



Leonard Family

My name is Stephanie Leonard, and I have two sons, Ames and Asher. When they were babies, we started noticing they were delayed with milestones and didn't take their first steps until after their second birthday. After countless hours of research, physical therapy, doctor appointments, MRIs, and genetic testing we finally received our answer as to why Ames and Asher were struggling.

On February 11, 2016 our lives changed forever. Ames and Asher were diagnosed with Spinocerebellar Ataxia (SCA) at the age three. It was heartbreaking. SCA is a rare, neurodegenerative disease causing poor coordination and balance (ataxia), difficulties with speech, swallowing and cognitive impairment as well as tremors and sometimes seizures. Sadly there is no cure, and it is often fatal.

Due to the Ataxia, Ames and Asher struggle with weakening of their legs and are currently wearing orthotics to help with balance, using walkers for stability for short distances and a wheelchair for longer. The twins also have difficulties with coordination of their hands, making it hard to achieve daily tasks such as eating with utensils, buttoning their clothes, and writing. Each day presents new challenges to overcome, but we have found much comfort through the special friendships we've established with other members of the National Ataxia Foundation, and we proudly call them our forever family.

Although this terrible disease has consumed our thoughts, filled our calendars with therapy and doctor appointments, and diminished our bank accounts, we strive to give Ames and Asher the most comfortable and normal life possible. We feel incredibly blessed to be the parents of such sweet boys who continue to amaze us with their social friendliness and eager playfulness. Over time we have shifted our focus to appreciate all that Ames and Asher can achieve daily rather than focusing solely on their limitations.

If we could offer any advice to others facing the same struggles, it would be this:

“Life is not easy. We have to view our struggles as a tool to make us stronger, accept the unaccepted, hope for the impossible, see beauty in everything, be thankful for every single thing around us, never back down from our passions, pray, believe, and have faith. We are the authors to our story and how we choose to write it.”

After reflecting on the year we have had, one thing is certain... We want Ames and Asher's story to have a beautiful ending. Today we are choosing to take baby steps through our challenged moments of heartbreak, and continuing to find joy in life as we journey through it.