

Welcome to the

2015 Canadian Marfan Association Conference

Diagnosis, Treatment and Management of
Marfan Syndrome and Genetic Aortic Disorders

Patient & Family Conference

Saturday, September 26th, 2015

UNIVERSITY OF OTTAWA HEART INSTITUTE
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2015 CMA Conference
Ottawa • Ontario • September 26th



Genetic Aortic Disorders
Association **Canada**

L'Association **Canadienne**
des Maladies Génétiques de l'Aorte

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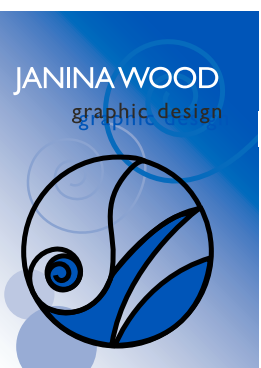
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Canadian Marfan Association



Genetic Aortic Disorders
Association Canada
L'Association Canadienne
des Maladies Génétiques de l'Aorte



WELCOME TO THE 17th CANADIAN MARFAN ASSOCIATION CONFERENCE

The Canadian Marfan Association (CMA) / "Genetic Aortic Disorders Association (GADA) Canada" Board of Directors and Professional Advisory Board, welcomes you to the CMA's 17th Conference in Ottawa, Ontario.

The CMA has been hosting conferences since 1990 and is proud to provide a unique approach in educating healthcare professionals, patients and their families on the diagnosis, treatment, and management of Marfan syndrome and other related genetic aortic disorders (GAD).

It is our objective to broaden our horizons, expand our educational resources, and increase access to research in order to provide healthcare professionals and patients with the tools to ensure early and accurate diagnosis, and proper treatment and management outcomes.

Do you have questions, comments or suggestions on how we, as an Association can improve? Please come talk to us. Members of the CMA Board of Directors – Josipa Paska, Lisa Iliadis and Sandra Topper along with Executive Director – Chrisanne Campos, are here to listen! If you miss us at the conference, give us a call or email.



The Canadian Marfan Association

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SATURDAY, SEPTEMBER 26TH, 2015

PATIENT & FAMILY CONFERENCE

8:00 – 8:30am REGISTRATION & BREAKFAST		
8:30 – 8:35	Welcome	Lucie Drouin
Aortic Management Panel		
8:35 – 8:40	Panel Introduction	Dr. Kwan-Leung Chan
8:45 – 9:15	Symptoms, diagnoses and management of Marfan Syndrome	Dr. Kwan-Leung Chan
9:15 – 9:45	Pediatric diagnoses and management of MFS and LDS	Dr. Lillian Lai
9:45 – 10:15	Other genetic aortic disorders (GAD), LDS, FTAD	Dr. Luc Beaudesne
10:15 – 10:30am MORNING BREAK		
10:30 – 11:00	Aortic surgery	Dr. Munir Boodhwani
11:00 – 12:00	Aortic Panel	Q&A session
12:00 – 1:00pm LUNCH		
GAD Research and Clinical Care Panel		
1:00 – 1:30	Spectrum of gene mutations involved in GAD: Syndromic and non-syndromic aortopathies	Dr. Julie Richer
1:30 – 2:00	Advance in ophthalmological treatments	Dr. Setareh Ziai
2:00 – 2:25	Exercise and Marfan Syndrome: Research data	Mitra Esfandiarei, PhD
2:25 – 2:50	Psycho-social aspects of living with MFS and other GAD	Joanne Morin, APN
2:50 – 3:15	Critical Role of TAC/GAD Clinics in the Management of Marfan and Other GAD	Leslie Raffin, RN
3:15 – 3:30pm AFTERNOON BREAK		
3:30 – 4:30	Aortic Management, GAD research and Clinical Care	Q&A session
4:30 – 4:40	CMA branching into GADA	Chrisanne Campos
4:40	Tirone David Award Presentation	Josipa Paska
4:45	Acknowledgements	Suzanne Drouin & Joshua Smith
4:50 – 5:30pm REFRESHMENTS AND NETWORKING		

