

Dear families and dear friends,

Matteo was 15 months old when we found him agonizing in his bed. We didn't understand what was happening but we knew for sure that his life was in danger and that ours was forever changing.

At the hospital doctors told us it was a big seizure and its possible causes were : leukemia, cancer, metabolic diseases, dystrophies or genetic diseases. They started to perform all the tests in order to understand what it was happening. In the meantime, our son was not himself anymore, he had continuous seizures, development regression etc.

After 1 year from that day, the diagnose came: " the illness of your son is called ring 14 syndrome"

Ok, I thought, now that we know his problem, we'll receive some information from doctors, how to cure him, what will be his future, what we'll have to face. At least , I reckoned, some answers will follow after their diagnose.

It was a great shock to find out that no answers were available, that no doctor had ever had any direct experience with kids suffering from this disease; as far as I was concerned, I had never heard expressions like "rare disease" or "orphan drugs".

I didn't know that there were neuro psychiatrists for children, my son, I said to myself, has no mental problems. I hardly knew what a geneticist was but it had never crossed my mind that one day I might have needed one of them.

How is it possible, I kept repeating in my mind, that in 2002 nobody can give me any kind of information about this ring 14 illness ? Has anyone ever met a child like my son ? It was really unacceptable !

Luckily and unexpectedly , from such an absurd and negative situation like this, something incredibly good happened: the birth of our fantastic association Ring 14.

I have briefly summarized my story because I am sure that everyone here involved has lived the same experiences my husband and I have done with our son Matteo and that, under certain aspects , we are still living.

I have written it because a dream is coming true and, if it is true for me, I am sure it will be the same for all of you.

Our Association, together with our researchers, is organizing a meeting where the best experts of the world will discuss, for the very first time, the ring 14 syndromes and what are the best strategies to follow in order to study and, let's hope, to cure our children's illnesses.

It is really incredible if you think that only eight years ago nobody knew anything about these diseases and tomorrow, the top 15 researchers of the world, are going to meet and focus on how to proceed on researching.

I don't want to create any false illusion, I have to be honest with you. We are far from having discovered a concrete and effective cure but I believe this is a great step ahead, so important that it will deeply affect research in the next future.

My letter is going to be delivered to all our associates in the world, from Australia to Usa and Canada, from France to Brazil, Sweden, Colombia, UK, Eire, Mexico, New Zealand, Suisse, Spain, Belgium, Germany, Norway and, of course, Italy !

We more than ever need all the help you can give in order to fund this project and the researches which, we hope, will be carried out after this important meeting.

As you know, we have always offered our services for free because we are aware of how expensive it is for a family to take care of their children suffering from such serious illnesses.

At the same time, considering the great opportunity we have, I ask everybody to try and do their best.

Every kind of initiative you can organize in order to raise funds will be great (dinners, stalls, shows, auction sales etc).

Fabbro Donatella from our association fabbro.donatella@ring14.it - cell. phone nr. +393457912306) is ready to help in both organizing and supporting any fundraising initiative (leaflets, newsletters ,banners, posters etc).

For the first time, somebody is willing to write the story of these Ring 14 illnesses and that somebody is you, us, our researchers !

We all know how much we have suffered from the first day we have discovered our children were ill. Our life has changed forever , it is very hard to go on when you know that you cannot do anything to change the course of action.

But the existence of our Association testify that we have never accepted this situation as unchangeable and now, more than ever, we all have to fight together for a better future for our children and I am confident we will succeed and win our battle !

Let's work together to achieve our goal !

My heartfelt thanks to everybody,



AIUTO E RICERCA PER I BAMBINI AFFETTI
DA MALATTIE GENETICHE RARE - ONLUS.
IMPEGNO, SOSTEGNO, FUTURO.

Stefania Azzali
President RING14 Association

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