



Dear families,

I am pleased to inform you that the second research by our researchers on status epilepticus has been published, with our funds and our support.

You can download the article from the home page of our website; it is clearly a technical article, which however we are confident may greatly help the doctors that treat your children, because it can help them get a better understanding of some aspects of this symptom, epilepsy, that is so devastating for our children.

But what is behind all this? Of course, there is the hard work of the association, that has raised funds and collected clinical information, and the hard work of the researchers who have studied them, but I want to take you beyond all this.....

For several weeks, my son Matteo, who was seven years old back then, had been behaving strangely. Somehow, my husband and I were relieved, because he no longer had clusters of 10 - 20 - 30 seizures a day, which, unless we managed to keep them in check, would have us rushing off to hospital.

Maybe he was feeling better, but....

Strange enough, now he had just one episode, an improvement, we told ourselves, but then he was still restless, he moved restlessly from one room to the next, sometimes for hours, he found no relief in anyone or anything, yet he was conscious, he moved around, he looked at you, sometimes he did what he was told, but.....

Days went by; somehow the situation did not seem to be so bad that we should "disturb" the doctor, but on the other side it was not normal; when Matteo was like that, he looked like a robot to me.

Until one day, after a seizure, Matteo kept behaving like that, so I decided to pick up the phone and call our neuropsychiatrist. Luckily, there was a place for an EEG and so, since we live just 10 minutes from the hospital, I went there, just to be on the safe side

We stayed in the hospital for 1 week!!!!

His restlessness, that strange behaviour was the result of an extremely serious epileptogenic inflammation, what the doctors call status epilepticus.

That was such a shock!

Predictably, we also felt very guilty for not having gone to the doctor earlier, but unfortunately we are "only" parents, even if our instinct

It is from that event that this important medical article has been written, so help for others has been born of a great suffering.

So, in these few lines, I would like to convey few, simple concepts, that you certainly know very well; they might sound trivial to you, but you should never forget them:

Observe your children, trust your instinct, always ask and tell your doctors what does not sound right to you, a gesture, an attitude, a change, do not be afraid to disturb them.

Remember how important your experience is, as well as your readiness to put together and send us your medical records; this article is proof of that. The end-product of the collection of clinical information provided by serious researchers are scientific publications.

Scientific publications are the very foundation of medicine, because through them doctors all over the world, who treat your children, can have more information and get a better understanding of these rare diseases, not just epilepsy but any other clinical problem.

So, let's join forces with courage and generosity, let's never forget what a wealth we can put together and give to others, how much we can do for our children, even in our own small way.

Kind regards,
Stefania Azzali
President RING14

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