



Rare Disease Day

Rare Disease Day 2015: Living with a Rare Disease

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

Monday, February 23rd
11 a.m.
State House, Great 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.

The complex nature of rare diseases, coupled with limited access to treatment and services, means that family members are often the primary source of solidarity, support and care for their loved ones. The Rare Disease Day 2015 theme **Living with a Rare Disease** pays tribute to the millions and millions of parents, siblings, grandparents, spouses, aunts, uncles, cousins, and friends whose daily lives are impacted and who are living **day-by-day, hand-in-hand** with rare disease patients.

Join us to recognize and raise awareness for rare disease and the research being done in Massachusetts to provide new treatments and cures.

Speakers include:

Chris Anselmo, Miyoshi Myopathy patient

Megan Duff, Neurofibromatosis type 1 patient

Lisa Cimino, mom of a Focal Segmental Glomerulosclerosis (FSGS) patient

Ilene Sussman, Executive Director, VHL Alliance (Emcee)

Pre-registration is not required, but is appreciated.

[Register online!](#)

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.

Hosted by:



Supporting Organizations

