

From: Cheryl Dean <cdean@gbscidp.ca>
Sent: Monday, March 13, 2023 10:38 PM
To: Meghan Lahti <MLahti@portmoody.ca>
Subject: GBS/CIDP Foundation of Canada Proclamation Request

My name is Cheryl Dean. I have been a Survivor since 2008 of a rare autoimmune illness called Guillain-Barré Syndrome. I am also a BC Liaison with the GBS/CIDP Foundation of Canada and have been a member of the Foundation since 2008.

As a Liaison, part of my role and the role of the other Liaisons is to support patients with GBS/CIDP and their variants, in and out of the hospital in the City of Port Moody area.

If it was not for Covid, we would be holding in-person events like peer-to-peer support group meetings and Walk & Roll events. Until we get back to our in-person support group meetings (which we are hoping to do later this year), we are offering virtual support group meetings approximately every 2 months (our next support group meeting is tentatively scheduled for a date to be determined in the 2nd week of April, 2023).

We have multiple liaisons in BC and we continue to support our patients and their families virtually or by phone, by email and by text. The Foundation's Medical Advisory Board includes prominent Neuromuscular Specialists across Canada including Dr. Kristine Chapman, who practices out of the Vancouver General Hospital.

The GBS/CIDP Foundation of Canada continues to support and educate patients and families upholding our Mission and Vision which can be found on the accompanying Tri-fold.

I have attached the Tri-fold, along with our Proclamation Request.

Please contact me with any questions or concerns you may have regarding the Port Moody City Council approving this proclamation.

Cheryl Dean,
GBS/CIDP Liaison



GBS/CIDP Foundation of Canada

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

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March 13, 2023

City of Port Moody City Council
100 Newport Drive
Port Moody, B.C.
V3H 5C3

Dear Mayor Meghan Lahti:

We are writing to respectfully request that the city of Port Moody proclaim May 2023 as GBS/CIDP Awareness Month. The Month of May, has been internationally designated as "GBS and CIDP Awareness Month" to educate the public and to focus attention on these rare conditions. The GBS/CIDP Foundation of Canada is a national, not for profit patient organization that supports patients and families afflicted with Guillain-Barré Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy, and variants such as Multifocal Motor Neuropathy. We serve patients through support, education, research and advocacy.

GBS has a sudden onset of symptoms, which can cause complete paralysis within a day. Recovery can be unpredictable, 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. The cause of these conditions is unknown, and can develop in any person, regardless of age, gender or ethnic background

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 group 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.

While considered rare diseases, in Canada GBS affects 2 in 100,000, and in Zika outbreaks 9-24 in 100,000. CIDP affects 5-7 in 100,000. For more information: www.gbscidp.ca
Please let us know if there is anything further you require for our proclamation request to be approved for this year and for subsequent years.

Please see the attached email or application from Cheryl Dean. Cheryl is a GBS survivor and is our lead BC liaison. She is supporting patients in your community.

Thank you for your consideration.

Kim Brooks
Patient Advocate & Volunteer Coordinator
kbrooks@gbscidp.ca
1-403-510-3170
www.gbscidp.ca

Canadian charity registration number: 887327906RR0001

Mission :

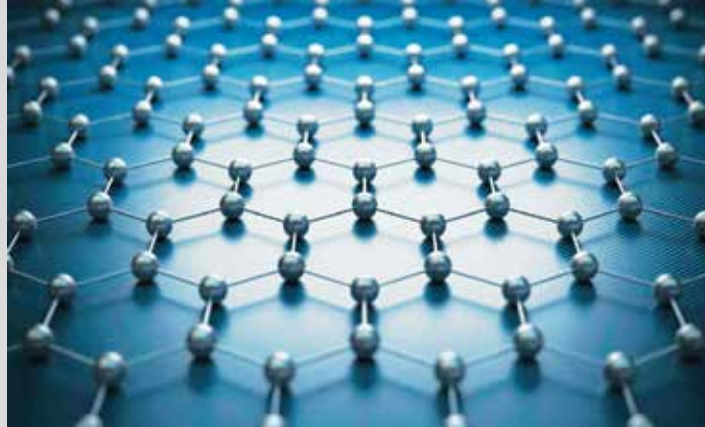
To engage in advocacy, including treatment access, (at the federal, provincial and grassroots levels) to improve the quality of life for individuals and families affected by GBS, CIDP, or variants such as MMN.

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*



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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.

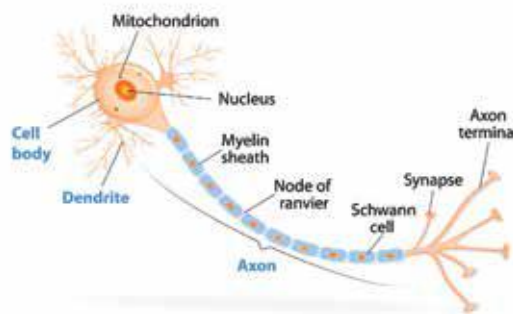


Treatments :

- 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



Proclamation

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 providing support, education, research, and advocacy, was founded so that no patient or family would go through GBS, CIDP, MMN or their variants alone.

