

Report to Corporate Services Committee

To: Chair and Members
Corporate Services Committee
From: Cathy Saunders, City Clerk
Subject: Application – Issuance of Proclamation – Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Awareness Month
Date: March 29, 2021

Recommendation

That, the Civic Administration BE ADVISED as to how Municipal Council wishes to proceed with the attached (Appendix “A”) Proclamation request.

Previous Reports Pertinent to this Matter

Corporate Services Committee – December 3, 2019
Corporate Services Committee – January 6, 2020
Corporate Services Committee – March 9, 2020

Background

The Issuance of Proclamations Policy is attached as Schedule “A” for information purposes.

Conclusion

The Civic Administration is seeking direction from the Municipal Council as to how they wish to proceed with the attached (Appendix “A”) proclamation request received March 1, 2021 from the GBS-CIDP Foundation of Canada requesting the month of May 2021 be proclaimed Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Awareness Month.


Submitted by: Cathy Saunders, City Clerk

Proclamation Request Form

Appendix "A"

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 2021
Proclamation Name Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Awareness Month
Proclamation Type (day, week or month) Month
Category (public awareness campaigns), (charitable fundraising campaigns), (arts and cultural celebrations) Public awareness campaign
Requester Name Darryl Bedford
Requester Telephone Number 519-636-2537
Requester Email Address dbedford@gbscidp.ca
Requester Address 86 Chesley Avenue, London, ON N5Z 2C1
Provide details of your Organization's Connection to London See letter: Importance of University Hospital Department of Neurology and Western University in the diagnosis, treatment, and research into GBS, CIDP, and variants.
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 1, 2021
NOTICE OF COLLECTION OF PERSONAL INFORMATION Personal information collected on this form is collected under the authority of the <i>Municipal Act, 2001, S.O. 2001, c. 25</i> 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, and Advocacy

Honorary Board

Larry Brennehan (*deceased*)
 Tom Feasby, MD
 Susan Keast
 Serge Payer
 Kenneth Shonk, MD

Executive Director

Donna Hartlen

Officers

Darryl Bedford
President
 Marilyn Rose
Vice-President
 Howard Huss
Treasurer

Board of Directors

Darryl Bedford
 Holly Gerlach
 Alexandre Grant
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 Dean Lower
 Marilyn Rose
 Pamela Stoikopoulos
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 Ron Van Holst

Medical Advisory Board

Steven Baker, MD
 Brenda Banwell, MD
 Timothy Benstead, MD
 Pierre Bourque, MD
 Vera Bril, MD
 Colin Chalk, MD
 Kristine Chapman, MD
 Angela Genge, MD
 Gillian Gibson, MD
 Angelika Hahn, MD
 Hans Katzberg, MD
 Kurt Kimpinski, MD
 Sandrine LaRue, MD
 Rami Massie, MD
 Elizabeth Pringle, MD
 Zaeem Siddiqi, MD
 Jiri Vajsar, MD
 Chris White, MD
 Douglas Zochodne, MD

March 1, 2021

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 2021 as GBS and CIDP Awareness Month in the City of London.

We hope to build on the awareness generated by last year's proclamation of May 5, 2020 as GBS-CIDP Foundation of Canada Day in London.

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 are able to 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.

In Canada GBS affects 2 in every 100,000 people, and during Zika outbreaks this can increase to 9 to 24 in every 100,000. CIDP affects 1 to 2 in every 100,000 people, and in some regions can be upwards of 1 to 9 of every 100,000.

The Foundation serves patients through support, education, research and advocacy. For further details, visit www.gbscidp.ca

Canadian charity registration number: 887327906RR0001

Connections to London

Last year, I noted the important role London's own LHSC University Hospital and Western University have in the diagnosis, treatment, and research into this family of conditions. Notably, I will highlight the contributions of Dr. Angelika Hahn MD and Dr. Kurt Kimpinski MD to the Foundation's national Medical Advisory Board.

Also, at Council last year, Councillor Peloza publicly shared her family's GBS story and encouraged Londoners to donate plasma. Blood plasma is needed to manufacture immunoglobulin, a primary treatment for these conditions.

We operate a support group for patients in the London area. Not only am I the President of the Board of Directors for the Foundation, I am also a CIDP patient myself.

2) Detailed information on the Event

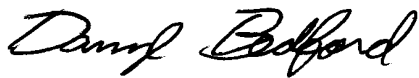
We are working to raise awareness of these rare conditions so that future patients get help sooner and will know that our organization is here to provide hope. We provide support and information through trained volunteers, our website, materials provided to hospitals, and organize local and online peer-to-peer support meetings. We provide patient educational events and build awareness within the medical community. We advocate for access to diagnosis and appropriate treatment, and also support Canadian research that aims 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.

