
# SPEAKER BIOS

## Sandra Anderson

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. In her time at Innomar she's had many leadership roles across the business including pharmacovigilance, training, patient support programs and new business development. 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).

## Jamie Bruce

Mr. Bruce is a co-founder of Khure Health, a former senior executive at Shoppers Drug Mart and a former Partner at Oliver Wyman, a leading global strategy consulting firm. He has significant experience working with healthcare organizations and electronic medical record platforms to create patient-oriented technology strategies designed to improve the cost and quality of healthcare.

## Craig Campbell

Craig Campbell is the Deputy Chair of Pediatrics and Division Head of Pediatric Neurology. He directs the multidisciplinary neuromuscular clinic based at Thames Valley Children's Centre and the Pediatric Neurophysiology Laboratory at Children's Hospital London Health Sciences Centre. He is an Associate Professor in Pediatrics, Clinical Neurological Sciences and Epidemiology at Western University and a Scientist at the Children's Health Research Institute.

## Niya Chari

Niya Chari joined the Canadian Breast Cancer Network in 2012. She leads the strategic direction of the organization's public relations and health policy strategy to inform healthcare decision-making. With over 15 years of policy development and advocacy experience, she also holds a Master of International Public Health degree from the University of Queensland, Australia and has influenced policy-making at the municipal, provincial, federal and global levels.

## Wayne Critchley

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 is regularly called upon to write and present on Canadian pharmaceutical issues. He is active with the Canadian Club of Ottawa where he served as President for 2012-13.

## Christine Dalgleish

Christine Dalgleish developed a passion for patient/family engagement while navigating a complex diagnostic journey with her youngest daughter, Abby, who has an ultra-rare genetic mutation. Christine is a member of the CHEO Family Advisory Council, the CHEO School Authority Board and the CHEO Research Institute Family Leader Program. Christine lives with her family in Ottawa and works full time in health care communications. She holds an honours BA from the University of Toronto.

## Linsay Davis

Linsay Davis is a Regional Medical Director at AveXis. She is a pharmacist and has a Masters degree in Health Policy from Columbia University. She works with physicians, payers, and governmental agencies in the United States to help further understand Spinal Muscular Atrophy and it's treatment options. She is committed to advancing understanding of Rare Disease and is looking forward to discussing gene therapy today.

## Bill Dempster

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.

## Kristy Dickinson

When Kristy was diagnosed with Ehlers-Danlos Syndrome at 37, her life changed in an instant. When she went looking for a solution to manage all of the administrative tasks that accompany life with a chronic illness, nothing existed. Kristy created Chronically Simple to manage her healthcare, and with the intention to empower others to do the same.

Chronically Simple alleviates the administrative burden, allowing patients and caregivers to manage the complexities of living with a chronic illness or disability, without additional, unneeded stress. Take control of the administrative work by linking prescriptions and test results to physicians, to appointments, to expenses, and care team members, giving you a truly holistic view of your healthcare. www.chronicallysimple.com

## Michael Duong

Michael is the Head of Personalized Healthcare for Hoffmann-La Roche Limited. In this role, Michael leads a team responsible for Roche's strategy to advance the personalization of healthcare in Canada. Michael also sits on the board of the Canadian Personalized Healthcare Innovation Network (CPHIN) which is a not for profit consortium of members from both public and private sectors focused on the acceleration of personalized healthcare for Canada.Michael received his undergraduate degree in Biology and Pharmacology and a Ph.D. in Medical Sciences with a specialization in Neuroscience, both from McMaster University.

## Cathy Evanochko

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

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

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.

## Brent Fraser

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.

## Daniel Gaudet

Daniel Gaudet, MD, Ph.D., is professor of medicine at University de Montreal and the scientific director of the Genome Quebec Technology Platform (biobank) in Chicoutimi. He founded the Université de Montréal Community Genomics Medicine Center, the Lipid Research Group and the Lipid Clinic at the Chicoutimi Hospital, where he was also director of research for ten years. In 2000, Dr. Gaudet founded ECOGENE-21. This huge enterprise in translational medicine aims at the development and evaluation of diagnostic tools, novel treatments, new knowledge and technologies from research in genetics and omic sciences, and their application to clinical practice at the community level. Dr. Gaudet is hugely concerned about access issues that promising drugable therapies might have to deal with.

