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.

Silas, 6 months

Birth and first symptoms

“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

“At the age of 1, Silas fell 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.”

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Hunter syndrome diagnosis

“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 favourite 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 paralysed. 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.”

Silas, 2

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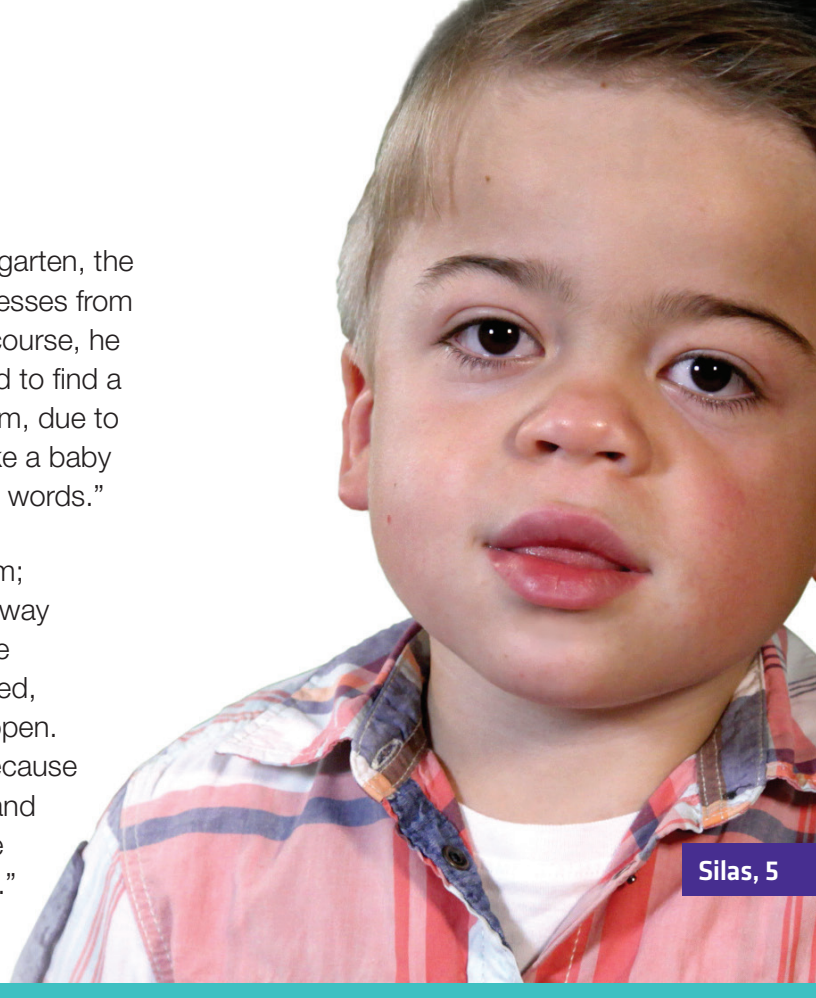
Current disease severity and life impact

"Whilst 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."



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