

SELECTING LOCATION OF MEETINGS

1. **Do not** hold meetings in your home because of potential liability issues. Do not give people rides to and from meetings or visit patients in their homes for the same reason.
2. Try to hold your meeting at a facility that does not charge for use of the room. As the Foundation is a non-profit organization and our source of funding is from donations, having to pay for a room is not productive. If you cannot avoid a room fee, discuss the amount of the fee with your Regional Director.
3. Select a convenient and comfortable location for your meeting. In selecting the optimum meeting place consider the distance that members will travel, the number of steps, the bathroom facilities, handicapped accessibility, and other things in the facility. Determine room size, table and chair arrangement, catering service requirements, and costs. Often the posted capacity of a room does not consider the space required for wheelchairs, scooters, or walkers. Sign an agreement (if required) with management specifying the date, time, and room arrangement details several weeks in advance of the meeting and before the meeting announcements are mailed. 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.
4. Consider meeting at a hospital, doctor's office, 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. Even though some members may not feel comfortable initially in meeting at a hospital (depending on their length of stay and experience), this feeling is generally not widespread and should not prevent you from exploring this possibility. If you want to meet at a hospital or rehabilitation center, contact the Director of Volunteer Services, Director of Rehabilitation Services, or the Hospital Administrator to determine their interest and level of support.
5. Consider a meeting at a restaurant having buffet style food or, if you are having a lunch or dinner meeting, select a restaurant that will arrange a menu for the event with at least three (3) menu choices. Try to keep cost per person to twenty dollars or less so that cost will not deter people from attending. Many restaurants will not charge for the room if you have a meal. When sending your invitations/meeting announcement, include a response sheet (F-13) including meal selection, number of guests, point of contact, and dollar amount they have enclosed for the meal. (This gives you a fairly accurate count of expected participants as they have paid for their meal in advance).
6. You should be able to hold a meeting for less than \$100 including room fee and light refreshments (coffee, tea, cider, soft drinks, cookies, nuts, pretzels, etc.). If at any time you find that you cannot hold a meeting for less than \$200, you must contact your Regional Director well in advance and discuss other possibilities. (see page B-8, Support Group Chapter Meetings)

SETUP AND ORGANIZATION OF MEETINGS

Use any of the following meeting tips that may fit your needs:

1. Try to set up your speaker, neurologist, podiatrist, nurse, therapist, mental health professional, etc. at least two (2) months prior to the meeting. Do not schedule meetings on religious holidays or when other major events are planned in your community (e.g. school breaks, sports events).
2. Ensure the meeting place is handicap accessible; entrance access, rest rooms, table space, etc.
3. Discuss your meeting plans with your Regional Director early in your planning. Your Regional Director can assist you with planning, identifying possible guest speakers, and provide their approval of your plans.
4. To reduce costs and make the distribution of meeting announcements less of a burden on each liaison, they will be sent by from the Foundation by U.S. Postal Service, using our non-profit postage rate, or by Email. Complete GBS Form 1002 (F-2 - *Request for Meeting Announcement Mailing*) and allow 6-8 weeks response time.
5. Announcements should be sent approximately six-weeks prior to the meeting. To reduce costs, use email when practical. Include patients, family members, hospitals, social workers, neurologists, respiratory specialists, nurses, podiatrists, therapist, family physicians or internists, and emergency room physicians. Include directions to the meeting place.
6. Place a newspaper announcement at least one week prior to the meeting. Some newspapers print a no-charge club announcement page on a regular basis. If there is a fee for the announcement, speak to your Regional Director about it before placing the order.
7. The Foundation cannot pay for meals at meetings. Purchase light refreshments and a pot of coffee (if not having a buffet meal at individual expense with the meeting). The Foundation will pay for commercially produced light refreshments (coffee, tea, cider, soft drinks, cookies, nuts, pretzels, etc.). Any food that is purchased, other than light refreshments, must be paid for by the meeting attendees. Serve only commercially purchased food and drink products at your support group meetings. There is an implied liability to the Foundation if someone were to become ill after eating contaminated home-prepared food or drink. It is prudent to avoid any situation in which the Foundation could become involved in liability issues due to someone becoming ill at a Foundation sponsored/authorized event.
8. Prepare name tags (Hello, my name is) for all participants. Color code for patients, family/friends, and medical professionals are available at most office supply stores. Use different colors to distinguish patients, caregivers, doctors, speakers, and guests, as appropriate.
9. Bring a camera to the meetings and take pictures to show at future meetings.
10. Keep a book with all the information starting with sending out the invitations to responses

