



**RARE**  
**DISEASE**  
**DAY**®

**2012**  
**29 FEBRUARY**

**@ WHITEHEAD INSTITUTE**

In recognition of International Rare Disease Day, Whitehead Institute is hosting a special event on the evening of February 29th from 7:30-9:00 pm, featuring Whitehead's latest groundbreaking rare disease research and non-profit advocacy efforts in the Boston area.

Whitehead Institute scientists and world-renowned biologists Harvey Lodish, David Sabatini and Yaniv Erlich will discuss their research on the fundamental biological processes underlying various rare diseases, including Diamond Blackfan Anemia, Tuberous Sclerosis and Tay-Sachs. Following the presentations, partner organizations will each lead a breakout session to discuss the various challenges and opportunities they face in the advocacy and promotion of rare disease research.

Whitehead Institute is located at Nine Cambridge Center, Cambridge, MA 02142.

Register for the event online at [pulse.wi.mit.edu](http://pulse.wi.mit.edu) or contact Lauren Gilbert at (617) 258-5489 or [lgilbert@wi.mit.edu](mailto:lgilbert@wi.mit.edu).

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WHITEHEAD INSTITUTE | NINE CAMBRIDGE CENTER, CAMBRIDGE, MA 02142 | NEWS AND EVENTS AT [PULSE.WI.MIT.EDU](http://PULSE.WI.MIT.EDU)

HOST ORGANIZATION:



WHITEHEAD INSTITUTE

Whitehead Institute is a world-renowned research institution dedicated to improving human health through basic research. By fostering a deeply collaborative culture and enabling the pursuit of wildly creative research, Whitehead provides the ideal environment for paradigm-shifting scientific achievements. For over twenty-five years, Whitehead faculty have delivered breakthroughs that have transformed our understanding of biology and accelerated the treatment human disease.

PARTNER ORGANIZATIONS:



The mission of the Caring for Carcinoid Foundation (CFCF) is to discover cures for carcinoid cancer, pancreatic neuroendocrine cancer, and related neuroendocrine cancers. CFCF also works to eliminate the suffering of patients, families, and caregivers affected by neuroendocrine cancers. Since its inception, CFCF has awarded over six million dollars in research grants to leading scientists at renowned research institutions.



The Crohn's & Colitis Foundation of America (CCFA) is dedicated to finding a cure for Crohn's disease and ulcerative colitis and to improving the lives of children and adults affected by these diseases. Current research efforts focus on all aspects of these diseases, with dedicated interest in identifying genetic make-up and bio-markers to easily diagnosis, assist in the prediction of disease progression, as well as to be able apply the appropriate treatment.



The National Tay-Sachs & Allied Diseases Association (NTSAD) is one of the oldest patient advocacy groups in the country. They focus on funding research, supporting over 500 families and individuals worldwide, and raising awareness to prevent diseases like Tay-Sachs. Today, NTSAD is recognized as a leading non-profit patient group with a demonstrated commitment to service, science and support.



Progeria is a fatal, "rapid aging" disease that afflicts children, who die of heart disease at an average age of 13 years. Founded in 1999 by the Massachusetts parents of a child with Progeria, The Progeria Research Foundation (PRF) is the only non-profit organization solely dedicated to finding treatments and the cure for Progeria, and is realizing these goals at a remarkable pace.



The Tuberous Sclerosis Alliance (TS Alliance) is the only national voluntary health organization dedicated to finding a cure for the genetic disorder known as tuberous sclerosis complex (TSC). The TS Alliance's mission is to improve the quality of life for individuals and families affected by TSC through the sponsorship of research, the development of programs, support services and resource information, and the development and implementation of public and professional education programs.