

# GBS/CIDP FOUNDATION OF CANADA

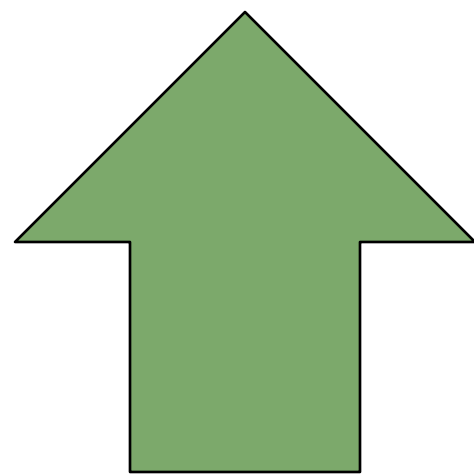
## A Year at a Glance

2024



### Outreach

2024



### Foundation Registrations

201%

### Medical Community Outreach



2,500+

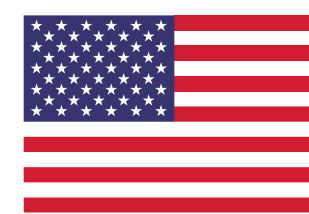
### Education

2024

### National Virtual Conference Registrations



262



39



30

### Support

2024



330+

### Patients and Families

Connected with over 330 patients and families in 2024.

150+

### Phone calls to patients and caregivers

Helping to ease their worries after diagnosis.



9 New Liaisons

### Awareness

2024



3 New Locations



45 Proclamations



23 Landmark Illuminations

### Research



1 Grant Announcement

### CONTACT US

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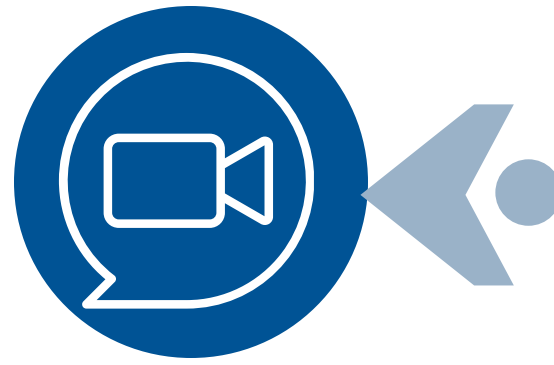
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2024



## Supporting Our Community



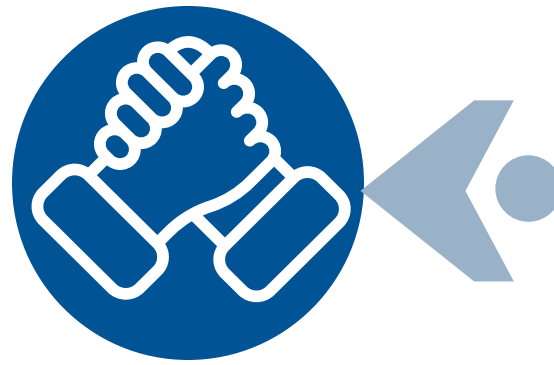
### ONLINE SUPPORT FOR PATIENTS AND CAREGIVERS

The Foundation is proud to offer regular meetings for both patients and caregivers, ensuring that everyone in our community receives the support they need.



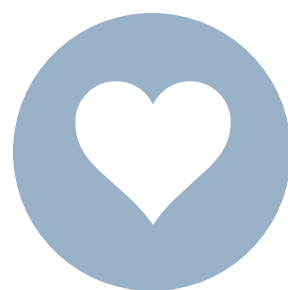
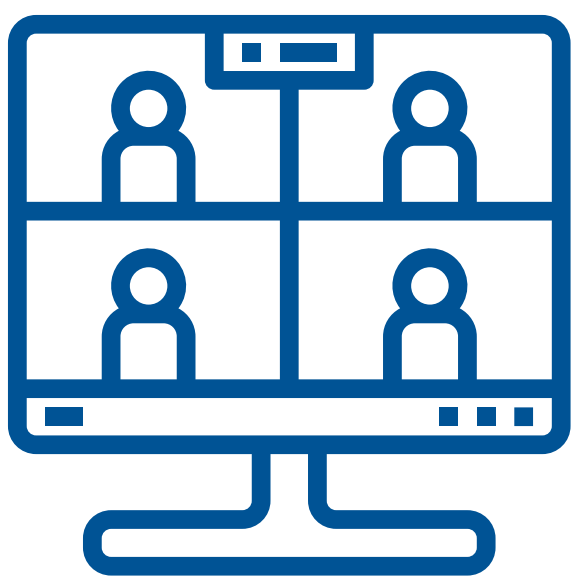
### CONNECTING ACROSS THE COUNTRY: IN-PERSON SUPPORT MEETINGS

The Foundation was pleased to host in-person meetings in Coquitlam, Edmonton, Montreal, Regina, and Quebec City in 2024.