SATURDAY, SEPTEMBER 26TH, 2015

CHILDREN & YOUTH PROGRAMS

8:00 – 8:30am	REGISTRATION & BREAKFAST	
8:30 – 9:00	Welcome & Getting to Know Each Other	Suzanne Drouin, Volunteer
	Morning Activities	
9:00 – 9:30	Learn about Your Smile	Dr. Sharhram Yazdani, DDS., Camille Lehoux, RDH & Connexion Dental Care Group
9:30 – 10:15	Fun & Interactive Board Games	Michel Duhaime (Y), Volunteer & Brenna Larkin (C), Volunteer
10:15 – 10:30am	MORNING BREAK	
10:30 – 11:30	Carleton University Magic Show	Students of Carleton University's Chemistry Department
11:30 – 12:00	Free Play	
12:00 – 1:00pm	LUNCH	
	Afternoon Activities	
1:00 – 1:15	Music & Dancing	Brenna Larkin, Volunteer
1:15 – 1:45	Exploring Your Heart	Krystina Chartrand, RN, CHEO Pediatric Cardiology Clinic
1:45 – 2:15	Art & Craft	Brenna Larkin (C), Volunteer
1:45 – 2:15	Learn about Your Genes	Dr. Andrea Yu, (Y), CHEO Medical Genetics Resident
2:15 – 3:00	Fun & Interactive Board Games	Michel Duhaime (Y), Volunteer & Brenna Larkin (C), Volunteer
3:00 – 3:15	Free Play	
3:15 – 3:30pm	AFTERNOON BREAK	
3:30 – 4:00	Storytelling	Suzanne Drouin, Volunteer & Caroline Archambault, Volunteer
4:00 – 4:30	Closing & Goodbye	Suzanne Drouin, Volunteer
4:40	Conference Award Presentation & Acknowledgements	
4:50 – 5:30pm	REFRESHMENTS AND NETWORKING	

*Children & youth will join their parents and others for lunch and breaks.

The Children & Youth Program has been made possible with the help of our special guests who are listed in the program and the support of the following donors & volunteers:

OUR DONORS:

Fred Barber, P.Eng.,
Amway Independent Business Owner, donated healthy snack items to all conference participants.

Dr. Sharhram Yazdani,
Connexion Dental Care Group, gave dental and oral hygiene supplies to the children and youth attending the conference.

Suzanne Drouin,
Drouin Coaching & Consulting, provided art & craft supplies.

OUR VOLUNTEERS:

Jacqueline & Suzanne Drouin,
Members and supporters of the Ottawa/Gatineau Marfan Peer Support Network and our group of young professionals...

Caroline Archambault,
Circulation Assistant, Ottawa Public Library, City of Ottawa

Michel Duhaime,
Networks Operations Manager, Grade A, IT Services

Rachel Duhaime,
Navigation Officer, Canadian Coast Guard

Brenna Larkin,
Early Childhood Educator, Le Cerf-Volant

Jean-Marc Leblanc,
Technical Team Lead, Industry Canada

SPEAKERS & PRESENTERS (in alphabetical order)



KWAN-LEUNG CHAN (BSc, MSc, MD, FRCPC) is a Cardiologist at the University of Ottawa Heart Institute and The Ottawa Hospital. He is also Professor in the Department of Medicine at the University of Ottawa.

Dr. Chan earned a BSc, MSc and MD from the University of Manitoba in Winnipeg. After doing his internship at the Health Science Centre in Winnipeg, he did residencies in Internal Medicine at the Toronto East General Hospital and at the University of Ottawa. In 1982, he was named Chief Resident of Internal Medicine at the National Defence Medical Centre in Ottawa, and in 1984, he became Chief Resident in Cardiology at the Heart Institute. He was certified as a Fellow of the Royal College of Physicians and Surgeons of Canada (FRCPC) in Internal Medicine in 1983 and Cardiology in 1984. Dr. Chan sits on the Executive Committee of the Canadian Society of Echocardiography and is a member of the Board of Directors of the American Society of Echocardiography.



