## Translating Arthritis: Knowledge to Action for Canadians

presented in partnership with the CIHR Institute of Musculoskeletal Health and Arthritis and The Arthritis Society









### **PROGRAM**

October 27-28, 2016 InterContinental Hotel, Montréal, Québec



Dear Delegate,

I am delighted to welcome you to the Arthritis Alliance of Canada's Annual Meeting, "Translating Arthritis: Knowledge to Action for Canadians", presented in partnership with the Canadian Institutes of Health Research Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA) and The Arthritis Society.

We are very fortunate to have Canada's leading experts in arthritis care and research; specialists, health care providers, researchers, trainees, industry, government affiliates and most importantly, consumers, for a very busy but very rewarding programme. The next two days will feature a fun and engaging panel discussion, workshops, educational sessions and an awards and networking dinner to celebrate our successes.

We look forward to engaging with all of you throughout the program, sharing best practices and continuing to work together on future initiatives. Planning of the Annual Meeting programme involves a great deal of work and we would like to thank our invited guest speakers, presenters and volunteers on all the planning committees that made this possible.

Finally, on behalf of the Board of Directors, a special thanks to each of you for collaborating with us to improve the lives of people living with arthritis. We are stronger together!

Sincerely,

Janet Yale

Chair, Arthritis Alliance of Canada

Board of Directors, Arthritis Alliance of Canada:

Ms. Janet Yale, Chair, The Arthritis Society Representative

Dr. Vandana Ahluwalia, Canadian Rheumatology Association Representative

Mr. Andrew Casey, Corporate Representative

Ms. Cheryl Koehn, Patient Representative

Ms. Terri Lupton, Member's Representative

Dr. Deborah Marshall, Research Representative

Dr. Dianne Mosher, Advisor and Past Chair

Mr. Doug Thomson, Canadian Orthopaedic Association Representative



Dear Colleagues,

On behalf of the Canadian Institutes of Health Research Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA), I would like to welcome you to the Arthritis Alliance of Canada's 4th Annual Meeting.

This year's meeting theme of "Translating Arthritis: Knowledge to Action for Canadians" is very near and dear to the Institute, especially given its legacy of patient engagement as established years ago by our inaugural scientific director, Dr. Cy Frank, Because of this theme, we are pleased to host a workshop this year with our Research Ambassadors as part of the AAC agenda on Patient Engagement in Research with a focus on biomedical research.

I would like to extend deepest thanks to all the distinguished guest speakers contributing to this year's meeting and look forward to hearing the compelling discussions that no doubt will arise. Many thanks also to the hard work of the organizers and their dedication to bringing everyone together for this important annual event.

I hope that everyone attending will be able to bring back to their respective communities, knowledge to put into action to improve quality of life for those living with such chronic conditions as arthritis.

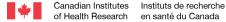
Sincerely,

Hani El-Gabalawy, MD, FRCPC, FCAHS

Scientific Director

Canadian Institutes of Health Research

Institute of Musculoskeletal Health and Arthritis





Thursday October 27, 2016		
7:00 am – 8:00 am	Continental Breakfast: The Arthritis Society Trainees	Foyer Saint Laurent
	thritis Alliance of Canada: I Meeting and Workshops	Salon Maisonneuve
8:00 am – 10:00 am	Continental Breakfast to be served in a meeting room  AAC Inflammatory Arthritis Models (IA) of Care Workshop: A Pan-Canadian Core Clinical Dataset for Rheumatoid Arthritis (RA)  Review work from the Core Clinical Dataset Models of Care work group. including an update on testing of the System-Level Performance Measures for IA and expansion of the measurement framework to include provider-level process measures and patient outcomes. This work provides context for the importance of the current project: Development of a Pan-Canadian Core Clinical Dataset for RA  Review and discussion of the proposed Pan-Canadian Core Clinical Dataset for RA  Provincial examples and discussion of the incorporation of the core clinical dataset into practice	Dr. Vandana Ahluwalia, Corporate Chief of Rheumatology, William Osler Health System, Brampton, ON  Dr. Claire Barber, Rheumatologist, Division of Rheumatology, University of Calgary, Calgary, AB  Dr. Cheryl Barnabe, Associate Professor, Departments of Medicine and Community Health Sciences, University of Calgary, Calgary, AB  Dr. Dianne Mosher, Division Chief of Rheumatology, University of Calgary, Calgary, AB  Dr. Michel Zummer, Division Chief of Rheumatology, CH Maisonneuve-Rosemont, Associate Professor, Université de Montréal, Montréal, QC
10:00 am – 10:15 am	Health Break/Transition: AAC guests	Foyer Salon Maisonneuve
10:15 am – 12:15 pm	AAC and College of Family Physicians of Canada (CFPC), collaborate to develop osteoarthritis (OA) toolkit for family practice: A clinical tool to effectively identify, assess, monitor, and care for the more than 4.3 Million Canadians living with OA  • Overview of the approach to developing the OA toolkit; progress to date  • Osteoarthritis quality improvement in primary care example and key learnings  • Implementation, dissemination and evaluation of the toolkit. What can you do to help?	Dr. Gillian Hawker, Sir John and Lady Eaton Professor, Department of Medicine, University of Toronto, ON Dr. Natasha Gakhal, Rheumatologist, Women's College Hospital, Toronto, ON Ms. Gunita Mitera, Director, Program and Practice Support, The College of Family Physicians of Canada, Mississauga, ON
12:15 pm – 1:00 pm	<b>Joint Networking Lunch:</b> AAC guests and The Arthritis Society Trainees	Foyer Salon Maisonneuve

