From: noreply@portmoody.ca <noreply@portmoody.ca> On Behalf Of Jennifer Enright
Sent: Tuesday, December 6, 2022 8:19 AM
To: Communications Alerts <communicationsalerts@portmoody.ca>
Subject: Amyloidosis Awareness Month March 2023

I am a patient and volunteer with the Canadian Amyloidosis Support Network, a federally registered non-profit organization that assists patients and families impacted by amyloidosis. Amyloidosis is a group of diseased caused by the buildup of abnormal proteins, known as amyloid, in one or more organs or tissues of the body. Left untreated, the disease can lead to organ failure and it can be fatal.

We are contacting municipalities to arrange to have proclamations approved recognizing March 2023 as Amyloidosis Awareness Month. March is the month recognized internationally by the Amyloidosis Foundation for any awareness campaign.

In the meantime, if you need additional information about amyloidosis, please visit the sites for the Amyloidosis Foundation, the Amyloidosis Research Consortium (ARC), Hereditary Amyloidosis Canada (HAC), and the Amyloidosis Alliance. The website for the Canadian Amyloidosis Support Network (CASN) is not available at this time, but information is available online at One Amyloidosis Voice at https://can01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.oneamyloidosisvoice.com%2Fplace%2Fcanadian-amyloidosis-support-network%2F&data=05%7C01%7Cjmills%40portmoody.ca%7C4fe8a6e7fdcb47ee5cb708daded2e9a2%7C2da13bb4c337480997a21b0aa65e7d77%7C0%7C0%7C638067294804170101%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=oBchkwDmDoMgFn4V8iOfaAmg%2Ft45D%2B2OkMZu3QjIn2M%3D&reserved=0. You can also visit our Facebook page.
Please also note that aside from Amyloidosis Awareness Month in March, World Amyloidosis Day is recognized each year now on October 26th. That date is now recognized on the calendar of health promotion days by the federal government. Please see the following link:
https://can01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.canada.ca%2Fen%2Fhealth-canada%2Fservices%2Fcalendar-health-promotion-days.html%23m10&data=05%7C01%7Cjmills%40portmoody.ca%7C4fe8a6e7fdcb47ee5cb708daded2e9a2%7C2da13bb4c337480997a21b0aa65e7d77%7C0%7C0%7C638067294804170101%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=fYLGTjjURprVlBAS%2FgmCptP%2FbUO0JFTtSKl1D4qboSE%3D&reserved=0
For a good background booklet on amyloidosis please see the following link:

https://can01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.amyloidosissupport.org%2FAmyloidAware_Booklet.pdf&data=05%7C01%7Cjmills%40portmoody.ca%7C4fe8a6e7fdcb47ee5cb708daded2e9a2%7C2da13bb4c337480997a21b0aa65e7d77%7C0%7C0%7C638067294804170101%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=OKopUzBXOuKRfKeSLpjyyAWZSaYPvX9wgk6Po6Rtm00%3D&reserved=0

Thanks, in advance, for any assistance you can provide.

Kind regards,

Jennifer Enright
[redacted] or [redacted]

Who is The Canadian Amyloidosis Support Network?

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.

Our Mission

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

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

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What Services Are Provided?

We operate the Canadian Amyloidosis Network patient support line and the www.thecasn.org website. Our website offers useful information on patient education; links to treatment centers, and support groups, national and international amyloidosis resources, as well as other important information.

Please visit our website at:
www.thecasn.org

The support network can help patients, caregivers and families stay informed about survivorship concerns and quality of life issues.

All of our activities are operated entirely by volunteers. Our major source of income is from contributions made at our website, fundraisers and patient memorials. All contributions support our mission, including the telephone line and website.

Please contact us anytime. We are here to help.
email: info@thecasn.org

The CASN Support Line:
Toll free number 1-877-303-4999

Marsha McWhinnie 647.351.0532
Norma Gilbert 403.255.1730
En Francais jeanguygiroux@videotron.ca

Canadian Amyloidosis Support Network

CASN
The 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 the disease can be recognized earlier and appropriately treated.

Please visit our website at:
www.thecasn.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 causing organ impairment or failure. Only within the past 20 years have physicians understood the specific make up and structure of amyloid protein.

While amyloidosis is not cancer, it is very serious and some types are treated at cancer treatment centres. Amyloidosis may be debilitating or life threatening. If undetected or treated symptomatically, the mortality rate is high.

Early diagnosis allows treatment to begin before the amyloid protein burden in the body becomes too great to overcome. Without treatment, for most forms of the disease, the outlook for patients is not good. Early diagnosis is the key to managing the disease.

8 people in a million are afflicted with Amyloidosis

What is the Challenge?

Because Amyloidosis is a rare disease, most primary care physicians do not recognize when they must test for it. This often results in delays in diagnosis and receiving appropriate and earliest possible treatment.

Types of Amyloidosis

Over twenty different types of amyloid have been described in human amyloidosis, each with a different clinical picture. The three major categories of systemic amyloidosis are:

LIGHT CHAIN (AL) – also called Primary. This is the most common form of amyloidosis, the cause of which is unknown. The bone marrow plasma cells produce mis-folded 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 if the deposition is not stopped. AL amyloidosis occurs with multiple myeloma in 10-15% of cases.

SECONDARY (AA) – This is a rarer form of the disease which may occur in the course of a chronic inflammatory disease or chronic infection such as rheumatoid arthritis, familial mediterranean fever (FMF), osteomyelitis, tuberculosis or inflammatory bowel disease. The kidneys are most commonly affected by AA amyloidosis.

FAMILIAL (AF) – As the name implies, this form of amyloiosis can be inherited, is the only form that is hereditary and is not as rare as originally thought. Presence of the disease is due to inheriting a gene which leads to production of proteins that have the potential for forming amyloid.

Other Amyloid Diseases – Other localized diseases involve amyloid protein deposits, but they **do not** have systemic implications. These include b2 Micro Globulin Amyloid, associated with type II diabetes, and Alzheimer's disease (b-Amyloid protein).

Symptoms

Symptoms vary widely because they are related to the organs that become affected with the amyloid deposits. Symptoms could include fatigue, weight loss, edema, a feeling of fullness, tingling and numbness in the lower extremities, shortness of breath, irregular heart rhythm and possibly an enlarged tongue.

With early diagnosis, the outlook for patients has shifted to hopeful in the last decade.

How is Amyloidosis Diagnosed?

The diagnosis starts with a thorough physical examination and history to identify specific body organ involvement. The symptoms presented will help determine tests to be performed.

Biopsy – Any diagnosis of amyloidosis must be confirmed with a positive biopsy. Samples may be taken from tissue or bone marrow.
Immunofixation Electrophoreses (IFE) – blood or 24 hour urine test for free light chains.
Serum Free Light Chain Assay (FLC) – indicates if the precursor protein to AL amyloid is present.
Serum Mutant Transthyretin – confirms gene mutation in familial amyloidosis.

Once amyloidosis is diagnosed, further analysis of type or sub-type is very important, since the treatments may differ.