

**Chordoma Foundation
First International Chordoma Community Conference**

Adult Agenda DAY 1 (Saturday, April 5, 2008)

7:00-7:45	Breakfast & Registration Location: Brookside Foyer
7:45-8:15	Welcome to the Chordoma Community: <i>Introducing the Chordoma Foundation Leadership</i> Speakers: Josh Sommer and Simone Sommer, MD, MPH Location: Brookside A&B
8:15-8:45	Making Connections: <i>Introductions of Community Members and conference logistics</i> Speaker: Heather Lee, PhD, SPHR. Location: Brookside A&B
9:00-3:30	Parallel Youth Conference Coordinator: Carolyn Rubenstein and Friends Location: Linden Oaks
9:00-9:45	Concurrent Session I ▪ The Parent's Ultimate Challenge - When Kids/Teens Have Chordoma Speaker: Julie Ries, Ph.D. Location: Glen Echo
9:00-9:45	Concurrent Session I ▪ Navigating the Insurance Maze in the US - Where do I begin? Speaker: Jennifer Libster, J.D., Georgetown University Health Policy Institute Location: Brookside A & B
9:00-9:45	Concurrent Session I ▪ Advice and Care for Caregivers Speaker: Brigid Guttmacher, M.A., L.P.C Location: Forest Glen
10:00-10:45	Concurrent Session II For the Bereaved, Our Loved Ones Live On Speaker: Brigid Guttmacher, M.A., L.P.C Location: Brookside A&B
10:00-10:45	Concurrent Session II ▪ What are my rights? - Understanding laws that protect the patient and caregiver Speaker: Kerry A. Shad, J.D. Location: Glen Echo
10:00-10:45	Concurrent Session II ▪ Alternative Coping: Negotiating the Biological and Psychological Dimensions of Pain Speaker: Melva Green, M.D., MBA, MPH Location: Forest Glen
10:45-11:00	BREAK in Forest Glen/ Glen Echo Foyer
11:00-11:45	Concurrent Session III ▪ Alternative Coping: Negotiating the Biological and Psychological Dimensions of Pain Speaker: Melva Green, M.D., MBA, MPH Location: Forest Glen
11:00-11:45	Concurrent Session III ▪ Navigating the Insurance Maze in the US - Where do I begin? Speaker: Jennifer Libster, J.D., Georgetown University Health Policy Institute Location: Brookside A & B
11:00-11:45	Concurrent Session III ▪ What are my rights? - Understanding laws that protect the patient and caregiver Speaker: Kerry A. Shad, J.D. Location: Glen Echo

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12:00-1:00	Chordoma Community Support Expo - Representatives from various vendors and organizations to support the Chordoma Community Location: Forest Glen/ Glen Echo Foyer
1:00-2:30	LUNCH: <i>Share a meal with physicians and researchers from around the globe</i> 1:45 - Panel Discussion: The Chordoma Experience - Patient and Parent <i>representatives discuss their journey</i> Location: Brookside A&B
2:30-3:15	What we know now : <i>Highlights from the Second Chordoma Research Workshop</i> - Clinical Overview of Chordoma - Familial Study - The Science of Chordoma Research - Treatments on the Horizon Location: Whiteflint Amphitheater
3:15-4:45	Ask the Experts: <i>Community and Expert Q & A</i> Location: Whiteflint Amphitheater
4:15-4:30	BREAK in Forest Glen/ Glen Echo Foyer
4:30-5:00	The Chordoma Foundation Research Roadmap - The Journey Towards a Cure Location: Whiteflint Amphitheater
5:00-5:30	Taking Action to Find a Cure - Beyond the research, how the Chordoma Foundation can support the Community Location: Whiteflint Amphitheater
5:30-6:30	<i>Please Visit our Vendors in Forest Glen/ Glen Echo Foyer</i>
6:30-9:30	DINNER Location: Brookside A&B

Adult Agenda DAY 2 (Sunday, April 6, 2008)

All Events will be held in Brookside A&B

8:15-9:00	Breakfast
9:00-10:00	We Can Make a Difference: <i>Navigating the Health Care System</i> Speaker: Delia Chiaramonte, M.D.
10:00-10:45	Toolkit for Making a Difference: <i>Empowerment for Advocacy and Fundraising</i> Speaker: Heather A. Lee, Ph.D.
10:45-11:00	BREAK in Forest Glen/ Glen Echo Foyer
11:00-11:45	Creating Chordoma Community Partnerships: <i>Connecting Champions Regionally, Nationally and Internationally</i> Facilitator: Steve Straus, Ph.D.
11:45-12:45	Carpe Diem - "Seize the Day": <i>Capitalizing on the power in the room, generating the next steps</i> Facilitator: Steve Straus, Ph.D.
12:45-1:00	Closing Remarks, Evaluation