Canadian Organization for Rare Disorders

Rare Disease Day Conference 2020

March 9 - 10, 2020
Delta Hotels Ottawa City Centre

Speaker Bios

Sandra Anderson
Innomar Strategies

Sandra joined Innomar in 2005. With more than 20 years of pharmaceutical and clinical experience, she oversees a diverse team of 60 associates focused on regulatory, reimbursement, health economics, market access, business development, marketing, and stakeholder relations. Sandra is a champion for the integrated model, the value of partnership and creating outstanding customer experiences. Sandra has deep knowledge of the Canadian healthcare landscape and the role specialty products play. She has particular expertise in rare diseases and market access. Sandra has a Bachelor of Arts degree from McMaster, an MBA with a focus on international marketing, and is a CCRA (Certified Clinical Research Associate).

Frank Béraud
Montreal InVivo

Holding more than 25 years of experience in the life sciences sector, Mr. Béraud has particularly acquired a solid expertise in business development. With a background in sales and marketing within multinationals in the field of clinical diagnostic, his career path has led him to assume responsibility for business development for an SME in the domain of biotechnology, in addition to working as a consultant within the industry as well as a technology transfer organization. Mr. Béraud has also worked on managing the policies and strategic development of an industrial association in the life sciences sector before joining Montréal InVivo's team. Highly socially engaged with schools and the health community, he currently chairs on the board of a community organization working towards the social and economic reintegration of individuals in situations of homelessness in Montreal (Le Sac à Dos).

Sophie Bernard
Montreal Clinical Research Institute

Physician and researcher, Sophie Bernard is a specialist in endocrinology and metabolic diseases. Dr. Sophie Bernard also practices medicine at the Centre hospitalier de l'Université de Montréal (CHUM) and she is an Assistant Professor in the Department of Medicine at the Faculty of Medicine of Université de Montréal. Dr. Bernard is the author and co-author of several scientific publications. She completed her medical degree at the University Claude Bernard-Lyon 1, in France, and obtained a specialization in endocrinology metabolism and nutrition as well as a PhD in biology of vascular diseases and a sub-specialization in lipid metabolism.

Megan Bettle
Health Canada

Megan Bettle joined Health Canada in 2005 as a drug safety reviewer, after a PhD and research in molecular biology and the genetics of rare diseases. Since then, she has taken on a number of roles in pre- and post-market drug review, cannabis policy, and tobacco and illicit drugs surveillance. She is currently the director of the new Centre for Regulatory Excellence, Statistics and Trials in the Biologics and Genetic Therapies Directorate, a role which includes horizontal science functions including regulatory intelligence, drug submissions management, regulation of clinical trials for biologics, pediatric strategies, and ongoing work on Health Canada's Regulatory Review of Drugs and Devices.

Kym Boycott
CHEO

Kym Boycott is Professor of Pediatrics at University of Ottawa, Clinical Geneticist at CHEO, and Senior Scientist at CHEO Research Institute. Her research program in rare disease genomics bridges clinical medicine and basic research to improve diagnosis and care. She leads Care4Rare, a pan-Canadian consortium integrating genomics to discover the genetic causes of rare disease and improve the health and wellbeing of affected families. To leverage these genetic discoveries, she co-leads the Canadian RDMM Network that catalyzes model organism research to understand the molecular mechanisms of rare disease genes. Globally, she moves the rare disease agenda forward through her roles in numerous international initiatives.

Ken Chapman
University Health Network

Dr. Chapman is Director of the Asthma and Airway Centre of the University Health Network, President of the Canadian Network for Respiratory Care and Director of the Canadian Registry for Alpha-1 Antitrypsin Deficiency.

A Professor of Medicine at the University of Toronto, Dr. Chapman is an internationally respected researcher and lecturer in the fields of asthma and COPD. With more that 18,000 citations to his published work, he is in the top 1% of cited medical researchers.

Wayne Critchley
Global Public Affairs

Wayne Critchley is Senior Associate with Global Public Affairs' Health & Life Sciences Practice, providing counsel to leading biopharmaceutical companies and other health policy stakeholders. Wayne served as Executive Director of the Patented Medicine Prices Review Board from 1990 to 2005 and as a Vice President of the Canadian Agency for Drugs and Technologies in Health in 2009. His private sector experience includes providing advice and counsel in one of Canada's leading law firms and he is widely recognized as an expert in pharmaceutical pricing, reimbursement and market access. Wayne served as Chair of the Canadian Organization for Rare Disorders from 2015-2019 and currently serves on the Board of Directors of the Macdonald-Laurier Institute. He is also active with the Canadian Club of Ottawa and served as President from 2012-2013.

