

**From:** Cheryl Dean [<mailto:cdean@gbscidp.ca>]  
**Sent:** March-17-21 11:29 PM  
**To:** Mayor Rob Vagramov <[RVagramov@portmoody.ca](mailto:RVagramov@portmoody.ca)>  
**Subject:** Proclamation Request

Mayor Rob Vagramov and the City of Port Moody City Council:

My name is Cheryl Dean and I am a BC Liaison and GBS Survivor with the GBS/CIDP Foundation and have been a member since 2008. As a Liaison, part of my role and the role of the other Liaisons is to support patients with GBS/CIDP in and out of hospitals in the Port Moody area. I lived in Port Moody and was a patient at Eagleridge Hospital on the High Intensity Unit after contracting GBS. If it was not for Covid, last May, we would have held a Walk & Roll event. Until we get back to our in-person support group meetings, we are offering virtual support group meetings approximately every 3 months (our next support group meeting is on May 16, 2021). 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 Medical's Advisory Board includes prominent Neurologists 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 a Proclamation Request.

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

*Cheryl Dean,*  
*GBS/CIDP Liaison*

## PROCLAMATION APPLICATION INFORMATION

Contact Information: BC GBS/CIDP Liaison, Cheryl Dean, 778-387-6997

Organization Name: GBS/CIDP Foundation of Canada

Organization Mailing Address: PO Box 80060, RPO Rossland Garden  
Whitby, ON L1R 0H1

Organization Phone Number: 1 (647) 560-6842

Organization Email: [info@gbscidp.ca](mailto:info@gbscidp.ca)

Organization Website: [www.gbscidp.ca](http://www.gbscidp.ca)

### **Proclamation Details**

Name of Cause: GBS/CIDP WARENESS MONTH

Description of Cause:

We are writing to respectfully request that the City of Port Moody proclaim May 2021 and more particular May 16, 2021 as GBS/CIDP Awareness Month. 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. We serve patients through support, education, research and advocacy. 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.

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 for patients and their families. 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.

For more information on these rare diseases, please go to [www.gbscidp.ca](http://www.gbscidp.ca).

Date: Month of May, more particularly May 16, 2021

Hosting Local Organization: GBS/CIDP (BC Division)

**DRAFT PROCLAMATION:**

**WHEREAS, the cause of GBS and CIDP is unknown. The length of the illness is unpredictable and can be characterized by the rapid onset of weakness and often, paralysis of the legs, arms, breathing muscles and face. Usually months of hospital care are required with patients and families facing an uncertain future, not knowing if and when recovery will occur. Some may face long-term disabilities of varying degrees. GBS or CIDP can develop in any person at any age, regardless of gender or ethnic background; and**

**WHEREAS, The Month of May, has been 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**

### Mission :

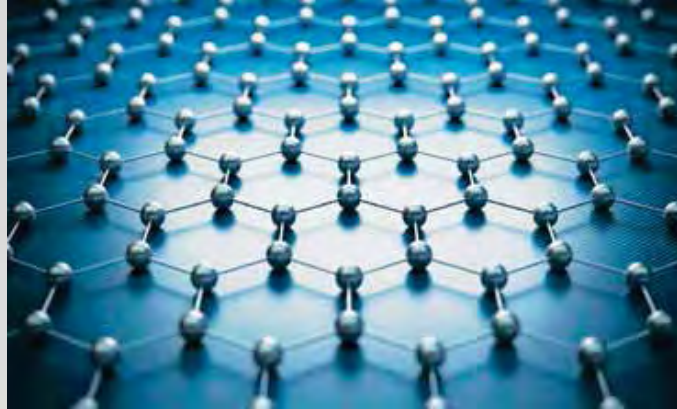
To engage in advocacy, including treatment access, (at the federal, provincial and grassroots levels) to improve the quality of life for individuals and families affected by GBS, CIDP, or variants such as MMN.

### 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](http://www.gbscidp.ca).*

Find us on :



Charity Registration: 887327906RR0001

**Guillain-Barré Syndrome**

**Chronic Inflammatory  
Demyelinating  
Polyneuropathy**

**Multifocal Motor Neuropathy**

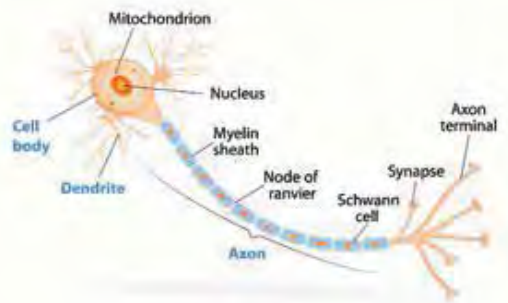
**Miller Fisher Syndrome &  
variants**



### 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.

**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.

### 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

#### Treatments :

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

#### Treatments :

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