1:00 pm – 2:00 pm	Panel Discussion: "Sunny Ways: Building A National Strategy to Overcome Arthritis"  Join us for an engaging discussion of politics, media and public policy issues confronting Ottawa as we reach the first year anniversary of the new government's election.	Ms. Janet Yale, Chair, Arthritis Alliance of Canada, Toronto, ON Mr. Yves Robillard, Member of Parliament for Marc-Aurèle-Fortin, Ottawa, ON  Panel Moderator: Mr. Scott Reid, CTV Political Analyst, Ottawa, ON Guest Panel Speakers: Mr. Tim Powers, Vice-Chairman Summa Strategies, Ottawa, ON Mr. Rob Silver, Carleton University, Ottawa, ON Ms. Marlene Floyd, Ottawa, ON
2:00 pm – 2:30 pm	<b>Joint Health Break:</b> AAC and CIHR-IM-HA's guests, and The Arthritis Society Trainees	Foyer Salon Maisonneuve
2:30 pm – 4:30 pm	CIHR-IMHA's Research Ambassadors Workshop and Panel Discussion: Patient Engagement in Research  Identify the spectrum of potential roles for patients in the design, assessment, and implementation of biomedical research  Become better informed about initiatives that various national and international organizations have undertaken for patient engagement in research  Explore partnerships that will facilitate and accelerate meaningful patient engagement in biomedical research	Mr. Sylvain Bédard, Patient Coordinator, Centre of Excellence on Patient and Public Partnership, Montreal, QC  Mr. Alexandre Berkesse, Manager, Partnership School, Centre of Excellence on Patient and Public Partnership, Montreal, QC  Dr. Hani El-Gabalawy, Scientific Director, CIHR Institute of Musculoskeletal Health and Arthritis, Winnipeg, MB  Ms. Suzanne Schrandt, Director of Patient Engagement, Arthritis Foundation, Atlanta, Georgia, USA  Mr. Allan Stordy, Patient Advocate, Calgary, AB Panel Moderator:  Dr. Debbie Feldman, PhD, Professor in Rehabilitation Sciences, University of Montreal, Montreal, QC
5:30 pm – 6:30 pm	Reception/Poster Viewing Session: The Arthritis Society Trainees and AAC Arthritis Consumer Organizations	Foyer Salon Maisonneuve
6:30 pm – 8:30 pm	Gala Dinner "Translating Arthritis: Knowledge to Action for Canadians":  • The Qualman-Davies Arthritis Consumer Community Leadership Award  • The Arthritis Society Trainee Awards  • The AAC Research Awards Program Launch	Salon Maisonneuve

Friday October 28, 2016		
	thritis Alliance of Canada: I Meeting and Workshops	Salon Maisonneuve
7:00 am – 8:00 am	<b>Joint Networking Breakfast:</b> AAC and CIHR-IMHA's guests, and The Arthritis Society Trainees	Foyer Salon Maisonneuve
8:00 am – 10:00 am	The Alliance Advantage: Working together to amplify the voice of arthritis in Canada  Alliance Advantage Framework  1. Issues  Identify regional issues aligned with AAC federal government engagement  Review priorities/ opportunities in the federal government's Year 2 agenda  2. Messages  What is our arthritis story? What are our policy recommendations?  What communication tools (conventional and digital) do we use to deliver our story and messages?  3. Mobilize  How can we best activate the power of our alliance?  Alliance Advantage in Action  Through the Alliance Advantage Framework, participants workshop recommendations to integrate regional issues and voices in support of AAC federal government engagement.	Ms. Michelle McLean, Vice-President, Hill and Knowlton Strategies, Ottawa, ON  Ms. Janet Yale, Chair, Arthritis Alliance of Canada, Toronto, ON  Mr. Kelly Lendvoy, Vice President, Communications and Public Affairs, Arthritis Consumer Experts, Vancouver, BC  Ms. Tania Alexander, Marketing Manager, Janssen Inc., Hamilton, ON  Ms. Gillian Kennedy, Manager, Government Affairs, AbbVie Canada, Toronto, ON  Dr. Frances LeBlanc, Manager, Government Relations, Canadian Chiropractic Association, Moncton, NB

