

Proclamation Request Form

Requests for the issuance of proclamations are governed by Council Policy (excerpted below). Requests must be received at least six (6) weeks in advance of the requested issuance date and may be emailed to the City Clerk at ClerksApprovalRequests@london.ca or mailed to City Hall, P.O. Box 5035 LONDON, ON, N6A 4L9.

Request details

Name of Organization GBS-CIDP Foundation of Canada
Date Proclamation Required May 2024
Proclamation Name GBS and CIDP Awareness Month
Proclamation Type (day, week or month) Month
Category (public awareness campaigns), (charitable fundraising campaigns), (arts and cultural celebrations) Public awareness campaign, charitable fundraising campaign (on May 11, 2024)
Requester Name Darryl Bedford
Requester Telephone Number [REDACTED]
Requester Email Address dbedford@gbscidp.ca
Requester Address [REDACTED] Chesley Avenue, London, ON N5Z 2C1
Provide details of your Organization's Connection to London I am a resident of London and President of the Foundation. See attached letter.
Required Supporting Documents <ul style="list-style-type: none">• Detail information on the Organization• Detail information on the Event• Confirmation of authorization from the Organization to submit the request
The undersigned confirms that I am the Official Representative of the Organization requesting the Proclamation and that by signing this Application, I acknowledge and agree that my organization complies with all City of London's Policies and By-laws
Signature  Date March 7, 2024
NOTICE OF COLLECTION OF PERSONAL INFORMATION Personal information collected on this form is collected under the authority of the <i>Municipal Act, 2001</i> , S.O. 2001, c. 25 and may also be used for purposes related to the Issuance of Proclamations Policy and Proclamation Request Form. Questions about this collection should be addressed to the City Clerk, 3rd floor, City Hall, 300 Dufferin Ave., London, ON N6A 4L9. Tel: 519-661-2489, ext. 4937, email: csaunder@london.ca



GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy
Support, Education, Research, Advocacy

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March 7, 2024

City Clerk
City of London
PO Box 5035
London, ON
N6A 4L9

Sent by e-mail: ClerksApprovalRequests@london.ca

This letter is in support of our application to proclaim May 2024 as GBS and CIDP Awareness Month in the City of London.

Connections to London

The proclamations that City Council issued in 2020 through 2023 have helped us build awareness and given hope to our patient groups.

I'm pleased to announce that we will be holding our **2nd Annual London Walk and Roll** event on **Saturday, May 11** at Springbank Gardens. We'll be starting our walk at the Guy Lombardo Pavilion, walking along the Maurice Chapman Parkway, and back to the Pavilion for a total distance of one kilometre. We'd love to have you join us!

Why do I walk in the Walk and Roll? Nearly 20 years ago, things had been going well for me. Then gradually, strange things started to happen. I'd feel tingling in both feet as though they were asleep. I'd shake them, but that made no difference. Gradually the tingling and numbness worked their way up both my feet, both my legs, both my hands, both my arms, and from the top of my spine down. Over many months, walking became more difficult. My legs felt stiff. If I was down on the floor, it was difficult to get up and I needed to grasp furniture or something else solid to steady myself. I could not grip jar lids or bottle caps. It took two hands to turn a key.

Over about a year, I went for test after test and waited patiently to get into University Hospital's neurology department which has a very long wait list. When I finally did get in, I was given an EMG and the technician said: "I've seen this pattern before. I think I know what this is. But I can't diagnose you, the neurologist will come in and tell you." Then I had my answer: Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).

I consider myself fortunate because my body responds well to IVIG (immunoglobulin) as a treatment. To this day, I still go into the hospital once

Canadian charity registration number: 887327906RR0001

every 6 weeks for IVIG. It's allowed me to live a full life. It's what allowed me to walk, run, and skate again and I'm happy for it. My CIDP is hidden to the rest of the world. I look healthy but you can't see the treatments, the occasional fatigue, and some of the other issues that sometimes still arise from this chronic disease.

I am fortunate because all those years ago I went to my doctor with these strange symptoms, and he believed me. *But it isn't hasn't been that way for everyone with CIDP.* That's why we need the GBS-CIDP Foundation to continue to raise awareness in the medical community and to support patients. *That is why I walk in the Walk and Roll.*

1) Detailed Information on the Organization

The GBS/CIDP Foundation of Canada is a national, not-for-profit patient organization that supports patients and families afflicted with Guillain-Barre Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy, and variants such as Multifocal Motor Neuropathy. These are rare autoimmune disorders where the body's immune system attacks the myelin sheath that protects the periphery nerves.

GBS has a sudden onset of symptoms, which can cause complete paralysis within a day. With an early diagnosis and prompt treatment, patients can recover, but are generally left with varying residual effects. Recovery and rehabilitation can take months or longer. CIDP is the chronic form of the condition with a slower progression that requires long term treatment for patients to reduce the chances of permanent nerve damage.

The Foundation serves patients through support, education, research, and advocacy. Visit our website gbscidp.ca for further information. Attached to this letter is sample language that you are welcome to adapt for your resolution.

2) Detailed information on the Event

Through our Walk and Roll events and other activities in May, are working to raise awareness of these rare conditions so that future patients get help sooner and will know that our organization is here to provide hope. We provide support and information through trained volunteers, our website, materials provided to hospitals, and organize local and online peer-to-peer support meetings. We provide patient educational events and build awareness within the medical community. We advocate for access to diagnosis and appropriate treatment. And we support Canadian researchers working to improve the quality of life of GBS, CIDP, and MMN patients.

3) Confirmation of Authorization to Submit the Request

As President of the Board of Directors, I am authorized to submit this application on behalf of the Foundation.

Once again, we wish to thank City Council for their previous proclamations. We look forward to the City's continued support of our activities.

Sincerely,



Darryl Bedford
President, Board of Directors
GBS-CIDP Foundation of Canada

Sample Resolution Language

You are welcome to use or adapt the following WHEREAS clauses in your motion:

WHEREAS, the Month of May has been internationally designated as "GBS and CIDP Awareness Month" to educate the public and to focus attention on Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), rare, paralyzing and potentially catastrophic disorders of the peripheral nerves; and

WHEREAS Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and their variants such as Multifocal Motor Neuropathy (MMN), are rare conditions which are paralyzing and potentially catastrophic inflammatory disorders of the peripheral nerves, which can be characterized by rapid onset of weakness and, often, paralysis of the legs, arms, breathing muscles and face, in some cases leading to complete paralysis and requiring life-sustaining hospital care, and

WHEREAS the cause of GBS, CIDP, and MMN is unknown, and these conditions can develop in any person, regardless of age, gender, or ethnic background, and

WHEREAS GBS, CIDP, and MMN have a slow and unpredictable recovery, patients, and their families face an uncertain future, usually requiring months of hospital care without knowing if or when they will recover, or whether they will face long-term disabilities. Earlier diagnosis, treatment, and access to rehabilitation services can improve the chances of avoiding permanent lifelong residual damage of the nerves, and

WHEREAS in 2003, GBS/CIDP Foundation of Canada, a patient organization was founded to provide support, education, research, and advocacy, was founded so that no patient or family would go through GBS, CIDP, MMN or their variants alone,

THEREFORE BE IT RESOLVED that...