CANADA's

Rare Disease Strategy: Blueprint for Personalized Healthcare for All

Commitment to Canada's Rare Disease Strategy by federal political parties means full steam ahead. With the promise of $500 million per year for Rare Disease Drugs, we must also build infrastructure for diagnosis, networked centres for treatment, supportive care, real world data analysis, and research. All of this is also the Blueprint for implementation of Canada's Personalized Healthcare Strategy, which will assure patients with "common" conditions also benefit from precision diagnosis, cellular and gene therapies, AI, and smart technologies that are transforming care from "hit and miss" best practice guidelines to personalized care pathways. Canada is ready to make personalized healthcare and precision medicines to be available to everyone, with rare and common conditions.

CONFERENCE AGENDA

Monday, November 18, 2019

Building Blocks of Precision Medicine and Personalized Healthcare

8:00 a.m. – 8:30 a.m.	Registration and Breakfast	Civic Ballroom
8:30 a.m. – 9:00 a.m.	Welcome and Objectives	Durhane Wong-Rieger, CORD
9:00 a.m. – 9:15 a.m.	Opening Plenary • Opportunities for Personalized Healthcare and Rare Diseases	Durhane Wong-Rieger
9:15 a.m. – 10:45 a.m.	Why Precision Medicine and Personalized Healthcare and Why Now? Links to Canada's Rare Disease Strategy The Future is Now • What if we could … cure cancer, restore sight to the blind, prevent hemophiliacs from bleeding, keep muscles from	**Moderator:** Durhane Wong-Rieger Marc LePage, Genome Canada

	weakening, bones from breaking, and lungs from collapsing? We can do most of that today. Here's how. • You are more than your genomes! Thanks to AI, your genomic, biologic, lifestyle, and other personal information can be used to personalize healthcare to manage, treat, and even prevent disease and illness. • Canada's Rare Disease Strategy: Blueprint for Personalized Healthcare? **Panel Discussion:** How do Systems Need to Change to Promote Access?	Michael Duong, Roche Danica Stanimirovic, National Research Council Daniel Gaudet, University of Montreal Christine Dalgleish, Patient Perspective Jamie Bruce, Khure Health
10:45 a.m. – 11:00 a.m.	**Networking Break**	
11:00 a.m. – 12:00 p.m.	**Examples of Transformative Technologies Driving Precision Medicine and Personalized Healthcare** • Genomics and Beyond • Patient-Engaged Healthcare: Personalized Tools to Monitor and Manage Healthcare • Big Data: Collect, Analyze, Aggregate Real-World Data • Sustainable Approaches to Product Development	**Moderator:** Oxana Illich, IQVIA Marc LePage, Genome Canada Daniel Gaudet, Ecogene-21 Kristy Dickinson, Chronically Simple Jian Wang, Health Canada Michael May, CCRM Maxwell Morgan, M4Kids (Pediatric Cancer Therapies)
12:00 p.m. – 1:00 p.m.	**Lunch**	**Optional:** Transparent Dialogue on Need for Transparency and Patient Voice in Access to Therapies
1:00 p.m. – 2:30 p.m.	**Examples of Traditional vs. Precision Therapies**	**Moderator:** Sandra Anderson, Innomar Strategies

	Precision Diagnosis: Molecular testing and Genome Sequencing Precision Therapies • Pharmacogenomics • Precision Medicines in Cancer • Gene therapies: Gene editing, replacing, inserting, neutralizing, modulating	James Kennedy, Centre for Addiction and Mental Health Niya Chari, CBCN Michael Duong, Roche Linsay Davis, AveXis Josh Silvertown, Bayer Canada
2:30 p.m. – 2:45 p.m.	Networking Break	
2:45 p.m. – 4:00 p.m.	Personalized Medicines: Access Opportunities & Challenges • Can Canada Afford a Cure? • Data Collection, Management, and Analysis • Value-Based Decision Making: Reimbursement based on Outcomes and Potential • Sustainable Development and Access: Getting to A Right Price	**Moderator:** Joan McCormick, IQVIA Biba Tinga, Sickle Cell Disease Association of Canada David Page, Canadian Hemophilia Society Celia Segel, ICER Brent Fraser, CADTH Brandon Levac, Bayer Canada
4:00 p.m. – 4:45 p.m.	Case Study: Lessons Learned from the Canadian Access to CAR-T Therapy Experience	**Moderator:** Bill Dempster, 3Sixty Public Affairs **Panel:** Helen Trifonopoulos, Novartis; Brent Fraser, CADTH; Jian Wang, Health Canada; Elizabeth Lye, Lymphoma Canada
4:45 p.m. – 5:00 p.m.	Wrap-Up and Preparation for Day 2 Workshops	Durhane Wong-Rieger

