



**Bone and Joint Decade
Global Network Conference
October 21-22, 2009
PATIENT ADVOCACY MEETING**



(Draft 9/26/09)

Tuesday, October 20

Evening Arrival of Patient Advocacy Delegates

Wednesday, October 21

BJD 2009 Patient Advocacy Meeting

0900

Welcome

Armin U. Kuder, Esquire
Member, International Steering Committee, Bone and Joint Decade

Presentation of Themes and Practical Information

Amye Leong, BJD Patient Advocacy Leader & Director of Strategic Relations

Sara Martin, BJD Communications Manager

**Facilitators: Brian Tjugum and John Lotspeich
Directors, Weber Shandwick, London**

1030

Coffee break

How to Change Health Priorities

- Who to contact
- Stating your case and follow-up
- When to lobby
- Coaching: Speaking about your cause to an elected official
Best Practice Examples: Chris Bossley, NAN Coordinator, New Zealand

1230

Lunch

1330

Mentoring & Learning by Example:

Amy Melnick, Arthritis Foundation, United States

Marios Kouloumas, PARE, Europe

Brief reports from both organisations:

1. Explanation of how the organization is structured
2. Discussion of how interaction with members is carried out
3. Update on the organization's current activities

1530

Coffee break

1545

Break out sessions

1700

Summary and End

1900

Patient Advocacy Dinner JW Marriott Hotel

Thursday, October 22, 2009 – Advocacy Day on Capitol Hill*

- 0730 **Buses departing hotel to Capitol Hill**
- 0800 **Welcome Breakfast for all Advocacy Day participants**
Capitol Hill Visitors Center HVC-215
- 0900 **Welcome and Briefing from Member(s) of Congress**
- Congressman Dave Camp (R-MI)
 - Congressman Charlie Melancon (D-LA)
 - Congressman John Dingell (D-MI)
- 1000 Congressional Oversight Hearing of three Bone and Joint related bills, to include opening remarks from high level BJD expert, expert witness testimony from physicians and patient testimonials for all three bills.
- 1120 Closing Statements
- 1130 Press Conference
- 1200 **Advocacy Day Luncheon**
Russell Caucus Room, Russell Senate Office Building
Keynote speakers:
- Senator Chuck Grassley (R-IA), Ranking Member, Finance Committee
 - Senator John Barrasso (R-WY)
 - Senator Charles Schumer (D-NY) (Invited)
 - Congresswoman Marcy Kaptur (D-OH) (Invited)
- 1330 **Experts in Arthritis**
Gold Room 2168 – Rayburn House Office Building
Keynote speaker:
- Congresswoman Anna Eshoo (D-CA)
- Panelists:
- David G. Borenstein, MD, FACP, FACR, United States
 - Peter Brooks, MD, FRACP, FRCP Edin., FAFRM, FAFPHM, Australia
 - John H. Klippel, MD, United States
 - Amye Leong, MBA, France and United States
 - Girish Mody, MBChB, MD, FRCP, FCP, South Africa
 - Carol A. Oatis, PT, PhD, United States
 - David S. Pisetsky, MD, PhD, United States
 - Christy Sandborg, MD, United States
- 1330-1730 **Congressional visits for patient/physician teams**
Visits scheduled throughout the afternoon.
Embassy visits scheduled for international patient advocates.
- 1830 **Reception, Canadian Embassy**
501 Pennsylvania Avenue, NW, Washington, DC
Speakers:
- Colin Carrier, MP, Parliamentary Secretary for Health, Canada
 - Lars Lidgren, MD, PhD, Chair, Bone and Joint Decade, Sweden
- Invitations extended to:
Bill Corr, Deputy Secretary, U.S. Department of Health and Human Services
Mike Levitt, Former Secretary, U.S. Department of Health and Human Services
The Honorable José Ángel Córdova Villalobos, Secretary of Health, Mexico

Reception kindly sponsored by Pfizer, Inc.

* Delegates to the BJD Global Network Conference are welcome to join activities during Advocacy Day on Capitol Hill.