



Many Rare Disorders, One Common Voice

October 1–2, 2010
Sheraton Ottawa Hotel

Draft Agenda

Friday, October 1, 2010		
TIME	TOPIC	LOCATION
8:00 AM – 8:30 AM	CONTINENTAL BREAKFAST AND REGISTRATION	
8:30 AM – 8:45 AM	Welcome Address	
8:45 AM – 9:45 AM	Dialogue on Canada's Plan for Rare Diseases Case Examples: <ul style="list-style-type: none">▪ Screening and Diagnosis▪ Clinical Trials▪ Health Technology Assessment for Rare Disorders▪ Off-label Treatment▪ Access to Expertise	
9:45 AM – 10:15 AM	Impact on Patients and Providers	
10:15 AM – 10:30 AM	REFRESHMENT BREAK	
10:30 AM – 12:30 PM	What are Canadian Initiatives	
12:30 PM – 1:30 PM	LUNCH	
1:30 PM – 3:00 PM	International Best Practices Centers of Reference/Database (Orpha.net) HTA Rare Diseases (Euro BIO/US BIO)	
3:00 PM – 3:15 PM	REFRESHMENT BREAK	
3:15 PM – 4:00 PM	Focused Small Group Discussions	
4:00 PM – 4:30 PM	Round Table Discussion – Towards a Canadian National Plan for Rare Disorders	



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Saturday, October 2, 2010		
TIME	TOPIC	LOCATION
8:00 AM – 8:30 AM	CONTINENTAL BREAKFAST	
8:30 AM – 8:45 AM	Sharing Best Practices (Introduction to Day 2)	
8:45 AM – 9:30 AM	International Rare Disease Organizations <ul style="list-style-type: none">▪ Rare Disease Collaborations	
9:30 AM – 11:00 AM	Marketplace Session #1 (Participants choose 2 sessions to attend) <ul style="list-style-type: none">▪ Choose from Topic List (see below)	
11:00 AM – 11:15 AM	REFRESHMENT BREAK	
11:15 AM – 12:00 PM	Marketplace Session #2 (Participants choose 2 sessions to attend) <ul style="list-style-type: none">▪ Choose from Topic List (see below)	
12:00 PM – 1:00 PM	LUNCH	
1:00 PM – 1:45 PM	Marketplace Session #3 (Participants choose 2 sessions to attend) <ul style="list-style-type: none">▪ Choose from Topic List (see below)	
1:45 PM – 2:30 PM	Marketplace Session #4 (Participants choose 2 sessions to attend) <ul style="list-style-type: none">▪ Choose from Topic List (see below)	
2:30 PM – 3:00 PM	Collaborating for Success – Plenary Discussion and Wrap Up	

Marketplace Topics

- Advocacy
- Drug Access (HTA)
- Fundraising
- Genetic Non-Discrimination
- Government Relations
- Help/Support Lines
- Media and Public Relations
- Parents
- Patient Registries
- Patient Submissions
- Planning
- Play/Decide
- Social Media
- Support
- Working with Drug Plans
- Working with HCP