10:15 am – 12:15 pm	<ul> <li>Arthritis Consumer-Patient Organizations and Groups Coalition Workshop:         Patients in Patient-Oriented Research: What Should it Look Like?         <ul> <li>To bring together key stakeholders to exchange knowledge, information and models of meaningful consumer-patient engagement, and participation in Canadian health research</li> <li>To identify opportunities to build meaningful and long-lasting linkages to SPOR SUPPORT Units, SPOR Networks and other research activities in Canada</li> </ul> </li> </ul>	Presenters:  Ms. Cheryl Koehn, Founder and President, Arthritis Consumer Experts, Vancouver, BC  Ms. Alison Hoens, Member, Arthritis Patient Advisory Board of the Arthritis Research Canada, Vancouver, BC  Dr. Beverly Holmes, Michael Smith Foundation for Health Research (MSFHR) and British Columbia SUPPORT Unit, Vancouver, BC  Mr. Tim Murphy, Provincial Platforms and SPOR, Alberta Innovates – Health Solutions, Edmonton, AB  Panelists:  Ms. Alison Hoens, Ms. Cheryl Koehn Dr. Beverly Holmes, Mr. Tim Murphy, and Dr. Sharon Straus, Professor, Vice Chair, and Director, Division of Geriatric Medicine, Department of Medicine, University of Toronto; Deputy Physician-In-Chief Director of the Knowledge Translation Program, St. Michael's Hospital, Toronto, ON
12:15 pm – 1:15 pm	AAC Annual General Meeting / Working Lunch AAC and CIHR-IMHA's guests, and The Arthritis Society Trainees	Salon Maisonneuve / Foyer Salon Maisonneuve
1:30 pm – 3:30 pm	AAC Research Workshop: Knowledge Translation Research and Practice in Disseminating and Implementing Arthritis Models of Care into Practice  Inform participants about different terms that exist for Knowledge Translation (KT)  Provide explanation of "what it is and what it isn't" Knowledge Translation (KT) science and practice and how to optimize its application into research and practice  Look at the KT Action framework; and addressing the different terms for KT, identify the key components of the IA Model of Care  Using key components of the AAC IA Model of Care, begin the development of a KT plan to support its implementation using recommended tools and resources	Dr. Kelli Allen, PhD, Research Professor of Medicine, Thurston Arthritis Research Center, University of North Carolina at Chapel Hill; Center for Health Services Research in Primary Care, Durham VA Medical Center, USA  Dr. Sharon Straus, MD, MSc, FRCPC, Professor, Vice Chair, and Director, Division of Geriatric Medicine, Department of Medicine, University of Toronto; Deputy Physician-In-Chief Director of the Knowledge Translation Program, St. Michael's Hospital, Toronto, ON  Ms. Alison Hoens, Consumer Representative/Arthritis Patient Advisory Board of Arthritis Research Canada, Vancouver, BC  Dr. Deborah Marshall, Associate Professor, Department of Community Health Sciences, Arthur JE Child Chair in Rheumatology Research, University of Calgary, Calgary, AB
Saturday October 29, 2016		

# **AAC Inflammatory Arthritis Models (IA) of Care Workshop:** A Pan-Canadian Core Clinical Dataset for Rheumatoid Arthritis (RA)



**Dr. Vandana Ahluwalia** heads the Rheumatology Division of the William Osler Health System in Brampton, Ontario. She sees patients in her Brampton community practice as well as in the Rheumatology/Orthopedics MSK clinic at Brampton Civic Hospital. Having completed her medical training at the University of Toronto, Dr. Ahluwalia did her Internal Medicine training and

Rheumatology fellowship at U of T with a subsequent research fellowship focused on lupus.

She has been actively involved in the Ontario Best Practices Research Initiative (OBRI), a provincial prospective registry of patients with rheumatoid arthritis. In 2010-2012, Dr. Ahluwalia held the position of President of the Ontario Rheumatology Association (ORA). She remains active within the ORA in her role as Director of Models of Care. She provided leadership for the Models of Care (MOC) committee focused on identifying strategies to accelerate access to care for patients with inflammatory arthritis; as well as the Electronic Medical Records (EMR) committee that championed provincial EMR adoption and the creation of rheumatology specific tools within certified EMR platforms. In 2012, Dr Ahluwalia received the "Community Rheumatologist of the Year" award from the University of Toronto, Rheumatology Division. In 2013, she received the ORA President's Award for her leadership and her commitment to excellence. In May 2016, she received the ORA's "Rheumatologist of the Year award" in recognition for her pioneering work in models of care. Most recently, Dr. Ahluwalia was elected to the Vice President position on the Canadian Rheumatology Association Board of Directors where she will continue her advocacy role.



**Dr. Claire Barber**, Rheumatologist, Division of Rheumatology, University of Calgary.

Claire Barber MD, PhD, FRCPC is a Assistant Professor in the Division of Rheumatology, Department of Medicine at the Cumming School of Medicine in the University of Calgary and a Research Scientist at Arthritis Research Canada. Her research program focuses on evaluating

and improving the quality of care of people living with arthritis. She collaborated with arthritis stakeholders across Canada and the Arthritis Alliance of Canada (AAC) to develop System-Level Performance Measures for Inflammatory Arthritis and is currently testing these measures across Canada. In an extension of this work, she is currently working with the AAC and stakeholders to develop a core set of data elements for rheumatoid arthritis (RA) to promote best clinical practices and high quality care.

She has also collaborated with the Canadian Rheumatology Association (CRA) on the first National Rheumatologist Workforce survey (Stand Up and Be Counted), this work has shown some regional shortages in the distribution of rheumatologists and provided valuable information for rheumatologist workforce planning in Canada. She has also been a longstanding member of the American Quality Measures Subcommittee, which develops and advises on quality measures in the United States.



