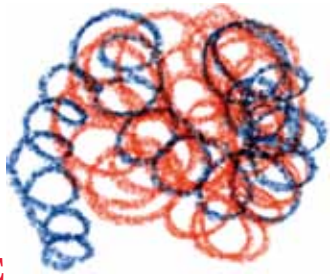


INDICE

Before describing our activities, I would like to help you understand what it means to have a child affected by a rare chromosomal disorder. Imagine what it would be like to wake up one spring morning, expecting a normal day with your family to unfold, but instead find yourself catapulted into a different reality, facing a disorder without a name and, when the name is announced, not to understand what it means. The name has no meaning or significance. It is: "Ring 14 Syndrome".

What does it mean? What should we expect? There are no answers, as there are few cases heard of in the world.

Then our new life begins, confronting words that were never part of our reality: epilepsy, severe learning difficulty, microcephaly and psychomotor disability. Above all, however, we learn that our son who is already "different" is now even more "different" because his condition is so very rare.

Our children have epilepsy, a type that is resistant to therapy and is difficult to treat. Many of them do not speak, or, even worse, could speak but persistent seizures slowly robbed them of their speech. Some have difficulty eating because of malformations of the palate. In some cases, they are able to be nourished only by naso-gastric intubation. Rather than continue with this long list of daily challenges, let us just say that their life is overwhelmingly difficult.

They go to nursery school. They go swimming, they go horse riding. They go, of course, to the hospital. In some cities and in some countries, no-one knows how to treat these children with Ring 14 Syndrome. It is such a rare condition. There are more questions than answers: "What can we do?" "What would you like us to do?" With this as a motivation, we, as parents, have channeled our desperation and harnessed our energy in the quest for a better life for our children. In May 2002, we formed the International Association of Ring 14 Syndrome ONLUS.

We started by gathering information on Ring 14 and have now extended our reach to include all the rare genetic diseases that result from chromosome 14 abnormalities: deletions, duplications, translocations. In 2009, we also opened a branch in France. We are the only organization in the world that concerns itself with this group of genetic disorders.

When we founded this association, we knew that the affected children, their families and the medical community had few options available to disseminate information about the symptoms and possible therapies. We continue our advocacy for our children, some of whom were not expected to survive more than a few years and are now celebrating their 30th birthdays. Some families had almost given up hope, but thanks to our organization and our support, they are now reenergized and have begun to hope for a better future for their children.

We know that these "diseases" are not preventable, nor are they entirely curable, but we started this endeavor eight years ago with the hope that, little by little, we could make some progress in researching treatment. Our organization has now reached beyond Europe and we hope that new projects and expanded research will lead to better lives for our children and their families. More efficient therapies and better control of symptoms can only improve the quality of life for our families.

Above all, we hope that our association will become a sounding board for everyone who is searching for answers and support.

STEFANIA AZZALI
President of Ring 14

INTRODUCTION

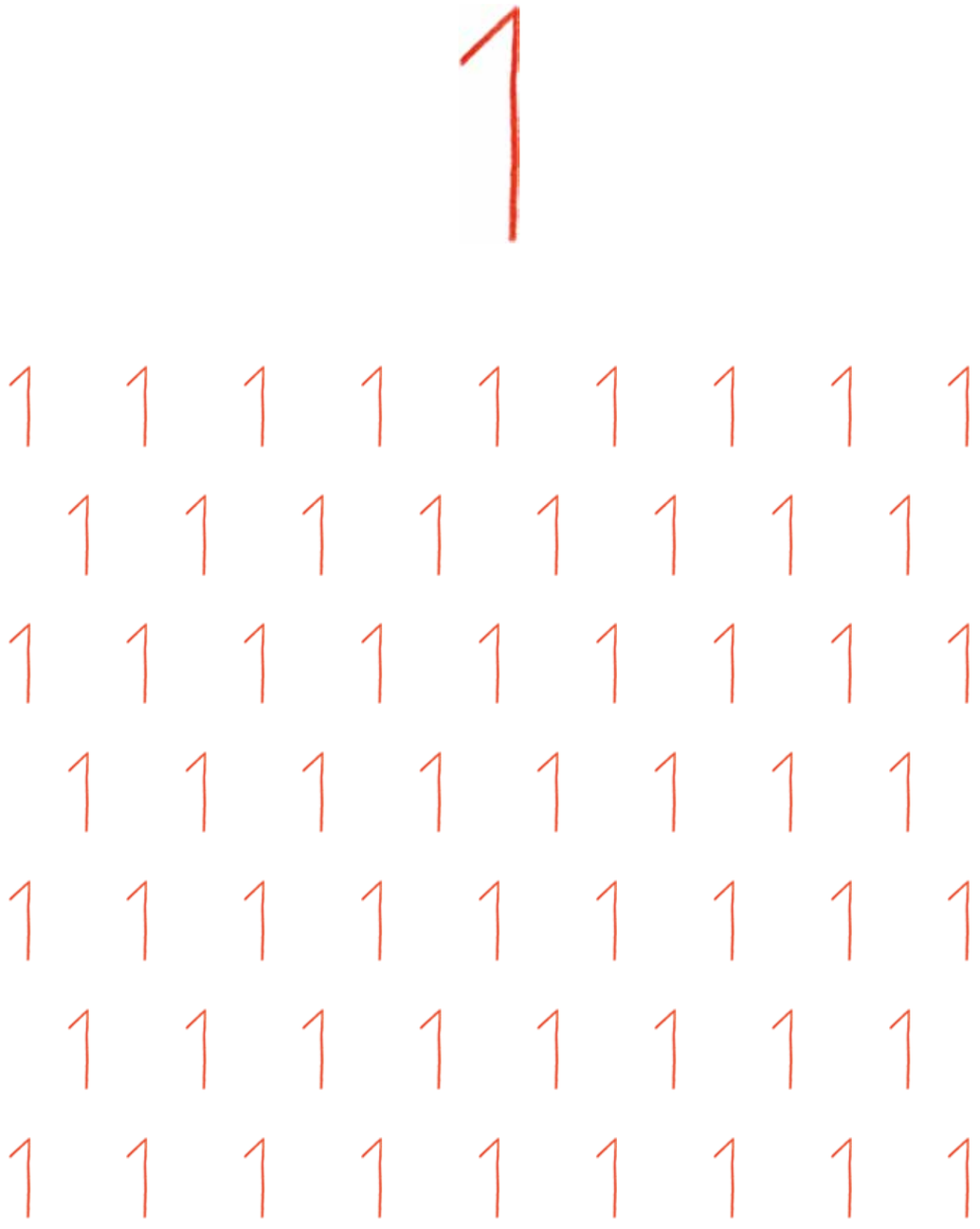
"RING 14: A FIRST REPORT".

The year 2009 was characterized by the decision to carry out, for the first time in the history of the association, an assessment of its aims and activities. It was a pivotal year in which it became clear that the association was evolving and its goals and its way of defining itself as an organization was changing. All those involved in Ring 14 shared this perception.

All organizations have life cycles and Ring 14 is no exception. Ring 14 is emerging from its "infancy" and is now entering its "adolescence". It is confronting new challenges, while at the same time enjoying a broader support base and better resources.

This publication represents an opportunity for the Association and for all those who have followed it in these formative years to summarize the following points: where we are now, how we are positioning ourselves for the future and how we are planning to achieve our goals. Because this is our first attempt to make such an assessment, we will focus more on our origins than about specific data, statistics or projects undertaken since 2009.

Our main objective is primarily and fundamentally to tell our story as clearly and comprehensively as possible, a story that includes our successes, our challenges and the friends who have accompanied us in this adventure.



RING 14: WHO WE ARE.

1.1 THE HISTORY, IDENTITY, OBJECTIVES AND VALUES.

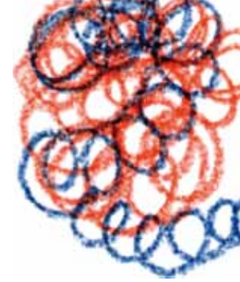
The International Association of Ring 14 was born as an “Onlus” in Reggio Emilia in May 2002 by a group of families with children affected by a rare and relatively unknown genetic disorder caused by a malformation of the 14th chromosome. Today, with a French branch open in 2009, it is the only organization that is focused on this pathology. Our children suffer from serious physical disabilities, frequent seizures, severe learning difficulties and susceptibility to gastrointestinal and pulmonary infections. The families and the physicians of the affected children have few resources available to them to develop a thorough clinical evaluation of their symptoms, pathology and possible therapy.

Legal status of the organization:
Ring 14 is an OdV (Volunteer Organization) registered in the Provincial Registry of Volunteer Organizations of Reggio Emilia.

Legal headquarters’ address: via V.M Hugo n. 34.
Operational headquarters’ address: Via Lusenti 1/1 42121 Reggio Emilia (tel/fax + 39 0522 421037).
Email: info@ring14.it
Web site: www.ring14.org
Locally, Ring 14 is associated with the CSV Dar Voce di Reggio Emilia and is part of the Association of the Disabled and of the Volunteer Movement Committee of the local AUSL.

Nationally, it is part of FEDERAMRARE (the Federation of Rare Diseases in Regione Emilia Romagna)(www.federamrare.altervista.org) and of CITTADINANZATTIVA, a non-profit organization and movement for the promotion and protection of the civil rights of citizens and consumers.
Internationally, the organization participates in the EUROCHROMNET, the European network on rare chromosomal diseases (www.chromosomehelpstation.com) and in EURORDIS, the European Organization for Rare Diseases (www.eurordis.com).

Scientific research requires financial support, but also resources such as the data and blood bank that we have developed over the years by collecting blood samples from our affected children and their families. These resources, which include complete clinical records, are available to the scientific community. At present, our data bank is the only one in the world on the Ring 14 Chromosome Syndrome.
A disability must not be seen only through the eyes of a clinician. It is also the story of a family: hopes for the future, challenges of everyday life, and the impact on the parents, siblings and grandparents. Ring14 believes that the **family** should always be the central focus, because if the family is given the proper support, the affected family member will have a better chance for a more normal life.
Like most childhood illnesses, this condition should not be seen as an isolated pathology, but as a problem that affects the entire family. Any approach or intervention should be fashioned to accommodate the family as well as its affected member.



Thus, the **objectives** of Ring14 are:
- *To spread the awareness of the disease* among physicians (pediatricians, geneticists) in order to make possible a more efficient diagnosis and to facilitate contact with the organization by the families concerned.
- *To encourage scientific research* in clinical, genetic, pharmacological and rehabilitative medicine; to finance research projects and to continue to enrich current data banks.
- *To offer support to the families* families with children affected by this serious, disabling condition; in the difficult moment of the diagnosis, to help them find the best possible professionals (physicians, speech therapists, educators, psychologists) who may help them to proactively deal with the consequences of having a family member with a serious genetic disorder.

Our **values** are:
- **Commitment**: although we are a non-profit organization, our economic model is that of a small business. We are committed to use all our resources with maximum efficiency without sacrificing our goals.
- **Support**: a commitment to alleviate the suffering of children and families affected by serious and devastating genetic disorders is the core of our organization and of its professional and volunteer staff.
- **Future**: We want to record the mechanics and characteristics of this disease, hoping that in the future there will be more efficient diagnoses, better therapies and stronger support groups for the families. We would like to increase and improve awareness of disabling conditions and their profound effects on families in our society.

It's possible to consult the Statute of the Association in the web site
http://www.ring14.org/eng/55/statute/

1.2 OUR ORGANIZATION.

Since 2002, our organization has made many inroads and grown in complexity in terms of initiatives and projects.

The core of our organization is our **membership**. A member is, according to our by-laws, anyone who participates in our activities and shares our goals.

Currently we have 56 members, most of whom are family members of children affected by ring 14 syndrome.

In addition, there are some members who are committed to our cause but not directly affected by the syndrome.

These members are admitted to the organization by the **Board of Directors** and have voting rights and can be elected to carry out official responsibilities.

The membership meets during the annual assembly to approve the budget. Only residents of Italy can be formal members and can participate in this assembly.

There are more than 150 families, primarily from Europe and the USA, that follow our activities, are committed to supporting our organization, if only informally, and can be considered associate members.

The Board of Directors is the ruling body of the organization and is responsible for all budgetary decisions and for the definition of short and long-term strategies, including allocations of resources.

Approval by the Board is required for all initiatives. In particular, the Board, which meets every two months, is asked to validate the political and strategic decisions the staff make.

The **BOARD OF DIRECTORS** is comprised of 10 members who represent the families and friends of the association and who have offered their time and commitment to us.
The current members, whose terms end in May 2011, are:

OFFICERS

Stefania Azzali (President)
Daniela Bruni (V.P.)