## Judith Glennie

Dr. Glennie is the President of J.L. Glennie Consulting Inc. and a senior member of the health care community, with over 25 years of experience in the national and international pharmaceutical policy world. Her public policy expertise is derived from her leadership roles as: Associate Director, Drug Programs Branch, Ontario Ministry of Health and Long-Term Care; Manager and Director roles at Health Canada's Health Products and Foods Branch; and, Federal Cabinet appointment to the Patented Medicine Prices Review Board. Prior to returning to the consulting world, she was also with Janssen Canada. Judy is also the Knowledge Broker Consultant for the PRISM research initiative, which focuses on rare disease drug policy research.

## Paulo Gomes

Mr. Gomes is a co-founder of Khure Health and Director of DoctorCare an organization that helps over 2000 primary care physicians optimize their practices to provide better patient care. For over a decade, Mr. Gomes has worked with clinicians and technology solutions to simplify physician workflows and increase the amount of time physicians spend on care.

## Oxana Illich

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, Toronto, Canada 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.

## James Kennedy

Dr. James L. Kennedy is Head of Molecular Science and Head of the Tanenbaum Centre for Pharmacogenetics in the Campbell Family Mental Health Research Institute at CAMH. He is Professor in the Department of Psychiatry and Institute of Medical Science at the University of Toronto.

## Jay Konduros

Jay is a person with factor IX hemophilia who has recently undergone experimental gene therapy. Born in Montreal in 1964, one of four children including an older brother with hemophilia, Jay's life has been interspersed with a multitude of bleeding episodes and recovery periods, treating with blood plasma, factor concentrate, and recombinant products. Jay has lived through many eras of hemophilia care and considers himself extremely fortunate to take part in such a life changing hemophilia therapy.

## Marc LePage

Before assuming this role in January 2016, he served as President and CEO of Génome Québec since December 2011, where he led a major increase in research activity and enhanced focus on the development of genomic applications within priority sectors within the province. Marc LePage 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, he 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.

## Brandon Levac

Brandon Levac is a Senior Manager in Bayer's Market Access department. He is responsible for patient access and stakeholder relations for Bayer's oncology portfolio and interfaces with public and private payers, HTA bodies and patient groups. Brandon has 10 years of Canadian market access experience in a variety of different roles, and has also held industry positions in sales and competitive intelligence both in Canada and globally.

## Mark Lundie

Mark received his PhD in Pharmacology & Toxicology from Queen's University in 1995. He has been with Pfizer Canada for 21 years and has been the Director of Medical Affairs for Rare Diseases since 2013. He also serves as a Director on the Boards of Clinical Trials Ontario, Ontario Genomics and the Center for Probed Development & Commercialization, as well as a reviewer with Ontario Genomics GAPP program.

## Elizabeth Lye

Elizabeth Lye is the Director of Research & Programs at Lymphoma Canada. Elizabeth's knowledge lies in cancer research and knowledge translation targeting patients, healthcare professionals and the public. Her role at Lymphoma Canada includes patient and HCP education, advocacy, and stakeholder relations. Elizabeth is passionate about ensuring lymphoma patients' needs, priorities and values are reflected in clinical research design, cancer care funding and health policy.

## Chris MacLeod

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.

## Michael May

Dr. May is President & CEO at the Centre for Commercialization of Regenerative Medicine (CCRM). A Canadian, not-for-profit that develops technologies, launches new companies and catalyzes investment in the field of regenerative medicine, including cell and gene therapy. Prior to CCRM, Michael was the President, and co-founder, of Rimon Therapeutics Ltd., a Toronto-based tissue engineering company developing novel medical polymers that possess drug-like activity.Dr. May completed his PhD in Chemical Engineering at the University of Toronto as an NSERC Scholar and was awarded the Martin Walmsley Fellowship for Technological Entrepreneurship.

## Joan McCormick

Since joining Brogan Inc. in 1992, Joan has been assisting major pharmaceutical companies in preparing pricing submissions to the Patented Medicine Prices Review Board (PMPRB) gaining extensive experience in the operation of the Canadian pharmaceutical market. Joan now leads the Price Regulation Consulting Team for IQVIA, providing analysis, advice and training. Joan obtained her Bachelor's degree in Life Sciences from Queen's University in Kingston and her Masters in Business Administration from the University of Ottawa.

## Bob McLay

Bob is Vice President and General Manager at Sobi Canada. He holds an MBA from Auburn University and BSc from the University of Guelph. Bob has over 23 years of experience in the pharmaceutical industry with multiple leadership roles in marketing, sales, patient access, supply chain, trade relations and business development. Previously, Bob held senior level positions with both large and small pharmaceutical companies including Merus Labs International, Takeda Canada, Graceway Pharmaceuticals and Pfizer Canada.

