CEO Update: Celebrating Rare Disease Day - A Conversation with MAGIC Foundation Co-Founder

March 3, 2022

Rare Disease Day, occurring each year on the last day of February, is a very special day for the rare disease community and for those of us privileged to work with organizations supporting those affected by rare disorders. At Lumos Pharma, we are currently focused on pediatric growth hormone deficiency (PGHD), one such rare disorder, and are honored to collaborate with the MAGIC Foundation, an organization that provides educational services and assistance to individuals living with growth disorders. We recently hosted Teresa Tucker, co-founder of the MAGIC Foundation, for an internal Town Hall discussion of PGHD and wanted to share insights from that conversation. Teresa's personal experience with a child with PGHD was truly inspiring and was what motivated her to co-found MAGIC so that she could help other families facing the same challenges she did with her son. Through her own experience and her work with MAGIC, Teresa knows firsthand how important it is to get a child with growth hormone deficiency diagnosed and treated.

Teresa's story began when she noticed her son, her second-born child, wasn't growing at a normal rate. She sensed there was something off when she compared her son's growth pattern with her daughter's – her first-born – and noticed that her son was not growing as fast as her daughter at the same age. Her pediatrician recognized the growth deficit, but, unfortunately, that didn't register with the pediatric endocrinologist she was referred to. This was 1986 – a time when parents might have even been blamed for their children's growth deficiencies, as happened with Teresa and her son.

While it took incredible persistence on Teresa's part, Teresa's son was ultimately diagnosed with PGHD, received treatment, and reached his predicted mid-parental height as an adult. Teresa co-founded MAGIC Foundation to ensure others would not experience the same challenges she faced getting an accurate diagnosis and treatment for this condition. Now, over 30 years after Teresa's experience, because of MAGIC, families have the support to press for a PGHD diagnosis and get treatment.

That said, the standard-of-care for children with growth hormone deficiency has been the same for 35 years, consisting of a daily injection of recombinant human growth hormone (rhGH) administered over an average of 7 years. When we asked how MAGIC families were viewing a recently approved once-weekly injectable and the potential for an oral therapy offered by Lumos Pharma, Teresa responded with enthusiasm. She indicated that the PGHD community was pleased to potentially have a number of different therapeutic options from which to choose. Teresa also noted that this community was excited to learn about the current clinical development of a potential oral therapy and indicated that there were those who had expressed interest in entering Lumos Pharma's OraGrowtH trials. She also acknowledged that having an oral therapeutic option could bring into the fold numerous children who could not, or would not, tolerate an injectable solution and, thereby, potentially increase the number of children with PGHD who would actually seek and receive treatment.

Our Lumos Pharma team was pleased to get Teresa's perspective on the challenges faced by the PGHD community and their search for support and solutions to address this condition. Her own experience and her portrayal of other families going through similar processes for diagnosis and treatment were enlightening. It is stories such as these that motivate Lumos Pharma to seek novel therapies for rare disorders such as PGHD, and we are thrilled to support the MAGIC Foundation and Rare Disease Day in an effort to raise awareness of rare disorders and improve the lives of those affected by these conditions.