

## Powerful Patient 2009 week 10

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### Healthcare and the Stimulus Act

Joyce speaks with Mary Dunkle, VP for Communications at the National Organization for Rare Disorders (NORD), about Rare Disease Day and the Healthcare implications of the Stimulus Act of 2009.



This show marks the first one where we talk live calls from listeners! We hope that you will join us in a future show. The live show will be Thursdays at 3 pm Eastern time. The replays will continue to be available at <http://powerfulpatient.org> and by podcast.

Mary Dunkle joined Joyce as co-host in celebration of Rare Disease Day. Last year the European Organization for Rare Diseases (EURORDIS) chose February 29th (a rare date!) to celebrate all rare diseases. This year NORD joins with them to create a worldwide annual event on the last day of February.

Each of the rare diseases affects fewer than 250,000 people in the United States, less than 0.1% of the population. However, there are more than 7000 rare diseases. The experience of dealing with a rare disease is not rare -- nearly one person in ten is dealing with some rare disease.

Callers today shared some of their own experiences with getting a diagnosis and dealing with a rare disease -- the frustrations of having to hunt for a doctor familiar with the rare disease, or in fact training a doctor in what you need him or her to know about your disease. Managing a rare disease is not easy for the patient. But with patience, persistence, and the fellowship of others who are treading the same path, one can muddle through.

The National Organization for Rare Disorders helps to connect people who are facing the same disease with one another, so that they can form a support group and together help each other and make the pathway easier for the next person facing the same challenges.

The VHL Family Alliance has been a full member of NORD since 1993. For an organization to join NORD, there is a process of review of the organization's incorporation documents and business practices which is a great learning experience for any organization. Membership also brings the opportunity to work with a peer group of other rare disease organizations. While the particulars of the diseases differ widely, there

are a broad range of similar challenges -- getting a diagnosis, finding appropriate treatments, issues of finance and incorporation, website development and finding other families, and providing family support. Rare disease organizations have many more similarities than differences.

National Organization for Rare Disorders, <http://rarediseases.org>

European Organisation for Rare Diseases, <http://www.eurordis.org>

VHL Family Alliance (von Hippel-Lindau disease), <http://vhl.org>

People with all complex medical conditions and disabilities are watching closely the newly emerging legislation and programs around the American Recovery and Reinvestment Act of 2009, otherwise known as the Stimulus Bill. The bill itself has been passed by both houses of Congress and signed into law in February 2009. However, it will take the best part of the next year to develop the details for each of these programs, hold public review, and put programs into action.

The President has launched a website to provide public information on the timelines, opportunities for public comment, and schedules for implementation of the various programs.

<http://recovery.gov>