DIRECTORS

Francesca Pivetti
Assunta Barile
Giovanni Bottazzo
Anna Maria Maiolo
Lorenza Mazzi
Andrea Russo
Anselmo Sanguanini
Paola Torelli






Our discussions revealed a clear need to identify scientists who can translate the strategies of our organization into research on Ring 14 Syndrome. To this end, the **"Scientific Advisory Board"**, composed of geneticists, clinicians and neurologists with expertise in this syndrome, was formed.

In 2009, a scientific article based on their research was published in the "American Journal of Genetics".
As a follow-up of this work, we have now begun a process of delineating more clearly the reciprocal roles and expectations of our association and of the Scientific Advisory Board so that we can be better positioned to address future challenges.

Scientific Advisory Board

Prof. G. Neri, Director of the Institute of Genetic Medicine at the Universita' Cattolica of Rome and Prof. M Zollino, Cytogenetics and Molecular Cytogenetic Services at the Universita' Cattolica of Rome. They shadowed and advised the Ring 14 Association from its very beginning and carried out the first systematic genetic studies aimed at understanding syndromes associated with chromosome 14 abnormalities.
Dr. G. Gobbi,Chief of Child Psychiatry at the Ospedale Maggiore of Bologna and Dr. E. Della Giustina, Chief of Child Psychiatry at the Ospedale Santa Maria di Reggio Emilia. Together with Dr. Gobbi, he developed the first clinical protocols for the study and observation of affected children. Their research also focuses on the study of epilepsy, which is the primary symptom of children with Ring 14.

Prof. E. Perucca, Professor of Pharmacology at the University of Pavia and Director of the Clinical Trial Centre of the Istituto di Neurologia IRCCS. He joined our Scientific Advisory Board in 2009 and has already had an important impact on the direction of the Association.

The Ring 14 Staff, composed of dedicated professionals, manages all the complex projects of the association. **The number of staff has grown over time** and the association is moving from a "spontaneous" beginning to become a more structured and professional organization.

Commitment is our guiding principle in all projects: commitment to advance our goals with the professionalism and dedication that our families deserve, while at the same time maximizing the use of our economic resources. To our donors, who believe in our organization and its projects, and to our families, who count on us for support and guidance, we owe a seriousness of purpose and economic efficiency. The management team of Ring 14 values the principles of mutual respect, transparency and professional responsibility, with special attention to providing opportunities and fulfilling the educational needs of individuals.

RING 14 STAFF 2009

Francesca Fiori: consultant; she joined our staff in 2009 with the task of improving the planning and supervision of projects. Francesca, along with the President, develops the Association's strategies, including fund raising, and handles relationships with the Board of Directors and the Scientific Advisory Board.

Paola Martinelli: a psychologist who has worked on Ring 14 since 2004 and epitomizes, along with the President, the history of our organization. She has the important and sensitive task of handling relations with the families and individuals who need our interventions, both in areas of support and in research. She is well versed in the psychological and medical profiles of our children and is a valued point of contact for all families in the daily management of the syndrome.

Tuja Puputti: joined Ring 14 in November 2009 and dedicates two mornings per week to essential secretarial tasks, providing support to our staff.

Alberto Sabatini: an expert in media and communication represents the voice of our Association in both the local and national media. Thanks to his professionalism,

Ring 14 has a constant presence in the local media and in various specialized national publications. This presence provides us with a visibility that is vital for an organization that exists, in no small part, because of the generosity of its donors.
Simona Giovannini: a physician who specializes in child neurology and psychiatry; she undertook the initial research in the genetics and neurology of the syndrome and created the clinical database. She has become an important scientific advisor of the Association. Thanks to her thorough understanding of the syndrome, she has become a key consultant in all the association's activities in the scientific arena, including communicating information about the disease.
Ilaria Debole: a psychologist who was responsible for the first edition of the innovative project titled "To be the brother of..." Her enthusiasm and dedication helped her overcome the many difficulties and uncertainties that accompany such new and creative endeavours.

Without the fundamental and invaluable assistance of our **VOLUNTEERS**, our professional and dedicated staff, the Scientific Advisory Board and the Board of Directors would not have been able to implement the projects of Ring 14.
Our generous volunteers give us their time, energy and talent, while asking nothing in return. Their gratification comes from knowing that they are contributing to an important cause, a cause that, more times than not, does not personally touch them.
The primary mover and the person behind just about everything is Lorenza Mazzi, a member of the Board of Directors who is responsible for the organization and coordination of the many groups of volunteers. Her talent in managing relationships has made her a key contact for all the volunteers and an invaluable asset for Ring 14.

RING 14 STAFF 2009

Our volunteers are divided into groups according to their activities:

Translators/Interpreters: These are professionals who translate all documents produced by our organization into English, French, Spanish and German. These include letters from families all over the world, stories of our children that are on our website and scientific papers. Clear translations allow us to communicate effectively everywhere in the world at no cost to us, thus saving precious resources.

Stall sale: These are the people who help raise money for us by making and selling hand-made crafts at events. By donating their time and talent to these activities, they also help raise awareness of our organization.

Professionals: These are people with a wide range of expertise who help us in many different ways: administration, law, finance, graphic design, personnel issues and office maintenance. From the simple to the complex, the tasks they perform allow us to improve the quality of our organization and to use our resources in the most efficient way possible. Among them, we would like to spotlight **Marina Rossi** who is our "numbers" person, managing our budget and assets. She keeps our finances in order and without her assistance this publication would not have been possible. She helps us manage the budgets for our many projects in a calm and efficient manner.

We would also like to recognize the many families around the world who have been instrumental in starting local groups as well as spearheading the fundraising in their own

cities. In particular, we would like to mention Paola Torelli and Marisa Prampolini, who have organized Pinnacolo tournaments for a number of years; the Abbruscato family for their fundraising efforts selling football shirts, and Gammadue, the volleyball team that sponsors Ring 14. The members of the **National Alpine** Association of Reggio Emilia deserve our thanks for helping us with projects large and small. And finally, we thank the Parish **Church of San Marco** (Canali di RE) for their many years of fundraising events, especially the wonderful dinners prepared by Giuseppe Mareggini and Elio Fumi.
All in all, there are many people who, over the years, have volunteered their time and their talents to our organization. We thank them, not only for what they have done, but also for their presence in our lives.

RING 14 STAFF 2009

Stall sales:

Azzali Francesca
Bertelli Alessandra
Biancolini Elena
Ferretti Valentina
Fumi Elio
Gatti Stefania
Guidetti Anna
Ingangi Assunta
Lo Scocco Sara
Lombardi Maria Letizia
Lotti Mara
Maluta Francesco
Mortari Maria
Orlandini Matilde
Prampolini Marisa
Prati Sandra
Rolle Aldina
Russo Monica
Torelli Paola
Valentina Carnevali
Vecchi Alessandra

Translators/Interpreters:

Bettati Elisabetta
Boni Maurizio
Burani Federica
Caiti Federica
Carpi Lucia
Da Rin Betta Sara
De Giovanni Monica
De Tommaso Samantha
Florian Marco
Fortuna Maria Paola
Maraner Fabrizio
Mistretta Antonella
Pauzenberger Claudia
Scaltriti Paola
Rugginenti Emanuela
Siligardi Chiara

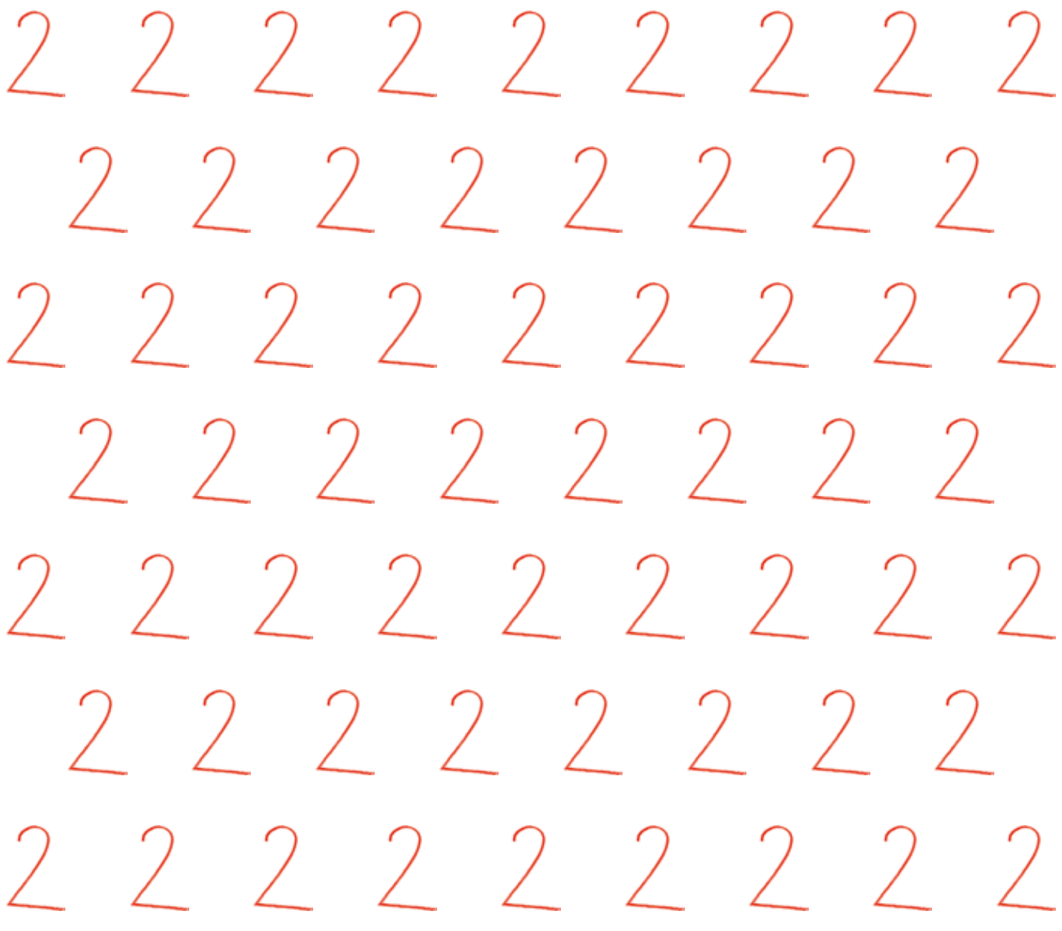
NAMES OF OUR VOLUNTEERS

Families who help with fundraising:

Bruni (Modena)
Gungui (Nuoro)
Maiolo (Novara)
Venditto (Como)
De Woody (Indiana, USA).

Professionals:

Assunta Ingangi: her weekly commitment allows us to work in a clean and comfortable working environment.
Valeria and Lisa Dalla Salda: provide help and consultation in the management of Human Resources for Ring 14.
Andrea Foletti and Pamela Cocconi from the graphics studio “Foletti and Petrillo”, redesigned the Ring14 logo and designed the graphics for this publication.
Francesca Preite and Sara Pratissoli: from the Law Offices of Preite and Miarai, provided legal consultation.
Marina Rossi: business consultant.
Sonia Mazzoni and Sandra Prati: helped in the design and presentation of handicrafts to be sold at events.
Annamaria Giustardi and Livia Saetti: author and illustrator, respectively, of the children’s story, “The Child of the Ring”, a moving story of a child affected by Ring 14 Syndrome.
Ivano Incerti: our volunteer photographer.
Matteo Rossi and Antonio De Castro: technical (IT) assistance.
Giuliana Soncini and Elena Bonini: nurses.



Chromosome 14 syndromes aren't simply rare, but, unfortunately, mainly unknown. There aren't any studies on the incidence and prevalence of this syndrome on the population and therefore we are not able to ascertain just how 'rare' it is.
We are challenged with writing the story of this syndrome, hoping to be able to treat its symptoms in the future, to make it easier to find a diagnosis and maybe, eventually, identify a cure.

Ring 14 syndrome and the conditions related to re-arrangements of chromosome 14: an in-depth analysis.

Let's first point out that this is a rare and still mainly unknown syndrome, therefore the actual number of people with Ring 14 is probably underestimated.

Genetic features: RING 14 means Chromosome 14 with a ring shape: it is an alteration of chromosome 14, in which the two tips of long and short arms join together. Chromosome 14, like all chromosomes, can be hit by different structural anomalies. These include partial, final or interstitial deletions of the long arm, balanced or unbalanced translocations with other chromosomes, in which the shape of the chromosome remains linear and doesn't become round, but where a part of material belonging to the chromosome gets lost. The first diagnosis for all these syndromes results from a simple blood test, called a karyotype, in which chromosomes are morphologically tested. Other techniques of molecular biology (for example FISH, CGH Array) become necessary to find out the quantity of lost material as well as other important details for pathology and research.

