

**For immediate release—
June 11, 2011**

The Climb, Jump, and Race for a Cure: Eleven-year-old with Glycogen Storage Disease Leads Extraordinary Fundraising Challenge

A child's outdoor stunt marathon helps fund Duke's research on gene therapy treatment for Glycogen Storage Disease.

Charlotte, NC – Christopher Chapman, an eleven-year-old with Glycogen Storage Disease type Ia (GSD-Ia), will go to great lengths (and spectacular heights) on Saturday June 11th to raise money for a gene therapy cure for the disease--an effort led by Duke physician and researcher, Dr. Dwight Koeberl. Starting at 8:30am at the U.S. National Whitewater Center in Charlotte, North Carolina, Christopher will ride a mountain bike for 3.5 miles, climb a 46-foot rock wall, fly on a 1,123-foot long mega zip-line, climb 32 feet to an 100-foot long zip-line, free fall from a 46-foot “Mega Jump” tower, cross high ropes and bridges on an aerial obstacle course, traverse a canyon and ride a whitewater raft...all in one day!

All of this from a young man who is fed liquid cornstarch through a tube every four hours to manage his life-threatening disease. Christopher was born with Glycogen Storage Disease type Ia, which means he does not produce the liver enzyme that stores and releases glucose, the sugar that all cells use for energy. By ingesting cornstarch and avoiding dietary sugar, Christopher is able to regulate his glucose levels and prevent serious complications of low blood sugar levels such as seizures and organ damage.

Unfortunately, this feeding treatment and special diet does not prevent the eventual liver damage that results from the missing enzyme, and many adults with the disease develop liver and kidney failure or liver cancer. The disease can also be fatal.

Still, there is hope. A gene therapy developed at Duke could give liver cells the correct genetic code for manufacturing the enzyme. In other words, Christopher, and others suffering from the disease, would not have to eat cornstarch every four hours for the rest of their lives.

Dwight Koeberl, MD, PhD, is the lead author of this study, and is an Associate Professor in the Department of Pediatrics at Duke Children's Hospital & Health Center where at least 100 patients are being treated for the disease. His research involves creating a virus that transfers the enzyme genes into liver cells. This gene therapy treatment replaces the missing enzyme in the liver of animals with the disease to fully normal levels and regulated blood glucose levels for up to a year. According to Koeberl, “the success of the new treatment...is a step toward developing a curative therapy for our patients...the key is finding funding.” Due to the rarity of this disease, there has been very little support from governmental or pharmaceutical sources. So, Christopher and his family decided to take on the fundraising challenge themselves.

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Christopher's plan for a day-long marathon of stunts and extreme outdoor activities aims to prove that this disease does not slow him down and that he would do just about anything to raise money for a cure.

At this point, Christopher and his family have raised nearly \$7,500 toward a cure for GSD. Now, Christopher is asking the community to join him on June 11 to help meet his goal of \$10,000. *If he reaches this goal, Christopher's aunt and uncle will match that amount dollar for dollar.* You can support his effort and learn more at: http://www.dukechildrens.org/about_us/newsroom/christopher_chapman_challenge.

For more information about the event, contact Robyn Soffera, Director of Annual Programs and Communications at the Duke Children's Office of Development by phone: (919) 385-3141 or by email: Robyn.soffera@duke.edu.

The on-site contact, Mary Chapman, can be reached by phone: (704) 787-8999.

About Duke Children's Hospital & Health Center:

Duke Children's Hospital & Health Center, located in Durham, N.C., is nationally ranked among the best in pediatric health care programs. Caring for children is our number one priority, from routine check-ups and immunizations to the treatment of life-threatening injuries and illnesses. At Duke Children's, we provide hope and the most advanced health care available. Offering innovative procedures including stem cell and bone marrow transplants as well as a variety of support services for our patients and their families, Duke Children's cares for children from around the world. We are also a critical local resource - taking care of 60 percent of Durham's children with more than 70 percent of patients coming from central North Carolina. For more information please visit www.dukechildrens.org.

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