



**NORD**  
National Organization for Rare Disorders

## **NORD Corporate Council**

### **Fall 2009 Meeting**

Wednesday, November 11

#### **Location**

Carnegie Endowment for International Peace Building  
The Root Room, Carnegie Conference Center  
1779 Massachusetts Avenue, NW  
Washington, DC

#### **Times**

Continental breakfast & registration will begin at 8:15 am.  
Sessions & presentations will run from 9:00 am until 4:30 pm.  
Reception & new DC office “open house” will follow until 7:00 pm.

#### **Meeting Registration**

Please RSVP to Jennifer Adkins at [jadkins@rarediseases.org](mailto:jadkins@rarediseases.org) or (202) 588-5700.

#### **Session Topics and Featured Speakers**

Welcome & Introduction

- Nancy Harris, Board of Directors, NORD
- Peter Saltonstall, President and CEO, NORD

Continued...

#### NORD Partners in Progress Summit and New Public Policy Priorities

- Wayne Pines, President, Regulatory Services & Health Care, APCO Worldwide (*Moderator*)
- Diane Dorman, Vice President, Public Policy, NORD
- Emil Kakkis, MD, PhD, President, Kakkis EveryLife Foundation
- Frank Sasinowski, JD, MPH, Partner, Hyman, Phelps & McNamara, PC

#### Industry Perspectives on Orphan Drug Development

- Steven Grossman, President, HPS Group, LLC (*Moderator*)
- Don Baker, PhD, Vice President, Quality Management, Baxter BioSciences
- Greg Brooks, Vice President, Global Strategic Marketing, New Technology, Allergan, Inc.
- Dr. Sylvie Gregoire, President, Shire Human Genetic Therapies

#### FDA Orphan Products Update and New Orphan Designation Workshops

- Timothy Coté, MD, MPH, Director, Office of Orphan Products Development, FDA

#### Rare Diseases Research at the National Institutes of Health

- Stephen Groft, PharmD, Director, Office of Rare Diseases Research, NIH

#### Translational Research and the NIH Therapeutics for Rare and Neglected Diseases Program

- Chris Austin, MD, Director, Chemical Genomics Center, NHGRI, NIH
- Melissa Ashlock, MD, Director, TRND Program, NHGRI, NIH

#### Investment Perspectives and Emerging-Company Issues

- Peter Saltonstall, President and CEO, NORD (*Moderator*)
- Dr. Sylvie Gregoire, President, Shire Human Genetic Therapies
- Patrick Lee, MD, MBA, Palo Alto Investors, LLC
- Steve Usdin, Senior Editor, BioCentury

#### Building Relationships with Empowered Patients and Rare Disease Day 2010

- Wendy White, Founder & President, Siren Interactive Corporation
- Mary Dunkle, Vice President, Communications, NORD

#### Closing Remarks

- Carolyn Asbury, PhD, Chair, Board of Directors, NORD