2

Clinical aspects: signs and symptoms related to partial linear deletions include psychomotor and mental retardation, multiple phenotype anomalies and are partially similar to those associated to RING 14.
RING 14 syndrome can be recognized, because it has some typical signs and symptoms. They affect the central nervous system and the retina, the immune and muscle-skeletal system and some little face dysmorphism.
Signs and symptoms differ in number and seriousness in each patient. The extent of mental and motor retardation and hypotonia is actually changeable, as well as microcephaly. Also, speech is usually damaged in a variable way, whilst epilepsy is a constant clinical sign and it usually appears very early; it is difficult to control it pharmacologically and cases of epileptic pain are not rare. An immunoglobulin deficiency (even a surface IgA) justifies the high risk of respiratory infections and probably gastrointestinal disorders, too. They are therefore case histories with big effects on psychomotor and connections development and on the person's self-sufficiency. There is the need of a medical and social help, both for the patient and his/her family, with consequent big psychological, medical and social costs.

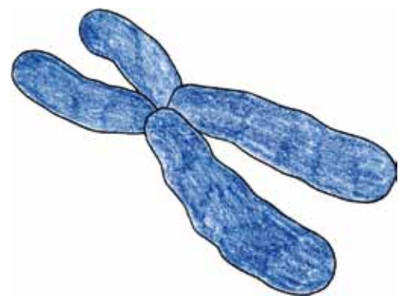
Repercussions of scientific and clinical research of molecular genetics.
These pathologies can be a vitally important model of study for the development of scientific knowledge, in particular for:

- The increase in the **number of diagnosed cases** in the world;
- The increase of the clinicians' awareness for **early diagnoses**;
- The study of some aspects of molecular genetics related to disabling conditions, such as **epilepsy** and **retinopathy**;
- The assumption of the models' monitoring and treatment, at a sanitary and social level, of **neuropsychiatric conditions of their age and growth rate.**

At a scientific level, therefore, their duties are to spread information, to support scientific research and to use our database.

2.1 INFORMATION SHARING.

Information is made available to all doctors and in particular to geneticists, children's neuropsychiatrists and paediatricians, to allow them to make a diagnosis (how many families in the world have a child affected by these nameless syndromes?), but also to make the diagnosis earlier – it is currently rather belated (when the baby is about one year old). Family doctors have a very important role in letting families get in touch with our Association, in order to offer them support and help when diagnosis is made and in subsequent months and years.
From the beginning, our activities have been characterized by the organization of ambitious and challenging scientific conferences as well as meetings which have involved our families around the world.




Grand Hotel
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2

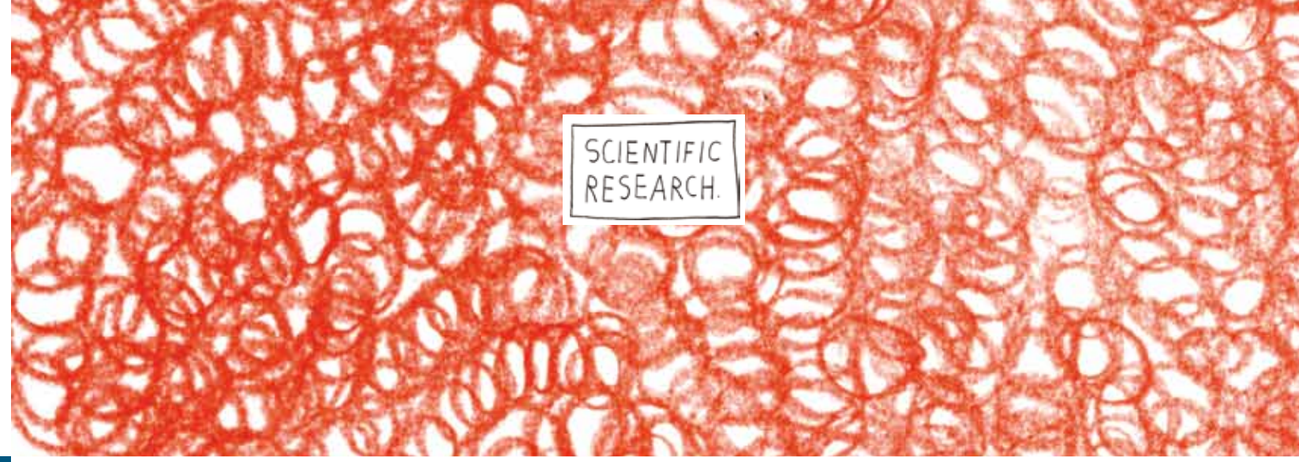
MEETINGS ORGANIZED BY RING14:

2003, May: Scientific Conference. It was organized together with Medical Association of Reggio Emilia with the title: "Genetic, clinical-pathological, neuropsychological aspects of chromosopathies, with particular reference to RING14 chromosopathy". It attracted the participation of many local doctors and paediatricians as well as the town's institutions and the press, allowing us to raise awareness of the syndrome, the activities promoted by our Association and provide a litmus test for future International Congresses.

2006, October: First International Congress (two days). The major speakers were our researchers and the members of our Scientific Committee, who touched on the principal subjects involved in these syndromes: basic genetic deficiency, diagnose, epilepsy and involved genes, most effective epileptic therapies, data collection and principal clinical symptoms. The second day was characterized by the analysis of rehabilitative, psychological and educational aspects to support the children.

We also listened to parents who shared their personal experiences. This event saw the participation of 120 professionals (doctors, nurses and therapists), 21 families from all over the world and more than 100 volunteers from some local associations. It was sponsored by different Health Authorities (Reggio Emilia, Modena, Bologna) and by the major Italian scientific companies.

2008, September: Second International Congress (three days). It was more comprehensive than the previous edition and covered three principal subjects: a workshop dedicated to ABA (Applied Behaviour Analysis) i.e. an innovative approach for the treatment of problematic behaviour; "The medical research and the caring of problematic behaviour" (an in-depth analysis of the genetic, clinical and epileptic aspects); "Families facing Doctors" (a round-table conference between the families, the Scientific Committee and the researchers). 270 professionals and 22 families from all over the world attended the meeting and more than 250 volunteers helped out. This congress was sponsored by many different local and national institutions.



2.2 SUPPORT RESEARCH.

Scientific research support is made possible thanks to study grant funds, doctorates or comes directly from research projects.

The aim is to throw light on the different aspects of the syndrome from a genetic, clinical and psychological point of view.

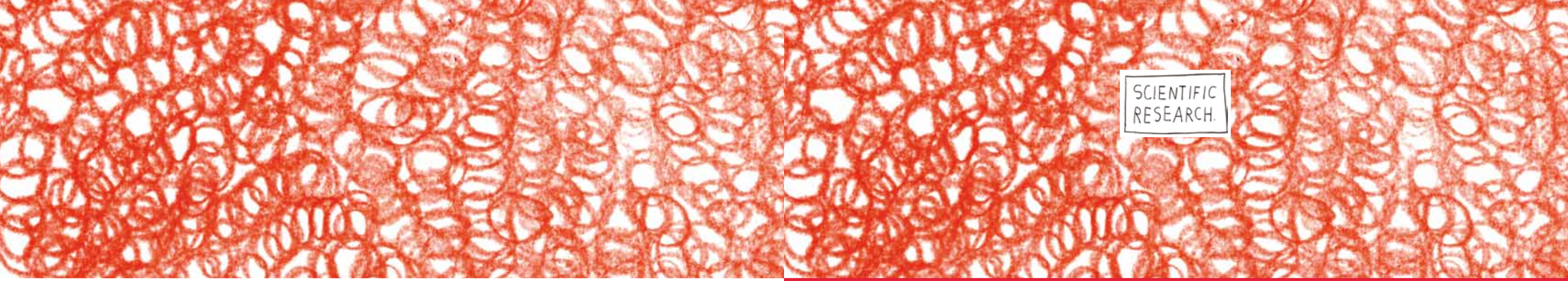
As nobody before us had developed in-depth research on our children's main symptoms and clinical problems, it has been our daily observation on the children that has allowed us to find the principal subjects which we have concentrated our attention on.

Our children frequently display the following: problematic behavior (symptoms similar to autism); clinical problems; frequent epileptic crises; deleted or absent speech.

In terms of syndromes with a **genetic** basis, back in 2004, it was obvious where we had to start from, to outline a more precise genetic profile and to find out exact correlations between what geneticians and doctors call FENOTYPE and GENOTYPE; i.e. trying to make connections between a person's clinical symptoms - in our case the quantity of lost genetic material (deletions, RING) or badly positioned ones (translocations) - and his/her genetic situation.

Generally, it is correct to think that the more lost genetic material, the bigger the symptoms, but it is also very important to try to understand what lost or damaged genes are contained and how important they were to control some functions of the human body.

The 'as above'concept implies a big scientific, financial and organizational effort, which has kept us busy since 2004 and which continues to be one of the principal challenge for the future.



From the beginning we could count on Professor Giovanni Neri's interest and dedication. He is the Director of Medical Genetics at Università Cattolica del Sacro Cuore in Rome and has been a member of our Scientific Committee since its foundation.
The first aim was to collect our children's blood samples, as well as a parent's one, in order to do all the necessary tests and analysis.

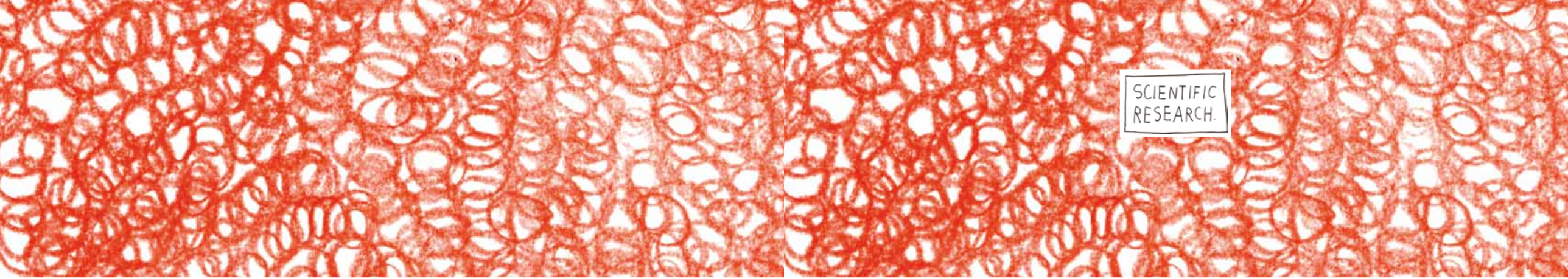
Study grants and doctorates supported by RING14 in the GENETIC area:

2004: annual study grant dedicated to the tests of the first blood samples received from the families.

2005/ 2007: three-year research doctorate assigned to Doctor Laura Semirara (Università Cattolica del Sacro Cuore in Rome) ended successfully with the discussion of her thesis "Ring14 Syndrome: Clinical-Genetic Data". It has been the first international study, conducted on 27 patients joining the Association, which used the FISH technique (Fluorescent Inside Ibridation). This technique is able to identify precisely where break and "loss" points of genetic material are in a chromosome.

2008: Doctor Orteschi's (Università Cattolica del Sacro Cuore in Rome) **study grant.** She has made another sophisticated analysis on our samples with MICRO ARRAY technique. This innovative, groundbreaking research, has given us an even more precise and detailed mapping of the genes lost in this syndrome, moreover it can identify their "expression", i.e. it helps us understand what these genes were deputed to and which their job inside the human body was. It is therefore very interesting both in basic genetic field and in medical diagnosis, where the genetic expression of healthy cells is compared to cells affected by the syndrome in question.

As a result of all these studies and in particular of the analysis with MICRO ARRAY technique, in June 2009 our research group, led by Professors Neri and Zollino, published a very important scientific article, an undisputed pillar in the knowledge of this syndrome, on the prestigious "American Journal of Medical Genetics" scientific review, which it placed on the cover.



Together with the research at a genetic level, we have also started in-depth studies on the **medical and clinical side**, thanks to the considerable help of two other members of our Scientific Committee: Doctor Della Giustina, head of Children Neuropsychiatric Department of Santa Maria Hospital in Reggio Emilia, and Doctor Gobbi, head of Children Neuropsychiatric Department of Maggiore Hospital in Bologna.

One of the difficulties that have constantly been faced by our families is to understand what kind of control has to be done (a patient of ours was diagnosed with the lack of a kidney at the age of 30); moreover, due to psychomotor retardation, our children are the classic "difficult patients": they are not able to tell what they feel and where they have pain, moreover they don't co-operate during medical examinations, because they are scared and don't understand what is happening. In order to help our families in these difficult medical circumstances and to let them interact with competent consultants who know these rare diseases, we have organized a **clinical protocol** in the two hospitals where our scientific consultants work: Santa Maria Hospital in Reggio Emilia and Maggiore Hospital in Bologna. Thanks to their co-operation we invited our Italian families to same-day hospital visits, during which the children underwent detailed screening and controls, in order to test their conditions and to give their families some advice and appropriate therapies. Our Association took care of all the operational organization, so as to make the families' visits as peaceful as possible, with the help of hospital volunteers and Association staff, who followed the patients step by step. These opportunities still exist, both for the new families who contact us, and for the old ones who want to do follow-up examinations.

