

# Talking to your doctor about Hereditary ATTR (hATTR) Amyloidosis

If you think you may be experiencing symptoms of hATTR amyloidosis, the first step is to have a discussion with your doctor. Bring this discussion guide to your next GP or specialist appointment – it covers everything you need to have an informed discussion with your doctor about hATTR.

If you haven't already, [complete the risk assessment](#) and bring the results with you to have a record of your symptoms. Having a comprehensive list of your symptoms will help your doctor better understand what you are experiencing.

## About hATTR Amyloidosis

hATTR amyloidosis is an inherited, rapidly progressive, and often fatal disease that affects an estimated 50,000 people worldwide. Although anyone can be at risk of hATTR amyloidosis, people of certain ethnicities are at higher risk. Diagnosis can be difficult as symptoms can differ greatly among patients and can affect multiple parts of the body, including the nervous (nerves), cardiovascular (heart), and gastrointestinal (digestive) systems.<sup>1,2,3</sup>

Some of the most common symptoms of hATTR are listed below but there are many more so it is important to talk to your doctor because if left untreated, the disease can progress quickly.

- Pain and numbness in the feet and hands
- Carpal tunnel syndrome
- Shortness of breath
- Fatigue
- Erectile dysfunction
- Digestive tract symptoms such as diarrhea or constipation



## Genetic Testing Confirms a Diagnosis of hATTR

Due to higher incidence of hATTR amyloidosis in certain ethnicities, people of African, Brazilian, French, Haitian, Irish, Japanese, Portuguese, or Swedish descent are considered at-risk.

If you are exhibiting symptoms or are within one of the at-risk populations and recognize a history of these symptoms in your family, ask your doctor about how you can get access to genetic testing. A medical genetic testing company called INVITAE does the testing at no charge and the process is simple.

## Questions for Your Doctor

Asking the right questions can help you get the most out of your appointment. It is suggested that you visit your doctor with this guide and if there is suspicion of hATTR, a referral can be made to a specialist listed below. A specialist can only see you with a referral from your doctor. Consider these suggestions, based on your circumstances, to help guide your conversation with your GP or specialist:

- I am experiencing symptoms and understand that I am more at risk for hATTR amyloidosis because of my ethnicity - how can I get genetic testing to determine if I carry the hATTR amyloidosis gene?
- I am experiencing symptoms of hATTR amyloidosis and would like to be referred to a specialist.
  - If concerned about symptoms related to the heart:
    - Can you provide a referral to a cardiologist?
  - If concerned about symptoms related to the nervous system (e.g.: brain, eyes, ears, nose, tongue, skin)
    - Can you provide a referral to a neurologist?

# Canadian Specialists and Experts in hATTR Amyloidosis

While hATTR is a rare disease, treatment options are available. If your self-assessment says you may be at risk, it is recommended to reach out to an Amyloidosis specialist who can help determine a possible diagnosis. However, it is important to know that only your doctor can refer you to a specialist, so keep the below information accessible to help with your next steps.

## Cardiologists and Neurologists

### British Columbia

**Dr. Michelle Mezei, Neurologist**  
Neuromuscular Diseases  
Gordon & Leslie Diamond Health Care Centre  
2775 Laurel Street  
Vancouver, British Columbia, V5Z 1M9  
Phone: 604-875-4405

**Dr. Calvin Tong, Cardiologist**  
Surrey Heart Function Clinic  
9750 140th Street  
Surrey, British Columbia, V3T 0G9  
Phone: 604-582-4550 ext. 764184

**Dr. Margot Davis, MD MSc FRCPC**  
Clinical Associate Professor, UBC Cardiology  
Director, UBC Division of Cardiology  
Gordon & Leslie Diamond Health Care Centre  
2775 Laurel Street – 9th Floor  
Vancouver, BC Canada V5Z 1M9  
Tel: (604) 875-5759 | Fax:(604) 875-4265

### Alberta

**Dr. Nowell Fine, Cardiologist**  
Cardiac Amyloidosis Clinic of Calgary  
4448 Front Street SE  
Calgary, Alberta, T3M 1M4  
Phone: 403-956-3748

### Saskatchewan

**Dr. Kerri Schellenberg, MD FRCPC CSCN(EMG) MMedEd**  
Associate Professor, Neurology -  
University of Saskatchewan  
Neuromuscular and EMG Clinic,  
ALS Clinic, EMG laboratory  
3-616 10th St. E, Saskatoon SK S7H 0G9  
Ph: 306-931-2858 | Fax: 306-931-2847

