Proclamation, Lighting or Flag Request at the Municipal Centre

Town of Okotoks Corporate Services
5 Elizabeth Street
Okotoks AB T1S 1K1
Inquiries: Phone 403.938.8900 or cao@okotoks.ca

Please Note: Please ensure your request has come in no less than 10 business days prior to the requested Start Date.

Name of the Requesting Organization *

CANADIAN AMYLOIDOSIS SUPPORT NETWORK (CASN)

Occasion Title *

AMYLOIDOSIS AWARENESS MONTH

Request Type *

- [x] Proclamation
- [x] Lighting of the Municipal Centre
- [ ] Honorary Flag Raising

If requesting a proclamation, the proclamation document must be uploaded below.

Which color(s) did you want to display? *

Please specify the lighting colour(s) your orgnization is requesting.

red

Proclamation Start Date *

3/1/2024

Proclamation End Date *

3/31/2024

Lighting Date *

9/15/2023

Please provide comments to support your request below:

I am a volunteer with the Canadian Amyloidosis Support Network (CASN), a federally registered non-profit organization that supports patients and families impacted by amyloidosis. Amyloidosis is a group of diseases caused by the buildup of abnormal proteins in organs and tissues of the body. Left untreated, the disease can result in organ failure and can be fatal.

One of our goals each year is to raise awareness about this disease during Amyloidosis Awareness Month so that more Canadians can recognize the signs and symptoms of amyloidosis. We wanted to submit a proclamation request to see about Okotoks recognizing March 2024 as Amyloidosis Awareness Month. And we also wanted to know if the Municipal Centre could be lit up in red on March 15, 2024 or on another date if this date is not available.

If you need more information, please contact me or the Secretary for CASN, Keith Dares, at casn.secretary@gmail.com. Keith is aware of the work I am doing to support our awareness campaign.

Kind regards,

Jennifer Enright

Contact Information

First Name *	Last Name *	Phone *
JENNIFER	ENRIGHT	[redacted]

Email *

[redacted]

Confirm Email *

[redacted]

Address *

Street Address

[redacted]

Street Address Line 2

[redacted]

City / Town

DUNDAS

Province

ON

Postal Code

[redacted]

Please upload the proclamation document and any other documents or details supporting your request (i.e.: letter from organization, promotional material, etc.). *

Amyloidosis Awareness Month Proclamation with final French Translation 25SEP2022 - Copy.docx 12.6KB

The personal information on this form is being collected under the authority of Section 33(c) of the Freedom of Information and Protection of Privacy (FOIP) Act and will be used to respond to your request. Should you have any questions regarding the collection or use of your personal information, please contact the FOIP Coordinator at foip@okotoks.ca or 403.938.8944.

Amyloidosis Awareness Month
March 2024

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.

THEREFORE Members of Okotoks Town Council, do hereby proclaim March 2024 as Amyloidosis Awareness Month in the Town of Okotoks.

Dated this 26th day of February, 2024

---- Original Signed ----

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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

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.