



FASTER TRACK

2009 IN REVIEW

During the Holiday Season more than ever, our thoughts turn gratefully to those who have made our progress possible. And in this spirit we say, simply but sincerely Thank You and Best Wishes for the Holiday Season and Happy New Year.

The end of the year is just the beginning: We are pressing forward to improve access to treatments for patients with the rarest disorders

After a few years of ruminating over the growing problems that slowed or prevented the development of treatments for the rarest of diseases, this is the year I decided I needed to do something about it. Naive and optimistic, there is no other way to conceive tackling what many think is an impossible task: reforming development for rare disease treatments. In the nearly 12 months from the time I sat in a coffee house with John Ditton, now our COO, and told him about the foundation and the need to change the world in this way, we have bolted out into the open and are driving a new agenda around improving how rare disease treatments get developed. People have heard us, and the discussion is beginning. **Read more on Emil's blog at <http://www.kakkis.org/blogs/>**

Legends of Golf Tournament

Don't miss this great opportunity to golf, network and relax before the start of the JP Morgan Health Conference. The Kakkis EveryLife Foundation, along with the Children's Rare Disease Network, the National MPS Society and the Ryan Foundation are co-hosting the Inaugural Legends of Golf Tournament. The Golf Tournament will be held at the **Presidio Golf Course in San Francisco on Sunday January 10, 2010**. Don't golf? Join us for wine tasting, some humor and a great meal. For more information go to <http://www.kakkis.org/golf/>

Dr. Emil Kakkis and Dr. Jenny Soriano complete \$1 million pledge to the MPS Society

In 2006, Drs. Emil Kakkis and his wife, Jenny Soriano pledged \$1 million dollars to the National MPS Society's Endowment Fund. The donation was scheduled to be given over five years; Drs. Kakkis and Soriano completed their pledge in December, 2009, one year earlier than scheduled. To read more go to http://www.mpsociety.org/content/4132/National_MPS_Society_News/

The EveryLife Art Contest — December 31st 2009 Deadline Approaching

Last chance to submit your art. The EveryLife Art Contest is open to all artists affected by a rare disease ages 5 and older. Artists may have a rare or undiagnosed disease or may be close friends, family members, or care takers of those with a rare or undiagnosed disease. Grand Prizes will be awarded in each of the 3 age categories: Children 5-11, Teens 12-17, & Adults 18+. [Employees or Board Members of the Kakkis EveryLife Foundation or their immediate family members are not eligible to participate.] To find out more information on the prizes and how to enter, please visit <http://www.kakkis.org/Contest/Contest.aspx> or email info@kakkis.org. Winners will be announced on Rare Disease Day, February 28, 2010.

FASTER TRACK to CURETHEPROCESS™

Through our newsletters, we hoped to have kept you informed of our efforts to get treatment development for orphan diseases back on the *fast track* through science-based regulatory reform. We encourage your questions, input and involvement on our mission to CURETHEPROCESS. Please email us at info@curetheprocess.org or call us directly at 415-884-0223 to see how you can help.