



HELP AND RESEARCH FOR CHILDREN AFFECTED WITH RARE GENETIC DISEASES - ONLUS







ASSOCIAZIONE INTERNAZIONALE RING14

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We are a ONLUS: we do not sell services but carry out all our

projects thanks to the support of all the people who believe in us

and want to fight with us.

You can help us with:

- a free donation (you can deduct it from your taxes) to be sent

to UNICREDIT BANCA IBAN:

IT 27 H 02008 12820 000003665310 IN FAVOUR OF 'ASSOCIAZIONE

INTERNAZIONALE RING14'

CODE BIC SWIFT: UNCRITM10R0

- credit card payable directly from our website



THE **RING 14 INTERNATIONAL ASSOCIATION** has been founded in Reggio Emilia, Italy in May 2002 as an initiative taken by a bunch of families with children hit by a rare and unknown genetic disease, whose diagnose is not a target but a start point. Which are its symptoms? What kind of development can we foresee for our son? Does any suitable treatment exist? Physicians have only a few tools at their disposal and can give only a few answers. It had started with just three families, but today RING14 includes hundreds and it is the only association in the world that deals with this disease, by promoting and financing clinical studies, research and any scientific activities.

THE DISEASE: THE CHROMOSOME 14 SYNDROMS



THE SOUND CHROMOSOME 14:

This is the basis of our gene pool. All of us we own 23 pairs.



THE RINGSHASPED CHROMOSOME 14:

The chromosome 14 in our children shows an altered structure, a ringshaped one.



THE CHROMOSOME 14 WITH DELETIONS AND TRANSLOCATIONS

The chromosome 14 of our children can also loose genetic material and undergo changes in its position.

THE SYMPTOMS:

The alterations in the chromosome 14 can cause several clinical symptoms like epilepsy, immunitarian deficiencies, frequent respiratory infections and a serious psychomotor retardation, particularly in the speech.



OUR TARGETS AND PLANS

Our dream is to write the history of this disease and give support to families in the world.

We are achieving this through the following projects:

- Genetic Research: in order to study the genes involved in these syndroms and their action
- Clinical Research: in order to study the main symptoms of these diseases
- Speech: in order to understand the reason why our children are often unable to speak or to communicate
- Families: in order to overcome their isolation and the lack of information, planning meetings and holidays
- Being siblings of...: a path as a support to anybody who has a disabled brother or sister
- Databanks: gathering blood samples and clinical data of our children and putting them at the disposal of the researchers
- International Workshop: it puts together worldwide known genetists and clinicians who investigate our diseases



OUR ORGANIZATION

- Families from all over the world, a staff of professionals and many volunteers
- A Scientific Board of researchers and international experts (genetists, clinicians, pediatricians)
- The cooperation with robust worldwide no profit partners (Telethon and TGBN, Hole in the Wall Foundation Dynamo Camp, Fondazione Pietro Manodori, Fondazione Tender To Nave Italia Onlus)