

February 1, 2014

Dear Senator Warren, Senator Markey, and Representative Tsongas,

I am writing to you about an illness that affects our family deeply. When our son Gavin was about three months old (in early 2007) we took him for his regular pediatric appointment and his doctor noticed that Gavin had many café au lait birth marks (one of the hallmark symptoms for NF1) and asked us about whether or not one of us had them as well. My husband Gary has had them his whole life but never thought anything of them. Gavin's pediatrician recommended that we see a genetic specialist and get tested to see if there was a possibility for NF. We had never even heard of Neurofibromatosis until that day of course. We saw a specialist at Children's Hospital in Boston a few weeks later and soon after we got the confirmation of an NF 1 diagnosis for both Gary and Gavin. Gary had no idea that he had NF and found this out at age 35. Gary was always a little reserved when it comes to talking about his



childhood because he grew up with learning disabilities. Gary had severe speech delays as well as learning delays. He had to attend a special school in Brighton where he basically lived there from Monday through Friday from age 5 up to age 12. The only diagnosis he ever received in that time was that he was delayed. He came a very long way and progressed much better than his doctors thought he would. At one point, Gary's mom told me that they had told her not to expect him to be able to drive a car or hold a regular job. He of course, has led a completely normal and happy life.

Thankfully, Gavin has only had some minor speech delays and a little motor skill delay so far. We consider ourselves very lucky. However, due to the knowledge that doctors and teachers have access to today and the expanded programs that are available, Gavin has had lots of help from the very beginning up to present day.

As a family, we have tried to be as positive and hopeful that we can be that Gavin will continue to have a normal and happy life even with the NF diagnosis. We are so happy to be part of the NF Northeast family network. By meeting so many other families with kids the same age range as Gavin we have definitely gained a lot of insight and strength from our shared experiences. We have also participated in many of their fundraising events. However, we cannot combat NF with fundraising alone, federal funding is vital. We hope that you continue to support NF research through the CDMRP and NIH.

Thank you,

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