Bill Dempster
3Sixty Public Affairs

As CEO of 3Sixty Public Affairs, Bill Dempster develops and implements high-impact government relations, policy and business strategies for clients in the health and life sciences sector. Bill draws on deep business, legal and government experience to help clients find mutually beneficial solutions to complex regulatory, reimbursement and policy problems. Bill has previously worked for Pfizer Canada, a Member of Parliament, the United Nations and major Canadian law firms. Bill has degrees in history (King's College), law (Queen's University), and a Masters of Arts in international affairs (Carleton University). Bill was called to the Bar of Ontario in 2002.

Doug Earle
Fighting Blindness Canada

Doug Earle serves as President & CEO of Fighting Blindness Canada since December 2018. A Certified Fundraising Executive with a proven track record of success, Doug engages Canada's vision community to accelerate vision research to discover new treatments and cures for blinding eye diseases and improve access of treatments and vision health care across Canada Doug is a motivating, tireless yet inspirational Fundraising Executive, politically astute, a translator of science and missions to engage donors to spark innovation that impact lives. Known for inspiring philanthropists to invest over $1 billion+ in organizations helping those in need and rejuvenating communities.

Cathy Evanochko
Tuberous Sclerosis Canada

Cathy Evanochko was an originating board member of Tuberous Sclerosis Canada Sclérose Tubéreuse (TSCST) at its inception in 1989. After serving on the Board for several years, she took a hiatus, but rejoined the Board again in 2009. Cathy is now serving as Co-Chair of Tuberous Sclerosis Canada Sclérose Tubéreuse. She joined the Canadian Organization for Rare Disorders Board in 2013 and currently serves as Co-Chair. Cathy and her family live in Calgary, Alberta.

Jane Farnham
BioScript Solutions

Jane Farnham is a seasoned healthcare executive, speaker and advocate. Jane currently holds the position of Vice President, Strategic Partnerships, External Relations and Advocacy with BioScript Solutions, an integrated provider of patient-centred health solutions for Canadians with complex medical conditions. Jane joined the Canadian Organization for Rare Disorders in 2018 and currently serves as Co-Chair. As the mother of a child with a rare disorder, Jane is a passionate advocate for the patient voice in health policy.

Jason Field
Life Sciences Ontario

Dr. Jason Field is President and CEO of Life Sciences Ontario (LSO). LSO collaborates with governments, academia, industry and other life science organizations across Canada to promote and encourage commercial success throughout the diverse sector. Jason obtained his PhD in Chemistry from the University of Massachusetts and his B.Sc from the University of Waterloo. Jason's professional experience includes the pharmaceutical industry and the Ontario government before joining LSO as Executive Director in October, 2011. He was appointed as President and CEO in April, 2014. He serves on several boards and advisory committees including UofT's Translational Research Program, ReMAP, BioTalent Canada and Research Canada.

Pamela Fralick
Innovative Medicines Canada

Pamela Fralick is an experienced leader who has been fostering positive change in Canada's health sector for decades. A convener and innovator, Ms. Fralick is one of Canada's leading, compassionate voices in the health sector. As the President of Innovative Medicines Canada, Ms. Fralick leads the industry association for Canada's innovative pharmaceutical companies, working with its members and communities to ensure Canadians have access to the medicines they need, when they need them

Brent Fraser
CADTH

Brent Fraser is CADTH Vice-President, Pharmaceutical Reviews, with responsibility for the CADTH drug products and services including the CADTH Common Drug Review (CDR), the pan-Canadian Oncology Drug Review (pCODR). Brent is dedicated to building a team based, client-oriented culture that values leadership, excellence, collaboration, and responsiveness. He champions customer service, business discipline, and ongoing process improvement, and he challenges his team to deliver high-quality, relevant, and timely assessments of drugs using the best available science, tools, and methodologies.

Bettina Hamelin
Ontario Genomics

Dr. Bettina Hamelin is the President and CEO of Ontario Genomics. Before assuming her current role in 2017, Bettina served as Vice-President of NSERC's Research Partnerships Directorate, where she was responsible for a range of programs designed to stimulate increased public/private sector collaboration and technology transfer by connecting the Canadian research enterprise to Canadian and global innovation stakeholders. Bettina has more than 15 years of experience in the biotech and international pharmaceutical industry as well as 10 years of academic experience as a tenured professor at the Faculty of Pharmacy at Université Laval.