**Dr. Cheryl Barnabe**, Associate Professor, Departments of Medicine and Community Health Sciences, University of Calgary, Calgary, AR

Dr. Barnabe is a rheumatologist and epidemiologist/health services researcher at the University of Calgary. Her research program seeks to identify and resolve care gaps in arthritis

service models provided to Indigenous populations in Canada. This program involves describing arthritis burden and outcomes in Indigenous populations, defining and evaluating new models of care, and developing patient-centered decision tools for arthritis treatments.

**Dr. Dianne Mosher**, Division Chief of Rheumatology, University of Calgary, AB

Dr. Dianne Mosher is currently Professor of Medicine and the Division Head of Rheumatology at the University of Calgary.

She is past president of the Canadian Rheumatology Association and co-author of "Living Well with Arthritis." She was involved in the development of several national initiatives including the "Arthritis Bill of Rights" and was co-chair of the 2005 "Summit on Standards for Arthritis Prevention and Care." For this work, she was awarded the 2008 CRA Distinguished Rheumatologist Award.

She is past president and current advisor to the Board of the Arthritis Alliance of Canada, a coalition of arthritis stakeholders. Under her guidance, they released "The Impact of Arthritis in Canada: Today and Over the Next 30 Years" and the "Joint Action on Arthritis: A Framework to Improve Arthritis Prevention and Care in Canada." She is part of the Inflammatory Models of Care Executive that released the document, "Pan-Canadian Approach to IA Models of Care."

Her research interests includes models of care for arthritis and outcome measures for patients with arthritis. In February 2013, she received the Governor General of Canada's Queen Elizabeth Diamond Jubilee Medal for her contributions to arthritis care in Canada.



**Dr. Michel Zummer**, Division Chief of Rheumatology, CH Maisonneuve-Rosemont, Associate Professor, Université de Montréal, QC

Michel Zummer, M.D., FRCPC received his M.D. from Université Laval, followed by specialty training in internal medicine and rheumatology at the Université de Montréal and McGill University.

Dr. Zummer, is the Chief of Rheumatology at Maisonneuve-Rosemont

Hospital and Associate Professor (professeur agrégé) at the Université de Montréal and Past-President of the Canadian Rheumatology Association and of the Association des Médecins Rhumatologues de Québec. He is currently a board member of the Spondylitis Research Consortium of Canada (SPARCC), the Panamerican League of Associations for Rheumatology (PANLAR), and co-chairs the Models of Care Committee at the Arthritis Alliance of Canada (AAC).

Currently, Dr. Zummer's main focus is improving health care delivery for individuals with rheumatological problems. In addition his research interests include Psoriatic Arthritis, Spondyloarthritis and Rheumatoid Arthritis.

AAC and College of Family Physicians of Canada (CFPC), collaborate to develop osteoarthritis (OA) toolkit for family practice: A clinical tool to effectively identify, assess, monitor, and care for the more than 4.3 Million Canadians living with OA



**Dr. Gillian Hawker** is the Sir John and Lady Eaton Professor and Chair of Medicine and a rheumatologist/health services researcher at the University of Toronto. Dr. Hawker is a passionate advocate for improving access and outcomes of care for people with osteoarthritis, OA, which is the focus of her research. Among her many contributions to the field, she has shed light on

gender disparities in use of total joint replacement surgery for people with hip and knee OA. For her continued contributions to osteoarthritis research, Dr. Hawker was honoured in 2013 by The Arthritis Society of Canada with a Queen's Jubilee Medal. Dr. Hawker has received continuous peer-reviewed research funding from the Canadian Institutes of Health Research since 1994 and has published more than 230 peer-reviewed articles. Dr. Hawker is a founding member of the Arthritis Alliance of Canada.



**Dr. Natasha Gakhal** is a full time rheumatologist at Women's College Hospital in Toronto, Ontario and is a lecturer with the University of Toronto. She has a Masters of Science in quality improvement and patient safety. Her interest is improving access to rheumatology care and improving links between family practice and subspecialty care.



**Ms. Gunita Mitera**, Director, Programs and Practice Support, College of Family Physicians of Canada.

Gunita Mitera is the Director of the Programs and Practice Support Department at the College of Family Physicians of Canada. The strategic objective of her department is to forge collaborations with like-minded organizations

to develop and implement relevant pan-Canadian practice support tools that support Canadian family physicians in their everyday practice. Prior to joining the College, Gunita worked for a pan-Canadian organization funded by Health Canada and lead the development and implementation of multi-jurisdictional quality

improvement initiatives in cancer diagnosis and treatment. Gunita is also a health services researcher focused on radiation therapy for cancer treatment, with approximately 51 first author publications.

### **Panel Discussion:** "Sunny Ways: Building A National Strategy to Overcome Arthritis"

#### **AAC Opening and Welcome Remarks:**



**Ms. Janet Yale** is the president and CEO of The Arthritis Society (Canada). Janet previously served as executive vice president at TELUS, and president and CEO of the Canadian Cable Television Association, along with other c-suite roles in private, public and not-for-profit organizations. Currently Janet chairs the Arthritis Alliance of Canada and the Ontario Trillium

Foundation, and sits on the boards of CARE Canada, Samara and the Ottawa Art Gallery. Janet is a recipient of the Queen Elizabeth II Diamond Jubilee Medal.



**Mr. Yves Robillard**, Member of Parliament for Marc-Aurèle-Fortin.

Born in Verdun in 1942, Yves Robillard arrived in Laval in Ste-Rose district at a young age. He would end up spending the majority of his life in this area.

