

# A DECADE OF Innovation

## Advances in the Treatment of Rare Diseases



Hill Lunch Briefing  
Friday, April 21, 2006  
12:00- 1:00 p.m.

B-339 Rayburn House Office Building

### AGENDA

#### Welcome

**Dr. Paul Antony, Chief Medical Officer**  
Pharmaceutical Research and Manufacturers of America

**Diane Dorman, Vice President, Public Policy**  
National Organization of Rare Disorders

**Dave Hirschhorn, Patient with Amyotrophic Lateral Sclerosis (ALS)**  
Arlington, VA

**Dr. Terry Heiman-Patterson, Professor and Vice Chair of the Department of Neurology, Director of the Division of Neuromuscular Disorders, and Director of the MDA/ALS Center of Hope ALS Clinic**  
Drexel University College of Medicine

**Sharon Terry, MA, President and CEO**  
Genetic Alliance

**Jack Johnson, Patient and Executive Director, Fabry Support & Information Group**  
Concordia, MO

**Dr. Edward Kaye, Vice President, Clinical Research**  
Genzyme, Inc.

#### Q&A