Another principal problem of our children is **epilepsy**, because crises come frequently and are difficult to be controlled pharmacologically. Patients must take a number of medicines, with serious side effects. Someone has vagus nerve stimulators in the thorax, some others undergo very strict diets hoping this could stop or lessen the crises. At present, however, there are no definitive and effective cures and the effectiveness of the adopted ones greatly depends on the different subjective reactions of the individual. It is therefore essential to collect data from the families concerned and analyse them closely and accurately. In 2009, the introduction of our Scientific Committee of Professor Perrucca, Professor of Pharmacology at Pavia University and Director of the Clinical Trial Centre at the Neurology Institute IRCCS (Mondino Foundation in Pavia), has set time aside in order to continue in this direction.

Study grants and research programmes in clinical-medical field:

2005/2007: funded a study grant and medical research programme for Doctor Angela Scarano and Doctor Daniele Frattini of Santa Maria Nuova Hospital in Reggio Emilia.

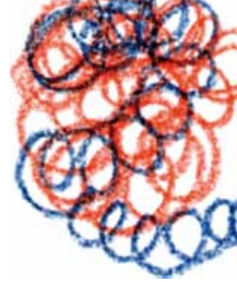
2004/2007: research doctorate awarded to Doctor Simona Giovannini (Maggiore Hospital in Bologna) ended with the presentation of the thesis "Electro-clinical Phenotype in Ring14 Syndrome and its correlation with genotype".

2008/2009: two-year study grant awarded to Doctor Simona Giovannini.

The aims of a.m. research programmes are various and range from the demonstration of the delicate cause-effect correlation between epilepsy and cognitive disorder to the demonstration of the functional identification of the brain areas that are more damaged on a neuropsychological level.

2

SCIENTIFIC RESEARCH.



Since 2008, we have opened another kind of research related to the analysis of the **speech** and the study of **autistic features** of our children. Speech delay and the presence of autistic features are variables can be found in all genetic alterations of chromosome 14. We have therefore started a first descriptive research, which continued throughout 2009, and concluded to compare the speech evolution in a group of our children and to connect it with genetic and neurological aspects. This project was developed in co-operation with Doctor Maiorano of the Psychology Faculty at Parma University. Research of all the speech areas (phonological, lexical, morpho-syntactic, pragmatic) has been carried out, both in production and comprehension, by using standardized materials.

We consider it very important to combine research and information sharing, in terms of **scientific publications** and our **participation at conventions**. The publication of our studies at an international level and in specialized reviews is vital, in order to spread the results among the scientific community and to attract attention on our syndrome. In all the publications we support, we request that our logo and our references appear, because they can represent an important channel to make ourselves known by families in the world, who are still "alone".

Publications and participations supported by RING14

ABSTRACTS AND POSTERS

October 14-15, 2004 in Pisa - **7th SIGU National Congress**: *"Chromosome Ring 14 syndrome: clinical and genetic aspects"*.

2005 - **8th SIGU National Congress:** *"Chromosome Ring 14 syndrome: clinical and genetic aspects"*.

November 8-10, 2006 - **9th SIGU National Congress:** *"Basal genetic defect in chromosome RING 14 syndrome and in partial 14q deletions"*.

June 26, 2009 - **NARRATIVE MEDICINE AND RARE DISEASES,** Italian National Health Institute: *"The stories of our children - Stories that unite us"*.

LECTURES

December 2008 - **6th S.I.R.M. National Congress in Modena:** *"Difficult behaviour is a message"*.

August 2008 - **International Congress in Canada:** *"The RING14 syndrome: clinical and molecular definition of a rare condition"*.

January 21-24, 2009 - **Neuropsychology of the years of growth days** in Bressanone: *"The neurolinguistic profile in chromosome 14 syndromes"*.

March 10, 2009 - **1st Convention of the Friends of Telethon Associations** in Riva del Garda: *"International RING14 Association"*.

August 5-9, 2009 - Philadelphia, **30th Annual David W. Smith Workshop on Malformations and Morphogenesis**: *"Epilepsy is the major manifestation in the RING14"*.

SCIENTIFIC ARTICLES

Giugno 2009 American Journal of Medical Genetics: *"The RING14 syndrome: clinical and molecular definition"*.

PRESENTATIONS AT CONFERENCES

8-10 November 2007 Bolzano CONFERENCE of S.I.N.P. (S.I.N.P: Italian Society of Paediatric Neurology): *"RING 14 chromosomopathy: a clinical-genetic study with the presentation of preliminary data and the dedicated database"*.

23 May 2008: *"Epilepsy in RING 14 syndrome"* Sacred Heart Catholic University.

21-24 January 2009, **Days of Neuropsychology of the Developmental Age**, Bressanone: *"The neurolinguistic profile in chromosome 14 syndromes"*.

THESES AND DOCTORATES

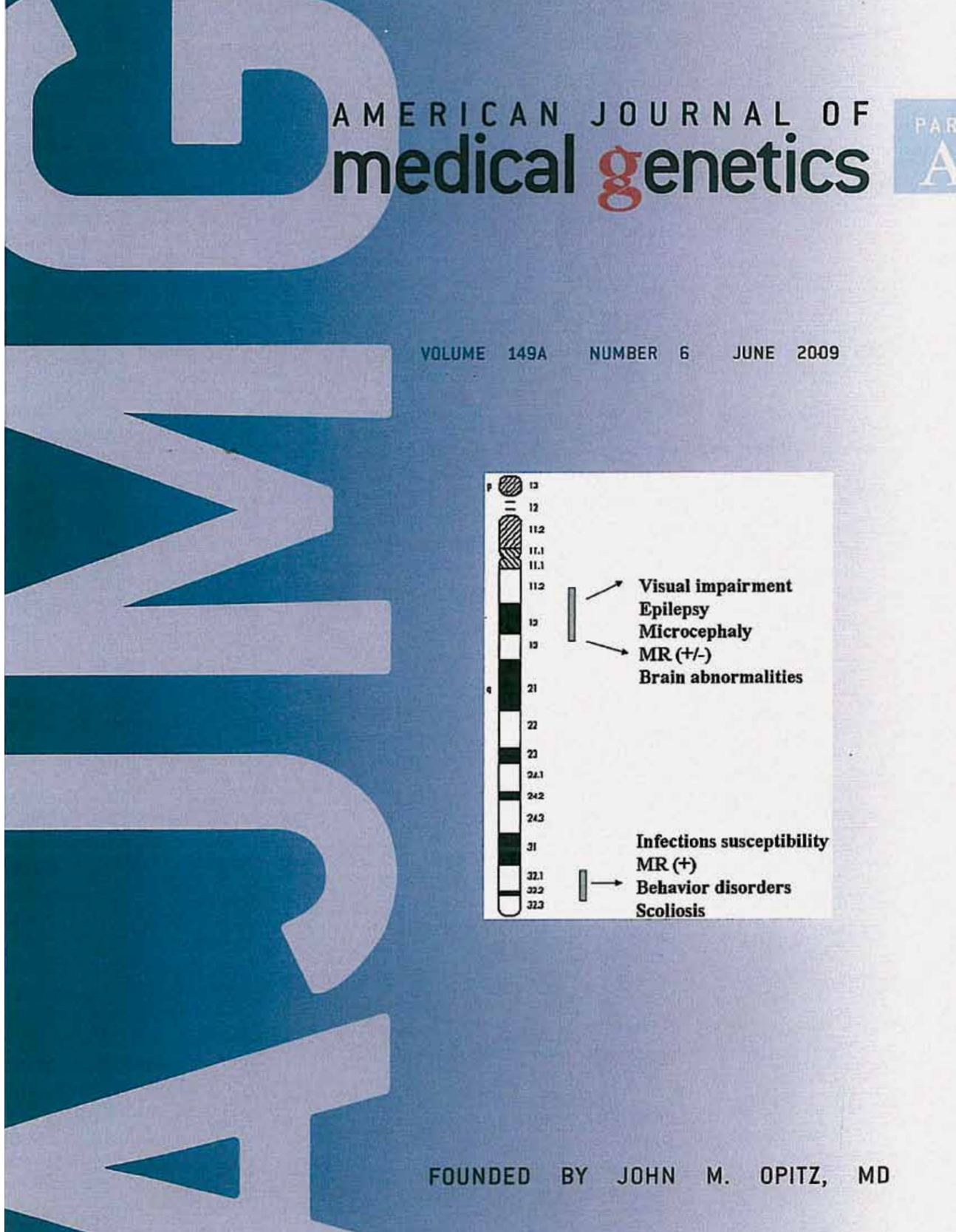
Year 2004-2005, **Thesis, Nursing Degree** Andrea Camdaten: *"Nursing assistance of children affected with RING 14 syndrome"*.

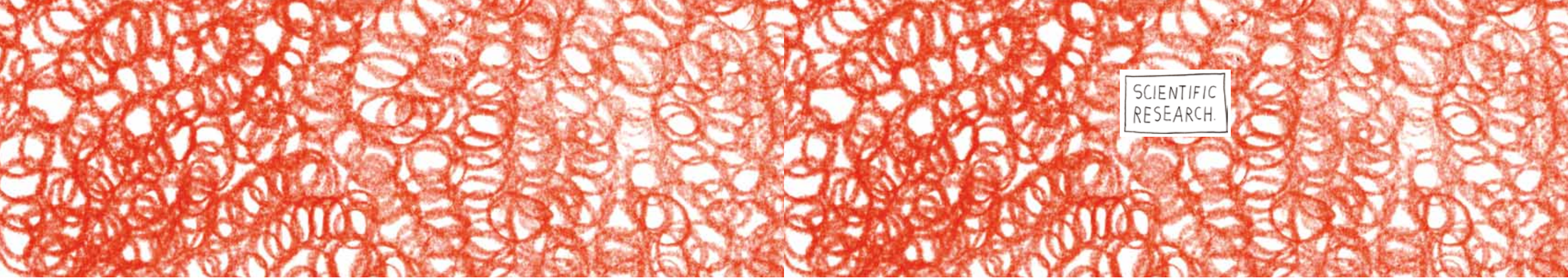
Year 2005-2006, **Term paper, high school diploma** Valentina Cocchi: *"The RING 14 syndrome"*.

Year 2006-2007, **Graduation thesis in Psychology** Elisa Fornaciari: *"RING 14 syndrome - clinical and rehabilitative aspects"*.

Year 2007-2008, **Research doctorate in Molecular Genetics** Dr. Laura Seminara: *"RING 14 syndrome: clinical-genetic aspects"*.

Year 2008-2009, **Research doctorate in Molecular Genetics** Dr. Simona Giovannini: *"Electro-clinical phenotype in RING 14 syndrome and correlations with the genotype"*.





2.3 DATA GATHERING.

Gathering data from patients is fundamental: counting on the support of the families, the Association was called in to make up for the fact that this syndrome isn't well known and is scarcely studied and especially because doctors lack available data to conduct studies and in-depth examinations. As such, starting in 2002 RING14 began gathering blood samples (from children and their parents) and has been processing and administering a complex questionnaire to gather all of the patients' clinical data. These are our precious databanks, unique in the world, which we are trying to share with the international scientific community in the most effective way possible.

