

GBS|CIDP Foundation International

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# INTERNATIONAL VOLUNTEER GUIDELINES



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# Introduction

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## Mission

The GBS|CIDP Foundation International is working for a future when no one with Guillain-Barre syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as multifocal motor neuropathy (MMN) suffers alone and everyone has access to the right diagnosis and the right treatment, right away.

Founded by Estelle Benson in 1980, the Foundation's reach and impact have grown steadily over four decades. Today the organization is comprised of 40,000 members, representing patients, family members, friends and caregivers in 190 chapters in 47 countries worldwide. True to its original charter, the GBS | CIDP Foundation is committed to supporting those touched by GBS | CIDP and variants and aims to ensure that every patient has access to an early and accurate diagnosis, proper treatment, and the opportunity for a good recovery.

## History of the GBS|CIDP Foundation International

In November 1979, Robert Benson was stricken with Guillain-Barré syndrome following a severe cold and cough. During the weeks that followed in the ICU, his wife, Estelle, was appalled that no information or supportive group existed concerning GBS. She vowed that, when and if he recovered, they would do something about it. Within 12 months, Estelle's commitment, PR savvy, and sheer will, enabled her first GBS support meeting. Eight people met in their home and the foundation for the Guillain-Barré Syndrome Support Group was laid.

As the GBS community expanded, the Foundation chapters in the Canada, the United Kingdom, Germany & the Netherlands became full-fledged organizations in their own right. Since that time, the Foundation has expanded its interests and established additional groups for GBS variants, including CIDP, Children with GBS, Children with CIDP, Axonal GBS'ers, Miller Fisher Variant Group, AMSAN Group, Campylobacter Precipitated GBS, and Teenagers with GBS.

In 2005, the Guillain-Barré Syndrome Foundation International, a non-profit 501(c)(3) organization, changed its name to the Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy Foundation International in recognition of the increasing numbers of CIDP patients. What started as a "good deed" is now an international organization. The GBS|CIDP Foundation International, beginning as a grass roots effort has become an international organization reaching six continents with almost 190 chapters and over 40,000 members creating a unique network ensuring that no GBS|CIDP patient or family is alone.

The Foundation's Medical Advisory Board consists of the top neurologists and in the world who generously lend their time and support to the foundation's efforts. These experts in the diagnosis, treatment, and research of GBS and CIDP, many of whom have authored textbooks on the disorders, are considered to be the "think-tank" of neuromuscular neurology. Additionally, through support, education, advocacy, and research, the Foundation hopes to solve the mysteries of this potentially catastrophic disorder and provide for past and future GBS/CIDP patients.

# The GBS|CIDP Foundation International Office

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## Roles of the GBS|CIDP Foundation Office –

- The office is responsible for the intake of new patient inquiries (via phone, email or web) and distribution of this inquiry to the closest geographical volunteer(s).
- The office will provide electronic materials for the new inquiry.
- The office maintains the patient database and is the sole owner of such information.
- The office will send all electronic notices for Chapter Meetings (as well as post these meetings on our Events Calendar, social media calendars, etc.)
- The office will provide up-to date information pertinent to our volunteers with quarterly Team Member Newsletters.

## Roles of the GBS|CIDP Liaison–

- To respond to patient inquiries in a timely fashion (24-48 hours if possible, remember how important initial contact can be for a newly diagnosed patient).
- To provide emotional support to GBS and CIDP patients and their families, but not medical advice relating to diagnosis, treatment, and/or medications.
- To maintain confidentiality on all patient information including Chapter membership lists.
- If possible, aim to host at least one meeting per year.

## Patient Contact & Visit Guidelines

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### Patient Contact

New patient inquiries come to the Foundation office in numerous ways – phone, email & website.

- When a new inquiry comes into the Foundation office, our staff will forward that information on to you, including any background the patient has provided, and their preferred method of communication (email or phone).
- Please connect to the patient in a timely fashion, remembering the importance of support in this extremely scary and uncertain time.
- Always copy (BCC, or blind carbon copy) your regional director on your response. If you followed up by phone, please let your regional director know that you have contacted the patient.
- Remember, you can always provide your own experience as a patient or caregiver, but never give medical advice.
- If you are ever uncomfortable or unsure regarding patient contact, please reach out to your regional director or the foundation office at any time. Referring a patient or family member back to the Foundation is completely fine!

