

The 1st International Congress on the Ring 14, an important event for the world medicine that our city had the honor to host, ended on October 14 2006. Doctors, researchers and many kids affected by this rare disease met for the first time, coming from all over the world.

It was almost by chance that I got into this adventure, which, even if very short, was of great intensity and human participation. This is a feeling that, I believe, was experienced by all those who had the privilege to participate to the event (I think that our Commi Pietro e Akela 1 would agree with me).

Coming out from a difficult period of my life, I felt, for a second, somewhat estranged from the routine of my daily life. I felt hovering on a reality that had been totally unknown to me but that became so important to me that even today I can see the thread that connects me to that day and to those children.

The unknown scares you. Before entering the ludoteca I was assailed by many doubts, thoughts, and questions. However, as soap bubbles appear and disappear quickly in front of our eyes, we, the volunteers, got rid of all the doubts and fears and let us guide by the smiles and eyes of the children. The children, after all, were only asking some attention.

To see families from Canada, Brazil, USA, France, Australia, Belgium, the UK, and Italy all together for the common cause to fight a disease that is still not well-known and much studied, made me think something that we all know but that everyday life makes us forget. We forget how many people live through enormous difficulties, which we barely notice because they are not in the media spotlight.

Few comments can be made on the words of parents and relatives who share something that they do not even completely know. Moreover, the fear of doing something wrong is always present. Parents also ask themselves if there may be some treatments that can improve already-compromised situations. They sometimes wonder about the quality of their kids' future life. There are many questions but unfortunately, for now, few answers.

In such dramatic cases, you wish you had a magic stick but, alas nobody has not still find it. So, snatching a smile from Moana, Quentin, Marie, Claudio, Riccardo, Giulia and all the others is already a great step forward, which also helps to break the indifference barriers that make our souls dry and gloom.

Like us - the scouts - several junior and senior people belonging to volunteer groups were present. The presence of the clowns, who usually work in the hospitals by providing a some joy to the kids, was very important in the days of the congress. Only the clowns' great patient could match Claudio's continuous requests for having Japanese greetings performed. It must be said that it is not easy to manage kids with different multi-faced problems and in different ages (some of them infants) and nationalities. However, I believe that our little stimuli managed to bring a glimpse of joy to the kids. It was unbelievable to see Moana (a seven year old Brazilian kid) motherly cuddling Giulia (an Italian kid of the same age) with face caresses and by making it sure that there was silence around Giulia while she was sleeping.

At the hotel entrance, I ran into a Canadian couple that thanked me for all the work done by the volunteers to watch and entertain the kids. The couple told me "You are special people", at that point I felt embarrassed because, after all, we had not done anything special. However, this makes you understand that what is little to us may mean a lot to others.

Giulia Bianco