ARE YOU MISSING HUNTER SYNDROME?

ACT EARLY*
HUNTER SYNDROME IS A PROGRESSIVE GENETIC DISEASE

*Consider the importance of early assessment, diagnosis, and follow-up by a specialist

A **rare combination** of common childhood complaints could indicate **Hunter syndrome (MPS II)**

Age 1-2 years

78% of HOS patients developed an **abdominal hernia**[1]

72% of HOS patients had **otitis media**[2]

Age 2-3 years

68% of HOS patients had enlarged **tonsils** or **adenoids**[1]

95% of HOS patients were described as having **facial dysmorphism**[1]

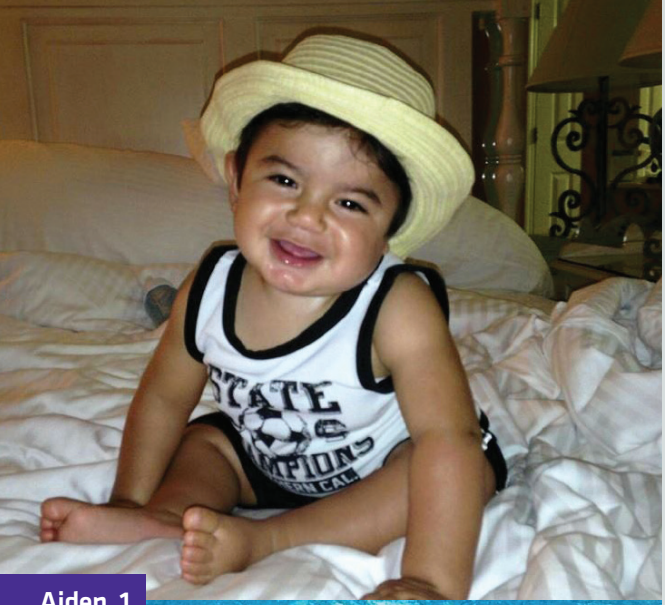
REFER TO A SPECIALIST TODAY

For more information, visit:

Huntersyndrome.info

MPS II = mucopolysaccharidosis type II

Median age of onset and prevalence data from HOS (Hunter Outcome Survey). 1. Wraith JE **et al**. Genet Med 2008; 10(7): 508–516. 2. Keilmann A **et al**. J Inherit Metab Dis 2012; 35(2): 343–353.



Aiden, 1

Birth and first symptoms

"Aiden was a beautiful healthy baby boy. He suffered frequent **ear infections** but our paediatrician told us they were "just typical." At the age of **18 months** old, around the time his brother, AJ, was born, he had his **adenoids removed** but he was still a happy baby. He loved playing with his younger brother; they did everything together."

First mention of an underlying disease

"At the age of 2, I noticed a delay in Aiden's speech development. I mentioned it to his paediatrician 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 paediatrician suggested that we see a geneticist."

"He suffered frequent ear infections but our paediatrician told us they were "just typical."

Hunter syndrome diagnosis

“By this time, his brother, AJ, was about 12 months old; Aiden was 2 and a half. 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 were wrong with Aiden; that the tips of his fingers were bent, the bridge of his nose was flat, and that 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.”

Aiden and AJ

“The tips of his fingers were bent, the bridge of his nose was flat, and he was hairy.”

Current disease severity and life impact

“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.”

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