January 27th 2010

Dr. Michael PRANZATELLI
National Pediatric Myoclonus Center
751 North Rutledge, Suite 3504
Springfield, IL 62702
USA

Dear Doctor,

A few years ago, in October 2004, we crossed the Atlantic to consult you concerning our 8-year-old daughter Victoria, who at the age of 13 months developed OMS with a neuroblastoma.

You were our last hope to treat Victoria's chronic OMS.

Luckily, you were able to propose a treatment (METHOTREXATE and RITUXIMAB) for our daughter.

Victoria is now 13 years old and we want to share with you the evolution of her illness and provide testimony of hope to families who are still in great suffering because of this pathology.

As we had indicated to you, the treatment by METHOTREXATE had to be interrupted due to a still stronger increase of her transaminases. The relay was conducted by two treatments of RITUXIMAB, at 1 month intervals. Following this last treatment, we gradually saw real improvement in our daughter's condition. Victoria had been very weakened by the treatment, but the abnormal neurological signs were lessened.

Even though there was nothing scientific to it, our daughter seemed better living near the ocean. The region of the Alps where we were living at the time was indeed known for propagating ears-nose and throat conditions in children due to the harsh climate and heightened pollution.

We therefore moved permanently in September 2007 to the Atlantic coast, to a town that already had the reputation of being beneficial to patients since the beginning of the 19th century, thanks to its privileged geographical situation between the ocean and the forest (presence of many pines).

This change has been particularly beneficial to Victoria, who has presented no more chronic signs of the disease. She is still followed University Hospital, who recognized no longer seeing characteristic signs of OMS as of April 2008.

Even if certain events (dysgraphia, fatigue) are sequelae of the disease, they themselves have significantly decreased.

Since entering middle school, and after much insistance on our part, Victoria has received help from an auxiliary school-life assistant who takes notes in school for her.

She thus follows class in an "ordinary" school. She is always very willing, very enthusiastic and highly motivated by school work.

Very well integrated in middle school and in her class, she follows its curriculum (currently in 7th grade), yet is dispensed from music, art and physical education classes in order to alleviate her class load and to avoid fatigue.

Her school results are very satisfactory with excellence in foreign languages and particularly in English!

Manipulations are still somewhat tricky, and for this reason she will not be able to have a manual profession. She is able to ride her bike without difficulty, and also swims the breaststroke perfectly.

From an orthopedic point of view, she still has very hollow feet and must wear splints during the night.

We know that the path will still be difficult but the accomplished journey shows us that we must never give up and must always have hope. That is the message that we would like to convey to all the families who are still faced with uncertainty and despair.

We allow you to reproduce our testimony, in part or in whole, and encourage you to continue your valuable work for children suffering from OMS.

Sincerely,

Catherine and Stephane