As a university graduate in pedagogy, technique recreation and human relations, he experienced an inspiring career as a high school teacher. Due to his curious and adventurous nature, he was eventually led to the world politics and Communications.

In recent years, he became more actively involved in federal politics, becoming also the president of the Liberal Association of Marc-Aurèle-Fortin, district where he lived and where he is today.

Now in Ottawa, he sits on the Standing Committee on Human Resources, Skills Development, Social Development and the Status of Disabled Persons. Yves is also part of interparliamentary group of Canadian-Lebanese friendship.

#### **Panel Moderator:**



Mr. Scott Reid, CTV Political Analyst

Scott Reid is a principal and co-founder of Feschuk.Reid and a communications professional who brings more than twenty year of experience in the design and execution of private and public sector communications strategies. From 1993 to 2006, Scott served in a variety of senior roles in the federal government including as Senior

Advisor and Director of Communications to Prime Minister Paul Martin. Scott serves as an on-air political analyst for CTV News and is on-air host and contributor at Newstalk 1010AM in Toronto. He also writes a column on national politics for the Ottawa Citizen.

#### **Guest Panel Speakers:**



**Mr. Tim Powers**, Vice-Chairman Summa Strategies

Tim Powers is Vice-Chairman of Summa Strategies and the Managing Director of Abacus Data. He offers clients a wide range of experience and expertise in the fields of business, communications, and public policy.

Mr. Powers has a Bachelor of Arts degree from Memorial University of Newfoundland, a Master of Arts degree (Atlantic Canada Studies) from St. Mary's University, and a Master of Sciences degree (Media and Communications) from the London School of Economics. Mr. Powers has also studied Public Sector Management at Harvard University. He is also a graduate of the Institute of Corporate Directors and has his ICD.D designation.

Mr. Powers is also a media commentator, appearing frequently on CBC's "Power and Politics" and Ottawa radio station CFRA. He also does a twice-weekly Ottawa report for VOCM in Newfoundland.

He is the Chairman of the Board of Directors for Rugby Canada, Lead Director of the Board of Directors for Park Lawn Corporation, and a Member of the Board of Trustees of the Centre for Addiction and Mental Health (CAMH).



Mr. Rob Silver, Carleton University

Rob Silver is currently a Distinguished Visiting Professor at Ryerson and the Practitioner-In-Residence at Carleton's Masters in Political Management Program.

A lawyer, political pundit and entrepreneur, until the end of 2015, Rob was a founding

partner at Crestview Strategy - a leading Canadian public affairs agency. While at Crestview he built a practice that included being the first Canadian policy consultant for Facebook, Amazon and Uber. He also provided strategic advice to senior executives at a range of publicly listed companies including one of Canada's largest financial institutions and one of the world's leading mining companies.

Rob used to be a regular panelist on CBC's Power and Politics' flagship Power Panel appearing twice weekly. Rob has also written about politics and policy for publications including the Globe and Mail and Macleans.

Rob sold his shares in Crestview and left CBC because of his wife's new job as Chief of Staff to the Prime Minister of Canada.

Rob has invested and worked with a number of digital and technology companies including purchasing Torontoist from its American owners who were shutting it down due to poor financial performance, helping to turn it around before selling it to St. Joseph's Media.

Rob won the 2016 National Fantasy Baseball Championships - the first Canadian to win the title.

In 2010 Rob was recognized as an International Political Rising Star by Campaigns and Elections Magazine. While in university, he was the most successful university debater in Canadian history winning two North American and two Canadian National debating championships.

Rob received his law degree from the University of Western Ontario and practiced at Oslers to start his professional career.



#### Ms. Marlene Floyd

From 2013-2015 Marlene served as Director of Operations and Outreach for Liberal Leader, and now Prime Minister, Justin Trudeau. Marlene has previously worked in the Regulatory and Government Affairs department of a national telecommunications company and has also served as an advisor to Prime Minister Paul

Martin and several federal Ministers on a diverse range of public policy matters. An avid volunteer, Marlene sits on several charity boards, is the Founder of Dress for Success Ottawa and has been a recipient of multiple honours for her extensive community involvement. Marlene is the proud mom of Maëlle and Élodie and is currently on maternity leave from her role as National Director, Corporate Affairs at Microsoft.

#### CIHR-IMHA's Research Ambassadors Workshop and Panel Discussion: Patient Engagement in Research



**Mr. Sylvain Bédard**, Patient Coordinator, Centre of Excellence on Patient and Public Partnership, Montreal, QC

A teacher and director of television and theatre, Sylvain Bédard first encountered transplantation in 1980 when diagnosed with HCM (hypertrophique cardiomyopathy), a genetic heart disease. Sylvain received a heart transplant in

2000 and has since embarked on remarkable expeditions including climbing Mont-Blanc in France (a 4800m ascent), and Bolivia's Sajama Mountain (6500m). A gold medalist at the World Transplant Games, he completed an expedition in the Sahara desert and co-created the "Transformative Journey – Engaging Life after Transplantation," a cross-Canada cycling expedition. A motivational speaker, he has spoken in support of transplantation at many conferences and published his journey in the Journal of Heart and Lung. His achievements have been covered by many major media outlets from Radio Canada to the Discovery channel. His medical adventures as a patient include arrhythmia, 3 pace-defibrillator implants, major blood clots, pulmonary embolism, major disc reconstruction and a number of other cardiac conditions... all with great recovery, a little more patient experience and a smile!