LUC M. BEAUCHESNE (MD, FRCPC, FACC) is a member of the Division of Cardiology at the University of Ottawa Heart Institute. He is Director of the Adult Congenital Heart Disease Clinic and the Fellowship Director at the Echocardiography Laboratory.

Dr. Beauchesne completed his medical studies at McGill University in Montreal and his postgraduate training at Dalhousie University in Halifax (Rotating Internship); Foothills Hospital in Calgary (Internal Medicine); and the Heart Institute (Cardiology). He subsequently completed Fellowships in Echocardiography at the Heart Institute and in Adult Congenital Heart Disease at the Mayo Clinic in Rochester, Minnesota. He subsequently received his certification in Cardiology from the Royal College of Physicians and Surgeons of Canada (FRCPC). He is a Fellow of the American College of Cardiology. Dr. Beauchesne is member of the Canadian Cardiovascular Society, the Canadian Society of Echocardiography, the American Society of Echocardiography, the Adult Congenital Health Network and the International Society of Adult Congenital Heart Disease. His research interests focus on adult congenital heart disease and echocardiography.



DR. LILLIAN LAI (MD) is a pediatric cardiologist at the Children's Hospital of Eastern Ontario.

She specializes in cardiac MRI and focuses clinical practice in connective tissue disorders while also seeing general pediatric cardiology patients. She completed her medical studies at Queen's University in Kingston (1997) and her post graduate training in Calgary (paediatrics), Toronto (pediatric cardiology), and Boston (pediatric cardiac ICU & cardiac MRI).



SETAREH ZIAI (MD, FRCSC) is an Assistant Professor of Ophthalmology at the University of Ottawa Eye Institute. She completed her undergraduate medical training at the University of Ottawa, followed by residency training in Ophthalmology at the University of Ottawa Eye Institute. She has completed two years of fellowship training in Cornea, External Disease, Anterior Segment and Refractive Surgery.

Her practice encompasses tertiary care clinical and surgical ophthalmology, with a focus on corneal transplantation, ocular tumour resection, anterior segment reconstruction and complex cataract surgery. She is heavily involved in clinical research, training of residents and surgical fellows, as well as politically with the Canadian Ophthalmological Society.



MUNIR BOODHWANI (BSc, MD) is a surgeon at the University of Ottawa Heart Institute. Dr. Boodhwani earned a BSc with High Distinction from the University of Toronto in 1997 and a medical degree from the University of Western Ontario in London, Ontario, in 2001. These were followed by a residency in cardiac surgery at the Heart Institute in 2004. In 2006, he served as a research fellow in cardiothoracic surgery at Beth Israel Deaconess Medical Center in Boston and earned a Masters in Medical Sciences from Harvard Medical School.

His clinical research interests include issues in complex coronary revascularization procedures and arterial grafting, the polymer-based delivery of endothelial progenitor cells for myocardial regeneration, cardiopulmonary bypass practices and clinical trials, neurocognitive outcomes following cardiac surgery, coronary physiology and pharmacology, and the effect of diabetes, hypercholesterolemia, and endothelial function on myocardial angiogenesis.



JULIE RICHER (MD, FRCPC, FCCMG) is a clinical medical geneticist at the Children's Hospital of Eastern Ontario and an assistant professor at the University of Ottawa. She is the program director for residency program in Medical Genetics at the University of Ottawa.

Her clinical practice primarily consists of the care of patients with underlying connective tissue disorders such as familial thoracic aneurysms. Dr. Richer also maintains a general genetics practice and is involved in the care of pediatrics and adult patients. Dr. Richer completed medical school at L'Université de Montreal, FRCPC in Medical Genetics at the University of Manitoba and a Fellowship in Medical Ethics at Harvard University. Dr. Richer is also particularly interested in ethical issues related to genetics. Her main areas of interest include perception of risk and issues related to disclosure of results derived from research using untargeted genetic testing as well as patenting of the human genome.