and the GBS Form 1003, Meeting Registration Form (F-3).

11. Have conference room set up with tables forming a closed rectangle and chairs on outside so everyone would be facing each other. Have three tables in back of room. Use one table for refreshments (if not a buffet or dinner meeting). One table should be set up for registration

12. Put up a bulletin board for articles of interest.

13. Have a written agenda (welcome, purpose of the meeting/organization, goals, introductions, etc.) for the meeting posted or available for hand out. Explain purpose of the support group chapter, the goals, and objectives. Ask each participant to introduce himself or herself and tell where they live and if they were a patient, family member, or professional. Ask each guest to share their experience with the group. Ask each GBS'er to fill out the GBS Support Group Survey Form (F-4) just before a short break. Direct the patients to complete before leaving to ensure we have up to date information. If they cannot finish during the meeting then they can finish at home and mail in at their expense. Only one form is needed per family.

14. If you have new patients or family members who have not seen the GBS DVD "Climbing to Recovery" (30:44 minutes) or the DVD "What is CIDP" (25:30 minutes), show these videos at the end of the meeting in case those who have already seen it want to leave.

15. You might consider asking a "Certified Instructor" in exercise programs such as "Body Recall" or "Senior-Cize" to address the group. These are senior citizen type exercises and work well for a GBS and CIDP patient upon release from rehabilitation. These programs may be found at Senior Citizen Centers, YMCA's, local hospitals, or churches. The cost for these programs is very reasonable.

16. You should be able to hold a meeting for less than \$100 including room fee and light refreshments (store bought coffee, tea, soft drinks, cookies, pretzels, etc.). If at any time you find that you cannot hold a meeting for less than \$200, you must contact your Regional Director well in advance and discuss other possibilities. (see page B-8, Support Group Chapter Meetings).

17. Submit your original receipts for costs incurred to the GBS/CIDP Foundation for reimbursement. **The Foundation can only reimburse the liaison.** If support group chapter members have incurred expenses, submit these receipts with your Request For Reimbursement Form (F-6). One check will be prepared by the Foundation and sent to you as the liaison. You can reimburse the chapter members when you receive reimbursement from the Foundation or earlier as you desire. You should call your Regional Director before the meeting to see if your anticipated expenses are considered reasonable. The form must be submitted within 30 days.

18. Submit the GBS/CIDP Support Group Chapter Meeting Report (F-10).

REQUESTING MAILING OF MEETING ANNOUNCEMENTS

Please follow these steps:

1. Notify your Regional Director with the date and location you are considering.
2. Send a copy of your draft meeting notice to your Regional Director for approval. Your Regional Director will send a copy of the approved meeting notice to the National Office. It will be posted on our web site.
3. Do not request meeting announcements be sent until you have discussed your plans with your Regional Director and have received his/her approval. Use GBS Form 1002 (F-2 - *Request for Meeting Announcement Mailing*)
4. You can control what addresses are used for distribution of your meeting announcements. Just inform the Foundation of the address of your meeting and how large an area around that location you want to include. The Foundation staff will do the rest.
5. All requests must be received 7-8 weeks prior to your meeting. Allow one week for your meeting notice to be processed and distributed
6. The Foundation will send you a list of addresses of people who are in the database. Please check this list for errors and notify the Foundation of any corrections to be made.
7. If you need to request a meeting box, please contact the Foundation. A meeting box normally contains copies of recent newsletters, a sign-in sheet, symposium flyers, blank name tags, generic liaison business cards, a GBS sign (if needed), copies of “An Overview for the Layperson, GBS/CIDP tri-fold brochures, copies of the Support Group Chapter Directory, copies of “Caring For A Child With GBS” and “A Handbook for Caregivers”, and remittance envelopes.
8. Speaker gifts are available upon request from the Foundation. If you have a speaker who speaks to your chapter on a repeat basis and has received the standard Foundation gift, the Foundation will authorize you to spend up to \$25 for a suitable gift. This purchase must be pre-approved.
9. Meeting announcements and meeting boxes will not be sent until the Foundations is notified by your Regional Director that they approve of the meeting schedule and agenda, location and anticipated cost of the event.
10. Please feel free to contact your Regional Director with any questions.

LIAISON REIMBURSEMENT POLICY - 2011

The Foundation is very appreciative of everything you do and we are always excited when meetings take place. We know that you are volunteers and you give us your valuable time. However, we must adhere to a strict reimbursement policy as set forth below.

- **The Foundation can only reimburse Support Group Chapter Liaisons for meeting or visit expenses.** If expenses are incurred by others for patient visits or meeting expenses, you, as the liaison, must turn in a request for reimbursement with receipts you receive from those who incurred the expense. The Foundation will reimburse you, then you can reimburse the person who incurred the expense.
- Your request for reimbursement must be submitted on a “Request for Reimbursement” form (Form 1006, Tab F-6). The form must be completed with all the details requested (date, name, address, quantity, description and price).
- Only meetings using mailing labels from the National Office will be honored and considered to be official meetings of the Foundation. Only expenses for official meetings will be reimbursed. The labels that the Foundation generates reflect the latest additions/corrections.
- **General:**
 - **ORIGINAL RECEIPTS MUST BE ATTACHED.** No receipt, no reimbursement, so PLEASE save your receipts. For items you purchase with your personal credit card, please send a copy of your credit card bill with the item highlighted or circled. Other non-related items on the bill can be crossed out.
 - If you wish to expedite payment for your expenses, you can scan your receipts and email them to the office (camille.yee@gbs-cidp.org). The check for reimbursement can be prepared, but will not be mailed until the original receipts are available at the Foundation.
 - Submit your request in a timely fashion, within 30 days of your meeting or when expenses are incurred.
 - People to contact for pre-approval are as follows:
 - Your Regional Director.
 - Camille Yee, Director, Education, Finance & Administration, camille.yee@gbs-cidp.org
 - Camille Yee can be reached by phone at 610-667-0131

- **Mileage:**

- The GBS/CIDP Foundation will reimburse for mileage at the Federal Government Rates in effect at the time of your trip. If your trip will be over 100 miles (round trip), you must seek approval for the reimbursement from your Regional Director before you make the trip. You can apply for reimbursement when:

- Visiting patients in hospitals or rehab centers. Usually one visit is sufficient. If more are required, discuss with your Regional Director beforehand. We will NOT reimburse for a home visit.
- When attending a support group chapter meeting.
- Running errands for the Foundation (purchasing stamps, supplies, photocopying or making arrangements for meetings, etc.)

- Mileage distance must be kept for each trip and then totaled on the “Request for Reimbursement form.” Example:

Purchased stamps & supplies5 miles
Visited patient in hospital, 2 times.....30 miles
35 miles

- Mileage amounts with NO description will NOT be reimbursed.
Example: Drove 35 miles.

- Use common sense when conducting liaison functions. Example: a liaison drove 35 miles round trip to a wholesale store to purchase a box of envelopes. The reimbursement costs for mileage was \$15.75. That was more than the cost of the box of envelopes. This doesn't appear to be reasonable. Now, if the liaison lived in a rural area and all stores that sold envelopes were located relatively in the same area, this would be a reasonable decision. However, could the envelopes have been purchase on a regular trip to town at another time? Perhaps other factors were involved. If so, explain on the Request for Reimbursement Form.

