



**RARE
DISEASE
DAY**

29 February 2012

FIFTH INTERNATIONAL RARE DISEASE DAY WEDNESDAY 29 FEBRUARY 2012

Wednesday 29 February is International Rare Disease Day. It is an exciting opportunity for ISMRD to bring attention to our cause and to raise funds.

There are lots of things happening around the world on this fifth International Rare Disease Day. Have a look at the following websites:

- **(US) National Organization for Rare disorders (NORD)** <http://rarediseaseday.us/>
- **(US) Federal Drug Administration (FDA)**
<http://www.fda.gov/ForIndustry/DevelopingProductsforRareDiseasesConditions/OOPDNewsArchive/ucm277194.htm>
- **The Global Genes Project for Rare Disease** <http://www.globalgenesproject.org/>
- **Rare Diseases Europe (EURORDIS)** www.rarediseaseday.org

Here are some things you could do to raise awareness of and funds for ISMRD:

- hold a raffle
- host a morning tea
- hold a lemonade stand
- ask your friends, colleagues, family to make a donation to ISMRD
- write a letter to the editor of your local paper, submit a press release or share information with your online network. NORD has created a press kit you can use. See <http://rarediseaseday.us/take-action-now/press-kit/>
- ask the biology teacher at your local high school to present a 1-3 biology curriculum developed by NORD specifically for Rare Disease Day. Go to <http://rarediseaseday.us/take-action-now/in-school-activities/> At this site there is also a program developed by the US National Institute of Health for school years 6-8, and other school activities relating to International Rare Diseases Day

Other Fun Things to do

- Purchase a Rare Diseases Day T-shirt or baseball cap or other merchandise at <http://www.cafepress.com/rarediseases>

- For those in the US, take part in the Hands across America photo display. There is an XBOX 360 Elite Bundle to win!

**Let's all get involved and promote awareness of our
Glycoprotein Storage Disorders!**

