



The Penn Medicine Orphan Disease Center (ODC) will host the 5th Annual Million Dollar Bike Ride on Sunday, May 20th, 2018 to raise money for rare disease research. The Million Dollar Bike Ride brings over 500 cyclists and volunteers to Penn's campus to ride either 13, 34, or 72 miles starting in the city, and ranging across the Greater Philadelphia region. In four years, the MDBR's 25+ teams have raised over \$6.4 million to fund research grants on the diseases they represent. The ODC ensures that 100% of the funds raised goes towards these pilot grants, with no overhead taken out.

The Penn Medicine Orphan Disease Center (ODC) was established to promote the development of therapies across a broad range of orphan diseases. Each of these diseases by definition is rare but collectively represents a substantial health care burden. Most orphan diseases manifest in children with premature mortality and/or significant disability and little is available in terms of treatments. In order to assemble a critical mass of intellectual and patient resources for any one disease, the ODC will reach beyond the borders of Penn and promote inter-institutional collaborations/partnerships. The ODC will develop transformative therapies using platform technologies that can be deployed across multiple rare diseases. We will emphasize disorders with substantial unmet need independent of their incidence and will strive to assure access to patients of all populations.

All funds raised by Disease Teams through pledges are used by the ODC to expand the scope and depth of the MDBR pilot grant program. Following the event, a Request for Application (RFA) will be broadly distributed to the international scientific community requesting pilot grant applications to study diseases for which designated money has been raised. The ODC is securing philanthropic and corporate donations that will be used to match dollar-for-dollar money raised by the cycling participants. Scientific leadership of the ODC and its extramural advisors will review the applications and make awards to those of the highest scientific merit which address the specific topics outlined in the RFA. The ODC will disperse the money to grantees and manage progress of the science and spending on the award.

To make a contribution on behalf of the MSUD Team and Scott Foster, visit the University of Pennsylvania Giving Page (see: <http://givingpages.upenn.edu/cureMSUD>).

2018 Million Dollar Bike Ride For MSUD



Remembering Scott Foster

Scott Foster, the son of Herb and Diane Foster was born in 1971. He was the first person born in Massachusetts to be diagnosed with Maple Syrup Urine Disease (MSUD) by the state's newborn screening program. Scott's first two years were very difficult. He was a frequent patient in the hospital, requiring visits every week or so. He became very sick and was hospitalized for nearly two months before recovering and going home.

For the next 20 years Scott did very well leading as normal a life as possible for a person with MSUD. He loved sports of all kinds, played baseball, was an excellent bowler and also worked at the family bowling business. After graduating from high school Scott attended the local community college, coming within a course of completing his Associates degree--a remarkable achievement for an individual with MSUD. Following in his dad's footsteps he interned at the Metropolitan Boston Transit Authority and was hired as a motorman on the red line. This was a great responsibility carrying thousands of passengers every week. He was so proud to be working for the MBTA. He also had a steady girlfriend and looked forward to his future.

After a brief illness, Scott succumbed to complications of MSUD and passed away when just 22 years old. He was a very caring person who would go out of his way to help someone in need. He is greatly missed by his family and all those who knew him. But in some important ways, his spirit lives on.

Scott's younger sister, Katie also has MSUD. Katie has survived this incurable disease, has grown and now has two children of her own. She is also a school teacher and teaches children with special needs.

To make a contribution on behalf of the MSUD Team and Scott Foster, visit the University of Pennsylvania Giving Page (see: <http://givingpages.upenn.edu/cureMSUD>). If you would like to register as a bike rider in the Million Dollar Bike ride, see:

https://www.alumni.upenn.edu/s/1587/gid2/wide_simple.aspx?sid=1587&pgid=16765&gid=2&cid=38198&ecid=38198&post_id=0 .