## Darlene Morden

Darlene a mother of two boys. Her eldest son Eric is 19 and has Duchenne muscular dystrophy. She works part-time as an accountant and part-time managing Eric's appointments. Since 2003, Darlene and her family, along with friends, have raised over $500,000 for Jesse's Journey - The Foundation for Gene & Cell Therapy. Earlier this year, Eric started post-secondary school at Carleton University in Ottawa.

## Maxwell Morgan

Max leads open science policy development and outreach, as well as translational initiatives for open innovation at SGC. In this role, Max helped found M4K Pharma Inc. ('Medicines for Kids') and continues to advise the company on the legal and policy aspects of its open drug discovery model. Prior to his work with SGC and M4K, Max was an intellectual property litigator and pharmaceutical regulatory lawyer, and more recently served as in-house counsel with Grand Challenges Canada. Max holds a B.Sc. from McGill University, a J.D. from the University of Toronto, and an LL.M. from Harvard Law School. He is also an adjunct professor at UofT's Faculty of Law

## David Page

David Page is Director of Health Policy for the Canadian Hemophilia Society (CHS). He served as a volunteer with the CHS from 1982 to 2001, including a 2-year term as President. He was National Executive Director from 2006 to 2018. David served on the Quebec Hemovigilance Committee advising the Minister of Health on blood safety issues from 1998 to 2006, including four years as president. He is currently chairperson of the Héma-Québec Safety Committee. David is a member of the World Federation of Hemophilia Coagulation Products Safety, Supply and Access Committee. David has severe factor IX deficiency.

## Neil Palmer

Neil Palmer is President and Principal Consultant of PDCI Market Access Inc (PDCI), a pricing and reimbursement consultancy founded as Palmer D'Angelo Consulting in 1996. 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.

## Terry Pirovolakis

Terry's youngest son was diagnosed with Spastic Paraplegia 50 (SPG50), a ultrarare neurodegenerative disease. Since that day, he has been on a mission to find a cure that will not only help his son, but all of the children affected by this terrible disease. He has begun to start work with the leading scientists in an effort to create a gene therapy treatment that will cure this disease.

## Nigel Rawson

Dr. Nigel Rawson is a pharmacoepidemiologist, pharmaceutical policy researcher, and President of Eastlake Research Group in Oakville, Ontario. Educated in the United Kingdom, he holds an MSc in statistics and a PhD in pharmacoepidemiology. Dr. Rawson has performed epidemiologic studies of the use of drugs and their outcomes for over 35 years and published more than 120 book chapters and articles in peer-reviewed journals.

## Danielle Rollmann

Danielle Rollmann is a Partner of Next Wave Consulting, focused on helping organizations plan for strategic growth in a dynamic market environment, design and build new capabilities and advance the next wave of innovation. Previously she led Access Priorities and International Policy within Pfizer's Global Policy team, where she worked on rare disease/gene therapy issues and alternative payment models. Prior, she was a partner in the Global Health Practice of Booz & Company, a general management consultancy.

## Celia Segel

Celia Segel serves as the Director of Comparative Effectiveness Research Policy Development. In this capacity, Celia supports collaboration with key industry leaders across pharmaceutical companies, pharmacy benefit managers, and payer organizations to promote evidence based policy. In the past year, Celia has led ICER's initiative in collaboration with government-run agencies in the U.K. and Canada to evaluate and establish methods for assessing potentially curative treatments. Celia joined ICER in Spring 2016, leading nearly ten drug evaluations to understand the comparative effectiveness and value of over 40 therapies collectively. Prior to her time at ICER, Celia worked as a political organizer and advocate in Massachusetts, running campaigns to improve access and affordability of health care. Celia has worked on a number of political campaigns in Pennsylvania, Vermont, and Massachusetts and also worked for Senator Al Franken in his DC office from 2009-2010. Celia graduated from Carleton College and received a Master in Public Policy at the Harvard Kennedy School.