Fred Horne
Horne and Associates

Fred Horne served as Alberta's Minister of Health from 2011-2014. A frequent speaker and panelist on health system issues in Canada, Fred is currently Principal of Horne and Associates, Health Policy Consultants, and Adjunct Professor with the University of Alberta's School of Public Health. He has over thirty years' experience in health policy development, health system design and transformation, and stakeholder engagement. Fred holds an MBA from Royal Roads University and the Certificate in Dispute Resolution from York University. He currently serves on a number of boards in the not-for-profit and private sectors.

Oxana Iliach
IQVIA

Oxana Iliach, PhD is a Senior Director Regulatory Affairs at Pediatric and Rare Disease Centre of Excellence at IQVIA. She works with the team of dedicated professionals to develop and implement practical and creative strategies for orphan drug development and regulatory submissions. She holds a MSc in Chemistry and PhD in Pharmaceutical Science. She completed her education in Saint Petersburg, Russia. She is a professor at Seneca College of Applied Arts and Technology and a member of CAPRA, DIA and RAPS. Oxana joined the board of the Canadian Organization for Rare Disorders in 2019 and currently serves as Executive Member-At-Large.

Carole Légaré
Health Canada

Dr Carole Légaré completed her medical training at the University of Ottawa, and her postgraduate pharmacoepidemiology and pharmacovigilance training at the London School of Hygiene and Tropical Medicine in the UK. She joined Health Canada in 2002 where she initially worked in pharmacovigilance. In 2013, she joined the Therapeutic Products Directorate as the Director of the Office of Clinical Trials, where she oversees all activities related to the approval and pharmacovigilance of clinical trials involving pharmaceuticals as well as Health Canada's Special Access Program. She is currently a member of the ICH E8 working group on General Considerations for Clinical Studies.

Marc LePage
Genome Canada

Marc served as President and CEO of Genome Canada from 2016 until his retirement in 2020. He also held role of President and CEO of Génome Québec, where he led a major increase in research activity and enhanced focus on the development of genomic applications within priority sectors within the province. He was also one of the pioneers behind the founding of Genome Canada in 2000. During his tenure as Executive Vice-President of Corporate Development, he made a significant contribution to the development of genomics in Canada. From 1994 to 2000, Marc worked as Director of Business Development for the Medical Research Council, where he was in charge of building international partnerships with the pharmaceutical industry, venture capital and foundations.

Fred Little
Pfizer Canada

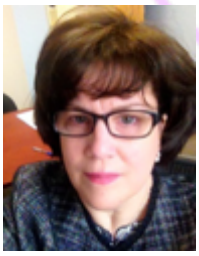
Fred Little is Rare Disease Canada Lead at Pfizer Canada. For over 23 years in the pharmaceutical industry, Fred brings an entrepreneurial and problem-solving mindset to his work and team, combined with a patient-first approach, passion for people and decisiveness. He has a breadth of both in-country and international experience where he launched first-in-class brands in more than 50 countries, managed policy and reimbursement, and demonstrated a high level of business acumen. He believes strongly in building high performance teams that include both cross-functional and diverse groups of people. Fred is a member of the Pfizer North American Leadership Team and the Canadian Leadership Counsel at Pfizer Canada and his philosophy is to bring rare disease medications to Canadians who need them as quickly as possible.

Alex MacKenzie
CHEO

Alex MacKenzie is an attending pediatrician at the Children's Hospital of Eastern Ontario (CHEO) in Ottawa, Canada and has served as the CEO and Science Director of the CHEO Research Institute as well as Vice President of Research for both CHEO and Canada's federal genomic research funding agency, Genome Canada. In addition to being a founding scientist of the AeGera biotech company, Dr. MacKenzie's laboratory has conducted translational research on the rare pediatric disorder spinal muscular atrophy over the past 25 years; in recent years, it has broadened its focus through the enhanced Care for Rare project to search for therapies for a larger number of rare genetic diseases.