**Mr. Alexandre Berkesse**, Manager, Partnership School, Centre of Excellence on Patient and Public Partnership, Montreal, QC

Management consultant and professor, social responsibility researcher and PhD candidate in philosophy, Alexandre has contributed since

2010 to the cultural and organizational transformation of healthcare both through working on health professionals' education as project manager of the MD program reform, and through the major continuous improvement movements in care in Quebec where he leads the integration of patient partnership in 19 health institutions. Since the beginning of 2014, he also accompanied five Canadian research networks in the elaboration and the implementation of their patient partnership strategy. Dr. Berkesse holds an MA in Theoretical Physics, an MSc in Management, a Certificate in Board Governance, and a PhD in philosophy.



#### Dr. Hani El-Gabalawy, MD FRCPC, FCAHS

Dr. Hani El-Gabalawy is the Scientific Director of the CIHR Institute of Musculoskeletal Health and Arthritis. He is also a Professor of Medicine and Immunology and a senior clinician scientist at the University of Manitoba. An internationally recognized rheumatologist, his research has focused on the mechanisms initiating and

sustaining joint inflammation in rheumatoid arthritis (RA). He has published landmark studies on synovial biology, the pathogenesis of early arthritis, and established a unique First Nations cohort to study gene-environment interactions in the pre-clinical phase of arthritis.



**Ms. Suzanne Schrandt**, Director of Patient Engagement, Arthritis Foundation, Atlanta, Georgia, USA

Schrandt joined the Arthritis Foundation last month, after serving as the Deputy Director of Patient Engagement for the Patient-Centered Outcomes Research Institute (PCORI) for almost four years. During her tenure with PCORI, she

helped to launch several key PCORI efforts including the creation of the Engagement Rubric and the Engagement Officer role, the Advisory Panel on Patient Engagement, the Pipeline to Proposal Awards initiative, the PCORI Ambassadors Program, and the Framework on Compensation (for Patient Partners in Research).

Schrandt has been involved with many patient and clinician education and advocacy initiatives since her own rheumatologic diagnosis at age 14. Her prior professional positions span health and disability law and policy. She received her law degree from the University of Kansas School of Law and is a member of the American Health Lawyers Association, the Kansas Bar Association, and Professional Responsibility in Medicine & Research.



Mr. Allan Stordy, Patient Advocate, Calgary, AB

Allan Stordy, President & CEO of Arete Human Resources Inc., is a recognized leader and innovator in the employee and business assistance program industry. Arete HR Inc., provides services to over 35,000 businesses. Allan developed a chronic disease at age 29 that severely impacted his life. He is a founding Board

Member and past President of the Canadian Skin Patient Alliance (CSPA). Allan served on the Advisory Board for the Canadian Institutes of Health Research (IMHA) from 2007-2014 is a member

of IMHA's Research Ambassadors and is a member of the National Steering Committee for the Strategy for Patient Oriented Research.



**Dr. Debbie Feldman**, PhD, Professor in Rehabilitation Sciences, University of Montreal, Montreal, OC

Dr. Debbie Ehrmann Feldman is a Professor in the Faculty of Medicine, School of Rehabilitation and director of graduate studies in rehabilitation sciences at Université de Montréal. Dr. Feldman is a physiotherapist who holds MSc and PhD

degrees in Epidemiology and Biostatistics. Her main research interests include health services research in patients with arthritis and other chronic diseases, rehabilitation and musculoskeletal health. She has supervised more than 30 graduate students, sat on numerous grant review panels, and has published extensively in peer reviewed journals. She is a strong proponent of patient engagement in research and she chairs the partners in knowledge translation committee and co-chairs the research ambassadors subcommittee of IMHA since 2010.

# **AAC Advocacy and Awareness Workshop:** The Alliance Advantage: Working together to amplify the voice of arthritis in Canada



**Ms. Michelle McLean**, Vice-President, Hill and Knowlton Strategies

Vice-president and group leader, public + corporate affairs

An experienced lawyer, public affairs and communications professional in both the corporate and not-for-profit sectors, Michelle

provides strategic counsel and support to a wide array of communications and public affairs clients, and takes a leading role in developing corporate communications, stakeholder engagement and government relations strategies and campaigns.

Michelle's background includes a decade of public affairs and communications experience, including almost three years as vice-president of public affairs at the Mental Health Commission of Canada (MHCC). During her time there, Michelle managed several national, large-scale projects, including a multi-year public relations and government relations campaign for the MHCC's homelessness project and the launch of the Mental Health Strategy for Canada, a campaign which was recognized by the leading medical journal The Lancet as having achieved remarkable success for a public mental health campaign.

Michelle has led and managed other national, large-scale campaigns, including a campaign for the funding of the Cancer Control Strategy for Canada. This national campaign, which relied on grassroots mobilization, traditional media relations and advocacy, resulted in a commitment by the federal government of \$260 million over five years, a record at the time.