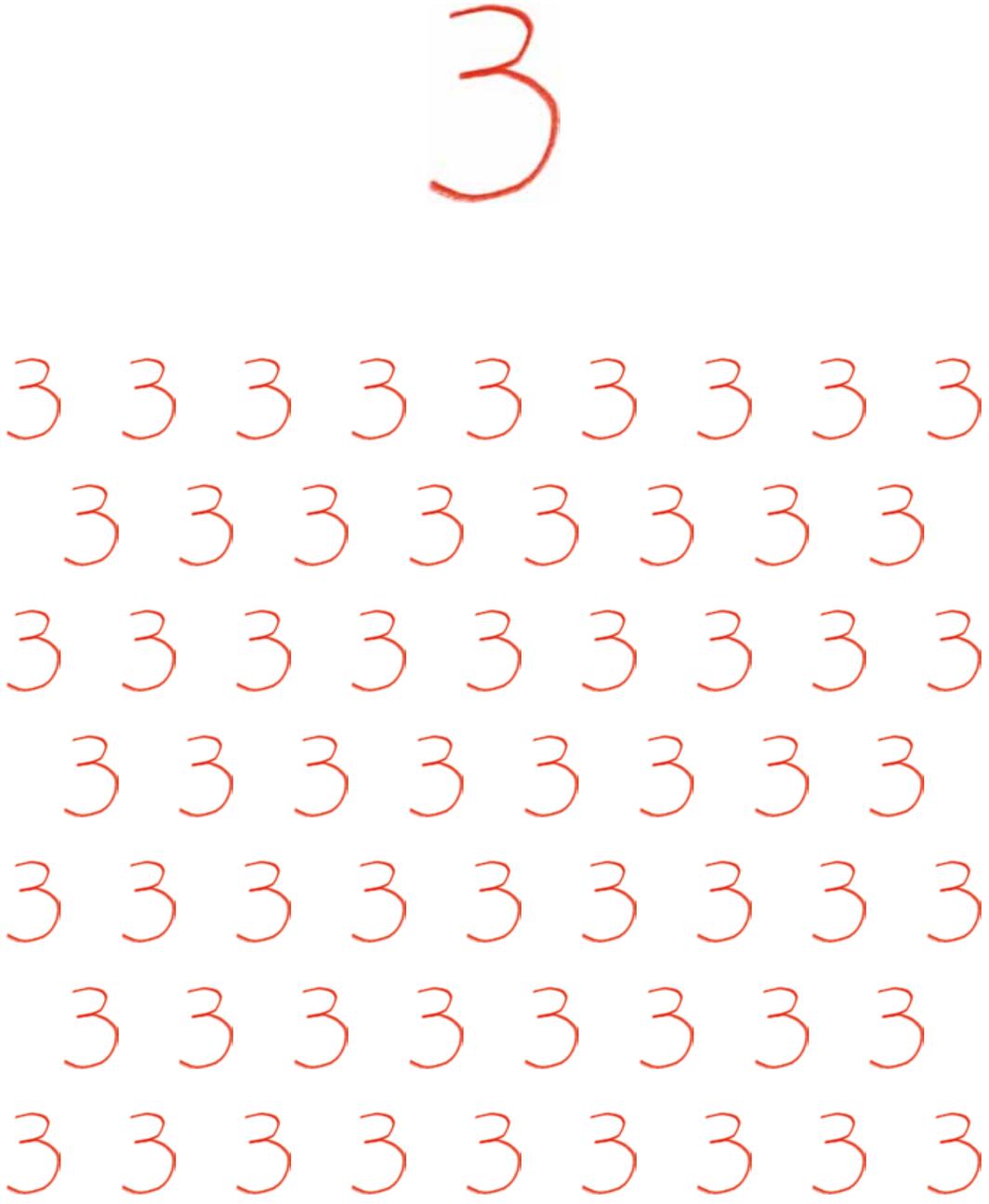
In December 2009 RING14 was the **first Italian association to make an agreement with the Telethon Genetic Biobanks Network** (T.G.B.N.) (http://www.biobanknetwork.org/): the biobanks are centres dedicated to storing the genetic material of patients to make them available to researchers worldwide. After careful examination, the Association decided on the T.G.B.N. Network and, in particular, the Biobank hosted at Galliera Hospital in Genoa.
This agreement is the stepping stone for RING14 to make the most of the data gathered to date and to disseminate it: an important step in the history of the Association which considers 2009 an undeniable success.

The RING14 databanks: an in-depth examination.
Genetic samples: these are blood samples taken from young patients and their parents that undergo various genetic tests by our researchers at the Institute of Genetics at the Catholic University of Rome. Clinical data: we collect information about the evolution of the child starting from the intrauterine phase, based on a long and complex questionnaire handed to families and their doctors (one part of which is specifically related to epileptic seizures). We also collect copies of all clinical and medical reports of the patients. This mass of data is then entered by a specialized doctor into a database that belongs to the Association, which is updated monthly by research doctors and managed by personalized software that has a password protected interface on a private website. The data gathered in it can be accessed by our researchers and others who request it that are motivated by research projects; numerous research criteria can be used and is a fundamental way to find out about the symptoms of these rare patients in an in-depth way. In summary, it contains 33 investigated clinical chapters, 400 investigated clinical subchapters, research criteria and customizable data extraction, photographs, reports, and EEG tracings.

2

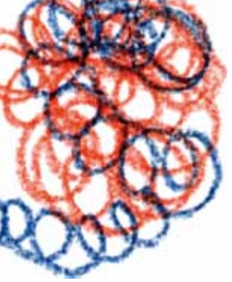
Our collaboration with the S. Maria Nuova Hospital in Reggio Emilia.
(Specifically with the Paediatric Neuropsychiatric Ward where some of our clinical researchers have worked).

2004: in collaboration with the Coordination of Social Centres for the Elderly and Vegetable Gardens of Reggio Emilia, we have donated an "**electroneurography machine**, potentials evoked and electromyography in childhood." This instrument is very important for diagnosing neuromuscular diseases and inflammatory processes affecting nerves and also to perfect and address the diagnosis of neurometabolic genetic disorders.
2006: RING14 has promoted the project "**Let's decorate the Neuropsychiatric ward**" launching a collaboration between Childhood Schools and a Hospital for the first time in the city: the rooms of the Neuropsychiatric ward were transformed, involving children of participating schools, making them more "children and family friendly" - see photos).
2007-2009: in collaboration with the Monodori Foundation, the company Landi Renzo and the help of the company ASMN, we were able to donate an important diagnostic tool called "**Gas Chromatograph System GC/MS - Perkin Elmer**" to the Hospital at a cost of □68,267, that, along with a biennial scholarship for a young medical researcher, made it possible to create a regional point of reference for rare neurometabolic diseases of the developmental stage. Very few Hospital centres in the Emilia-Romagna Region conduct similar investigations.



SOCIAL PROJECTS.

The approach that characterized RING14 in its conception and realization were activities that went beyond a strictly scientific framework and instead regarded support, help, and attention for the disability though an essential foundation: considering the **family** unit as a whole. Often, in fact, attention is focalized on the disabled person, on his needs for care and rehabilitation, the diagnosis, and often the family unit is referred to exclusively in terms of needs for economic support for caring for the disabled person. RING14 instead looks at the family as a "place" in which virtuous changes can be promoted that involve and can benefit all various members and, therefore, also the disabled person. This concept is manifested in the planning conceived and aimed at the family as a whole, its well-being and its relief.



3

SOCIAL PROJECTS.

3.1. FAMILY ASSISTANCE.

"It can't be true."
"There must be a mistake."
"They're wrong and it would be better to get a second opinion."
"Everything will resolve itself"
The diagnosis of chronic disorders or diseases is always information that tragically disrupts the life of a person and his family; the arrival of a situation involving a handicap is seen as a cruel stroke of fate that becomes especially hard to accept in a culture that values efficiency, beauty and communication.
People don't want to hear about the disease and it hurts them or they detest the idea that their lifestyle or their opportunities must be resized or altered because of the child's health conditions; so the first encounter with the unexpected reality of a disability is always a fundamental moment for parents, one whose ramifications last overtime and influence subsequent adaptations to the situation of the handicap.
When the diagnosis arrives during early or late childhood it's often a "catastrophe" with ambivalent connotations for parents: on the one hand there's a detachment from normal life, a feeling of loss of all things normal that had been built up until that moment about the child; on the other hand a storm is expected for the future, in the sense that the prognosis of a chronic disease or handicap suddenly changes the horizon of life for the entire family. They wonder how daily life will change, what their future will be like and that of their child, and if they'll be able to face it all.
In most cases the family needs adequate psychological support to face these diagnoses.

The family finds itself truly alone to face a drama that isn't only about how to handle the disease, but also about how to rebuild a psychological and existential context of reference. This is why the Association was developed. Since the beginning of its activity, it has offered a service structured to give psychological assistance and family counselling aimed at parents in contact with the Association. The service is dedicated to patients and their families in order to support them during the delicate time when they are informed of the diagnosis and in the daily difficulties that arise from handing the disability.
The Association drew up its guidelines by listening to parents and family dynamics to define its plan of action.

3.2 THE APPROACH TO THE DISEASE: "NARRATIVE MEDICINE" AND OUR CHILDREN'S STORIES.

At diagnosis questions begin flowing from parents about their child's growth:
"Will he ever be able to say mommy-daddy?"
"Will she walk?"
These questions that aren't easy to answer; this is a rare condition (a doctor has a rather low probability of encountering a child with this chromosomal alteration during the course of his career), the evolution of some symptoms are known, and it's recognized that the disease is incompatible with life, but not much more than this is known. So, although a diagnosis may seem to some like a point of arrival, in reality it's only the point of departure…
Where can parents get information? Scientific literature (if a parent is even capable of

SOCIAL PROJECTS.

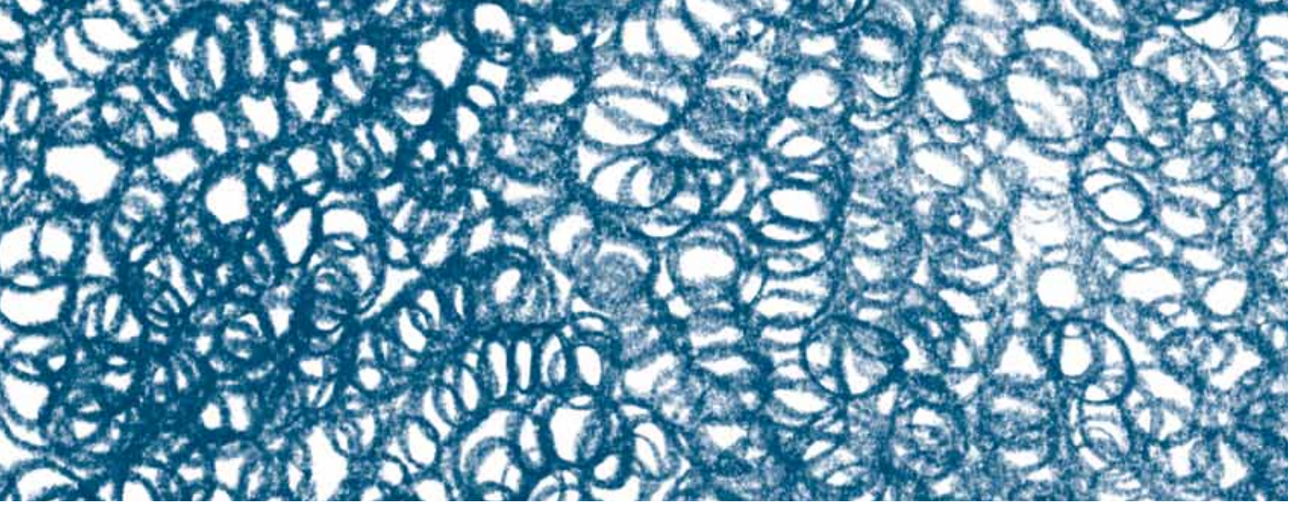
reading it) is rather scarce and mainly has to do with medical aspects. Even the Internet, which is a notable source of information, doesn't have much about it.

The most effective method has turned out to be the **sharing of written stories of those who possess awareness: the parents**.

To begin with, telling a story helps alleviate the suffering a person attributes to his or her experience. Different authors have highlighted the importance of the knowledge gleaned from the stories that give meaning to the experience a person lives. It's through the narration and the relationship with the others who are considered indispensible that sense is made of these experiences.

The act of telling your story gives you opportunity to create a different version of your life and yourself, making it possible to have a public and to give the meaning of the experience a new context.

That's how the project "Our children's stories" arose. It can be found on the RING14 Association website. The information about this syndrome from scientific research exclusively covers medical aspects, so the Association decided to gather the children's "real life" stories, willingly written by their parents, so that the experience of a few can become the awareness of many.

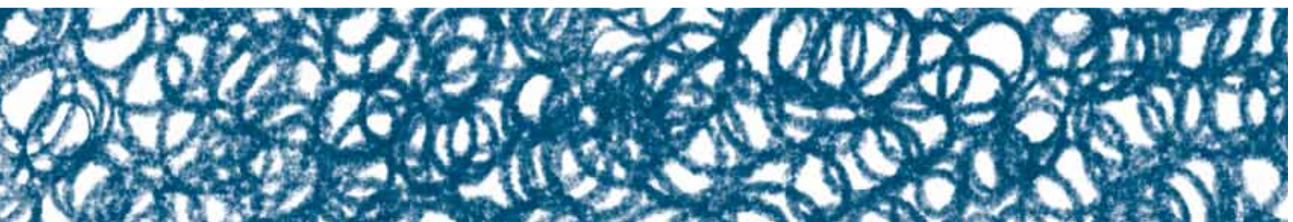


Some passages from "Our children's stories"

...In 1990, my husband and I participated in a genetic study with P.; they were looking for Fragile X Syndrome, instead Ring 14 was diagnosed and not Fragile X. P. is affected with epilepsy, mental retardation, microcephaly, difficulty with motor skills and he's hypotonic like a baby. His mental functions are like those of a 10 year old child, but he can't read or write, and he speaks slowly, although he has a broad vocabulary...

