AIUTO E RICERCA PER I BAMBINI AFFETTI
DA MALATTIE GENETICHE RARE - ONLUS

IMPEGNO, SOSTEGNO, FUTURO.

Let's talk about language !

The results of the study on the delay of the development of language in children affected by chromosome 14 syndromes, financed by RING14 Onlus, have been published
The data are now at the disposal of the international scientific community

What kind of therapy for the delay of the development of language?
Language is the most direct way the Self expresses itself. It enables us to communicate, interact and share every moment of our existence. However not everybody is able to develop it , as it is the case for children affected by chromosome 14 syndromes. In their case **this function is often damaged** and also shows delays in their development and neurological problems. As a consequence their level of understanding is good but they are unable to **communicate and express themselves p**roperly, with problems in their behaviour as they are **closed to the outside world**.
Up to date the national and international researches have never gone deep into this matter of the language of the children affected by chromosome 14 aberrations. That's why physicians and speech therapists cannot reckon on a significant medical literature and put in practice effective therapies. What is commonly done is to apply to a speech therapist and in some cases use alternative languages, like gestures, images or computers. Anyway, understanding the problems language/speech entails could mean detecting targeted therapeutic paths, able to improve a kid's life as well as the life of his family.

Since 2010, a constantly evolving project
That's why the **International Association RING14 Onlus of Reggio Emilia**, engaged since 10 years in the scientific research against the rare genetic disease Ring14, has decided to finance the **project "Development of the language in children with chromosome 14 aberrations**", in cooperation with the **Psychology Department of the Università degli Studi of Milano-Bicocca**.

This project, which started in 2010 and still ongoing, aims at describing the linguistic peculiarities of children affected by these syndromes, in order to give families a suitable therapeutical prospect. The study is lead by **Ph.D. Laura D'Odorico, Professor at the Psychology Department of Università degli Studi Milano-Bicocca** and has envolved 4 children, who were followed during one year. Their development and communication skills were evaluated 3 times each semester by means of examination sessions and organised tests (Griffith Scales to measure their psychomotor development) lead by **doctor Laura Zampini and doctor Paola Zanchi.** "*Linguistic skills among children showing a similar clinical history look extremely variable"* explains Professor Laura D'Odorico "*Our study aims at discovering those factors that would favour an adequate linguistic development in some children, in view of a possible implementation of rehabilitation programs for the ones who seem to have more troubles*"

The results made available to the international scientific community
The language project has already lead to interesting results. The last data, combined with those already gathered during the past years and published on the **international magazine Clinical Linguistics & Phonetics** (November-December 2012) demonstrate that there is a high individual variability. Taking into account the genetic features, it appeared that the **width of the deletion has no relation with a more or less favourable evolution course**. This means that the children who lack in a higher portion of genetic material will not necessarily be affected in their growth.
The ones who show autistic features will instead face unfavourable consequences in their linguistic and psychomotor development: out of 4 evaluated children, the two of them who showed autistic features had a lower level of growth during the lapse of time compared to the others. Such results states how important it is to detect autistic features at an early stage in order to strengthen as much as possible every single communication skill. "*Studies in retarded speech*" underlines **Stefania Azzali, Chairwoman of Associazione Internazionale RING14 Onlus,** "*come from a real need: to detect effective therapies able to treat this heavy symptom of a disease that isolates our children and creates troubles every day in a family. The first goal – gather accurate and objective data on speech and its evolution in kids affected by rare syndromes – has been achieved. Now we expect that this project may find the interest of the international scientific community. RING14 Onlus will be happy to share protocols and knowledge gathered up to now*"

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Engagement, support, future: the International Association RING14 Onlus
It has been founded in 2002 in Reggio Emilia, Italy, by the initiative of a bunch of families with children affected by a rare genetic disease caused by aberrations of chromosome 14. It has rigorously worked for 10 years in order to give support to those who live daily situations of serious disability and to promote projects of international scientific research. Engagement, support and future are the values that encourage RING14's staff and volunteers. Their air is to mitigate suffering of children and families and write the history of this ravaging and almost unknown pathology, by favouring the development of more and more early diagnosis, helping discover effective therapies and strengthening the contacts between specialists and people.

For contacts:

Stefania Azzali
presidenza@ring14.it
Dettagli del PROGETTO
Foto

RING14 Onlus
Help and research for children affected by rare genetic diseases
Via Lusenti 1/1, 42121 Reggio Emilia
T. 0522.421037
www.ring14.org