



Rare Disease Day

February 28, 2009

Raising awareness of rare diseases and
the need for safe, effective treatments

- [The NIH Office of Rare Diseases Research](#)
- [Rare Disease Day Poster \(PDF, 10MB\)](#)
- [National Organization for Rare Disorders](#)
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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 2009 is "Patient Centered Care" and is dedicated to improving the quality of life of all people living with rare diseases, including access to appropriate diagnoses and care.

There are about 7000 rare diseases identified in the United States. About 80% of rare diseases are genetic in origin and about 75% 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 last year in Europe on February 29, 2008. February 29th was chosen since it is a rare day and it is symbolic of rare diseases. This year is the first time that Rare Disease Day will be observed in the U.S. The National Organization for Rare Disorders is serving as the coordinator of this activity in the United States. The hope is that this will become an annual global event on the last day of February. In addition to 17 European countries participating in Rare Disease Day, the United States is joined by Argentina, Australia, Canada, China, Columbia, and Taiwan in celebrating Rare Disease Day 2009.

Progeria Briefing

Timed to correspond with the celebration of Rare Disease Day 2009, the Coalition for the Life Sciences is hosting a briefing of the Congressional Biomedical Research Caucus on "Children Aging Before Their Time: Can Progeria Now Be Treated?" The Congressional Biomedical Research Caucus provides a forum where members and staff can interact directly with preeminent researchers responsible for important scientific discoveries. For details, view the [progeria briefing - \(PDF, 37KB\)](#).

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