Michelle has twice been named as a Top 100 Lobbyist in Ottawa. Some of Michelle's past and current clients include CADTH,

the Canadian Partnership Against Cancer, the Mental Health Commission of Canada, Partners for Mental Health, TRIUMF, CSL Behring Canada, Hoffmann-La Roche, Pfizer, Abbott, Ovarian Cancer Canada, Ontario Hospital Association, Research Canada, Cochrane Canada, the Alliance for the Canadian Arthritis Program, and ALS Canada.

Michelle completed her undergraduate degree at Queen's University, and her law degree at the University of Western Ontario. She spent four years as a litigation associate at Osler, Hoskin & Harcourt, LLP.

**Ms. Janet Yale** (see Panel Discussion: "Sunny Ways: Building A National Strategy to Overcome Arthritis")



Mr. Kelly Lendvoy joined Arthritis Consumer Experts (ACE) in 2012 and is responsible for integrating ACE's public engagement and stakeholder communication strategies for consumers-patients, healthcare professionals, private health insurers and governments. Kelly brings more than 20 years of experience working in communications and public affairs with both

agencies and private sector clients in Vancouver and Toronto; managing integrated teams on complex, strategic projects focused on stakeholder relations, public engagement, corporate communications and government relations. Prior to joining ACE, Kelly served as Vice-President, Communications, with H+K Strategies, a leading global communications consultancy, where he led major communications initiatives for national clients across various industries and sectors, focusing on healthcare.

As a senior strategist, Kelly draws upon his background in issues and reputation management and coalition advocacy and is credited for innovative communications methods and advocacy and awareness programs in the majority of provinces and territories for healthcare organizations, including ACE, Arthritis Research Canada, Best Medicines Coalition, Better Pharmacare Coalition, Rick Hansen Foundation, Western Allergy Services, BC Coalition of Osteoporosis Physicians and Canadian Society of Intestinal Research.



**Ms. Tania Alexander** is a Marketing Manager at Janssen Inc. with responsibility for the Rheumatology I.V. Portfolio.

Prior to joining Janssen, Tania held positions in various Commercial and Medical functions at Pfizer Canada and Dimethaid Healthcare Inc., spanning 15 years.

Notable is her service as a clinical social worker in frontline healthcare in the private and public sectors; including the provision of individual and group counselling, management of the local employee assistance program and corporate policy development.

She continues to contribute to the IA community with her ongoing commitment to innovation in healthcare solutions and passion for knowledge translation and dissemination.

**Ms. Gillian (Jill) Kennedy** is a government affairs manager for AbbVie Canada - working primarily on Ontario issues and priorities.

Her experience and expertise comes primarily from the 5 years she spent working for the Ministry of Health in Ontario, where she worked on some of the more complex and high profile files of the day. She also spent a short time working for Janssen in a similar government affairs role to the one she is in now. Gillian has an undergraduate degree in Biochemistry from McGill and an MBA from the Schulich school of Business (York).



**Dr. Frances LeBlanc** is the Manager of Government Relations at the Canadian Chiropractic Association and has worked to support advocacy and policy activities since 2009. Frances' joined the CCA full-time after graduating from the Canadian Memorial Chiropractic College in 2010 after completing undergraduate and graduate education in

psychology at the Université de Moncton. Frances' also completed a Master's in Public Policy, Administration and Law at York University in 2014. Complementary to her work in advocacy, Frances' remains committed to clinical practice, as well as supports various research endeavours as a member of a number of review groups and as a best practice collaborator for the Canadian Chiropractic Guideline Initiative (CCGI).

**Arthritis Consumer-Patient Organizations and Groups Coalition Workshop:** Patients in Patient-Oriented Research: What Should it Look Like?



Ms. Cheryl Koehn is an arthritis advocate, community leader, published author and 28-year survivor of rheumatoid arthritis. She is the founder and president of Arthritis Consumer Experts, Canada's largest, longest running arthritis patient organization. She has served as Co-Chair of the Summit on Standards for Arthritis Prevention, co-founded the Best Medicines

Coalition, was a two-time chair of the Better Pharmacare Coalition, and is a CIHR co-investigator and collaborator. Ms. Koehn is presently the consumer representative Board Member of the Arthritis Alliance of Canada.



Ms. Alison Hoens is a Co-Chair of the Arthritis Patient Advisory Board (APAB) – the consumer arm of Arthritis Research Canada. She was diagnosed with rheumatoid arthritis in 2012. Alison is a physiotherapist and her area of specialization is knowledge translation. She holds two positions: (1) the Physical Therapy Knowledge Broker (supported by a partnership

between the University of British Columbia Faculty of Medicine Department of Physical Therapy, Physiotherapy Association of BC and the research institutes of Vancouver Coastal Health and Providence Healthcare) and (2) the Physiotherapy Research, Education and Practice Coordinator (Providence Healthcare).



**Dr. Beverly Holmes**, Michael Smith Foundation for Health Research (MSFHR) and British Columbia SUPPORT Unit, Vancouver, BC

Beverly Holmes is Vice-President, Research & Impact at the Michael Smith Foundation for Health Research (MSFHR), where she is responsible for funding programs, strategic initiatives, impact analysis, and knowledge

translation. Currently, she is also serving as executive lead for the BC SUPPORT Unit.