### Ontario

**Dr. Gary R. Small, Co-Director MB ChB PhD MRCP**  
Cardiac Amyloid Clinic  
University of Ottawa Heart Institute  
40 Ruskin Street  
Ottawa, Ontario, K1Y 4W7  
Phone: 613-696-7000 ext. 1700

**Wilma J. Koopman, Nurse Practitioner MScN PhD**  
Neuromuscular Clinic  
London Health Sciences Centre  
339 Windermere Road  
London, Ontario, N6A 5A5  
Phone: 519-663-3041

**Dr. Ryan Davey, Cardiologist MD, FRCPC, FACC**  
Advance Heart Failure, Transplant,  
and Pulmonary Hypertension  
London Health Sciences  
339 Windermere Road  
London, Ontario, N6A 5A5  
Phone: 519-663-3428

**Dr. Steven K. Baker, BA, BEd, MSc, MD, FRCPC(C), CSCN (EMG)**  
Associate Professor, McMaster University  
Department of Medicine  
Peripheral Neuropathy Clinic  
Divisions of Physical Medicine and Neurology  
HHAC Chair in Neuromuscular Rehabilitation  
300 Wellington Street North  
Hamilton, Ontario, L8L 8E7  
Phone: 905-525-9140 ext. 76946

**Dr. Amer A. Ghavanini, MD PhD FRCPC CSCN(EMG)**  
Clinical Assistant Professor, University of Toronto  
Division Head of Neurology  
Trillium Health Partners  
100 Queensway West  
Mississauga, Ontario, L5B 1B8  
Phone: 905-848-7100

**Dr. Vera Bril, BSc, FRCPC, MD**  
Prosserman Family Neuromuscular Clinic  
University Health Network  
Toronto General Hospital  
200 Elizabeth Street, 5 Eaton  
Toronto, ON M5G 2C4  
P: (416) 340-3315

### Quebec

**Institut de Cardiologie de Montréal**  
Programme Amyloïdose  
5000 rue Bélanger  
Montreal, Quebec, H1T 1C8  
Phone: 514-376-3330

**Centre Universitaire de Santé McGill - CUSM**  
Programme Amyloïdose  
1000 boul Décarie  
Montreal, Quebec, H4A 3J1  
Phone: 514-934-1934

**Centre Hospitalier de l'Université de Montréal - CHUM**  
Programme Amyloïdose  
1000 rue Saint-Denis  
Montreal, Quebec, H2X 0C1  
Phone: 514-890-8000  
Fax: 514-412-7709  
www.amylochum.com

**Dr. Alexis Gagnon**  
Clinique Neuro-Outaouais  
209 Rue Gamelin, #200  
Gatineau, Quebec, J8Y 1W2  
Phone: 819-777-2500

### New Brunswick

**Dr. Chadi Darwich, Neurologist**  
Hopital Georges-L.-Dumont  
330 Ave Université  
Moncton, New Brunswick, E1C 2Z3  
Phone: 506-862-4000

### Nova Scotia

**Dr. Kim Anderson, Cardiologist**  
QEII – Halifax Infirmary  
1796 Summer Street  
Halifax, Nova Scotia, B3H 3A7  
Phone: 902-473-2700

### Newfoundland

**Health Sciences Centre**  
Congestive Heart Failure Clinic  
300 Prince Philip Parkway  
St. John's, Newfoundland, A1B 3V6  
Phone: 709-777-6300

Find out more information and get support through  
Hereditary Amyloidosis Canada.

Email: [info@madhattr.ca](mailto:info@madhattr.ca)  
Phone: 905-580-2802

<sup>1</sup> Mohty D, Damy T, Cosnay P, et al. Cardiac amyloidosis: updates in diagnosis and management. Arch Cardiovasc Dis. 2013;106(10):528-540.  
<sup>2</sup> Hanna M. Novel drugs targeting transthyretin amyloidosis. Curr Heart Fail Rep. 2014;11(1):50- 57.  
<sup>3</sup> Hawkins PN, Ando Y, Dispenzeri A, Gonzalez-Duarte A, Adams D, Suhr OB. Evolving landscape in the management of transthyretin amyloidosis. Ann Med. 2015;47(8):625-638.