MITRA ESFANDIARI, PHD, is an assistant professor of Biomedical Sciences at Midwestern University in Arizona, USA, and an adjunct professor of Pharmacology at the University of British Columbia in Vancouver, Canada. Her research has a focus on understanding the underlying mechanisms contributing to the progression of aortic aneurysm, and the protective effects that exercise may have on the progression of Marfan associated aortic aneurysm. Dr. Esfandiari's research is supported by the Canadian Institutes of Health Research, Rare disease foundation, and the Marfan Foundation.



JOANNE MORIN (RN(EC), MSCN) is the advanced practice nurse in the Adult Congenital Heart Disease (ACHD) Clinic at the University of Ottawa Heart Institute. Joanne completed her master's degree at the University of Ottawa. Her thesis topic was looking at the needs of patients and families awaiting cardiac surgery. She went on to earn her nurse practitioner certificate in primary health care at the University of Ottawa.

Joanne is a member of the Nurse Practitioner's Association of Ontario (NPAO), the Canadian Council of Cardiovascular Nurses (CCCN), The Canadian Adult Congenital Heart (CACH) Network, and the International Society of Adult Congenital Heart Disease (ISACHD). She holds a joint appointment with the University of Ottawa. Joanne has a background in critical care nursing. She has worked with cardiac patients for over 25 years. In 2002, she joined the ACHD team at the University of Ottawa Heart Institute where she oversees the care of 2,000 patients. Joanne's interests are in ACHD, patient and family support as well as pregnancy and contraception.



LESLIE RAFFIN (RN, BSN) has 30 years nursing experience including ER, ICU Pediatric Cardiology Step-down, Cardiology clinic and 3rd world outreach clinic. She has a special interest in Pain management and Connective Tissue Disease and has been the coordinator of several studies and clinic trials.

Currently working on a 5 year multi- arm study of Marfan and Loeys Dietz syndromes with Dr. George Sandor at BC Children's Hospital in Vancouver, British Columbia.



LUCIE DROUIN LEBLANC, MEMBER, OTTAWA/GATINEAU MARFAN PEER SUPPORT NETWORK, knows what it is to live with heart disease. Born a month after the death of her father in 1958 of congestive heart failure, Lucie is diagnosed with congenital heart disease. At the age of 5, she undergoes an experimental mechanical heart-lung assisted open heart surgery in Montreal. Married with two children, her daughter was diagnosed with Marfan Syndrome in 2000 after an eye exam. In 2001, the diagnosis was confirmed by genetic analysis including Lucie and 6 family members. Since then there has been surgeries, death of a sister and a nephew, worry, and thankfully support from the staff at the UOHI.



SUZANNE DROUIN, MEMBER, OTTAWA/GATINEAU MARFAN PEER SUPPORT NETWORK, has actively supported the CMA since the passing of her sister and her nephew from aortic dissections within months of each other in the fall of 2001. Genetic testing later confirmed the cause as Marfan Syndrome, and 7 close family members also diagnosed with the disorder are currently being treated at the UOHI. A former nurse and college educator, Suzanne pursues her lifelong interest in alleviating suffering and promoting wellbeing through her work as a certified integral master coach.



JOSHUA SMITH, CPA, CA, graduated with a Bachelor of Commerce from the University of Ottawa in 2002 and began working with Welch LLP in 2006. He obtained his CA designation in 2008. Joshua worked on a number of government compliance audits, as well as audits for private sector and not-for-profit clients.

Since 2007, Joshua has been a member of the Welch LLP Ottawa Tax Group focused on maximizing corporate cash flows through proper tax planning, organizational and operational structures. He leads the Welch costing group for Scientific Research and Experimental Development, Ontario Interactive Digital Media and other tax credit claims as well as other business incentives. Joshua is a board member and treasurer of the Maple Leaf Chapter of the Association of Old Crows, an organization promoting the sharing of new ideas and information and the dissemination of new research and knowledge in the fields of Electronic Warfare and Information Operations throughout Canadian government, industry and academia. Joshua has also been a key contributor to the TiE Ottawa Board of Directors.



