MPS II & YOU
PATIENT STORIES

The stories that feature below may not be typical of all people who have Hunter syndrome. There is a range of severity associated with Hunter syndrome and symptoms can manifest differently depending on the severity of the disease.

Told by Toni-Ann, mother of Aiden and AJ

Told by Natalie, mother of Silas

Birth and first symptoms

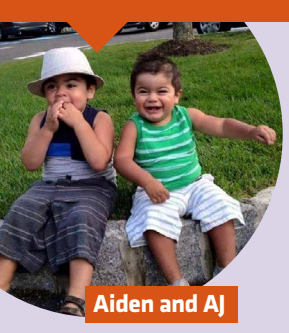

Aiden, age 1

"He had frequent ear infections, which we were told are typical for this age. He had his adenoids removed but he was still a happy baby, then 18 months later, I had AJ. He loved playing with his younger brother; they did everything together."


Natalie and Silas

"My husband and I felt like the luckiest people on earth when we held our little boy for the first time. However, around the age of 6 months, we noticed that the back of Silas's head was becoming flatter and that he had difficulties holding his head up. He also didn't like being laid down on his stomach."

First mention of an underlying disease


Aiden and AJ

"At the age of 2, I noticed a delay in Aiden's speech development. I mentioned it to his pediatrician and he was referred for an assessment. They confirmed that he needed occupational therapy, physiotherapy, and speech therapy. We figured he was a boy; he was being lazy, no big deal. After a year, his pediatrician suggested that we see a geneticist."


Silas, 6 months

"At the age of 1, Silas became ill with a severe cold, high temperature, and obstructive bronchitis. A doctor asked us if Silas's head circumference had been checked because he thought his head was unusually large, which upset me. To me, our little boy was perfect and yes, he had a big head, but Silas was a big child."

Finding an answer


Aiden and AJ

"By this time, his brother, AJ was about 12 months old; Aiden was 3 years old. AJ came with us to the appointment because we didn't have a babysitter.

As soon as we sat down, the geneticist started pointing out all the things that she noticed about Aiden; that the tips of his fingers were bent, the bridge of his nose was flat, and he was hairy. She then turned to my other son, the baby, AJ, and said that she could tell that he had the same symptoms.

She suspected MPS II… It was very difficult to hear. I told myself that she was wrong but, when we got home, I saw pictures of other boys with MPS II, and they were my boys."


Silas, age 2

"When he was 2, our little boy had an MRI scan. I was sitting on the hospital bed with Silas on my lap reading through his favorite book when the door opened. I looked at the expressions of the two doctors and immediately knew that something was wrong.

The consultant told us that the MRI showed an abnormality that might be a symptom of a rare disease called mucopolysaccharidosis. I was completely paralyzed. I couldn't even cry.

We had to wait a month for the blood test results to confirm that Silas had Hunter syndrome. It's hard when you think your child is healthy and then you are told you've got a really, really sick child who could die. It was horrible. It is still horrible."

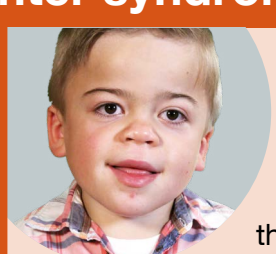
Living with Hunter syndrome


Aiden, Toni-Ann, and AJ

"They love to play, they are very social. They have a special bond, and I think it's because everything they go through, they go through together.

Our boys have taught us a lot. You know, they may not be able to speak much, but they've changed us as people for sure.

I see everything that they have to go through, day after day, and they do it all with a smile, a giggle, and a laugh."


Silas, age 6

"While Silas has a lot of fun at kindergarten, the downside is that he is exposed to illnesses from the other children at school, and, of course, he always catches them. It was also hard to find a nursery and school that could take him, due to his learning difficulties. He's almost like a baby as he doesn't speak more than a few words.

There is also little interaction from him; we cannot play together in the same way that you can with healthy children. We have to ensure that all doors are locked, because he'll just run out if they are open. We have to close every cupboard, because he might play with something sharp and injure himself or his friends. These are problems we face in our everyday life."

Hunter syndrome: MPS II & You

Our MPS II & You Facebook page aims to provide a safe space for people whose lives have been touched by Hunter syndrome.

We understand that everyone's Hunter Syndrome journey is unique, and we realize how important it is to be surrounded by a supportive community. We hope this platform will enable members of the community to connect, share their stories, and stand united.

"The support has been amazing to say the least. The support is from everywhere; our whole community knows the boys…It's just all positive, happy, hope, that's all we've got."


Toni-Ann, mother of Aiden and AJ

Championing those whose lives have been touched by Hunter syndrome

For more information and resources, speak to your doctor and visit **hunterpatients.com**