- **Travel:** From time to time the Foundation will ask that you attend a meeting. If it is at the request of the Foundation or pre-approved, your travel expenses will be reimbursed.

- **Airfare:**

Book your flights as early as possible, a mandatory 21 days ahead of travel. The earlier you make reservations, the cheaper the price. If this is not possible, get flight cost information and call the Foundation office for approval. You will only be reimbursed for COACH fares booked at the lowest price available at the time of booking. If you wish to fly first class or business class you will be asked to pay the difference.

- Only timely reservations will be honored. Reservations made less than twenty-one (21) days before your travel will NOT be honored without prior approval as stated above.
- The Foundation cannot reimburse you for the use of frequent flyer or similar promotional fares.

- For up to a two night overnight stay, it is expected that one carry on bag will be sufficient for your travel. For longer stays, the Foundation will reimburse for additional checked bags/suitcases, etc., only with prior approval.
- If you plan on parking your car at the airport while on GBS/CIDP business, we will ONLY reimburse for “long term parking.” If you park at any other location (short term, valet parking, visitors parking, etc.) we will ask you to pay the difference.
- If you wish to make a stop for personal reasons, please find out what the airfare would be for the least expensive flight from your originating city to the meeting place city and return. That is the amount we will reimburse.

Example. You reside in Texas and the meeting is in Philadelphia. You decide to visit family in Atlanta then catch a flight to Philadelphia. We will only reimburse what the airfare is from Texas to Philadelphia and return.

○ **Rail:**

- We will only reimburse for COACH fares.
- We will not reimburse for upgrades such as business class or first class seats.
- If you wish to travel by Metroliner or Acela Express, etc., you will be asked to pay the difference.

○ **Car:**

- We will reimburse up to the equivalent cost of an airline coach fare checked in a timely manner. In other words, your transportation by car cannot exceed the cost of the airfare.
- Reimbursement will be made at the Internal Revenue Service standard rates for non-profit organizations in effect at that time.
- This reimbursement also includes tolls, lodging, and food.

Example: You live in California and have been asked to attend a meeting in Texas. The round-trip airfare from California to Texas is \$300. \$300 will be the maximum amount the Foundation will reimburse you. Therefore, if during your trip your mileage, tolls, lodging costs \$295, you will be reimbursed \$295. However, if your total comes to \$400 you will be reimbursed \$300.00 since that would be the cost of the airfare.

○ **Travel Meals:**

- If your scheduled airline trip has you in the airport between connecting flights during the normal lunch hour, we will reimburse up to \$15 for lunch.
- If you arrive at the designated meeting place on the day before the meeting and no meals are planned by the Foundation for that day, you will be reimbursed up to \$15 for lunch and up to \$25 for the evening meal.
- For most Foundation sponsored events, there will be an evening meal planned for the day of your arrival, meals on each meeting day, and breakfast on the

day of departure. If you choose not to attend a sponsored meal and choose to eat elsewhere, the Foundation will not reimburse this meal expense. We will NOT reimburse for any alcoholic beverages.

- **Telephone:**
 - We will reimburse any long distance calls made to patients, on patients' behalf, to other liaisons, or to the Foundation. Please send the telephone bill with amounts circled. Non-related telephone numbers on the bill can be crossed out.

- **Making Copies and Printing:**
 - We will reimburse for copies as necessary. It is often less expensive to have items copied or printed if you use a commercial facility such as Kinko's, Office Depot, or Staples rather than printing or making copies at home. When you add up the costs of paper, printer cartridges, and other supplies, the cost per copy can surprise you. We do not reimburse for color copies!

- **Speaker Gifts:**
 - Speaker gifts are available upon request from the Foundation. If you have a speaker who speaks to your support group chapter on a repeat basis and has received the standard Foundation gift, the Foundation will authorize you to spend up to \$25 for a suitable gift. This purchase must be pre-approved by the Foundation Office.