...R. is now a happy 13 month old baby and she finally likes eating! She likes listening to music and being outside in the garden. She is sociable and has a smile that melts your heart...She's aware of her surroundings and always looks around with interest...She likes her toys can handle the small ones...

G. and I still have to accept the fact that R. is different from other children, we don't know if she'll be able to walk and we don't know about the development level she'll reach in the future, but she's our special baby and whatever happens we'll do the best we can to help her so she'll be well. The name R. means "precious jewel" and that's exactly what she is for us.



From all the constantly updated stories it is possible to gather different types of information:

A) About emotions and thoughts of the parents at different stages of their experience: in particular, feelings connected to the communication of the diagnosis and the desire to share experiences and knowledge begin to appear.

B) About the characteristics of associated disorders and the effectiveness of different therapies: many stories provide information about the presence of neurological and internal disorders, their characteristics, effectiveness of the therapy and prognosis.

C) About development opportunities offered to children: the stories provide information about the opportunities that are offered to the development in the fields of communications, sports and participation in social events. The narrations of these aspects of life are so important because they communicate in a quick and simple way that **no person "coincides" with his/her syndrome**: development can occur only if there are opportunities; opportunities have to be created, facilitated and made accessible.

D) About development in various stages of life, intellectual efficiency, language, adaptation and participation: the majority of the narrative contains detailed descriptions of development.

E) About Quality of Life: the narratives contain, explicitly, an assessment of the Quality of Life.

The narration, with its ability to take away/manage the problem, can synthesize and provide all this information making possible, by an individual process, the emergence of a collective knowledge of both the disease and the emotions. Also, after each narration, we no longer have an anonymous "Ring14 case", but a person with his/her history, life and emotions.

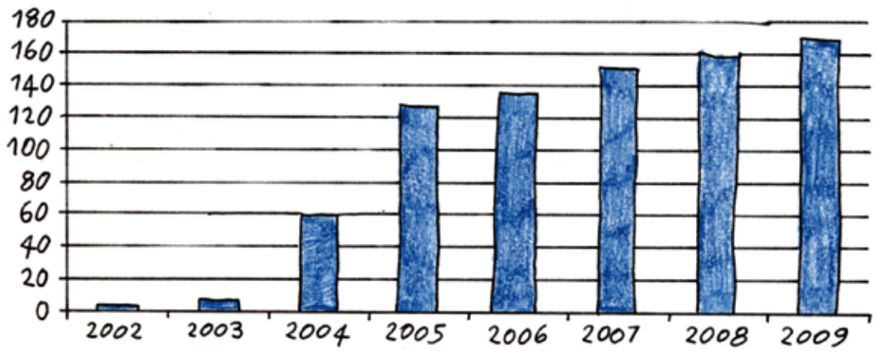
3

SOCIAL PROJECTS.

3.3 PLANS FOR THE FAMILIES' WELL-BEING.

Ring 14 interventions consistently try to realize the theoretical arguments outlined above by identifying activities and opportunities that can help and support the family as a whole. Thus, in this context must be considered the meeting occasions organized for the families around the world in conjunction with the **International scientific conventions** in 2006 and 2008, which obey to the need of know each other, feel accepted and not "different" or "rare", exchange information, emotions, difficulties, losses, successes, share moments of joy and serenity but also have the opportunity to listen and understand the (few) experts on our medical syndrome. Achieving all this in parallel with the scientific program, has not been easy: for example, it was needed a playroom for our "special" children and an adequate logistics system for all the families. We did it thanks to a real mobilization of local volunteers (100 volunteers mobilized in the first edition and 250 in the second). In 2009, we launched for our families the first experience at **Dynamo Camp**. Holidays are usually a relaxing moment of escape from the routine, during which you can sit and enjoy a book or a newspaper, freeing yourself from daily worries. But it is not always the case for our families: they have to be "chasing" after their child, have to stay constantly at his/her side controlling that he/she does not put anything in his/her mouth, the he/she do not throw any object at the nearest person, or that due to a crisis occurred during the night, the day after cannot leave the bedroom or even need emergency medical assistance. Starting from this premise, the Association has tried to find a place where the "special" needs of these families could be answered: where there are other families who know what it means to have a disabled child and would not judge but understand, in which the children, but also their healthy siblings, can enjoy activities focused on being together, including parents, in which everyone can have some time for themselves, a place in which share, relax, have fun, feel reassured by the presence of a competent and available staff that is always prepared to answer any need or emergency; a place where serenity is the goal of everybody. The question arises whether such a place actually exists or is just utopia. Well, yes, exists! In 2009, the extraordinary team of Dynamo Camp has provided its premises completely free of charge, an amazing structure in green surroundings above the hills of the city of Pistoia, to five families of Ring 14 who have been able to enjoy a five days holiday with all the "benefits" described above.

Increase in the number of families, from 2002 to 2009.



WHAT IS DYNAMO CAMP?

Dynamo Camp (http://www.dynamocamp.org/) is a Therapeutic Recreation camp; it is the first camp in Italy specifically designed to offer a serene holiday to children aged 7 to 17 suffering from serious or chronic diseases and their families.

The Camp is located in the province of Pistoia, on the green Tuscan-Emilian Appennines hills, within a WWF affiliated oasis.

Among the many offerings, the guests of the camp can enjoy an indoor swimming pool, a didactic farm, an entertaining theater, an adventure park and beautiful walks in the woods: the love for beauty and nature is combined with the high professionalism of the staff and volunteers within an exciting atmosphere of peace and friendship, as confirmed by one of our families: "We returned home reluctantly from Dynamo Camp; it has been an unforgettable experience, thanks again to you all at Ring 14 for the opportunity you have offered to us. For families like ours (but I think it would be for all) Dynamo Camp is a little paradise on earth and in fact it is run by heavenly figures, real angels on earth."

Dynamo Camp is the first in Italy of the family of Hole in the Wall Camps founded by Paul Newman and asset worldwide.

The first camp was opened in 1988 in Connecticut and currently there are 11 camps in the world in full operation, while others are in progress (www.holeinthewallcamps.org). Overall, more than 165 thousand children from 50 U.S. states and 39 nations in the project have taken part. The camps house more than 150 diseases and involve more than 10,000 volunteers every year.

Still in 2009 we ventured into another innovative project, that was particularly important for us: the **project "Being siblings of..."**, which was dedicated to a group of pre-teens boys and girls that have in common the fact of having siblings with severe disabilities. The "Siblings of..." are often mentioned in scientific literature, which draws the attention on some recurring characteristics due to the specificity and sensitivity of the family context. However, it has rarely been created a specific project or initiative for them that could offer exclusive attention and moments to share: this was the starting point of the project "Being siblings of...". An adventurous planning project that has brought our 13 boys to walk along a path of a year characterized by regular monthly meetings: dinners, trips, discussions, comparisons and insights, and culminated in the one week long journey on board of a brig of the Italian Navy. That has been an exceptional occasion where to strengthen the group and encourage children to a "high" comparison. During the project, and in a totally spontaneous way, the parents of the boys have established friendly relationships, so that among the "unexpected" results, a group of families united by the same problems but in a joyful and playful context has been created. The project "Siblings of..." has been promoted by the **Association Ring14** in partnership with the **Prader Willi Association of Parma** and the **Tender to Nave Foundation of Genoa**, thanks to which we could live the navigation experience. The group was managed by a team of two teachers of the Social Cooperative Creative in Reggio Emilia, a psychologist and a coordinator of Ring14. Only two children belonged to family members of Ring14, but we believed in the importance of the project and the necessity to include all those who showed interest in this opportunity. The participation in the project
has cost to the families an annual fee of 70 Euros.

3

SOCIAL PROJECTS.

OUR DEVELOPMENT IN THE WORLD.

In year 2009 we realized another dream: the opening of Ring 14 in France, the first “twin” association abroad. In order to develop the research on our syndrome and to be able to obtain cooperation from our families, it is essential for us to have an international vocation. The opening of a seat in France is a very important step, because it allows us to use our strategies in a more effective and direct way. The French Association is born as an independent one and it is totally free from Ring Italy, even if it has co-opted our constitution and it has been founded by a group of families, as it is ours. The model is that of a mutual cooperation on the basic strategies of Ring 14, which also the French association seeks and focuses its funds for, and of an essential support in the relationship with the families for the collection of the clinical and genetic data.

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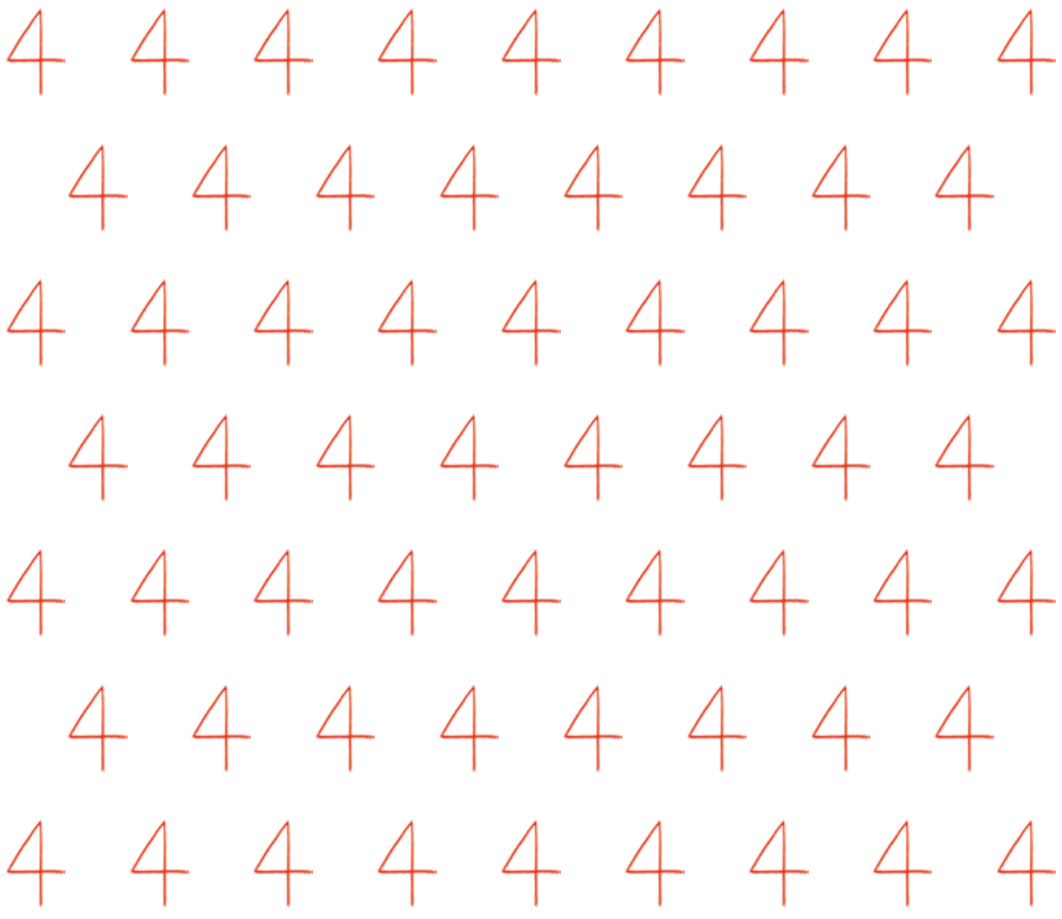


OUR NUMBERS... AND WHO ALLOWED US TO OBTAIN THEM!

4.1 INCOME AND EXPENSES IN YEAR 2009.

The financial statement of the association is arranged on December 31 every year.
Until last financial year the association made a simple cash-flow statement, but in 2009 financial year, due to its growth, it has arranged a financial statement, in accordance with the law related to non-profit organizations, Law no.460/199, and within advice of Italian Council of Graduates in Economics Management concerning the arrangement of non-profit organizations statements of accounts. Therefore this is the first ordinary annual statement of activities.
Total activities in year 2009 are □159.022, thanks to the incomes from operating activities (membership fees and “5x1000” donations) and fund raising ones (which take the lion’s share with □122.067).
Total expenses are □138.032 mainly due to projects and collaborators costs.
The amount of our net earnings is □20.990.