Chris MacLeod
Canadian Cystic Fibrosis Treatment Society

Chris MacLeod is a founding Partner of Cambridge LLP. His practice focuses on complex business litigation including cross-border dispute resolution, multi-jurisdictional litigation, and private international law. Chris lives with a rare form of cystic fibrosis and serves as Chair of the Canadian Cystic Fibrosis Treatment Society which advocates that patients with CF should have access to any medication their doctor prescribes.



Cate McCready
BIOTECanada

Cate McCready joined BIOTECanada in 2001 and currently serves in the role of Vice President External Affairs. Her role with BIOTECanada encompasses the development of national programs designed to inform and highlight the value of biotechnology innovation in Canada. A particular focus of her work has been to support regulatory and access to rare disease medicines for Canadian patients. Her experience includes more than eight years of service within the federal government. This included legislative and communications roles for federal ministers and as a senior advisor to the Prime Minister of Canada. Prior to her federal government experience, she served in corporate and non-profit roles for national organizations.

Chris McMaster
CIHR

Dr. McMaster is the Scientific Director of the Institute of Genetics for the Canadian Institutes of Health Research. His is also a Professor of Pharmacology in the Faculty of Medicine at Dalhousie University. Previously, he was the Carnegie and Rockefeller Professor and Head of Pharmacology at Dalhousie University, and was the Assistant Dean for Graduate and Post-doctoral Studies in the Faculty of Medicine at Dalhousie University. Dr. McMaster has identified several human genes and their functions, including many associated with inherited human disease. His work on therapeutics has resulted in a potential therapy for congenital sideroblastic anemia that is in Phase 2 trials, and has lead compounds undergoing development for the treatment of the inherited blinding disorder familial exudative vitreoretinopathy, inherited Parkinson's disease, and a form of muscular dystrophy.

Dev Menon
University of Alberta

Dr. Menon is currently Professor and Senior Advisor in the Health Technology & Policy Unit at the University of Alberta School of Public Health. He was the first Executive Director of CADTH, which, at the time, was known as the Canadian Coordinating Office for Health Technology Assessment (CCOHTA). In the early nineties, Dr. Menon helped establish the first international network of HTA agencies. In the course of his 34-year career as a professor, Dr. Menon has introduced students to HTA and its importance for decision-makers, and encouraged them to participate in the process as HTA producers, methodologists, knowledge mobilizers, and users.

Alex Munter
CHEO

Since 2011, Alex has served as President and CEO of the Children's Hospital of Eastern Ontario (CHEO). He has helped CHEO earn recognition as one of Canada's most admired corporate cultures and a leader in research, health technology and patient-centred care. Previously, Alex was CEO of the Champlain LHIN. Alex has won numerous awards for his contributions to the community, including the Centre for Addiction and Mental Health, the Canadian Institute for Child Health, United Way/Centraide Ottawa, the Federal Business Development Bank, and Leadership Ottawa.

Neil Palmer
PDCI Market Access Inc.

Neil Palmer is President and Principal Consultant of PDCI Market Access Inc (PDCI), a pricing and reimbursement consultancy. In addition to PCDI, Neil has worked for RTI Health Solutions, the Patented Medicine Prices Review Board (PMPRB), the Health Division of Statistics Canada and the research group of the Kellogg Centre for Advanced Studies in Primary Care in Montreal. He has more than 20 years of experience in pharmaceutical pricing and reimbursement and is a frequent speaker at pharmaceutical conferences in North America and Europe. Professor Palmer received his B.A. in Economics and Geography from the University of Western Ontario in Canada.

Beth Potter
University of Ottawa

Dr. Beth Potter has been a faculty member in the School of Epidemiology and Public Health since 2007. She holds a PhD in epidemiology from the University of Western Ontario (2003) and an MSc in applied human nutrition from the University of Guelph (1998). Dr. Potter has a long-standing interest in maternal and child health. Her research uses quantitative, qualitative, and mixed methods, focusing in two related areas: clinical interventions and family-centred health services for rare diseases in children; and disease screening, particularly newborn and prenatal screening

Cheryl Rockman-Greenberg
Max Rady College of Medicine - University of Manitoba

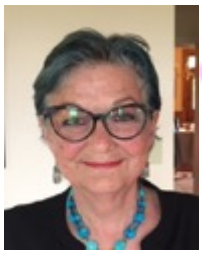
Dr. Greenberg is Professor and Head of the Department of Pediatrics and Child Health, University of Manitoba and Medical Director, Child Health Program, Winnipeg Regional Health Authority. She has held these positions since April 2004. She is the Director of the Metabolic Service and a clinical geneticist in the Program in Genetics and Metabolism since 1992 and 1979 respectively and is a Professor in the Department of Pediatrics and Child Health and the Department of Biochemistry and Medical Genetics, University of Manitoba since 1994. In 2018, Dr Greenberg was inducted into the Canadian Medical Hall of Fame and appointed to the Order of Canada as an Officer of the Order in 2019.

