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 HOS = Hunter Outcome Survey

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. 3. Burton BK, Giugliani R. Eur J Pediatr 2012; 171(4): 631-639

2.5 months

Age 1.5

Age 2

Birth and first symptoms

“At the age of one Leander was diagnosed with hydrocephalus and had to be operated on, fast. So he had a shunt implanted. After that, his development advanced; we were very lucky.”

First mention of an underlying disease

“At the age of 2, we remarked that he was not very well. Leander’s hearing was poor. There was no diagnosis and we wondered what was wrong. We went to some doctors, but they didn’t have any answers.”

“Leander’s hearing was poor. We went to some doctors, but they didn’t have any answers.”

Hunter syndrome diagnosis

“At the age of 3, they said he’s got Hunter syndrome. I felt very depressed, very sad.

First, you look on the internet. The doctors couldn’t explain much to us. They didn’t know the problems: they sent us to a special hospital, a hospital with special doctors to explain it.”

Current disease severity and life impact

“We cannot do anything together. We have an eight year old daughter, but she cannot play with her brother, and the family cannot do anything together. We cannot go on holidays, we cannot go to the cinema together, we cannot play together. So it’s a very hard life.

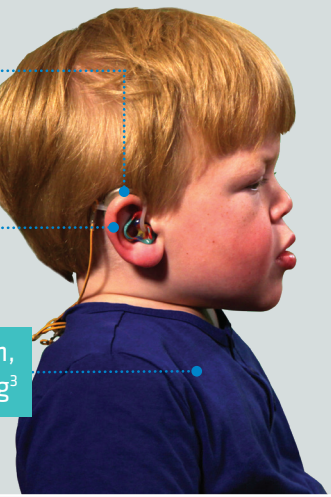
But my advice would be to enjoy life, enjoy the moments you have together, enjoy that you have got a son, just enjoy it.”

Age 3

Age 5

“Enjoy the moments you have together, enjoy that you have got a son, just enjoy it.”

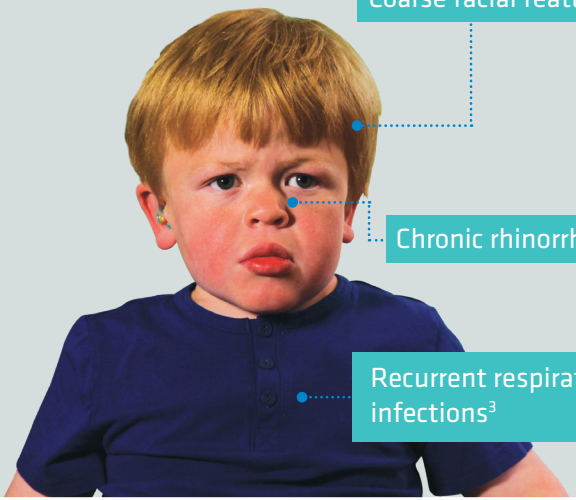
Red flag symptoms of Hunter syndrome



Hearing loss[3]

Recurrent otitis media[3]

Upper airway restriction, noisy breathing, snoring[3]



Coarse facial features[3]

Chronic rhinorrhoea[3]

Recurrent respiratory infections[3]

Hepatomegaly[3]

Umbilical and inguinal hernias[3]

Joint stiffness[3]

Developmental delay and/or speech delay[3]

Heart murmur[3]

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