### BUILDING A COMMUNITY OF CARE AND CONNECTION

This year, over 330 patients and caregivers took part in our support meetings, building a network of care and mutual support.



Connecting with over 330 patients and families in 2024.



5 In-person and 30 + Online Support Group Meetings

## THANK YOU

A huge thank you to all the liaisons who hosted support group meetings or reached out to someone who was newly diagnosed. Your care for patients makes a world of difference!

## PHONE CALLS

Over 150 calls to patients and their families. Helping to ease their worries after diagnosis.



## OUR COMMITMENT

That no patient or their families will have to go through these conditions alone.

# National Volunteer Week

April 14-20, 2024



## EVERY MOMENT MATTERS

#NVW2024 #EveryMomentMatters

★ 2024 ★

### Volunteers



9 NEW LIAISONS IN 2024

82 ACTIVE VOLUNTEERS



### VOLUNTEER RECRUITMENT EVENTS

This year, the Foundation hosted 4 Volunteer Information Sessions in 4 cities.



### REGIONAL MEETINGS

In 2024, 6 regional meetings were held where volunteers collaborated with staff to plan activities.



### PATIENTS CONNECTED WITH SUPPORT LIAISONS

Over 50 patients received one-on-one support from trained volunteers who have experienced similar challenges and truly understand.

### VOLUNTEER ACTIVITIES

- 24 liaisons participated in Walk and Rolls
- 13 liaisons hosted or co-hosted support group meetings
- 30 liaisons were involved in awareness month activities
- 4 liaisons represented the foundation at medical conferences
- 5 liaisons took part in advocacy initiatives
- 3 liaisons lead educational events
- 2 liaisons wrote articles

VOLUNTEERS ARE AT THE HEART OF EVERYTHING WE DO, FROM WALK AND ROLLS TO PATIENT SUPPORT AND AWARENESS-RAISING, THEIR DEDICATION ENSURES THAT PATIENTS AND CAREGIVERS FEEL SUPPORTED, INFORMED, AND EMPOWERED TO FACE THESE CHALLENGING CONDITIONS.

### Walter Keast Award 2023

#### MIRANDA & AMELIYA PELLETT

Our first mother-daughter liaison team. Miranda and Ameliya are passionate about increasing GBS awareness. They also raised \$1,145.00 dollars to support critical programs.

Miranda & Ameliya have volunteered their time in 2023 to:

- Rare Disease Day video
- Montreal Walk and Roll
- New Patient Video
- Journey presentation for the 2023 International Symposium
- Patient communication
- Raising awareness on Facebook



The Walter Keast Award is presented annually through nomination to an individual in the Canadian GBS/CIDP community who exhibits an exemplary commitment, one that resembles Walter's dedication to patients and families through his many years of volunteer work for the Foundation.



CELEBRATING OUR LIAISONS WE THANK YOU ALL!