- **Support Group Chapter Meetings:**
 - The GBS/CIDP Foundation International is a charitable organization whose funding comes from donations provided by individuals and corporations. This source of funding has its limits and is always scarce. That being the case, we encourage all liaisons to be frugal with the Foundation's funds. We would like our liaisons to hold meetings spending less than \$100 on each, although that is not always possible. However, you should be able to hold a meeting for less than \$200 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 \$200, you must contact your Regional Director well in advance and discuss other possibilities. We do not reimburse for meals to be served at meetings unless pre-approved by the Foundation.
 - 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.

- **Out of the ordinary:**
 - Anything that is not mentioned above must be pre-approved.
 - No pre-approval, no reimbursement!

GBS/CIDP RELATED WEBSITES

Access to Benefits Coalition (Medicare, Drugs) - The Access to Benefits Coalition is dedicated to ensuring that Medicare beneficiaries with limited means (including people aged 65 and over as well as younger people with disabilities who qualify) know about and make the best use of all available resources for accessing prescription drugs and reducing their costs. Coalition members share an interest in helping the millions of people with Medicare who are eligible for this Extra Help secure the prescription coverage they need to maintain their health and improve the quality of their lives. There is Extra Help with the costs associated with this coverage for people with limited incomes and resources. For people who qualify, Medicare pays 85 to 100 percent of all prescription costs.

www.accesstobenefits.org

Advocacy for Patients with Chronic Illness, 860-674-1370 - Advocacy for Patients with Chronic Illness, Inc. will provide advocacy services not including litigation. They have a team of staff, volunteers, and student interns working with over 1500 patients per year. They will file appeals for you with insurance companies. If your claim cannot be resolved without litigation, they will attempt to refer you to an attorney in your area to bring suit on your behalf. **www.advocacyforpatients.org**

Angel Flight (patient transportation), 918-749-8992 - Angel Flight is a non-profit charitable organization of pilots, volunteers, and friends. They will arrange free air transportation for any legitimate, charitable, medically related need. This service is available to individuals, and health care organizations. They will also arrange transportation of those people who are financially distressed, or who are in a time-critical, non-emergency situation due to their medical condition. **www.angelflight.com**

American Academy of Neurology (AAN) - AAN.com for Patients and Caregivers helps patients and family understand neurology and the science behind neurologic disorders and treatments. They also provide a [list of studies](#) currently seeking patients.

www.patients.aan.com

BenefitsCheckUp - BenefitsCheckUp is free service of the National Council on Aging (NCOA). Many adults over 55 need help paying for prescription drugs, health care, utilities, and other basic needs. There are over 2,000 federal, state, and private benefits programs available to help. BenefitsCheckUp helps identify benefits that could save money and cover the costs of everyday expenses. Here are the types of expenses people may get help with: Medications, Food, Utilities, Legal, Health care, Housing, In-home services, Taxes, Transportation, and Employment Training. **www.benefitscheckup.org**

Benefit Finder. - This is the official benefits website of the U.S. government. It informs citizens of benefits they may be eligible for and also provides information on how to apply for assistance. www.benefits.gov

Carers UK - This is a United Kingdom (UK) site that provides information and advice about caring for caregivers. Although some of the material is naturally focused on the UK, the materials apply to most any caregiver. www.carersuk.org

Caring Bridge - Provides free, personal and private websites that connect people experiencing a health challenge with family and friends. CaringBridge websites offer a personal and private space to communicate and show support, saving time and emotional energy when health matters most. www.caringbridge.com

Center for Medicare Advocacy - The Center for Medicare Advocacy, Inc. is a national, non-profit, non-partisan education and advocacy organization that works to advance fair access to Medicare and to quality health care. The Center was established in 1986 and focuses on the needs of Medicare beneficiaries, people with chronic conditions, and those in need of long term care. The organization is involved in writing, education, and advocacy activities of importance to Medicare beneficiaries nationwide. www.medicareadvocacy.org

