



**NORD**  
National Organization for Rare Disorders

## **NORD Corporate Council**

### **Spring 2010 Meeting**

Tuesday, May 18

#### **Location**

The Liaison Hotel – Capitol Hill  
Metropolitan Room  
415 New Jersey Avenue, NW  
Washington, DC 20001

#### **Times**

Continental breakfast & registration will begin at 8:00 am  
Sessions & presentations will run from 9:00 am until 4:00 pm

#### **Meeting Registration**

Please RSVP to Audrey Ashley at [aashley@rarediseases.org](mailto:aashley@rarediseases.org) or 203-744-0100

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

Welcome & Introduction

- Peter Saltonstall, President and CEO, NORD

Orphan Products Update from FDA

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

A New Focus on Rare Diseases at Center for Drug Evaluation and Research (CDER)

- Anne Pariser, MD, Associate Director for Rare Diseases, Office of New Drugs, CDER, FDA

Continued...

#### The Center for Orphan Drug Research, University of Minnesota

- James Cloyd, PharmD, Director and Professor, Orphan Drug Development

#### NORD Focus Groups on Orphan Product Development

- Noah Pines, President, Gen Inc.

#### NIH-FDA Collaboration on Rare Diseases

- Wayne Pines, President, Regulatory Services & Health Care, APCO Worldwide (*Moderator*)
- Stephen Groft, PharmD, Director, Office of Rare Diseases Research, NIH
- Nisha Jain, MD, Chief, Clinical Review Branch, OBRR, CBER, FDA
- William Matthew, PhD, Director, Office of Translational Research, NINDS, NIH
- Anne Pariser, MD, Associate Director for Rare Diseases, CDER, FDA

#### Compassionate Allowances for Patients with Rare Diseases

- Nancy Schoenberg, Director, Office of Compassionate Allowances & Disability Outreach, SSA

#### Health Care Reform and the Rare Disease Community

- Jennifer Duck, Vice President, Pfizer Inc.
- Paul Kim, Partner, Foley Hoag
- Frank Sasinowski, Partner, Hyman, Phelps & McNamara

#### Updates from NORD

- Diane Dorman, Vice President, Public Policy
- Mary Dunkle, Vice President, Communications
- Maria Hardin, Vice President, Patient Services

#### Medunik Canada

- Eric Gervais, Executive Vice President, Medunik Canada

#### Special Address from EURORDIS

- Yann Le Cam, CEO, European Organization for Rare Diseases (EURORDIS)

#### Closing Remarks

- Nancy Harris, Board of Directors, NORD