



Rare Disease Day

# Rare Disease Day 2014

Join MassBio, VHL Alliance, member companies, patient groups, patients and legislators to recognize Rare Disease Day.

**Friday, February 28th  
11 a.m.  
State House, Nurses Hall, Boston**

The last day of February has been designated as Rare Disease Day in Massachusetts to call attention to the public health issues associated with rare diseases, which affect nearly 30 million Americans and countless others around the world. Join us to recognize and raise awareness for the research being done in rare disease.

Speakers include:

**Sen. Karen Spilka**, Co-Chair, Biotech Caucus

**Former Boston Mayor Ray Flynn**, whose grandson has a rare physical disorder

**Pamela Gavin**, Chief Operating Officer, National Organization for Rare Disorders

**Katie Brandt**, Caregiver & Volunteer Coordinator, Association for Frontotemporal Degeneration

**Carmen Camacho**, Patient, Hermansky-Pudlak Syndrome Network Inc.

**Ilene Sussman**, Executive Director, VHL Alliance (Emcee)

Please join us to recognize Rare Disease Day and the research being done in Massachusetts to treat and cure rare disease. Together, we can raise awareness of rare disease.

**Alone we are rare. Together we are strong.**

*MassBio will coordinate visits to legislative offices for any patient, patient advocate, industry advocate or other stakeholder who would like to participate. If you are interested, please email [communications@massbio.org](mailto:communications@massbio.org).*

**Hosted by:**



## Supporting Organizations



## Other Rare Disease Day Events

### Hear O.U.R. Voice Art Project Reception

Join the Rare Disease United Foundation in historic Doric Hall at the Massachusetts State House and view art by rare disease patients and their loved ones. The Art Exhibit will be on display beginning February 24, 2014 and continue through the week, ending on February 28, 2014, World Rare Disease Day.

The reception will be held Friday, February 28<sup>th</sup> at noon in the Great Hall (2<sup>nd</sup> Floor).

### Agenda

- Welcome Rep. Paul Heroux
- Acknowledgments - Patricia Weltin, Rare Disease United Foundation
- Speaker - Sandi Carter Brown, Rare Disease United Foundation/patient advocate
- Speaker - Jenn McNary - Duchenne Muscular Dystrophy
- Speaker - Olivia Weltin
- Video Clips- Senator Warren
- Senator Markey
- Sarah Cooke