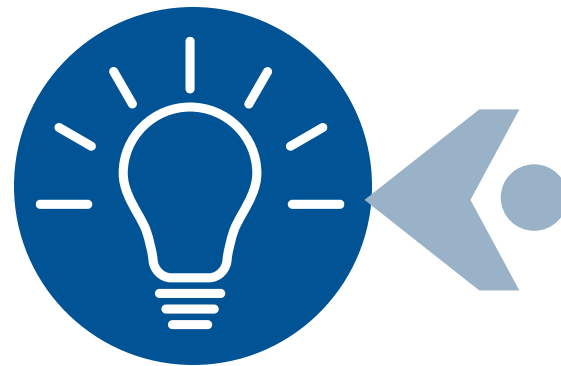




2024

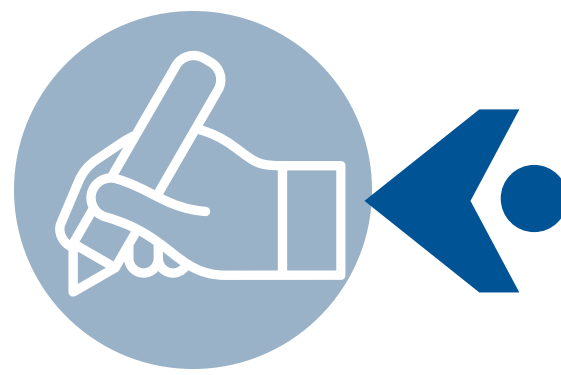


Education



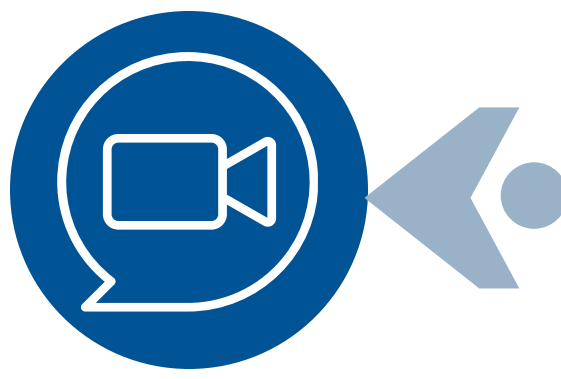
## CONDITION VIDEO (VARIANTS)

We are in the final editing stage of our next condition video, which explores our rare variant conditions.



## EDUCATIONAL INSERVICES

Connected with over 18 allied health providers and 33 student nurses.



## 2-DAY NATIONAL VIRTUAL CONFERENCE

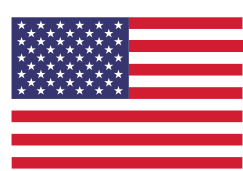
331 Registered attendees  
8 Relevant sessions  
12 Speakers

**CIDP Patient Night**  
An educational event collaboration with the University of Calgary that also included a chance for patients to participate in CIDP research.



262

Registered



39

Registered



30

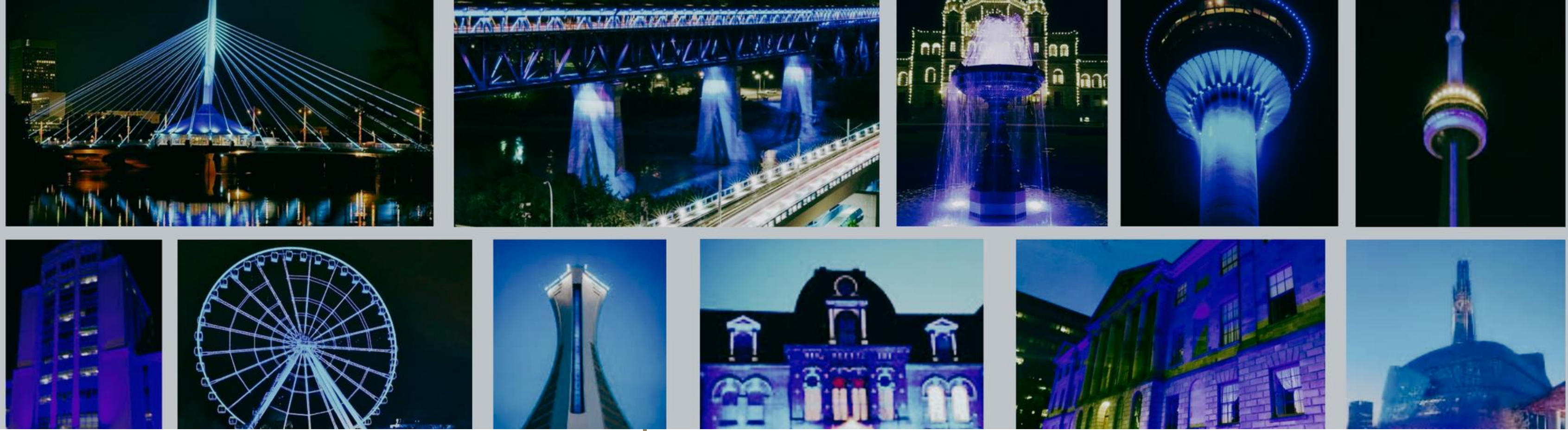
Registered

In a cyber world, we are able to expand our reach and make education accessible to patients near and far.



