

Our Mission

The Canadian Amyloidosis Support Network, Inc. is committed to improving survivability and quality of life of amyloidosis patients.

We accomplish this by:

1. Promoting amyloidosis disease awareness in the medical community so it can be recognized earlier and appropriately treated.
2. Providing patient education, advocacy, support groups and resources.
3. Supporting high-value research projects.

The Canadian Amyloidosis Support Network, Inc. is a federally registered, not-for-profit, all volunteer organization, formed by amyloidosis patients and those close to them. We are committed to making a positive difference in the lives of patients and families affected by amyloidosis.

Donate at amyloidosiscanada.org
Tax receipts will be issued.

Charitable Registration
#85343 1583 RR0001

Services Provided

Patient Support phone and e-mail

CASN Website dedicated to presenting relevant and reliable information, including:

- * Education for patients, families and medical professionals
- * A listing of treatment centres
- * A schedule of upcoming educational and awareness events
- * Links to other support groups and international sources of information

CASN Facebook Group provides a forum for connections, information sharing and peer support. Everyone is welcome to join the conversation.



www.amyloidosiscanada.org

e-mail: casn.secretary@gmail.com

Additional web resources:

AL & AA www.amyloidosis.org

hATTR & ATTRwt www.madhattr.ca

Canadian Amyloidosis Support Network



*Early diagnosis is key to
managing the disease*

**The Canadian Amyloidosis Support
Network is committed to:**

-  Connecting patients and families with medical and support systems.
-  Supporting awareness and education for patients, families and medical professionals so Amyloidosis can be diagnosed earlier and appropriately treated.

www.amyloidosiscanada.org

What is Amyloidosis?

Amyloidosis represents a group of diseases in which one or more organ systems in the body accumulate deposits of abnormal proteins (“amyloid”), causing organ impairment or failure. Only within the past 30 years have physicians understood the specific make up and structure of amyloid protein.

Amyloidosis is very serious: it is not a cancer, but some types of amyloidosis are treated at cancer treatment centres. Amyloidosis may be debilitating or life threatening. If the disease is undetected, or if only the symptoms are treated, the disease continues to progress

Early diagnosis allows appropriate treatment to begin before the amyloid protein in the body becomes too great to overcome. With appropriate treatment and management of symptoms, the outlook and survivability of amyloidosis patients is improving.

Amyloidosis is often misdiagnosed because its symptoms mimic other, more common diseases.

What is the Challenge?

Because Amyloidosis is a rare disease with symptoms that mimic other more common conditions, diagnosis is oftentimes delayed as many primary care physicians do not recognize when they should test for amyloidosis. Delays in a diagnosis of amyloidosis results in delays receiving appropriate treatment.

Early diagnosis is key to managing the disease.

Types of Amyloidosis

Over 40 different types of amyloid are known in human amyloidosis, each with a different clinical presentation. The major categories of systemic amyloidosis are:

LIGHT CHAIN (AL) AL (“Primary”) amyloidosis is caused when bone marrow plasma cells produce misfolded proteins, (parts of antibodies called “light chains”), that travel through the body and deposit as amyloid in various organs (heart, kidney, GI tract and peripheral nerves), ultimately causing organ failure. AL amyloidosis is concurrent in 10-15% of multiple myeloma diagnoses.

SECONDARY (AA) A form of the disease which may occur in the course of a chronic inflammatory disease/chronic infection. (ie. Rheumatoid arthritis, IBD, etc.) The kidneys are most often affected by AA amyloidosis.

TRANSTHYRETIN (ATTR) Two sub-types of Amyloidosis occur when the transthyretin protein misfolds:

HEREDITARY (hATTR) is due to inheritance of a specific gene which leads to production of protein that has the potential to misfold and form amyloid. Genetic testing screens for specific mutations.

WILD TYPE (ATTRwt) amyloidosis occurs as a consequence of aging. Historically under-diagnosed, more cases are being diagnosed due to advancements in diagnostic procedures.

Other localized amyloid diseases involve amyloid protein deposits without systemic involvement.

Symptoms

Symptoms vary widely dependant upon which organs become affected with amyloid deposits. Symptoms could include fatigue, weight loss, edema, a feeling of fullness, numbness and tingling in the lower extremities, shortness of breath, irregular heart rhythm, fainting, heart failure of unknown cause, enlarged tongue, pre-orbital purpura (bruising around eyes), etc.

With early diagnosis and availability of new treatments, the outlook for patients has shifted to hopeful in the last decade.

The Path to Diagnosis

Diagnosis begins with identification of organ involvement. Symptoms determine which tests will be performed. Some tests are:

Biopsy A tissue sample which may be used in the diagnosis of amyloidosis.

Congo Red Stain to detect the presence of amyloid in tissue samples.

Genetic Testing confirms gene mutation in hereditary amyloidosis using **DNA testing** to identify a known gene mutation.

Immunofixation Electrophoresis (IFE) Blood or 24-hour urine test for free light chains.

Serum Free Light Chain Assay (FLC) detects the precursor protein to AL amyloid.

Tc-99m pyrophosphate scan detects and diagnoses transthyretin cardiac amyloidosis.

Once amyloidosis is diagnosed, further analysis of type or sub-type is very important to ensure appropriate treatment is received.