## Patient Visitation

- When you visit the patient, be sure to let the family know that you will be coming either alone or with your caregiver (or your loved one if you yourself are the caregiver). Do not take anyone with you unless you have prior permission due to privacy regulations. Most families/ caregivers appreciate receiving information from the perspective of someone who has had this experience. The caregiver you take with you should be familiar with this guideline. Remember – always ask first.
- If the patient can talk have her/him do as much of the talking as possible. Have her or him tell you about their case, but beware that the patient might experience fatigue so don't let him/her overdo it.
- The patient will have many questions and will be very interested in your case. Answer all questions honestly, but be on the optimistic side. Provide the patient with a short overview of your case, the extent of your involvement, and the extent of your recovery. You may use statistics from the Foundation, or your own experience, but always remind the patient that everyone recovers differently and at their own pace.
- Tell the patient that most GBS and CIDP patients make a good recovery. If the question concerning the extent of recovery arises, do not assure a 100% recovery. You should state that most patients recover and lead normal lives. Refer to your own case – that you recovered and are now making visits.
- Tell the patient that some patients in the acute phase of GBS while being ventilated, may experience hallucinations (very real-like, vivid dreams). Ask the patient if he/she does as well and if so, make sure the family and/or nursing staff are aware of this so they can reassure the patient.
- Stress the importance of cooperation with the doctors, nurses, and the therapists and the importance of therapy to prevent muscle atrophy.
- If patient is unable to talk and if he/she is up to it, tell her/him about GBS or CIDP and your own case. If he can blink his eyes ask her/him to blink once for “yes” and twice for “no” to facilitate dialogue. If he/she can move his /her fingers, refer to the Foundation's Communication Cards (the office can email some to you or the family ahead of your visit – please note that they are in English)
- **Try to not over-stay. Patients tire easily, and the family is likely overwhelmed.**
- Be aware that patients might be very sensitive to touch (even experience pain) so refrain from touching them without asking.
- Tell patient or family member about your support group chapter and invite them to your next meeting.
- Don't forget the caregiver and family members. They will have the same anxieties as the patient, only they are often alone in their caregiver role. The patient has a team of doctors, nurses, and therapists to look after him/her, but the spouse or caregiver is often overlooked. Caution caregivers to take good care of themselves. It is common for caregivers to put so much effort into the care of the patient that they, themselves, become ill. Parent caregivers to children are especially susceptible to neglecting themselves.
- When you have a new GBS or CIDP patient, ask the family if it's OK to ask other recovered patients to send a get-well card to the patient at the home address. This has been very successful and is a great morale boost to family members and patients. Many people include notes of encouragement. Comments must always be in a positive mode. We also have a Global Card Alert system where interested people from all over will send cards to patients if notified. Contact the office to get the patient included in our Card Alert Program.

## DID YOU KNOW?

The Foundation office provides resources for those with medical questions. We can submit a question to our Global Medical Advisory Board (responses are typically received in a few days). Also, the patient can have their physician reach out to our office, and we can connect them with a Global Medical Advisory board physician for a free consultation as part of our Doctor to Doctor program.

# Chapter Meeting

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## Organizing a Chapter Meeting

- Find a Location:
  - Select a convenient and comfortable location for your meeting. In selecting the optimum meeting place consider the distance that members will travel (such as a centralized location with easy access by public transport if applicable), the number of steps, the bathroom facilities and handicapped accessibility.
  - Determine room size, table and chair arrangement, and costs. Often the posted capacity of a room does not consider the space required for wheelchairs, scooters, or walkers. If a contract obligating the Foundation to pay for space, services, etc., is required, it must be sent to the Foundation for approval and signature at least six weeks in advance of the meeting.
  - Meeting spaces that are free of cost are always preferred.
  - Consider meeting at a hospital, rehabilitation center, senior center, library, civic or fraternal organization, or church. These facilities are often receptive and even eager to cooperate with you in providing physical facilities and even limited financial resources to support groups.
  - If necessary, ensure that there is adequate audio/visual for your speaker.
- Secure a Date & Time:
  - Please do not book your meetings over federal or religious holidays.
  - Meetings are typically held on Saturdays for 2-3 hours. For example, 10am-noon. However, weekday meetings are okay, allowing time for those who are employed to attend (for example 18:00 – 20:00)
  - Do not book over meal times if possible.
  - Be sure to book the room with enough time for set-up, clean-up & for members to spend time together before & after.
- Identify a Speaker & Select a Topic:
  - Some suggestions for speakers include: Neurologists, Physical & Occupational Therapists, Social or Case Workers, Psychologists, Nutritionists, Alternative Medical Professionals, RNs, Infusion Nurses, etc.
  - Suggested topics for Neurologists or medical professionals can include: What's New in Research, Treatment Options, Ask the Expert (we can include a question section on the online registration form), and GBS, CIDP basics, treatment & recovery, and managing residuals.
  - Suggested topics for other speakers can include: Emotional Health, Caring for the Caregiver, Alternative Therapies, Fatigue, Quality of Life, Exercise on Own, Adaptability, nutrition, pain management, etc.

