

Testimony from Jennifer and Brian Kelly  
S.B. No. 275: Designate Sanfilippo Awareness Day  
Ohio Senate Health, Human Services and Medicaid Committee  
November 17<sup>th</sup>, 2020

Chairman Burke and Members of the Senate Health, Human Services and Medicaid Committee:

Hello, we are Jennifer and Brian Kelly, and we'd like to thank you for the opportunity to testify on behalf of S.B. 275; we would also like to personally thank Senator Kunze for her strong support and sponsorship of this bill.

We find this day of our testimony, November 17<sup>th</sup>, to be quite fortunate because just yesterday was the second National Sanfilippo Awareness Day. This is a day when all of the Sanfilippo families, together, spread the word about these wonderful children with this terrible disease. A day where we seek out the hope of others. On this day, we encourage supporters, new and old, to wear purple and share pictures of themselves holding hands. But of all of those words, we'd like to emphasize the word *second*. There has only been *two* of these national "awareness" days. For children like our son, Oliver, there is no time to spare. For children like our Oliver, they might not still be with us for a tenth awareness day. With time against him and them, we believe there is only one way to beat it and find a cure, and that is through action and knowledge—by spreading awareness.

We feel so privileged to be here and tell you about Oliver, which we cannot rightfully do without also telling you about Sanfilippo. Oliver is our oldest, having turned five in early April. He is as beautiful as he is on the inside as he is on the outside. In many ways you might not notice that Oliver is different. He likes to play with toys, he likes pepperoni pizza, he likes watching movies, he likes snuggling under the covers, he likes a good trip to the playground, he likes hanging around his friends and getting into mishaps with his younger sister, Reagan.

But look closer, listen more carefully. He does not hold a long conversation, on any subject. He doesn't always speak clearly or in full sentences. He is starting to lose the ability to recite and acknowledge his letters and his numbers. He struggles with fine motor skills and is behind on gross motor. Just yesterday with a lot of help he pedaled his bicycle with trainers a half a block up our street; that took over twenty minutes and probably felt like a mile to him. He has disruptive sleep. He is not aware of his safety or of the safety of others. He has behavior issues and can be too physical and is often prone to prolonged tantrums. He does not always listen well; he has trouble focusing on activities. As you can imagine, this makes school a challenge for him. He has a whole host of doctors and therapists; he is picked and poked more than any child should ever be. As you can imagine more, this makes life a challenge for him. And from what we understand of Sanfilippo, these are his good days. We can't bear the thought of him not being able to talk or walk or swallow. We can't bear the thought of him not recognizing his mom and dad and sister. We can't bear the thought of him not being Oliver, much more, a day when he is not with us.

After several long months of testing and searching for answers, Oliver was diagnosed with Sanfilippo Syndrome—or MPS III type B—in October 2019. Like probably all of you, we had never heard of it. The devastation we felt that day remains just as vivid and real as it does today. Most devastating of all was when we found out it is terminal and has no cure. Sanfilippo is a nasty monster. It's basically a slight genetic defect, a missing enzyme to break-down natural cellular waste. Sounds small, but today as we stand here, Oliver is not expected to make it past his teens, and even if he does, he will likely be suffering from severe dementia – which is why this disease is likened to childhood Alzheimer's.

But this is merely about Oliver, this is not who he is, how we see him. We believe Oliver runs at the Speed of Love. He loves people; he loves being present for all of life's tiny little activities; he loves being hugged; he loves giving hugs; he loves being where the action is; he loves trying to help; he loves saying 'I love you', at the end of the day, and in the middle, and in the beginning and all of those many, many, many times in between. We need more people like Oliver in this world. His love is truly unconditional. No, it is not an easy love but it has sheer muscle and it breathes and it is relentless – and it unstoppable. Why then do these special people with Sanfilippo get such little time? Maybe all this active love actually breaks their hearts.

So no, we do not have normal days. We have Oliver days. We have live-the-moment-celebrate-everything days. That is his gift to us and everyone around him.

Finally, what we have also sadly discovered is that this disease is not as rare as it feels. There are hundreds of families and children in the U.S. and around the world dealing with Sanfilippo. Though we have found strength in them as well, what we have found more importantly is that they have already assembled an army of supporters to spread awareness and to advocate and fund research. This research, and there is much going on, is promising, but there is much, much more to go. So, it is with more than hope that we believe there will be a cure someday, for Oliver's sake and all of these other children with Sanfilippo. They are all just too special and giving for what they have been given.

We thank you for your time, and Oliver does, too.

Jennifer and Brian Kelly