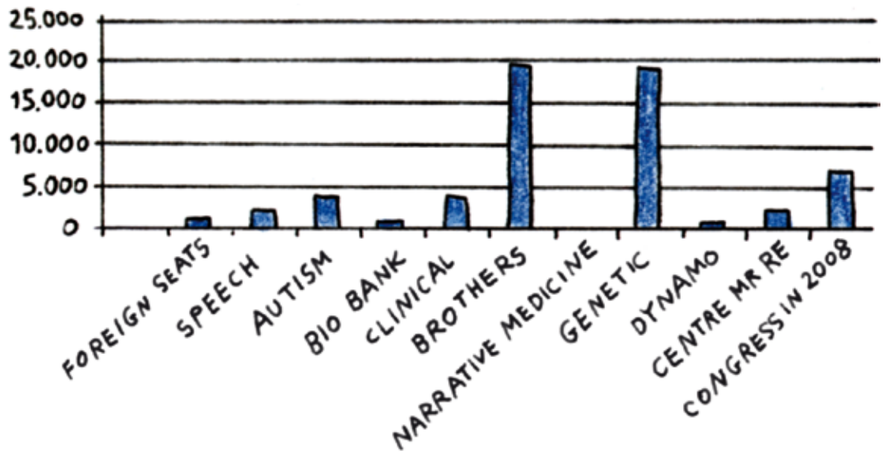
You can look at our complete statement at www.ring14.it.

4

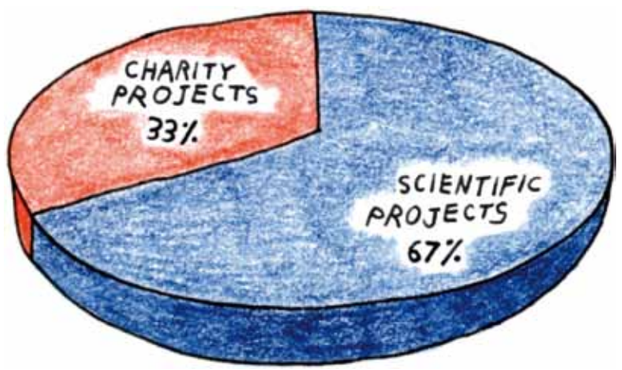
OUR NUMBERS... AND WHO ALLOWED US TO OBTAIN THEM!

4.2 A READING OF THE NUMBERS BEYOND NUMBERS.

Detail of the resources spent for our projects in year 2009.
The chart shows the projects, which we gave our resources in year 2009 to.
The genetic study and the innovative project "To be brothers and sisters of..." stand out and catalyzed our biggest efforts, together with the settling of the expenses related to the international congress of 2008 and of our grant for the Rare Syndromes Center at Santa Maria Hospital in Reggio Emilia. It is significant the realization of the observations of our children as regards autism and, finally, the opening of the French seat.



Subdivision of resources by project typology.
In this chart RING14 engagement is represented both in scientific projects (researches on speech and autism, Bio bank, clinical research, genetic, Rare Syndromes Centre and Congress of year 2008) for a total of □40.751 , and in charity projects (Dynamo Camp in year 2009, Narrative Medicine, "To be brothers and sisters of..." project) for a total of □20.362. Even if we have maintained and increased our attention towards all the initiatives for the wellness of our families, the activities related to the support and the development of scientific research remain preponderant and are typical of the identity of our association. We need to specify that the expenses in charity area are more moderate also thanks to our project partners' remarkable support (Dynamo Camp and Tender To Nave Foundation, who met part of their expenses).



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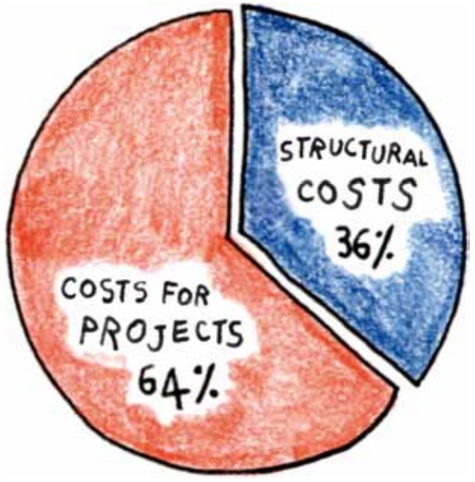
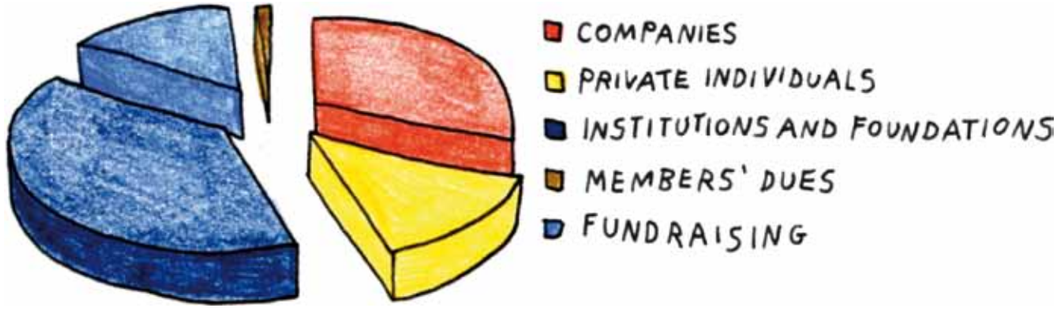
OUR NUMBERS... AND WHO ALLOWED US TO OBTAIN THEM!

Breakdown of resources by structure and projects.
For Ring14, 2009 has been rich in big structural investments: we have opened a twin association in France and a new office, increasing the number of our collaborators. Nevertheless, the majority of our resources are used directly to carry out our projects.



Subdivision of resources by origin.
As seen in the chart below, our major sources of funding include institutions, foundations and companies, who contribute more than □90.000. But a significant portion of our funding (around □40.000) also comes from individuals, through direct donations or participation in fundraising events. As the next chart shows, contributions from private sources - both private individuals and private organizations - represent our most significant source of funding.



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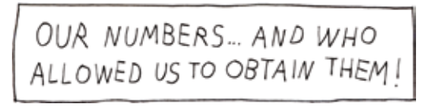
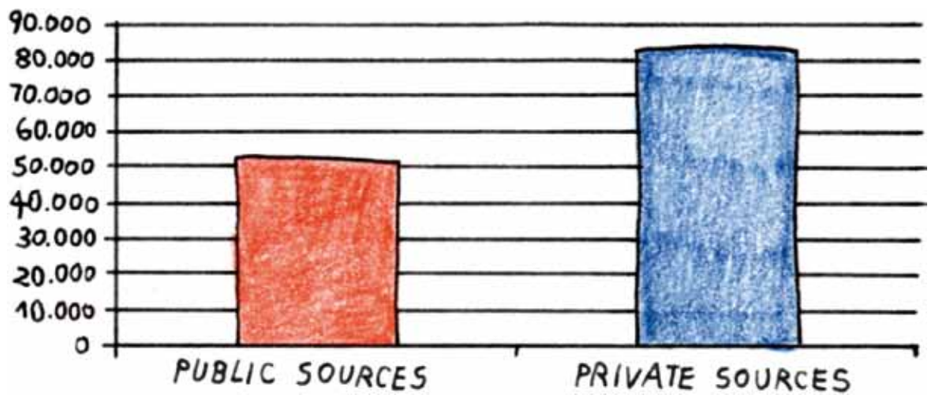


Subdivision of resources by public and private sources.



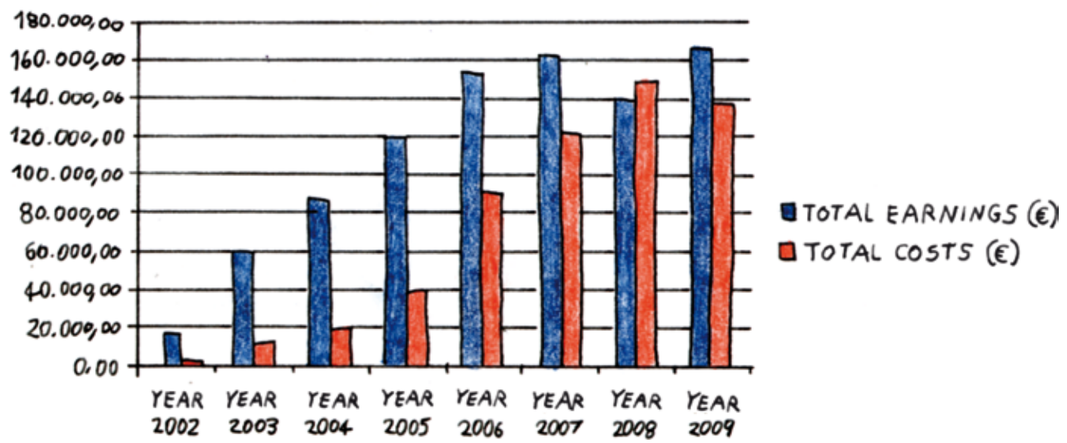
Historical cost/revenue comparison.

This chart illustrates the balance between income and spending from the association's beginning up to the present day.

It highlights the adeptness and conscientiousness of our operation: though successfully increasing the volume of our activities and financing each year, we make it a high priority to consistently set aside funds. This allows us not only the ability to respond to the unexpected and immediate needs of new projects, but also to handle any drop in funding tied to fluctuations in the world economy, making it possible to continue our current projects.

But don't let the graphic fool you -- these numbers do not mean we are "rich." As with all non-profit associations, the resources we receive are always used exclusively for operations and projects!

The reserves we set aside during the first few years have allowed us to face the difficult challenges described in the following pages.



OUR NUMBERS... AND WHO ALLOWED US TO OBTAIN THEM!

4.3 OUR DONORS AND FUNDRAISING ACTIVITIES.

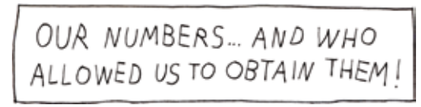
Our fundraising activities can be divided into three main categories according to donor type:

Private: This category includes the very large number of private individuals who remember us each month by sending donations for our projects and initiatives, participating in our "bomboniere solidali" (donation certificate wedding favors) programs, dinners or sweepstakes that we frequently organize, or buying merchandise at our exposition support booths. These people represent our core group, supporting our operations through a constant (and therefore vital) flow of funding. Thanks to them, funds donated through the website 5xmille.it have become a regular and significant source of funding on our balance sheet.

Companies: The expression "few but high in quality" aptly describes our friends in the business arena. Because our current building is inadequate for our staff level, we have not yet been able to set up and maintain a fundraising strategy to increase the number of companies contributing to our cause.

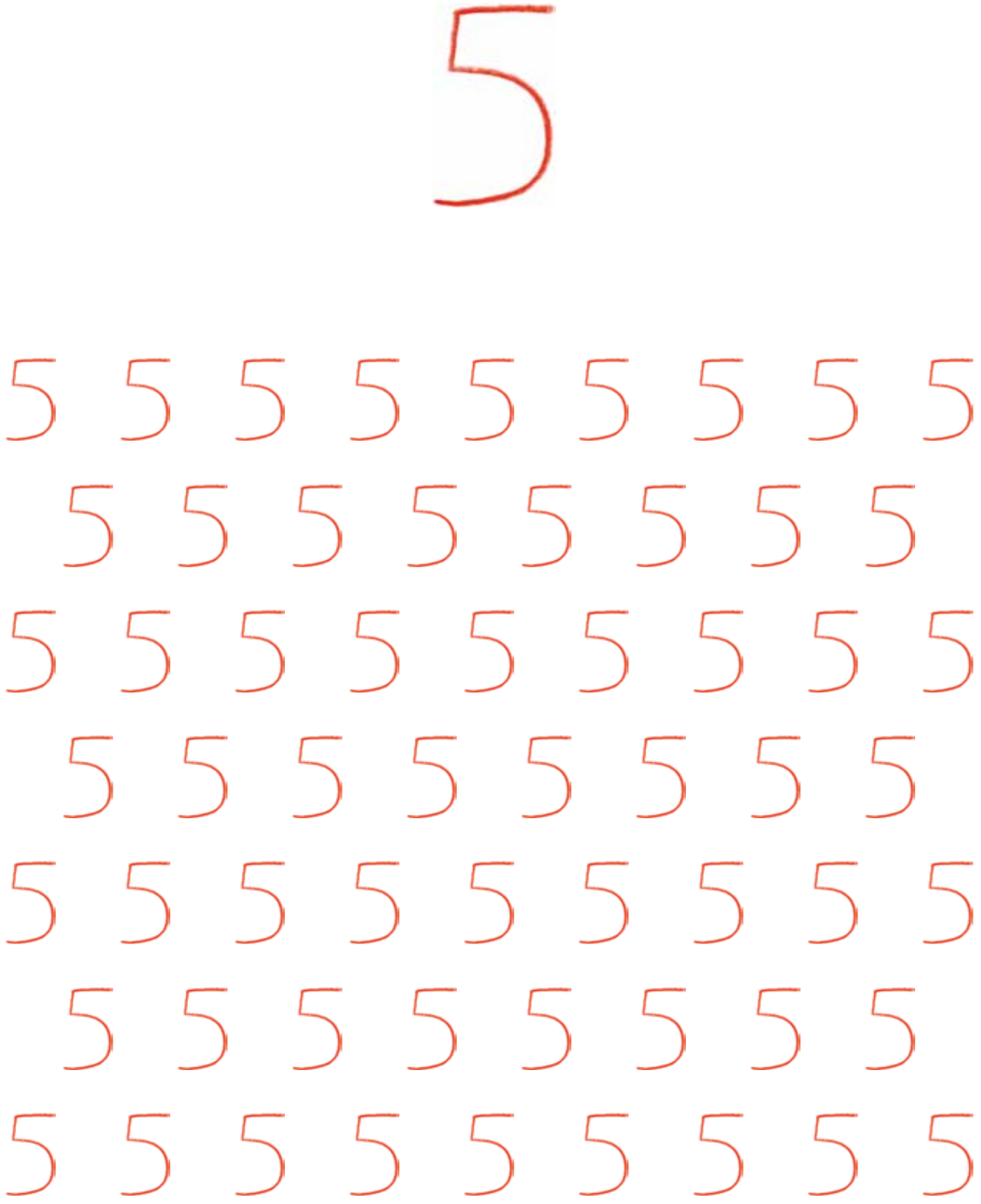
Nevertheless, we have been able to continually rely on our business donors, even amid the current economic crisis.