Centers for Medicare and Medicaid Services – The official U. S. website for Medicare. It provides information on drug and health plans and other Medicare related needs. www.medicare.gov also www.cms.hhs.gov

Disability Information Resource (U.S. Dept. of Labor)- Disability.gov is the federal government website for comprehensive information on disability programs and services in communities nationwide. The site links to more than 14,000 resources from federal, state, and local government agencies; academic institutions; and nonprofit organizations. You can find answers to questions about everything from Social Security to employment to affordable and accessible housing. www.disability.gov

Easter Seal Services - Easter Seals provides exceptional services, education, outreach, and advocacy so that people living with disabilities can live, learn, work, and play in our communities. They can help with medical equipment needs. www.easterseals.com

Emedicine – This is a medical reference site that provides information on drugs, diseases, and procedures. www.emedicine.com

Family Caregiver Alliance - Family Caregiver Alliance was the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. Long recognized as a pioneer in health services, FCA now offers programs at national, state, and local levels to support and sustain caregivers. www.caregiver.org

Family USA - Families USA is a national nonprofit, non-partisan organization dedicated to the achievement of high-quality, affordable health care for all Americans. They provide key health contacts, state government links, news and views from each state, and other resources that might be helpful such as health insurance assistance programs by state. www.familiesusa.org

Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) (Formerly the GBS Support Group - United Kingdom) GAIN is a registered Charitable Incorporated Organization (CIO) based in the United Kingdom that offers support and information to those affected by Guillain-Barré Syndrome, CIDP and other associated inflammatory neuropathies throughout the UK and Ireland. The website is a good source of information on GBS/CIDP and variants. www.gaincharity.org.uk

HelpingYouCare™ -This is a good resource for any caregiver, not just for caregivers of seniors. Their mission is to provide you the constantly updated, serious and helpful news, information, education, practical tools, resources & support you need as a caregiver, and to contribute your suggestions as a caregiver, along with those of experts, for the improvement of our health and long-term care systems. www.helpingyoucare.com

Hill-Burton Free and Reduced Cost Health Care - In 1946, Congress passed a law that gave hospitals, nursing homes and other health facilities grants and loans for construction and modernization. In return, they agreed to provide a reasonable volume of services to persons unable to pay and to make their services available to all persons residing in the facility's area. The program stopped providing funds in 1997, but about 300 health care facilities nationwide are still obligated to provide free or reduced-cost care. www.hrsa.gov/gethealthcare/affordable/hillburton/

Kaiser Foundation Consumer Guide - The Kaiser Foundation Consumer Guide is a guide to handling disputes with your employer or private health plan, by state. www.kff.org/consumerguide/7350.cfm or www.statehealthfacts.org.

Medicare Rights Center - The Medicare Rights Center is an independent, national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives. www.medicarerights.org.

MedMonk - MedMonk improves access to specialty medications and can assist patients who demonstrate financial hardship obtain medications at the point of care. www.medmonk.com.

National Institute of Neurological Disorders and Stroke (NINDS) - NINDS conducts and supports research on brain and nervous system disorders. Created by the U.S. Congress in 1950, NINDS is one of the more than two-dozen research institutes and centers that comprise the National Institutes of Health (NIH). The NIH, located in Bethesda, Maryland, is an agency of the Public Health Service within the U.S. Department of Health and Human Services. www.ninds.nih.gov.

National Organization for Rare Diseases (NORD), 203-744-0100, - NORD, a 501(c)(3) organization, is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. NORD serves all stakeholders in the rare disease community, including patients and their families, patient organizations, researchers, medical professionals, and companies developing orphan products. www.rarediseases.org.

National Patient Travel Center, 800-296-1217, - The National Patient Travel Center provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help available in the national charitable medical air transportation network. www.patienttravel.org

National Respite Locator Service, 919-490-5527 - Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult. The National Respite Locator Service helps parents, family caregivers, and professionals find respite services in their state and local area to match their specific needs. <http://respitelocator.org>.