## EDUCATIONAL INSERVICES

BC Liaison Cheryl Dean told her GBS story and provided an interactive CIDP Patient Journey experience to over 50 allied health providers and nurses this year!



★ 2024 ★  
**AWARENESS**

**New - Light It Up  
 for GBS and CIDP**



**8 WALK AND ROLLS +  
 2 Virtual Walks**

Calgary - Coquitlam - Edmonton - London  
 Montreal - Regina - Toronto - York Region



**GBS-CIDP (MAY)  
 AWARENESS MONTH**

Proclamations: 2 provinces, 42 cities,  
 and Health Canada  
 Light it Up Campaign: 23 landmark  
 illuminations



**NEW IN 2024: MMN (FEBRUARY)  
 AWARENESS MONTH**

We actively participated in MMN Awareness  
 Month by leading a social media campaign  
 and promoting new MMN patient videos



WE ARE GRATEFUL TO ALL LIAISONS AND  
 COMMUNITY MEMBERS WHO SUBMITTED  
 PROCLAMATIONS, TOOK PART IN ILLUMINATIONS,  
 AND PARTICIPATED IN AWARENESS MONTH AND  
 RARE DISEASE DAY SOCIAL MEDIA CAMPAIGNS.

EACH ACTION MAKES A DIFFERENCE IN THE LIVES  
 OF FUTURE PATIENTS!

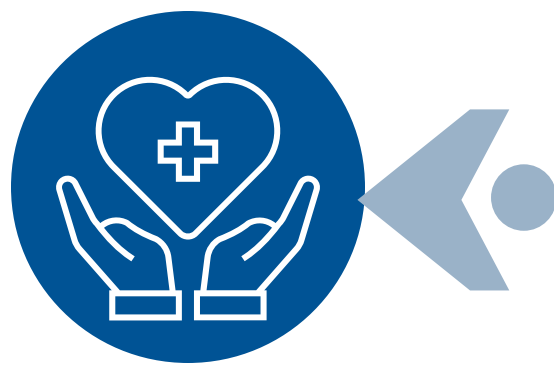
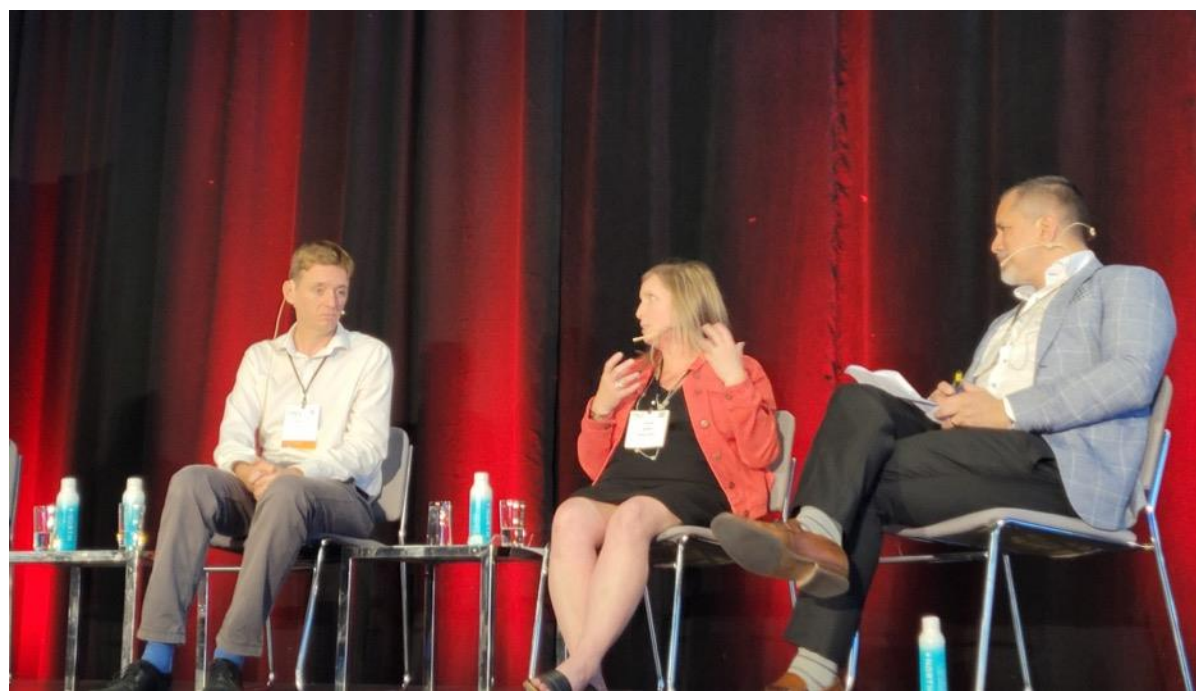