Maureen Smith
CORD

Maureen Smith, M.Ed., has a long history of collaboration with the medical community subsequent to a rare disease diagnosis in childhood and has been serving on various committees and advisory groups for the past 20 years. She has been a member of the Board of Directors of CORD since 2008. Maureen joined the Advocacy Committee of Rare Diseases International in 2017. She is a member of PCORI's Rare Disease Advisory Panel. Maureen is a co-investigator on two pan-Canadian research projects in paediatric rare diseases and has participated in a number of Cochrane projects. She is a patient member on two provincial health technology assessment committees.

Tania Stafinski
University of Alberta

Tania Stafinski is Director of the Health Technology and Policy Unit in the School of Public Health, University of Alberta, teaches a graduate level course in HTA and is a mentor in the Fellowship Program in Health System Improvement. She holds an MSc in epidemiology and a PhD in public health sciences, both from the University of Alberta.



Robin Sully
Myeloma Canada

Robin is a retired international lawyer with 20 years of experience supporting rule of law and human rights programs in Asia, Africa, the Caribbean and Eastern Europe. In 2012 she was diagnosed with Multiple Myeloma and is currently Co-chair of the Ottawa-Gatineau Myeloma Community Support Network; a member of the Ottawa-Gatineau Myeloma Walk Committee; Chair of the Multiple Myeloma Ontario Advocacy Committee and a Board Member of Arnprior Regional Health (ARH).

Biba Tinga
Sickle Cell Disease Association of Canada

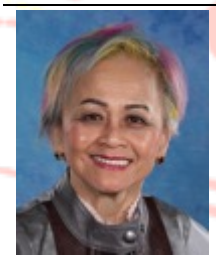
Canada/Association d'anémie falciforme du Canada (SCDAC/AAFC). Prior to serving in this role, she served as the Vice-President of the organization from 2014 to 2017. As a parent of a young adult living with sickle cell disease, she has a unique understanding of the needs of the patients and the families dealing with the disease. For more than 10 years she has leveraged her experience of experimenting with new drugs or treatment option, the risk and stigma associated with SCD to advocate on behalf the families.

Elizabeth Toller
Health Canada

Elizabeth Toller is an experienced policy specialist and public sector leader with over eleven years' experience working in the Government of Canada. Her passion for health issues and social policy has seen Elizabeth split her time in government between Health Canada, Immigration, Refugees, and Citizenship Canada, and the Privy Council Office. Elizabeth currently serves as the Executive Director for Regulatory Innovation in Health Canada's Health Products and Food Branch, driving the modernization of Canada's food and drug regulations in support of innovation and competitiveness.

Karen Voin
CLIHA

Karen Voin is Vice President, Group Benefits and Anti-Fraud for the Canadian Life and Health Insurance Association (CLHIA). In this role, Karen is responsible for overseeing and advocating for the industry's extensive interests related to health and disability insurance, in addition to the industry's anti-fraud strategy. Prior to joining CLHIA in 2011, Karen worked for various life and health insurance organizations in a leadership capacity.



Durhane Wong-Rieger
CORD

Dr. Wong-Rieger is Chair of Rare Disease International, Vice-Chair of Asia Pacific Rare Disease International, member of the Editorial Board of The Patient Patient Centred Outcomes Research, member of the Global Commission to End the Diagnosis Odyssey for Rare Diseases and member of Health Technology Assessment International Patient /Citizen Involvement Interest Group. In Canada, she is President & CEO of the Canadian Organization for Rare Disorders, Chair of the Consumer Advocare Network, President & CEO of the Institute for Optimizing Health Outcomes and Chair of

Canadian Heart Patient Alliance. She is a certified Health Coach and has served on numerous health policy advisory committees and panels and is a member of Ontario's Rare Disease Implementation Working Group and member of Genome Canada Steering Committee for the Rare Disease Precision Health Initiative. Durhane has a PhD in psychology from McGill University and was professor at the University of Windsor. She is a trainer and frequent lecturer and author of three books and many articles.

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 that have supported this conference.