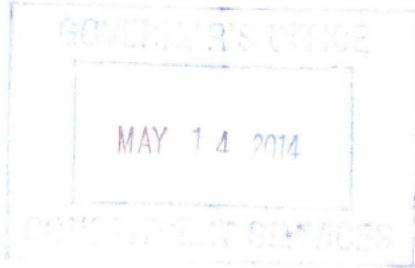


5-9-2014

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Governor Deval Patrick
State House
Office of the Governor
Room 360
Boston, MA 02133

Dear Governor Patrick:

As a constituent and (*a person living with scoliosis / a parent of a scoliosis patient / a scoliosis advocate*), I am writing to ask you declare June 2014 to be National Scoliosis Awareness Month and sign the National Scoliosis Awareness Month proclamation request from the Scoliosis Research Society (SRS).

Now in its third year, National Scoliosis Awareness Month is observed in June to disseminate information about scoliosis and highlight the growing need for education, early detection and public awareness of the physical, emotional, and economic impact of the condition, and provide support and hope to all people affected by scoliosis.

The need for early detection and public awareness has become more important now that the benefits of bracing found in the NIH-funded BRAIST study were released. The results of this study confirmed the effectiveness of bracing for scoliosis and how this may help prevent surgeries for future scoliosis patients.

Scoliosis has affected my life by...Hi, I'm Izzy. I would seem like just an ordinary girl, but I have a whole other side to me. I have scoliosis. This is my journey. (so far)

In 5th grade, we had a screening test in gym. At first, I was a little scared. I went home to tell my parents and they said hopefully I don't have it considering my little sister does. I had gym class the next day and we were playing dodge ball. She was calling kid after kid after kid. I heard my name, dropped the ball and ran to get my back checked. I didn't like gym that much because it hurt my back for some reason. We had to bend over like we were diving, and relax our shoulders. I had done this at the doctors about 6 months ago. There was nothing then so

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nothing's going to be here now. She had this strange look on her face. Then I continued dodge ball. The next day before gym class, I got called down to the nurses. When I got there, she brought me to the back room and did the same things the gym teacher told me to do, but did it multiple times. She said that there was something. She gave me some papers and called my mom. I couldn't stop thinking about it the whole day. I was in class that day thinking that everything was fine. I mean, I obviously don't have scoliosis. Do I? My mom checked my back everyday until we saw my pediatrician. I woke up one morning, and remembered that I was going to the doctor. I got ready, and hopped in the car. I was pretending I didn't feel good, but then I remembered that I have to get it checked anyway. When we got there, we checked in and waited. I heard my name. I just froze, I didn't know what to do. I went out back where I got my height and weight. I was put into a room where i was told to put on a johnny. Then, my doctor knocked. He did the same things my gym teacher AND nurse did. He didn't do anything except for send me down to get X-rays. I was only 11 at the time, so then my little 11 year old self walking to xrays so scared. It was a nice, may afternoon, and I was getting this done. 20 minutes later, he came in, and sat down. The sunlight was gleaming through the window. It was silent. "She defiantly has scoliosis." We're the words I will never ever forget. He wrote me a paper for physical therapy, which scared me even more because I didn't even know what it was or what they would be doing to me. In August of 2012, I went to my first appointment with my orthopedist. He looked at some X-rays and looked at my back, did some measuring, and told me that I will need an MRI, wear a back brace, and that I have congenial scoliosis. I was so confused. Everything was going by so fast. I was having thoughts like, what's going to happen? Am I going to be okay? I had my MRI in September of 2012, and they told me that I have a small opening my spinal canal. Then, on November 13th 2012, I got my very first back brace. It was so uncomfortable and I was dreading until I had to wear it to school. I slowly eased my way into and started wearing it to bed. Then in December of 2012 I started wearing it to school, which was a struggle. I couldn't carry anything, I had to sit on a cushion, and take the elevator. I wasn't allowed to play sports and had to take modified gym. I was so happy when school ended, no more of this. I swam all summer, which was so much fun and felt great on my back. I was also continuing to do physical therapy, since 5th grade. I then noticed that the brace started to be really tight, and it didn't fit anymore. I changed doctors in that summer. In September of 2013, I missed the second day of 7th grade and went to my new doctors. He said my brace didn't fit because my curves increased. I got fitted for another back brace. On September 23rd 2013 I got my second back brace. I now go to the doctors every 4 months and

continue to wear my back brace 23 hours a day, and fight. In school, I still can't hold anything, but I don't sit on a cushion and don't do modified gym unless my back hurts. I still go to physical therapy, also. I have a bunch of social networking and helps girls and boys with scoliosis! I also got to design my own bracelet and key-chain, and with that money I buy build-a-bears to give to kids in the hospital who are having scoliosis surgery. I will continue to fight every day until my scoliosis journey is done. I am involved in a group call Curvy Girls which is for girls who have Scoliosis and we get together every month and talk about fashion, our braces and how Scoliosis affects our lives.

By officially signing the National Scoliosis Awareness Month proclamation for **Massachusetts**, you will help highlight the growing need for education, early detection and awareness of scoliosis. Our goal is for every state, district and commonwealth to officially declare, by proclamation, their observance of National Scoliosis Awareness Month during the month of June and I am hoping you will join us!

Thank you for your time and consideration.

[Redacted signature area]