Newsbites

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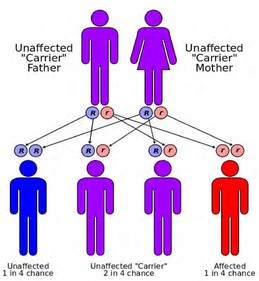
A closer look at Hurler Syndrome

Definition :
Hurler syndrome is an inherited disease of metabolism in which a person cannot break down long chains of sugar molecules called glycosaminoglycans (formerly called mucopolysaccharides).

Hurler syndrome (MPS I H) belongs to a group of diseases called mucopolysaccharidoses, or MPS. The other types of MPS include MPS I- HS (Hurler-Scheie Disease) and MPS I- S (Scheie Disease).

Incidence:
Incidence of MPS I-H has been reported to be 1:100,000 per child birth. There are no reports that suggest any correlation to a specific sex or ethnicity. (1)



Hurler Syndrome is an autosomal recessive disorder. Hence only a person born with two defective copies of the gene (IDUA) develops the sydrome.

Causes:
People suffering from Hurler syndrome are unable to produce an enzyme called Lysosomal alpha-L-iduronidase. This enzyme helps break down long chains of sugar molecules that are found throughout the body, often in mucus and in fluid around the joints. Without this, glycosaminoglycans build up and damage various organs, including the heart.

Symptoms:
Symptoms can range from mild to severe.
Common symptoms of Hurler syndrome include

- having a short stature
- mental retardation
- difficulty in breathing
- corneal clouding
- chronic runny nose

The symptoms typically appear between 6 months to 2 years of age. Children affected with this condition usually live past the age of 5 but unfortunately do not survive beyond 10 years of age.

Treatment:
Enzyme replacement therapy is done in order to provide alpha-L iduronidase (that is lacking) to the body. This is done through ingestion of medications like Laronidase (Aldurazyme). This medicine has shown to be effective in improving problems associated with breathing, growth, heart, bones and joints. However, enzyme replacement therapy is not yet advised for children who have MPS I with mental retardation like Scheie Syndrome and Hurler-Scheie Syndrome.

Bone marrow transplant is another treatment option for people suffering from Hurler Syndrome.

Treatment using cord blood stem cells:
Haematopoietic stem cell transplants have become a valuable treatment for Hurler Syndrome, as transplanted cells can generate new, healthy, enzyme producing blood cells to replace the diseased cells. These donor cells will deliver enzymes to all organs, including the brain and can prevent disease progression. Cord blood stem cells have been effectively used to treat children with the syndrome. These cells may increase the levels of Lysosomal alpha-L-iduronidase, which consequently may allow them to live longer with fewer complications.

A research report published by Blood Journal compares the treatment of Hurler Syndrome with bone marrow stem cells and cord blood stem cells. While the survival rate in both cases were almost the same, the study found that the highest rates of event free survival occurred in patients receiving transplants from matched sibling cells or fully matched unrelated umbilical cord blood (both had 81% event free survival). (2) The press release issued by the organisation even goes to state that umbilical cord blood transplants may be the effective alternative to matched donor stem cells. (3)

References:

(1) http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3341767/

(2) http://bloodjournal.hematologylibrary.org/content/early/2013/03/13/blood-2012-09-455238

(3) http://www.prnewswire.com/news-releases/cord-blood-transplants-may-be-an-effective-alternative-to-matched-donor-stem-cells-for-children-with-rare-metabolic-disorder-197981631.html

Mother Care Forum: Coming Soon

After receiving an overwhelming response from Ahmedabad, Mother Care Forum is now all set to entertain the mothers-to-be of Surat and Mumbai.

Mother Care Forum
Ante-natal Care Program

Sail through the journey of pregnancy with fun learning sessions!
Diet & nutrition, infant care, belly dancing for pregnant women and much more.

Surat : 13th July, 2014 **Mumbai : 3rd August, 2014**

To know more contact us now!

Events

Soon-to-be mommies enjoying interactive Mummy & Tummy sessions across various cities.


Hyderabad


Mumbai


Pune

Why parents choose Babycell

"After learning about the life-saving properties of stem cells, we could not miss this one time opportunity to secure our baby's life by preserving her stem cells. We are glad that we found Babycell !!!! There are several positive factors that made our decision easier, one of which is the security of their lab location at Lonavla, Maharashtra. We were profoundly impressed to see the laboratory infrastructure and the processing technology. They also provide some exciting value added services. Overall it was a great experience and we will definitely recommend it to all our friends and loved ones."

Mr. Pravin Raj Purohit & Mrs. Shalu Purohit, Mumbai