**New Patient  
 Videos**  
 The Foundation  
 released 7 new ultra-  
 rare patient stories for  
 Rare Disease Day





# 2024 MEDICAL CONFERENCES



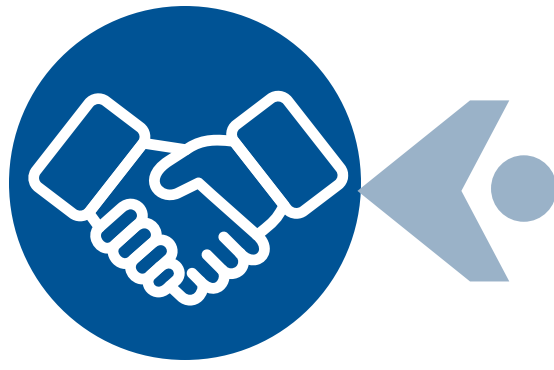
## 6 MEDICAL CONFERENCES

In 2024, we were forward facing to over 2500 Healthcare Providers.



## 250+ COMMUNICATION CARDS

Communication cards, designed to help ICU patients express their needs, were distributed to over 250 nurses and doctors!



## 3X INVITED TO SPEAK

Our Executive Director, Donna Hartlen, was invited to share her expertise at three events this year, including one in Washington.



# THANK YOU

WE ARE INCREDIBLY GRATEFUL TO OUR LIAISONS WHO WERE PRESENT AT THE MEDICAL CONFERENCES, NOT ONLY RAISING AWARENESS BUT ALSO ENSURING THAT THE PATIENT VOICE REMAINS FRONT AND CENTER WHEN DISCUSSING OUR CONDITIONS WITH MEDICAL PROFESSIONALS.



Each conference we attend raises awareness of our conditions and equips healthcare professionals with the knowledge to better support our patients.



KEEPING THE PATIENT  
VOICE  
FRONT AND CENTER



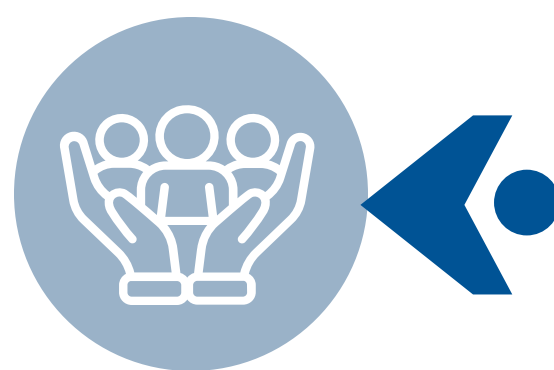
★ 2024 ★  
WALK AND ROLL

**Raised  
\$72,441.09**



**8 WALK AND ROLLS +  
2 VIRTUAL WALKS**

Calgary - Coquitlam - Edmonton  
London - Montreal - Regina  
Toronto - York Region



**PARTICIPANTS AND  
DONORS**

222 participants and 433  
individual donors



**2 NATIONAL SPONSORS  
& 1 LOCAL SPONSOR**

Takeda - Gold Sponsor  
Grifols - Gold Sponsor  
Yubukan Karate - Bronze Sponsor



**TO ALL THAT  
PARTICIPATED OR  
DONATED  
WE THANK YOU!**

Canadian Walk and Rolls have funds sent to 2 areas: programs and/or Canadian research. The Foundation raises funds through sponsors, private donors and philanthropic funds, but we do not receive funds from Government grants or other patient organizations. The funds we raise through Walk and Rolls are primarily used for program initiatives such as:

- SUPPORT – ONLINE AND IN-PERSON MEETINGS, PATIENT ADVOCACY, AND HOSPITAL VISITATION
- MEDICAL PROFESSIONAL EDUCATION AND OUTREACH
- PATIENT EDUCATION
- WEBSITE AND SOCIAL MEDIA
- ADVOCACY
- VOLUNTEER SUPPORT, TRAINING AND RECRUITMENT