JOSIPA PASKA, PRESIDENT CMA/GADA, is a volunteer with the Canadian Marfan Association/GADA Canada. She is the President of the Board and is actively engaged in association's activities.

Jo first learned of Marfan syndrome in 1990 when a colleague at work informed her that his 18-month-old son has a severe, rare disorder called Marfan. Since that day in 1990 Jo has been involved with the Canadian Marfan Association. The first 10 years fundraising and in 2000 she joined the Board of the CMA. She became the President of the Board for the first time in 2001. Jo's portfolio at CMA also includes work with the aortic clinics across Canada and on the steering committee of MAC. She played an instrumental role in the formation of MAC. MAC is CMA's global program, the role of which is to ascertain research-based guidelines on clinical features, diagnostic criteria and treatment protocols for each genetic aortic disorder (GAD). The information is intended to assist physicians in designing a most effective treatment approach for each GAD patient depending on their genetic mutation, thus ensure the best outcome for each patient.

Josipa is a former executive who ran oils and fats food businesses in Canada and United States for Unilever, AAK and TRT. She is a founder and Managing Director of FOCI, Fats and Oils Competitive Intelligence advising agency. Jo lives in Toronto and keeps close to the CMA/GADA office, just in case...



CHRISANNE CAMPOS, PHD, is the new Executive Director for the Canadian Marfan Association/ Genetic Aortic Disorders Association (GADA) Canada. She has a PhD in Molecular Biology from Ohio University, USA. She also has a MSc in Biochemistry. Following her PhD, she pursued research with the University of Glasgow, UK. Her research was in cancer biology, focussing on the molecular mechanisms triggered by DNA damage signals. With her strong research skills and scientific background, she feels privileged to be a part of the Canadian Marfan Association to be able to extend relevant research developments and make a difference among the Canadian community. She is working to develop the Association's programs and patient resources while increasing awareness of Marfan syndrome & related genetic aortic disorders (GAD) across Canada.



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ACKNOWLEDGEMENTS

The Canadian Marfan Association (CMA) / Genetic Aortic Disorders Association (GADA) Canada, Board of Directors and Professional Advisory Board would like to thank all of those who were instrumental in the planning, promotion and coordination of this year's Family Conference in Ottawa. We could not be more grateful for your time, talent and support.

We would like to thank the local planning committee, across the University of Ottawa Heart Institute (UOHI) and CHEO for their commitment to educating patients and their families and supporting the CMA / GADA's mission.

We are extremely grateful to the Ottawa/Gatineau Marfan Peer Support Network, for their dedication and hard work to organize the Children & Youth program and help the CMA / GADA staff coordinate other conference plans.

A very special thank you to Ann Van Dam, Chief Executive Assistant to the President and CEO, UOHI, for her invaluable assistance in setting up the venue for the conference and for her brilliant technical support.

Without the generous support of our sponsors, donors, volunteers, speakers and presenters, we would not be able to achieve our mission to save lives and increase the quality of life for patients affected by Marfan syndrome and other genetic aortic disorders (GAD).

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General Session and Panel Discussion Disclaimer

The Canadian Marfan Association (CMA) / Genetic Aortic Disorders Association (GADA) Canada, is a health advocacy organization. The CMA / GADA does not provide medical advice or treatment. We are not a healthcare provider. All information provided by the CMA / GADA is general information about Marfan syndrome and related genetic aortic disorders (GAD). Information provided by the CMA / GADA is not a substitute for medical treatment or psychological care. It is vital that you talk with your medical healthcare providers regarding the diagnosis and treatment of Marfan syndrome and related GAD and your particular symptoms and features. Minors should consult with a parent or legal guardian when considering treatment and healthcare providers.

Thank you for attending the
2015 Canadian Marfan Association Conference!

For more information or to make a donation,
join our network or contact us at...



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