Finally, we wish to thank City Council for their recognition of our Foundation and work with last year's proclamation. We look forward to the City's continued support of our activities.

Sincerely,



Darryl Bedford
President, Board of Directors (London, Ontario)
GBS-CIDP Foundation of Canada

Mission :

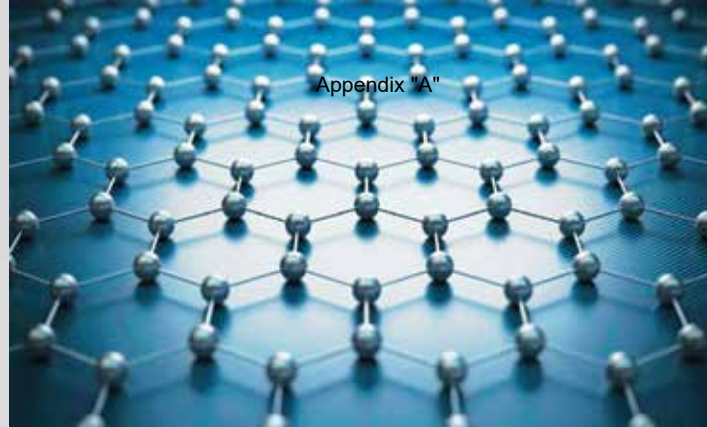
To engage in advocacy, including treatment access, (at the federal, provincial and grassroots levels) to improve the quality of life for individuals and families affected by GBS, CIDP, or variants such as MMN.

Vision :

Every person affected by GBS, CIDP, or variants such as MMN, will have access to early and accurate diagnosis, expert interdisciplinary treatment and support, and through continued research, a cure will be developed.

GBS/CIDP Foundation of Canada is a registered Canadian charity. Our foundation is made up of trained caring volunteers who have had GBS, CIDP, and variants, who are dedicated to the support of our patient community in hopes that no patient goes through these disorders alone.

If you or someone you know would like more information, please contact the foundation. Medical professionals are welcome to contact us for literature and to get more information on how to connect your patients with the foundation.



For more information, please contact:

*Support • Education • Research
• Advocacy*



GBS/CIDP Foundation of Canada
3100 Garden Street
PO Box 80060 RPO Rossland Garden
Whitby, ON L1R 0H1

1(647) 560-6842
info@gbscidp.ca
www.gbscidp.ca

The foundation is extremely fortunate to have the commitment and expertise of dedicated neurologists that are on our Medical Advisory Board. For a list, visit www.gbscidp.ca.

Find us on :



Charity Registration: 887327906RR0001

Guillain-Barré Syndrome

**Chronic Inflammatory
Demyelinating
Polyneuropathy**

Multifocal Motor Neuropathy

**Miller Fisher Syndrome &
variants**



Guillain-Barré Syndrome (GBS)

is an inflammatory disorder of the peripheral nerves, those outside the brain and spinal cord. Rapid onset of weakness and often paralysis of the legs and arms within a few weeks of onset accompany this disorder. Back pain or pain in the extremities as well as numbness and tingling can also be part of the initial presentation. Patients during early days of onset may require intensive care to monitor breathing and other body functions. Rehabilitation helps during the recovery phase, which can take months or even years. GBS can affect any person, at any age, of either gender, or any ethnic background. **Miller Fisher Syndrome (MFS)** is a variant of GBS which also presents rapidly and affects the peripheral nerves. However, MFS more commonly causes unsteadiness and imbalance and affects the eye muscles causing double vision, visual blurring or droopy eyelids.

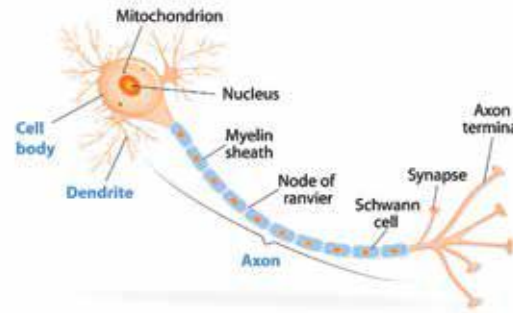


Treatments :

- High dose of intravenous immunoglobulin (IVIG)
- Plasma Exchange

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

is an inflammatory disorder of the peripheral nerves. There is increasing weakness as well as numbness and tingling of the legs and arms that can develop over a period of a few months and symptoms continue if untreated. It is caused by damage to the covering of then nerves, called myelin. If treated early and aggressively, therapies can limit the damage to the nerves and contribute to a better quality of life. Like GBS, CIDP can start at any age, and with either gender.



