



# Rare Disease Day

## 28 February & 1 March 2013

Patients and Researchers, Partners for Life!

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### Rare Disease Day at NIH (RDD@NIH)

On February 28, and March 1, 2013, the National Institutes of Health (NIH) celebrated the sixth annual Rare Disease Day with a 2-day-long celebration and recognition of the various rare diseases research activities supported by the NIH Office of Rare Diseases Research, the NIH Clinical Center, other NIH Institutes and Centers; the Food and Drug Administration's Office of Orphan Product Development; other Federal Government agencies; the National Organization for Rare Disorders; and the Genetic Alliance. Rare Disease Day at NIH (RDD@NIH) was held in the Natcher Auditorium (Building 45) from 8:30 a.m. to 5:00 p.m. on Thursday and from 8:30 a.m. to 4:00 p.m. on Friday. Attendance was free and open to the public.

In addition to the various scheduled talks ([see agenda](#)), there were posters and exhibits from many groups relevant to the rare diseases research community displayed. In association with the Global Genes Project, we again encouraged all attendees to wear their favorite pair of jeans.

The Rare Disease Day 2013 event can be viewed using the following links:

[Day 1 – Thursday, February 28](#)

[Day 2 – Friday, March 1](#)

To add the ORDR RDD widget to your Web site, copy and paste the following code:



**US Sponsor NORD**  
**Rare Disease Day**

**2.28.2014**

**Countdown:**

**59 · 08 · 54 · 51**

### About Rare Disease Day

Rare Disease Day was established to raise awareness with the public about rare diseases, the challenges encountered by those affected, the importance of research to develop diagnostics and treatments, and the impact of these diseases on patients' lives. The focus of Rare Disease Day 2010 was 'Patients and Researchers, Partners for Life!' and is aligned with ORDR's philosophy that researchers need to work closely with patients and patient advocacy groups to maximize chances for success. This philosophy has been put into practice in our very successful [Rare Diseases Clinical Research Network](#).

There are about 7000 rare diseases identified in the United States. About 80 percent of rare diseases are genetic in origin and it is estimated that about half of all rare diseases affect children. Rare diseases can be chronic, progressive, debilitating, disabling, severe and life-threatening. Information is often scarce and research is usually insufficient. People affected face challenges

such as delays in obtaining a diagnosis, misdiagnosis, psychological burden and lack of support services for the patient and family. The goals remain for rare disease patients to obtain the highest attainable standard of health and to be provided the resources required to overcome common obstacles in their lives.

By highlighting these issues, the NIH Office of Rare Diseases Research hopes to

- Raise awareness of rare diseases
- Strengthen the voice of patients and patient advocacy groups
- Give hope and information to patients
- Bring stakeholders closer together
- Coordinate policy actions within the United States and with other countries
- Inspire continued growth of the awareness of rare diseases
- Emphasize rare disease research and the search for new therapeutics
- Get equality in access to care and treatment

The first Rare Disease Day sponsored by EURORDIS was held in Europe on February 29, 2008. February 29th was chosen since it is a rare day and it is symbolic of rare diseases. 2009 was the first time that Rare Disease Day was observed in the U.S. In addition to 17 European countries participating in Rare Disease Day 2009, the United States was joined by Argentina, Australia, Canada, China, Colombia, and Taiwan in celebrating the first global Rare Disease Day. The National Organization for Rare Disorders serves as the coordinator of this activity in the United States.

### The Global Genes Project



Global Genes Project is a leading rare and genetic disease patient advocacy organization led by Team RARE (Rare advocacy, Awareness, Research, Education) and promotes the needs of the rare and genetic disease community under a unifying symbol of hope – the Blue Denim Genes Ribbon™.

What began as a grassroots movement in 2009 to use the simple concept of "jeans and genes" to increase awareness for rare and genetic disorders has grown to over 400 global organizations. Their mission is centered on increasing rare disease awareness, public and physician education, building community through social media and supporting research initiatives to find treatments and cures for rare and genetic diseases.

Global Genes organizes a Wear That You Care™ awareness campaign on World Rare Disease Day where supporters wear the Genes Ribbon™ and their favorite pair of jeans to show support for people fighting rare and genetic diseases. They encourage patients and family advocates to share their stories through social media via creative photo campaigns and blog articles. In 2013, the organization will launch a Twitter campaign with the hashtags #careaboutrare and #wearthatyoucare.

For more information on how to receive Blue Denim Genes Ribbons™ and how to participate in the Wear That You Care™ campaign, visit <http://globalgenes.org/world-rare-disease-day/>.

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