- **Let the director of International Affairs and the home office know about your upcoming meeting.**
  - The office will:
    - Add your meeting to the Foundation Website's Events Calendar
    - Add your meeting to our Facebook Events Page
    - Send out email invitations to all local members (an initial invite, one month out, and a one week out reminder)
  
- **Day of Your Meeting**
  - Arrive early to your meeting & set up a registration table with materials.
  - Seating can be set in numerous ways, classroom style seating is very popular, as well as rounds or with tables all facing one another in a square formation – make sure there is plenty of space for those with walkers & wheelchairs.
  - Once members have arrived and settled, introduce yourself to the group.
  - Once the presentation has finished, allow for a brief question & answer if appropriate. Try to not let anyone 'take over' the meeting. Remind members that they will have time to connect & share their stories at the end.
  - If the group is large enough, break the room up into thirds – GBS Patients, CIDP Patients & Caregivers. Allow time for members to meet and connect for the remainder of the meeting.
  
- **Chapter Meeting Reimbursement**
  - The Foundation will provide reimbursement for each liaison to host one meeting per year. All costs associated with this meeting must be preapproved by the Foundation in order to receive reimbursement.
  - We encourage all liaisons to be frugal with the Foundations funds. We would like our liaisons to hold meetings spending less than \$150 USD on each, although that is not always possible. However, you should be able to hold a meeting for less than \$250 USD including room fee, light refreshments (store bought coffee, tea, cider, soft drinks, cookies, nuts, pretzels, etc.). If at any time you find that you cannot hold a meeting for less than \$250, please contact the office for pre-approval.
  - Rentals for meeting rooms, supplies, audio/visual equipment, and decorations must also be pre-approved by the Foundation. Locations include hotels, community centers, libraries, places of worship, etc. If a contract obligating the Foundation to pay for space, services, etc., is required, it must be sent to the Foundation for approval and signature at least six weeks in advance of the meeting.

# The Liaison Portal

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## Accessing the Portal

The liaison portal is available for volunteers **ONLY**. Please do not give the password or log in information to anyone outside of our organization. Password: **SUPPORTGBSCIDP**

- To Access the Liaison Portal visit our website at GBS-CIDP.org and scroll to the very bottom & click 'Liaisons'
- Liaison Directory - This is also for internal purposes only. Please never share another liaison's name or contact information without consulting the office first.

## Legal Incorporation of Allied Support Groups

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The GBS|CIDP Foundation will provide reimbursement for pre-approved legal fees if you would like to create a legal entity for your group in your country. In order to begin the process of a legal incorporation the Foundation will ask that you sign a Memorandum of Understanding (MOU) which will outline the roles and responsibilities of your group & the related roles and responsibilities of the Foundation to support you.

### *Some examples of the Foundation's role:*

- To provide financial resources in the form of reimbursable (pre-approved) funding for legal fees of incorporation (up to \$3,000USD).
- To provide resources such as electronic educational materials that you can print
- To allow use of the Foundation's logo, and provide a personalized logo for your group (according to guidelines)

### *Some examples of your group's role:*

- To maintain some form of a database of patient information (while adhering to your country's privacy laws)
- To work with the Foundation and to promote Foundation events (when applicable)
- To maintain the integrity of our organization, and to function with our four mission pillars

Remember:

We are all here to work together with one voice, the same message & mission; to support the patient community!