



# Canadian Marfan Association

## Branches Off To Genetic Aortic Disorders Association (GADA) Canada

University of Ottawa Heart Institute, ON  
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# CANADIAN MARFAN ASSOCIATION



- ▶ 30 years ago very little was known about Marfan Syndrome (MFS)
- ▶ In 1986, CMA was established to promote awareness and support research of Marfan Syndrome
- ▶ Today, Marfan Syndrome is well researched and diagnostic criteria and treatment protocols are firmly established.

**Elizabeth McHenry**





# MARFANS ARE NOT ALONE

- ▶ Many new genes with mutations have been identified causing different rare disorders with aortic aneurysm and dissection, just as in Marfan
- ▶ Patients with newly discovered genetic aortic disorders present different symptoms from Marfan and each other, but many times are treated according to MFS protocols
- ▶ CMA Board and PAB (clinicians and researchers) realized the need for support to all the other rare GADs

# CMA IS BECOME GADA CANADA



## MISSION

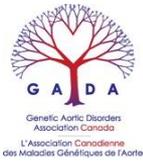
- Today GADA Canada is established and is dedicated to becoming the trusted source of information for GADs in Canada
- Facilitate the development of multi-disciplinary clinics for the treatment of genetic aortic disorders (GAD) across Canada
- Establish diagnostic criteria and standard of care for each GAD

# Montalcino Aortic Consortium (MAC)



- ▶ In 2013 CMA organised an international meeting of researchers and clinicians from medical centres around the world to discuss diagnoses and management of aortopathies, caused by newly discovered genetic mutations
- ▶ The goal of MAC is to create an **open source registry** to better define and diagnose genetic aortic disorders

# Montalcino Aortic Consortium (MAC)



- ▶ In the two short years of its existence, MAC established the largest global registry of clinical and genetic information from patients with confirmed genetic mutations causing aortic disorders
- ▶ The first MAC Registry research on **comparison of features and clinical management of aortic disease caused by TGFBR1 and TGFBR2 mutations** (442 patients) will be presented at the ASHG meeting in Baltimore in October 2015

# AWARENESS & EDUCATION



- ▶ GADA will continue working with its 18 member Professional Advisory Board and the MAC group of clinicians, researchers and scientists to serve our communities with accurate up to date information
- ▶ GADA will continue working closely with local Peer Group Networks in Vancouver, Calgary, Toronto, Ottawa, Montreal, and Halifax
- ▶ GADA will continue the history of national medical conferences to educate patients, their families as well as the medical community

# Research



- ▶ GADA will continue fostering research in Genetic Aortic Disorders and ensure the research is further translated to patient care
- ▶ *Annual Research Grant*

# FUNDRAISING



- ▶ We can't do it without your support! How can you help?
  - Host local fundraisers in your community
  - Join the local peer network groups
  - Become a member by making a donation



# CONNECT WITH US!!



STAY UP TO DATE

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# Acknowledgements



- ▶ Thank you for attending and your support
- ▶ Thank you to our speakers and presenters
- ▶ Thank you to the local planning team
- ▶ Special thanks to the Ottawa/Gatineau Peer Support group and the volunteers and to Anne VanDam
- ▶ Thank you to our sponsors and donors

