



Photo Opportunity

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First Clinical Trial in the U.S. Studies Babies with Rare Disorder *Children's Hospital Oakland, first and only hospital in the country conducting MPS infant drug study*

MPS Awareness Day
Thursday, May 15, 2008, 10:30am-11:30am
Children's Hospital Oakland Research Institute (CHORI)
5700 Martin Luther King Jr. Way (park in gated lot off Aileen St.)
Oakland, CA

May 12, 2008 (Oakland, CA) – Children's Hospital & Research Center Oakland is the first and only hospital in the nation conducting a clinical drug trial aimed at helping infants reduce symptoms linked to a rare disease called MPS VI (also known as Maroteaux-Lamy syndrome). This devastating disorder stunts growth, limits movement, and causes severe airway problems that can lead to early death. The hospital will host International MPS Awareness Day at its research institute.

The National MPS Society, in partnership with biopharmaceutical companies BioMarin, Genzyme and Shire Human Genetic Therapies will mark this special day with events for patients, families and the medical community at two venues: at Children's Hospital Oakland Research Institute (CHORI) in Oakland, CA and at the North Carolina General Assembly Legislative Building in Raleigh, NC.

MPS affects 1 in 25,000 children. The genetic disorder occurs when the body is unable to produce a specific enzyme that breaks down a complex sugar called a glycosaminoglycan. There are seven MPS diseases, MPS I, MPS II, MPS III, MPS IV, MPS VI, MPS VII, and MPS IX. MPS VI affects about 1 in 300,000 people. Many MPS VI patients die from disease-related complications between childhood and early adulthood.

There is no cure, but treatments such as recombinant DNA derived enzyme replacement therapy are available to treat three of the MPS diseases— MPS I (Hurler, or Hurler-Scheie syndrome), MPS II (Hunter syndrome) and MPS VI (Maroteaux-Lamy syndrome). However, it is devastating to know that there are still many families around the country who are unaware that treatment, and in turn, hope, exists. Additional details can be found here: http://www.mpsociety.org/content/4185/MPS_Awareness_Day_2008/

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