.org](mailto:info@ring14.org)

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