

Canadian Expert Patients in Health Technology Conference

Nov 7 – 8, 2016

HYATT REGENCY TORONTO
370 King Street West, Toronto

Assuring Innovative Therapies

Innovative health technologies, including therapies, devices, and medical procedures, are transforming once fatal diseases to chronic conditions, reducing the impact of physical and mental challenges, and significantly improving quality of life for patients and families. Importantly, patient advocates and patient organizations are playing key roles in the design and development of new therapies.

Sadly, innovations to access have not kept pace. On one hand, public health programmes and private insurers are raising concerns about rising healthcare costs and budget impacts driven not only by innovative therapies but also incremental improvements in older products as well as increasing demand from an aging population with more complex illnesses.

On the other hand, patient advocates, increasingly aware of options, are pressing for and gaining legitimate roles in access and policy decisions. However, not all patients are adequately represented or adequately prepared to participate in all phases of drug development and access, and indeed the opportunities for engagement are perhaps exceeding the capacity of the patient community to take full advantage. Limitations apply whether the patient groups are well resourced, multi-stakeholder, charitable organizations or small, family-based, single-cause, volunteer-run groups.

Objectives of CEPHT Conference

Educate: Inform patients and patient advocates about innovations in health technologies and emerging issues that affect access.

Enquire: Consult with patient advocates and organizations to ensure the patient perspective is central in health access decisions at all levels from individual to systems.

Empower: Provide training and resources to increase capacity of patient advocates and organizations to advocate effectively on at all levels on access decision.

Engage: Actively facilitate meaningful engagement of patient advocates with other stakeholders in all processes of health technology development and access.

Format

The conference combines expert presentations, panel discussions, interactive polling and feedback, small-group deliberations, and integrative plenary sessions.

Monday, November 7 (King Ballroom)

8:00 am – 8:30 am

Registration

Continental breakfast

8:30 am – 9:00 am

Conference Welcome

Durhane Wong-Rieger, Canadian Organization for Rare Disorders

Patient Testimonial

Value of Innovation

Carole Watson, Janssen

Moderator: Bill Dempster, 3Sixty Public Affairs

PANEL 1: Canada's Strategy for Rare Diseases

9:00 am – 9:45 am

First Report from Working Group on Ontario's Rare Disease Strategy

Durhane Wong-Rieger (CORD)

Working Groups on Diagnosis and Prevention, Expert Care, Community Support, Access to Therapies, Research: Current Status

Kym Boycott (Care4Rare)

Paul Lasko (CIHR - Institute of Genetics)

9:45 am – 10:10 am

Canada's Orphan Drug Regulatory Framework: What Health Canada is doing now and what is yet to come

Liz-Anne Gillham-Eisen (Health Canada)

10:10 am – 10:30 am

panCanadian Newborn Screening Guidelines

Pranesh Chakraborty (CHEO)

10:30 am – 10:45 am

BREAK

10:45 am – 11:25 am

Centres of Expertise: Platform for diagnosis, patient registries and databases, best practice care and management of drug therapies, coordination of community-based support, research initiatives

Ian Stedman (CORD), Ron Laxer (The Hospital for Sick Children)

Sonja Durinck (Canadian Pituitary Patient Network), Shereen Ezzat (University Hospital Network)

- Example of Autoinflammatory diseases
 - Example of Pituitary Tumours
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11:25 am – 11:45 am

Panel Q & A

All speakers

11:45 am – 12:45 pm

LUNCH

PANEL 2: New Health Technologies

12:45 pm – 1:00 pm	VIDEO: Genomic Sequencing 101	
1:00 pm – 1:20 pm	Emerging technologies in diagnostics: newborn screening, genome sequencing, human phenotype ontology	Kym Boycott (Care4Rare)
1:20 pm – 1:40 pm	PhenomeCentral & Matchmaker Exchange	Michael Brudno & Orion Buske (University of Toronto)
1:40 pm – 2:00 pm	Registries: CoRDS	Angela VanVeldhuizen (Sanford Health)
2:00 pm – 2:20 pm	Perspectives from Canada	Chander Sehgal (Innovative Medicines Canada)
2:20 pm – 2:35 pm	BREAK	

PANEL 3: Emerging Technologies in Treatment

2:35 pm – 2:55 pm	Advances in Gene Therapy	Eyal Grunebaum (The Hospital for Sick Children)
2:55 pm – 3:15 pm	Updates in Metabolic Treatments	Sylvia Stockler (BC Children's Hospital)
3:15 pm – 3:35 pm	Developments in precision/personalized therapies	Robert Petit (Advaxis)
3:35 pm – 3:55 pm	Biomarkers	Wendy Morton (Merck)

