



Dear friends

This year I will take advantage of a special occasion to wish you all a Merry Christmas, even though a little in advance...

Already before my sons were born, I used to follow with much attention the tv marathon Telethon, contributing, on my part, with donations, for this gave me confidence and I thought that, having a rare disease was really a terrible thing.

When the Ring 14 syndrome was diagnosed to my son, a rare syndrome among the rarest, a fortiori I continued to follow the Telethon investigations, also trying to borrow, in our little Association, the style, the transparency and effectiveness in achieving our goals.

Being able to take part, create a link between them and our association, being enabled to share projects, access their financing, take part to their TV Marathon, were all aims of which I often thought about, but which appeared all so far to me. There are many associations of people affected with rare diseases, some much greater than us, much "elder". I never thought we would ever had the occasion of making these wishes come true.

Instead...

In 2009 we have been the first association in Italy and Europe to conclude a pilot agreement with one of the Bio Banks of TGBN Telethon, at the Ospedale Galliera of Genova, thanks to which, all the precious blood samples of our families in the World are gathered, preserved and at the disposal of all the investigators. Thanks to this agreement, Telethon will be a useful template for many other associations of rare-diseased.

This month, the Telethon marathon is about to start on Rai TV network.

I had the honor of being invited, together with my family, to participate to Telethon broadcasting on Saturday 18th December, on air on RAI 2, in the range hour 17.00-19. In studio, with us who are going to tell about our history linked to the RING14 syndrome, there will also be Prof. Franca Dagna Bricarelli to enhance the scientific aspect of Bio-Banks and, of course, the connection with Ring 14.

It will be a hard effort for us to go to Rome with Matteo, it will be a stress to take part to a direct tv broadcast with him; who knows him, knows he is an adorable child, but sometimes his behavior is unpredictable, especially in new situations.

But we do this willingly:

We do this with our heart because, being there, offers us the possibility to make us acquainted by a greater public of families and doctors,

We do this, because we would like to share this acknowledgement with all those people who helped us until nowadays, with the investigators who believed in our will to go forward, although we started from zero,

We do this, to express gratitude and thanks to the many donors who allowed us fulfilling many projects, to the friends and volunteers who follow and support us,

We do this, to represent all the families contacting us from all over the World, and share with us our hopes and dreams

This is the most beautiful present we could receive for Christmas, the acknowledgement by such a virtuous Association, and an example for many, of our seriousness and clarity of purpose: **OUR CHILDREN FIRST OF ALL!**

Many wishes for Christmas to you all!
Stefania Azzali

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