Tuesday, November 19, 2019

Collaborating to Design Access to Precision Medicines & Personalized Healthcare

8:00 a.m. – 8:30 a.m.	**Breakfast**	Civic Ballroom
8:30 a.m. – 9:00 a.m.	**Implementing Personalized Healthcare: A Change in Structure or Change in Culture?**	Durhane Wong-Rieger
9:00 a.m. – 9:30 a.m.	**Cell and Gene Therapy Pipeline: What is here, coming, and anticipated?**	**Moderator:** Jane Farnham, BioScript Solutions **Panelists:** Mark Lundie, Pfizer Canada; Danielle Rollmann, MIT FoCUS
9:30 a.m. – 10:00 a.m.	**Choosing Gene Therapy: How Patients' and Parents Are Making Tough Choices**	**Moderator:** Durhane Wong-Rieger Jordan Janz, Barb Kulik; Jay Konduros, Hemophilia; Susi Vander Wyk, CureSMA; Darlene Morden, Stand Up for Duchenne; Terry Pirovolakis, CureSPG50
10:00 a.m. – 10:45 a.m.	**What Canadians Might Learn from USA Financing Models for Durable/Curative Therapies: MIT NEWDIGS FoCUS Toolkit**	Danielle Rollmann, MIT FoCUS
10:45 a.m. – 11:00 a.m.	**Networking Break**	
11:00 a.m. – 11:30 a.m.	**775 Days to Launch: Developing the Roadmap to Canada's Rare Disease Strategy and Rare Disease Drug Program** (and Seizing on Government's Commitment for Policy and $1 billion Fund in 2022)	**Moderator:** Bill Dempster, 3Sixty Public Affairs **Panelists:** Durhane Wong-Rieger; Cathy Evanochko, TSC Canada; Daniel Gaudet, University of Montreal; Bob McLay, RAREi

11:30 a.m. – 12:30 p.m.	Changing Access, Changing Lives: Bringing Rare Disease and Precision Medicines to Canadians	**Moderator:** Judith Glennie, J.L. Glennie Consulting Inc **Panelists:** Suzanne White; Chris MacLeod, Canadian Cystic Fibrosis Treatment Society; Craig Campbell, LHSC; Jeff Wandzura, Curatio
12:30 p.m. – 1:30 p.m.	Lunch	**Optional:** Dialogue on Charting 2-year Roadmap to Realizing Canada's Rare Disease Strategy
1:30 p.m. – 2:00 p.m.	Khure Health: How new technologies and AI are enabling Primary Care Providers to identify rare diseases and deliver personalized care	Paolo Gomes, Khure Health
2:00 p.m.– 3:15 p.m.	Opportunities or Challenges: Need for Transparent Consultation and Reality-Based Thinking on Canadian Drug Pricing and Access to Innovation; How to Make PMPRB Guidelines, HTA, and National Pharmacare Work for Patients	**Moderator:** Wayne Critchley, Global Public Affairs **Panelists:** Neil Palmer, PDCI Market Access Inc; Nigel Rawson, Eastlake Research Group; Jane Farnham, BioScript Solutions; Jason Field, Life Sciences Ontario
3:15 p.m. – 3:30 p.m.	Next Steps	All

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We are especially grateful to the following that have supported this conference.

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