Beverly received both her MA and PhD from SFU's School of Communication, where she studied knowledge translation and health communication. Prior to joining MSFHR in 2010, Beverly spent 13 years as a health communications and KT consultant, researcher and writer. She has also held communications management positions in several not-for-profit organizations including The Arthritis Society and United Way of the Lower Mainland.

Beverly's research interests are knowledge translation, discourse analysis, health communication, risk communication, and public involvement in health research. She holds adjunct appointments at UBC's School of Population and at SFU's Faculty of Health Sciences.



**Mr. Tim Murphy,** Provincial Platforms and SPOR, Alberta Innovates – Health Solutions, Edmonton, AB

Tim Murphy has more than 20 years of senior executive leadership experience in the health care sector. Prior to joining Alberta Innovates Health Solutions as the Vice President, Provincial Platforms and SPOR. Tim established an

independent consulting practice and worked with clients such as: the CHILD Foundation, the Institute for Health System Transformation and Sustainability, and the Movember Foundation. Prior to establishing his consulting role, Tim was the inaugural Senior Vice President at the Michael Smith Foundation for Health Research (MSFHR)- a provincial research organization based in Vancouver. He joined the Foundation after working for more than 10 years in senior management positions with two comprehensive Academic Oncology Centres- Princess Margaret Hospital (1992-1997) and the British Columbia Cancer Agency (1997-2002). Tim holds a Bachelor of Science Degree, Life Sciences from Queen's University (1989); a Masters of Health Administration from the University of Toronto (1992); and, a Masters of Business Administration from Queen's University (2006). In 2007, he received his Certified Management Accountant (CMA) designation.

#### **AAC Research Workshop:** Knowledge Translation Research and Practice in Disseminating and Implementing Arthritis Models of Care into Practice



**Dr. Kelli Allen**, PhD, Research Professor of Medicine, Thurston Arthritis Research Center, University of North Carolina at Chapel Hill; Center for Health Services Research in Primary Care, Durham VA Medical Center, USA

Dr. Allen is a Research Professor of Medicine at the Thurston Arthritis Research Center, University of North Carolina Chapel Hill and the Durham

VA Medical Center. She is a health services researcher and exercise scientist whose research focuses on improving care and outcomes for patients with osteoarthritis and other chronic pain conditions. Her current research focuses on: 1) Development and testing of patient and provider-based interventions to improve osteoarthritis treatment and self-care, 2) Identifying causes of disparities in osteoarthritis outcomes and developing interventions to reduce disparities, 3) Promoting informed decision-making among patients with osteoarthritis, particularly women and racial / ethnic minorities.



**Dr. Sharon Straus**, MD, MSc, FRCPC, Professor, Vice Chair, and Director, Division of Geriatric Medicine, Department of Medicine, University of Toronto; Deputy Physician-In-Chief Director of the Knowledge Translation Program St. Michael's Hospital, Toronto, Ontario

Dr. Straus is a Professor in the Department of Medicine at the University of Toronto. She

holds a Tier 1 Canada Research Chair in Knowledge Translation and Quality of Care and more than \$30 million in peer reviewed research grants as a principal investigator. She has >300 publications, and has supervised >25 graduate students from different disciplines including clinical epidemiology, health informatics and human factors engineering. She is co-PI of KT Canada, a CIHR and CFI funded national, Clinical Research Initiative, PI of KT Canada's CIHR-funded Strategic Training Initiative in Health Research and PI of a network meta-analysis team grant for the Drug Safety and Effectiveness Network. She is Division Director of Geriatric Medicine at the University of Toronto and Director of the KT Program at the Li Ka Shing Knowledge Institute of St. Michael's. She has authored three books. Evidence-based medicine: How to practice and teach it is in its fourth edition, and has been published in 9 languages; Knowledge Translation in Health Care, is now in its second edition; and the first edition of Mentorship in Academic Medicine.

**Ms. Alison Hoens** (see Arthritis Consumer-Patient Organizations and Groups Coalition Workshop)



**Dr. Deborah Marshall**, Associate Professor, Department of Community Health Sciences, Arthur JE Child Chair in Rheumatology Research, University of Calgary, Alberta

Dr. Deborah Marshall holds a Canada Research Chair, Health Services and Systems Research as a Professor at the University of Calgary and Arthur J.E. Child Chair of Rheumatology Outcomes

Research in the McCaig Institute of Bone and Joint Health. She is the Director of Health Technology Assessment at the Alberta Bone and Joint Health Institute, a Senior Scientist of Arthritis Research Canada, and a member of the O'Brien Institute of Public Health. She has experience in technology assessment agencies academic, and pharmaceutical/diagnostics industry research settings in Canada, the United States, and Europe. Her research program focuses on methods to improve the effectiveness and efficiency of health care services using methods to measure patient preferences. cost-effectiveness analysis, and dynamic simulation systems modeling of health care delivery. She is a founding co-investigator of the Patient and Community Engagement Research (PaCER) Program at the University of Calgary. Dr. Marshall is an active member of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) as the Past President of the Board of Directors and its international Task Forces on stated preferences methods and dynamic simulation modeling, and a member Board of Directors for Health Technology Assessment International (HTAi). Dr. Marshall is presently is the co-chair of the Research Committee and the member of the Board of Directors of the Arthritis Alliance

of Canada.	
Notes:	

Notes:	



















Thank you to our sponsors