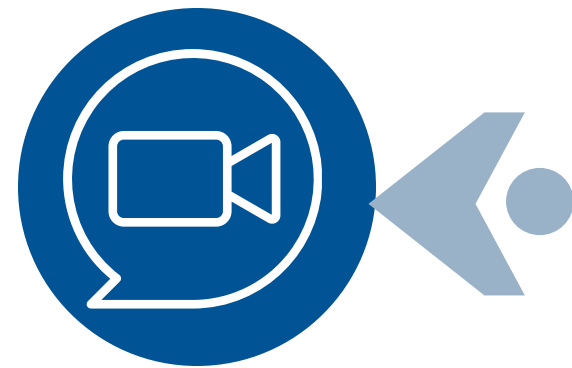
**SUPERTURTLES**

We get better slowly but surely!



★ 2024 ★

**Advocacy**



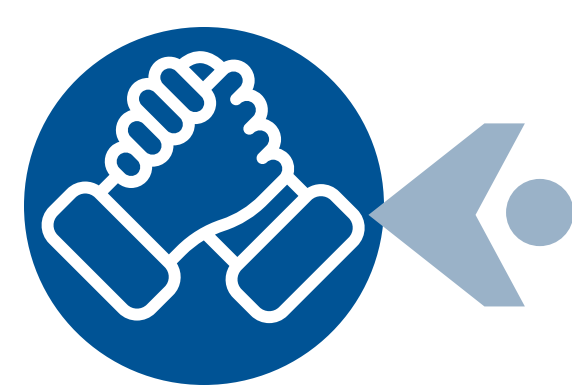
**MS AND NEUROIMMUNE SUMMIT 2.0 - DR. TERRY WAHLS**

Donna Hartlen, Exec. Dir., spoke to an anticipated attendance of 75K+ about her patient story and the work of the foundation.



**TREATMENT ACCESS**

We are an active stakeholder with Canadian Blood Services and Hema-Quebec



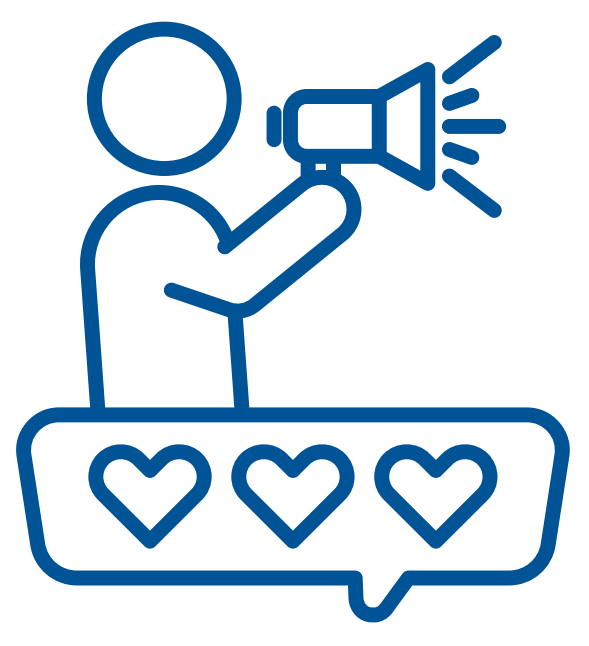
**PAID PLASMA DONATION**

In 2024, we advocated for municipal support of paid-plasma centres in Hamilton, Toronto, and Whitby

**PLASMA PROTEIN THERAPEUTICS ASSOCIATION**

GBS/CIDP Foundation of Canada was invited to participate on a Canadian advocacy panel at this year's PPTA forum in Washington, DC.. Also representing GBS, CIDP, and MMN patients were the GBS|CIDP Foundation International and Corbin Wittington, who shared his CIDP patient journey.

**MEMBER ORGANIZATION**



Network Rare Blood Disorders Organization



Neurological Health Charities Canada

**DEDICATED SUPPORT LIAISONS CONNECT WITH LOCAL PATIENTS AND CAREGIVERS TO PROVIDE SELF-ADVOCACY GUIDANCE BASED ON THEIR OWN LIVED EXPERIENCES.**