Institutions, Foundations, Associations: From its inception, Ring14 has been rooted in the local area, relying on support from our local institutions. These include advocacy groups such as Dar Voce (an important financing channel), service associations such as the Lion's Club, the local Manodori Foundation, which has never missed its important annual contribution, and the Liffi Group, an association of food lovers who donate their time and incredible talents every year, organizing magnificent dinners whose proceeds go to support Ring14. In 2009, we began to expand our reach, presenting proposals to institutions and foundations outside of our region. We will continue and expand this strategy throughout the coming year.



COMPANIES: PRINCIPAL PROJECT DONORS (2002/2009)	
Genetics	EUREC - BARILLA
Language assistance to families	MARIELLA BURANI
Meetings	MECART
MR RE Center	LANDI

INSTITUTIONS: PRINCIPAL PROJECT DONORS (2002/2009)	
Genetics	MANODORI FOUNDATION - LIONS
Meetings	DAR VOCE - MANODORI FOUNDATION
MR RE Center	MANODORI FOUNDATION
“Big Brothers”	MANODORI FOUNDATION Emilia Romagna Region
Foreign offices	DAR VOCE
Clinical protocol/database	MANODORI FOUNDATION RE INDUSTRIAL ASSOCIATION - LIONS



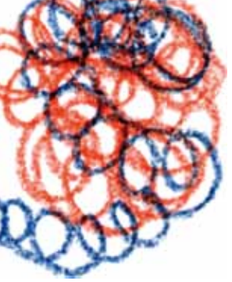
THE CHALLENGES AHEAD.

Scientific research

In this area a great amount remains to be done: documenting the history of an unknown disease, as we have been doing, is long and arduous work. Research on pharmacological resistance must be conducted, foundational genetic investigation must be continued, knowledge of its symptoms, so closely related to autism, must be expanded, and possible therapies must be analyzed - perhaps even those effective on children. To ensure efficiency and coherence, the Ring14 Scientific Committee's work is to identify the most important goals and areas of study to be pursued.

The collection of family data, blood samples and clinical information will undoubtedly continue to be our primary path of development, side by side with the TGBN Network. We also must improve our knowledge of **epilepsy**, understanding that it has specific symptoms when seen in children, understanding its progression over the course of years, identifying the most appropriate drugs for treatment, and together with geneticists, identifying the genes responsible.

Another important project slated for 2011 is the organization of an international brainstorming session in the United States. For the first time in the world, a group of respected international researchers from different disciplines will have the opportunity to study the syndrome, and use the current body of research to identify strategies for the near future.



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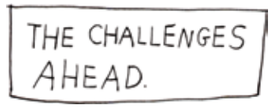
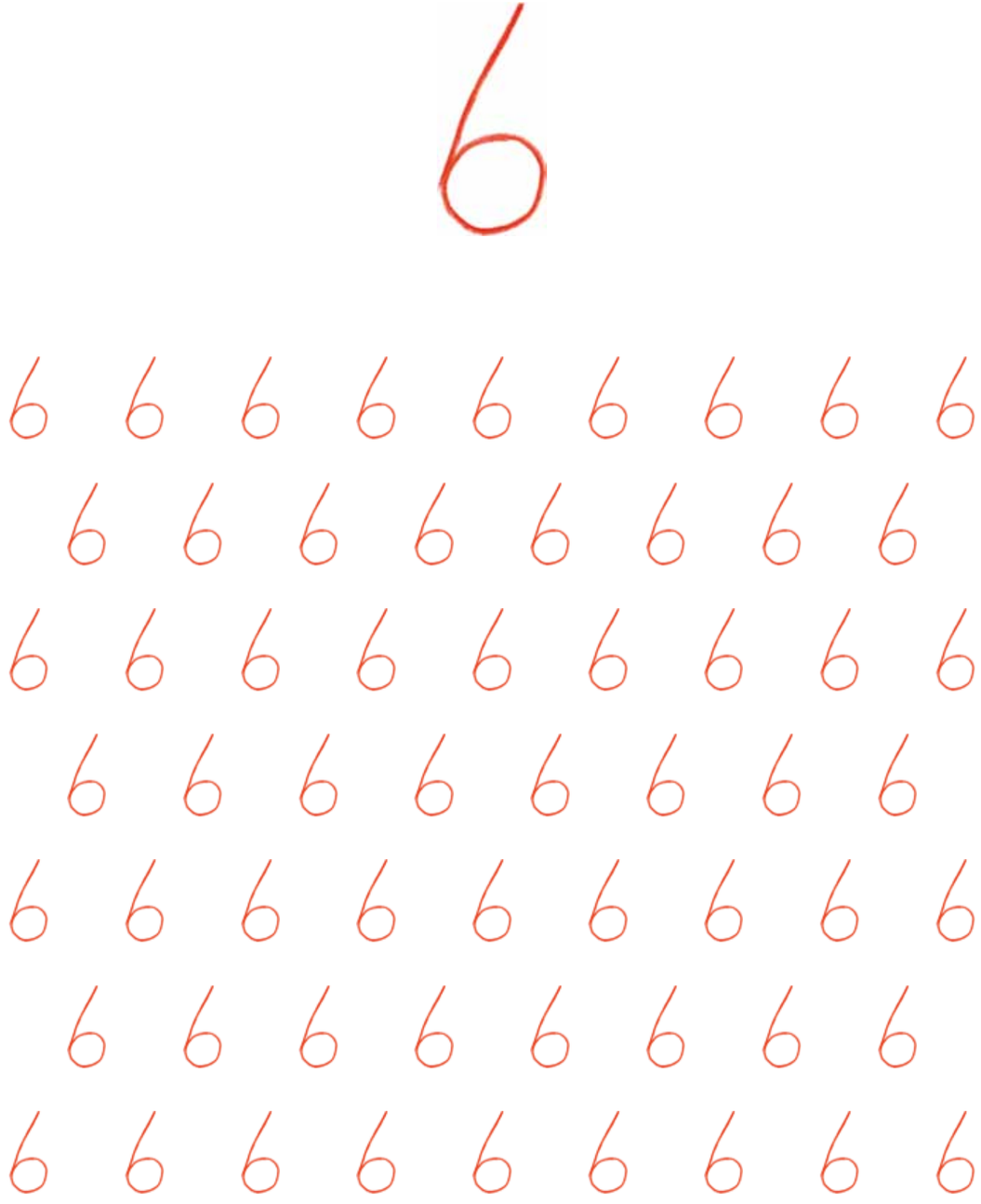


With regard to language, a new study, in collaboration with the University of Milan Bicocca, is being planned for 2010. The study, which takes place over a period of two years, produces "snapshots" of the development of language in two stages: prelinguistic and linguistic. This additional research could provide important therapeutic and developmental clues for families. Observations and assessments during the study on language have shown that many children have a number of problem behaviors which resemble autism, some of which are surely caused by disturbances in communication. A behavior problem is defined as conduct that is destructive and/or dangerous to the individual, to others, or to the environment, or which impedes learning and social interaction. We have noted that these behaviors are frequently degenerative, and are significantly similar to those of autism spectrum disorders. The diagnosis of autism is not usually indicated for our disease. However, given autism's association with other genetic syndromes, autism could be part of the clinical picture here. If we succeed in creating a neurocognitive profile – the goal of our upcoming research - and confirm the presence of autistic symptoms, we could identify intensive care rehabilitation techniques for families, powerful impacting the quality of life for these children.

Social planning

Dynamo Camp 2010: After the wonderful 2009 pilot project (see related project 3.3, "Projects for family welfare") Ring14 and Dynamo have concluded an extraordinary agreement that will allow nineteen Ring14 families from around the world to spend a holiday at Dynamo Camp, exclusively reserved for them, from 6 to 14 August ... free of charge for the entire family! This is a tremendous opportunity to offer a high-level response to the needs of families, to learn about and share strategies with our main stakeholders – families! - and to strengthen ties with the extraordinary staff of Dynamo Camp. "**Big Brothers, 2010**": Although originally planned as a one-time event, after our experience in 2009 we found ourselves with a wonderful, close-knit group of guys willing to continue the adventure, inspired to continue working with families. This prompted a rethinking of the project, and the start of a new challenge: to establish a permanent group and to get to know the strengths and talents of its individual members. In this way, we will be able to work out the best ways to offer families advice and guidelines for peaceful management of family relations and opportunities to meet with experts, and seek out and focusing on best practices and communication education. Given the success of the initiative, we are urgently seeking ways to offer this opportunity to "brothers" of other ages and with other experiences, with the dream of turning this one-time adventure into a regular event for many families.



WHAT THEY'RE SAYING ABOUT US

RING14 IN THE MEDIA: HEADLINES FROM MAJOR NEWS ARTICLES, 2002-2009.

2002

Gazzetta di Reggio - 30 November 2002: *"An association of parents dealing with rare diseases"*.
Il Resto del Carlino - 28 December 2002: *"Allies against a rare disease"*.

2003

Gazzetta di Reggio - 17 May 2003: *"Ring14 organizes a conference on chromosomal anomalies"*.

2004

Hospitals of Life Journal, Bologna AUSL - January 2004: *"More information on Ring14"*.
Gazzetta di Reggio - 18 September 2004: *"Ring14 an aid to research"*.

2005

Giornale di Reggio - 18 February 2005: *"My battle against Ring14"*.
Gazzetta di Reggio - 14 May 2005: *"A meeting with Ring14"*.

2006

Eurochromnet Newsletter - March 2006: *"Recent developments on Ring14"*.
Emilianet - 10 October 2006: *"Rare diseases, genetic research, infantile neuropsychiatry: the first international meeting of Ring14"*.

2007

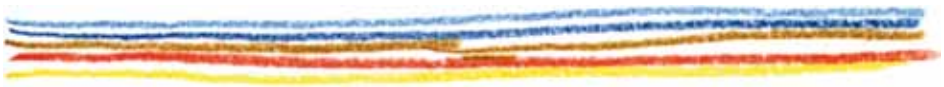
Gazzetta d'Alba - 13 March 2007: *"Thanks to the women of Vezza d'Alba, from Ring14"*.
Evening Post (Bristol) - 30 August 2007: *"Mother's mission to support others"*.

2008

Gazzetta di Reggio - 27 February 2008: *"European Rare Diseases Day, the international association Ring14 is there"*.
Il Resto del Carlino - 26 September 2008: *"Handball: a special goal for Ring14"*.
Gazzetta di Reggio - 12 November 2008: *"Genetic diseases: the t-shirt for the cure"*.
La Libertà - 29 November 2008: *"With Ring14, the first project for siblings of disabled children"*.

2009

Gazzetta di Reggio - 23 May 2009: *"Being the sibling of a disabled child."*.
HC Magazine - 28 August 2009: *"Ring14 makes it onto the cover of the American Journal of Medical Genetics"*.
Il Resto del Carlino - 1 September 2009: *"The adventure at sea begins for the siblings of disabled kids"*.
Unione Sarda - 11 November 2009: *"Solitary struggle of a family against Ring14: now an association offers help and information"*.
Il Resto del Carlino - 8 December 2009: *"The Reggio-Emilia association Ring14 signs an agreement to collect DNA"*.
Giornale **Opinione delle Libertà** - 12 December 2009: *"Ring14 Syndrome: the facts"*.



To learn more about our projects and activities, visit our website: www.ring14.org

To support our projects, you can:

- Contribute 0.05% of your income to the Ring14 Association at http://www.5-per-mille.it/ - enter 91105800352 in the Tax ID box. This will not increase your tax burden, but it will bring a smile to the faces of many families.
- Make a free donation to the RING14 Association using Unicredit Bank account IBAN IT27H0200812820000003665310.

Contributions are deductible from taxable income.