Carter Alfson

Carter Alfson was diagnosed with Congenital Myasthenic Syndrome (CMS) when he was just 4 ½ years old. Like myasthenia gravis (MG), CMS is characterized by weakness and fatigue resulting from problems at the neuromuscular junction but, while MG is typically an acquired autoimmune disease, CMS is inherited.

There are many types of CMS. Depending on the type, symptoms may vary from mild to severe, but generally include weakness, fatigue and ptosis (droopy eyelids). The earlier the onset of CMS, the more severe the symptoms are likely to be.

"Carter has had a hard life, to put it mildly," said his mother, Kristian Alfson. Now seven years old, Carter has endured numerous hospital visits and many stays, and has been on a ventilator 12 times in his young lifetime."

Having gone the majority of his life undiagnosed, Carter suffered greatly – he was not able to walk, play or reach the same early milestones that children typically do.

With the help of his treatments, Carter now enjoys running, playing, swinging, and swimming, though he must be extra cautious since his bones and muscles aren't as strong as most other kids' are.

"Once Carter was finally able to start walking, life for us was completely different," Kristian said. "At the time, I was doing almost everything for him – I carried him almost everywhere and I fed him, sending him to school on baby food because he couldn't chew adequately. It was so wonderful to see this newfound strength that I'd always wished he would have!"

Although Carter's mother never thought she'd see her son walk, she now hopes that he might play a sport someday. Carter's first goal, however, is to make it one year ventilator-free.

"I've raised Carter to not know that he has a disability, pushing for him to be as independent as possible," his mother said. "I try my hardest to be his rock, but really, he's mine."

To learn more about how you can help create a world without MG, visit http://www.myasthenia.org/Howcanlhelp.aspx.