## Josh Silvertown

Josh is the Senior Manager, Medical Affairs Strategist (Oncology) for Bayer Canada leading medical affairs for TRK fusion cancer therapies in Canada. Prior to this role, Josh was a Medical Scientific Advisor (Hematology) for Bayer Canada leading medical affairs for the hemophilia portfolio. Prior to Bayer, Josh worked in executive roles for Toronto-based biotech companies focused on the development and commercialisation of drug (Armour Therapeutics) and diagnostic device (Quantum Dental Technologies) products. Josh also worked at AXON Clinical Research in Manhattan, New York, as the Director of Scientific Affairs and Business Development. Josh did his post-doctorate at the Ontario Cancer Institute in Toronto, his PhD in Biomedical Sciences at the University of Guelph, and MBA from the Ivey School of Business at Western University.

## Danica Stanimirovic

Danica Stanimirovic, MD, PhD is Director of the Translational Bioscience Department, NRC's Human Health Therapeutics Research Centre. She manages a portfolio of R&D projects in partnership with academia and Canadian and international biopharma companies, to develop de-risk and advance antibody- and gene therapies through preclinical development. A recipient of several Canadian and international awards, she has authored over 170 manuscripts and 20 patents in the field of integrative neuroscience, innovative biologics and brain drug delivery.

## Biba Tinga

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.

## Helen Trifonopoulos

Helen Trifonopoulos is the Head of Health Policy and Patient Access at Novartis Oncology. She leads a team of professionals responsible for health economics and outcomes research, value and access strategy, government and stakeholder relations, and health systems partnerships. Helen has over 20 years of experience in the pharmaceutical industry working for Merck and Novartis. She has held roles in commercial, medical education, policy and reimbursement across multiple therapeutic areas and various phases of the product life cycle. Most recently, Helen has had the privilege of working in novel areas like immuno-oncology and cell and gene therapies. Helen holds a Bachelor of Arts in Political Science from McGill University and an MBA from the John Molson School of Business.

## Susi Vander Wyk

Susi Vander Wyk became involved with the SMA community after the diagnoses of her daughter. After a brief grieving period, she heavily involved herself in Canadian SMA. She initiated patient and peer support programs as well as fundraising for research. She spent 10 years on the board for Cure SMA Canada before her 10-year position as executive director. Cure SMA Canada is the national patient group dedicated to supporting patients affected by Spinal Muscular Atrophy.

## Jeff Wandzura

Jeff Wandzura is a pharmacist, entrepreneur and digital health executive who is passionate about using data and technology to solve challenges facing patients and the healthcare community. Jeff founded two digital health ventures (MobiCare Health & PatientPrep) that were later acquired, and he's held senior roles in biotech, hospital IT and specialty pharmacy organizations. Jeff has been recognized as one of Canada's Next 36 and CBC's Future 40.

## Jian Wang

Dr. Jian Wang manages a team of scientific and clinical evaluators responsible for pre-market risk/benefit assessment. His division has regulatory responsibility for assessing non-clinical, pharmacology and clinical data for biological drugs for the treatment of haematological, oncological, and infectious diseases. At the moment, radiopharmaceuticals, gene therapies and biosimilars (regardless of their indications) are also regulated by the Division. Dr. Wang has broad regulatory experience in pre-market drug regulations for generics, biologics and biosimilars. He joined the Health Canada Pesticide Management Regulatory Agency in 1996. Then, he worked for the Therapeutic Products Directorate (TPD) prior to working at the Biologics and Genetic Therapies Directorate (BGTD). He actively participates in various Health Canada, ICH, WHO and DIA working groups and expert committees. He is a member of WHO drafting group for "Guidelines on evaluation of monoclonal antibodies as similar biotherapeutic products" and DIA Biosimilar Conference Program Committee (since 2013).

## Suzanne White

Using evidence-based methodologies and a person-centric approach, Suzanne leverages her skills in human factor's engineering to conduct Quality of Life studies. The results from the data collections are used for the development of registries, raise awareness, inform patient groups of membership unmet needs; and /or for drug approvals. The goal is to integrate the lived experiences into health care for meaningful outcomes. She is a person with an ultra-rare disease.

## Durhane Wong-Rieger

Durhane Wong-Rieger is President of CORD, Chair of Consumer Advocare Network, President of the Institute for Optimizing Health Outcomes, Chair of Canadian Heart Patient Alliance and member of Genome Canada Steering Committee for the Rare Disease Precision Health Initiative. Internationally, she serves as Chair of Rare Disease International, Chair of International Rare Disease Research Consortium Patient Advocates Constituency, Board member of Asia Pacific Alliance of Rare Disease Organizations, and member of the Editorial Board of The Patient. She has a PhD in psychology from McGill University.

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.

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