SCHEDULE C

APPLICATION FOR PROCLAMATION

Please complete and submit your completed form to the Town Clerk at least 3 weeks in advance of the occasion

ORGANIZATION NAME: Canadian Amyloidosis Support Network (CASN)

CONTACT NAME: Jennifer Enright

ADDRESS: [redacted]

PHONE: [redacted] **EMAIL:** [redacted]

PROCLAMATION REQUESTED (Name/Title of proclamation)

Amyloidosis Awareness Month

DATES OF PROCLAMATION (Please check and insert dates)

☐ Day(s) _____ ☐ Week _____

☒ Month March 2023

PURPOSE OF PROCLAMATION (Please check all that apply)

☐ Civic Promotions ☒ Public Awareness Campaign ☐ Charitable Fundraising Campaign

☐ Arts and Cultural Celebration ☐ Special Honour for Individual or Organization

☐ Other (please explain) _____

DESCRIPTION OF YOUR ORGANIZATION (please include a brief description and any other relevant information related to your request. Additional information/documentation may be attached to this application)

The Canadian Amyloidosis Support Network (CASN) is a federally registered non-profit organization that supports patients and families impacted by amylolidosis.

Has the same or a similar proclamation been requested of the Town of The Blue Mountains Council in the past?

☐ Yes (insert date of previous request) _____

☒ No

Please provide the draft wording for your proclamation for Council consideration in order to receive an official signed proclamation from the Mayor.

☐ Proclamation flag (please provide photo of the proposed flag if applicable)

SIGNATURE: [redacted] **DATE:** October 11, 2022

FOR OFFICE USE ONLY:

Date Request Received: _____

Proclamation Outcome:

☐ Approved ☐ Denied ☐ Other: _____

Approved / Denied By: _____

Approval Date: _____

Additional Comments: _____

WHEREAS, March is Amyloidosis Awareness Month, a month dedicated to raising awareness, funding research, and supporting those living with amyloidosis and their loved ones; and

WHEREAS, Amyloidosis is a group of diseases that occurs when an abnormal protein, known as amyloid, builds up in the tissues and organs of the body. Left untreated, the disease can result in organ failure and can be fatal; and

WHEREAS, Amyloidosis can mimic the signs and symptoms of more common medical conditions and the disease can be challenging to diagnose; and

WHEREAS, Amyloidosis often affects people who are older or middle aged; however, younger people have been diagnosed with this disease; and

WHEREAS, Some of the signs and symptoms of amyloidosis can include shortness of breath, weight loss, fatigue, swelling in the ankles and legs, numbness in the hands and feet, foamy urine, carpal tunnel syndrome, bruising around the eyes, and an enlarged tongue; and

WHEREAS, Early diagnosis can lead to better outcomes for both patients and their families; and

WHEREAS, Raising awareness about all the amyloidosis diseases, including hereditary and non-hereditary forms of the disease, can contribute to the building of healthier communities across Canada.

ATTENDU QUE mars est le Mois de la sensibilisation à l'amylose, un mois consacré à la sensibilisation, au financement de la recherche et au soutien des personnes atteintes d'amylose et de leurs proches; et

ATTENDU QUE l'amylose est un groupe de maladies qui se développe lorsqu'une protéine se replie de façon anormale, entrainant des dépôts d'amyloïde, s'accumulant dans les tissus et les organes du corps. Si elle n'est pas traitée, la maladie peut entraîner une défaillance d'organe et peut être fatale; et

ATTENDU QUE l'amylose peut imiter les signes et les symptômes de situations médicales plus courantes et que la maladie peut être difficile à diagnostiquer; et

ATTENDU QUE l'amylose touche souvent les personnes âgées ou d'âge moyen; cependant, des personnes plus jeunes ont reçu un diagnostic de cette maladie; et

ATTENDU QUE certains des signes et symptômes de l'amylose peuvent inclure l'essoufflement, la perte de poids, la fatigue, des œdèmes des chevilles et des jambes, l'engourdissement des mains et des pieds, l'urine mousseuse, le syndrome du canal carpien, les ecchymoses autour des yeux et une langueépaissie ;et

ATTENDU QUE le diagnostic précoce peut mener à de meilleurs résultats pour les patients et leurs familles; et

ATTENDU QUE la sensibilisation à tous les types d'amyloses, y compris les formes héréditaires et non héréditaires de la maladie, peut contribuer à l'édification de communautés plus saines partout au Canada.

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.

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.

Charitable Registeration
85343 1583 RR0001

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