Acquired Motor Sensory Neuropathy (AMSAN)

, also known as Lewis Sumner Syndrome is often considered a variant of CIDP. It shares many features with CIDP but typically has a more asymmetric (more side to side differences), and multifocal (specific areas affected) presentation compared to patients with CIDP.

Treatments :

- Immunotherapies, (IVIG, SCIG)
- Plasma Exchange
- Prednisone
- Immunosuppressives

Multifocal Motor Neuropathy (MMN)

is an inflammatory nerve disease affecting the myelin sheath, or the insulation of nerves, similar to CIDP and GBS. It typically has a slow course over many years and affects the arms with weakness in the muscles that bend the fingers, however any nerve and muscle group can be affected. On nerve testing (EMG), "blocking" of the responses to the nerves that go to the muscles is seen. Sometimes, antibodies to a molecule called GM1-ganglioside are present and can be detected with additional testing. This can help with the diagnosis.

Treatments :

- Immunotherapies, such as IVIG
- Plasma Exchange
- In contrast to CIDP, MMN is not usually responsive to medications such as prednisone or other immunosuppressives

Services Available :

- Hospital visitation by knowledgeable volunteers
- Telephone support
- Local support group meetings
- Educational material
- Names of physicians specializing in the disorders
- Educational presentations
- Newsletters
- National & Regional Conferences
- Research funding
- Patient advocacy
- Awareness events
- Patient stories



Issuance of Proclamations Policy

Policy Name: Issuance of Proclamations Policy

Legislative History: Adopted September 19, 2017 (By-law No. CPOL.-115-367); Amended July 24, 2018 (By-law No. CPOL.-115(a)-418)

Last Review Date: January 6, 2020

Service Area Lead: City Clerk

1. Policy Statement

1.1 This policy sets out the requirements for the issuance of proclamations.

2. Definitions

2.1 Not applicable.

3. Applicability

3.1 This policy shall apply to any request for the issuance of proclamations on behalf of the City of London.

4. The Policy

4.1. Proclamations are ceremonial documents issued and signed by the Mayor on behalf of City of London Council that officially recognizes public awareness campaigns; charitable fundraising campaigns; and arts and cultural celebrations of organizations that reside/operate within the City of London. The requester must clearly identify the significance and connection of the proclamation to the mandate and goals as set out in the City of London's Strategic Plan. A proclamation does not constitute a personal or civic endorsement.

Application Process

- a) Proclamations requests are to be submitted on the City of London Application form to the City Clerk's Office at least six (6) weeks in advance of the requested issuance date.
- b) The Application must provide sufficient background information about the organization, cause or event being proclaimed and the proposed text for inclusion in the proclamation. The proposed text is subject to approval by the City of London to ensure compliance with City of London's policies and by-laws.
- c) Upon receipt of the Application, the City Clerk's Office will review the Application in accordance with this Policy and if the Application appears to be in compliance with the Policy, the Application will be placed on the next available Corporate Services Committee meeting for consideration.
- d) The Corporate Services Committee will review the Application and provide a recommendation to the Municipal Council for consideration with respect to the disposition of the Applications.

SCHEDULE "A"

Administration of Policy:

- e) The cause or event must contribute to the economic, social and cultural fabric of the City of London.
- f) Repeat requests must be submitted on an annual basis.
- g) An organization may request one proclamation per calendar year.
- h) Organization do not have exclusive rights to the day, week, or month being proclaimed.
- i) Proclamations of a similar topic will be issued on a first come first served basis.
- j) The City of London will not incur any expenses relating to the advertising or promotion of a proclamation. Recipients are responsible for the promotion of the proclamation, organization of related activities and for all associated costs.
- k) Proclamations will not be issued for:
 - Matters of political controversy, ideological or religious beliefs or individual conviction.
 - Events or organizations with no direct connection to the City of London.
 - Campaigns or events contrary to City of London policies or by-laws.
 - National, Independence or Republic Days.
 - Campaign or events intended for profit-making purposes.
 - Recognition of individuals.
 - Recognition of events or organizations that espouse discrimination, hatred, violence or racism.
 - Matters attempting to influence government policy.
 - Matters designed to incite hatred or disorder.
- l) The City of London reserves the right to refuse to issue a proclamation.