PANEL 4: Patient-Centred Access

3:55 pm – 4:15 pm	Adaptive Pathways and Lifecycle Approach (ADAPTSMART)	Alicia Granados (Sanofi Genzyme)
4:15 pm – 4:45 pm	Patient Engagement in Drug Review	Helen Mai (CADTH), Adam Waiser (Canadian Cancer Action Network)

Tuesday, November 8 (King Ballroom)

8:00 am – 8:30 am **Continental breakfast**

8:30 am – 9:00 am **Day One Recap**
Durhane Wong-Rieger

Keynote Address

Rare Alliance Canada: A Vision for Rare Diseases in Canada

Ronald Cohn, The Hospital for Sick Children

Why Canada Still Needs an Orphan Drug Framework

Peter Brenders, Sanofi Genzyme

Moderator: Wayne Critchley, CORD/Global Public Affairs

PANEL 1: Principles for Sustainable Access: Rebuilding Trust

Panel Chair: Durhane Wong-Rieger

9:00 am – 9:10 am	PharmaDiplomacy: Principles for Collaborative Mutually Acceptable Drug Pricing	Becky Buell (Meteos)
9:10 am – 9:20 am	Evidence-Based Approach to Assuring Value for Orphan Drugs	Pam Gavin (NORD)
9:20 am – 9:40 am	Incorporating Patient Preferences Into the HTA Deliberative Framework: The Patient Values Project	Filomena Servidio-Italiano (Colorectal Cancer Association of Canada)
9:40 am – 10:10 am	Managing Value for Sponsors and Users in Public and Private Drug Plans	Angie Wong (Ontario Ministry of Health & Long Term Care) Stephen Frank (Canadian Life and Health Insurance Association)
10:10 am – 10:45 am	Panel Discussion	All
10:45 am – 11:00 am	BREAK	

PANEL 2: Achieving Value-based Pricing: Challenges & Opportunities

Panel Chair: Wayne Critchley

11:00 am – 11:10 am	PMPRB Guidelines Modernization	Doug Clark (Patented Medicine Prices Review Board)
11:10 am – 11:20 am	Ensuring Values-based Assessments for Innovative Therapies	Brent Fraser (CADTH)
11:20 am – 11:30 am	A Joint Approach to Value-based Access for Public Drug Plans	Imran Ali (pCPA)
11:30 am – 11:50 am	An Economics Perspective on Drug Prices	Audrey Laporte (University of Toronto)

11:50 am – 12:15 pm	Panel Discussion	All
12:15 pm – 1:00 pm	LUNCH	
1:00 pm – 1:10 pm	Invited Speaker	Michael Harris, MPP Kitchener-Conestoga

PANEL 3: Innovating Solutions to Sustainable Drug Access

Panel Chair: Mark Krueger

1:10 pm – 1:30 pm	Special Access and Advanced Access Programmes	Marion Law (Health Canada)
1:30 pm – 1:50 pm	Optimal Use of Medication: the quest for real-world evidence.	Julie Frappier (Data 4 Actions)
1:50 pm – 2:10 pm	Multi-criteria Approach	Dima Samaha (LASER Analytica)
2:10 pm – 2:30 pm	Applying Innovative Solutions to Canada's Orphan Product Access Strategy	Mark Krueger (MK&A)
2:30 pm – 2:45 pm	BREAK	

PANEL 4: Biosimilars

Panel Chair: Durhane Wong-Rieger

2:45 pm – 3:30 pm	Appropriate Place in Therapy	Allan Miranda (Janssen), John Snowden (Amgen), Dawn Richards (Canadian Arthritis Patient Alliance), Seema Nagpal (Canadian Diabetes Association),
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PANEL 5: Most Important Panel of the Conference

Panel Chair: Mark Krueger

3:30 pm – 4:00 pm	Thoughtful Reflections – Impactful Actions Panel of Esteemed Experts	Sandra Anderson (Innomar Strategies), Paul Lasko (CIHR - Institute of Genetics), Maureen Smith (CORD), Sylvia Stockler (BC Children's Hospital)
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The Canadian Organization for Rare Disorders acknowledges the contribution of all our Corporate Partners to improving the lives of patients and families with rare disorders. We are especially grateful to the following partners that have supported this conference.

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