



Orphan Drugs: Improving the Health of Every Patient

U.S. Chamber of Commerce | Washington, D.C.

Thursday, June 4, 2009

8:30 a.m. – 9:00 a.m.
Briefing Center

9:00 a.m. – 9:05 a.m.
Briefing Center

9:05 a.m. – 9:25 a.m.
Briefing Center

9:25 a.m. – 10:25 a.m.
Briefing Center

Registration and Continental Breakfast

Welcoming Remarks

- **Randel K. Johnson**
Vice President, Labor, Immigration, and Employee Benefits
U.S. Chamber of Commerce

Keynote Address

- **Michael J. Astrue**
Commissioner
U.S. Social Security Administration

Introduced by:

Randel K. Johnson

How to Facilitate Innovation and Access to Orphan Drugs

- **Diane Edquist Dorman**
Vice President, Public Policy
National Organization for Rare Disorders
- **W. Bradford Gary**
Vice President, Government Operations
Allergan, Inc.
- **Winston Wong, Pharm.D.**
Associate Vice President, Pharmacy Management
CareFirst BlueCross BlueShield

Discussion Leader:

James O'Leary, Chief Innovation Officer, Genetic Alliance

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10:25 a.m. – 10:45 a.m.
Briefing Center

10:45 a.m. – 11:45 a.m.
Briefing Center

11:45 a.m. – 12:45 p.m.
Briefing Center

12:45 p.m.
Briefing Center

Networking Break

The Challenges of Marketing & Developing Orphan Drugs

- **Jeffrey A. Kelman, M.D., MMSc**
Chief Medical Officer, Center for Beneficiary Choices
Centers for Medicare and Medicaid Services,
U.S. Department of Health and Human Services
- **Stephen C. Groft, Pharm.D.**
Director, Office of Rare Diseases Research
National Institutes of Health
- **Jean R. Slutsky, P.A., M.S.P.H.**
Director, Center for Outcomes and Evidence,
Agency for Healthcare Research and Quality,
U.S. Department of Health and Human Services
- **Barry H. Thompson, M.D., F.A.A.P., F.A.C.M.G.**
Medical Director
American College of Medical Genetics

Discussion Leader:

Timothy R. Coté, M.D., M.P.H., Director, Office of Orphan Products
Development, U.S. Food and Drug Administration

Video Presentation and Luncheon Address

Presentation:

- **Simon Ibell**
Board Member
Canadian MPS Society

Keynote Address:

- **Angus Russell**
Chief Executive Officer
Shire plc

Introduced and moderated by:

Arthur J. Rothkopf, Senior Vice President, U.S. Chamber of Commerce,
and Executive Vice President, National Chamber Foundation

Adjourn

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