Needy Meds 800-503-6897- NeedyMeds is a 501(c)(3) non-profit information resource devoted to helping people in need find assistance programs to help them afford their medications and costs related to health care. NeedyMeds' mission is to be the best source of accurate, comprehensive, and up-to-date information on programs that help people facing problems paying for medications and health care; to assist those in need in applying to programs; and to provide health-related education using innovative methods. NeedyMeds provides a free drug discount card that offers a discount of up to 80% at more than 63,000 pharmacies nationwide. www.needymeds.com.

Partnership for Prescription Assistance, 888-477-2669, - The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many will get their medications free or nearly free. www.pparx.org.

Patient Advocate Foundation, 800-532-5274, - Patient Advocate Foundation is a national non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination, and/or debt crisis matters relative to their diagnosis through case managers and attorneys. Patient Advocate Foundation seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability. www.patientadvocate.org.

Patient Services, Incorporated (PSI), 800-366-7741 - PSI provides a "safety net" for patients with chronic illnesses, such as CIDP, who are struggling to keep up with expensive insurance premiums and co-payments. PSI evaluates an individual's financial, medical, and insurance situation to determine who is eligible for assistance. www.uneedpsi.org.

Plasma Protein Therapeutics Association (PPTA) – PPTA is the primary advocate for the world's leading source plasma collectors and producers of plasma-derived and recombinant biological therapeutics. The medicines produced by PPTA members are used in treating life-threatening diseases and serious medical conditions including bleeding disorders, immune system deficiencies, alpha-1 antitrypsin deficiencies, burns, and shock. They provide a Patient Notification System that is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls. www.pptaglobal.org

RxAssist - Patient assistance programs are run by pharmaceutical companies to provide free medications to people who cannot afford to buy their medicine. RxAssist offers a comprehensive database of these patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need. All in one place. www.rxassist.org

Social Security Administration, 800-772-1213 – This is the official website of the U. S. Social Security Administration. It provides a comprehensive collection of information on Social Security topics and also provides online applications for many services. www.socialsecurity.gov

Social Security Administration Blue Book - This edition of Disability Evaluation Under Social Security, (also known as the Blue Book), has been specially prepared to provide physicians and other health professionals with an understanding of the disability programs administered by the Social Security Administration. It explains how each program works, and the kinds of information a health professional can furnish to help ensure sound and prompt decisions on disability claims. www.ssa.gov/disability/professionals/bluebook.

The Assistance Fund, 877-245-4412, - The Assistance Fund is a 501(c)3 nonprofit organization created to make advanced biotech therapies available to the underinsured. As new scientific discoveries are brought to the market and diagnostics are created to establish appropriate therapy guidelines, The assistance Funds works with individuals to make access a reality. More than just a funding resource, The Assistance Fund provides a continuum of services for those with chronic and life threatening illnesses. www.assistfund.org

The Medicine Program - The Medicine Program is a Patient Advocate Organization and is FREE service. Their goal is to assist you and your family find, apply and qualify for the right Patient Assistance Program(s). By working closely with you, your doctor and the drug manufacturers they help cut through the red tape and assist you in receiving your medicine free or almost free-of-charge. www.themedicineprogram.com

U. S. Government Healthcare Information - The United States does not have a government medical plan to cover the entire population. In general, people in the United States pay for their own medical care, however, you may be able to obtain federal or state healthcare assistance if you meet certain requirements. The links in this website provide important information about how to find low-cost healthcare and other federal and state healthcare programs.

www.welcometousa.gov/Healthcare_families/Health_insurance.htm

U. S. Department of Labor – Employee Benefits Security Administration (EBSA) - The EBSA website provides a myriad of information on employer insurance programs, COBRA, HIPPA, and other employee benefits. **www.dol.gov/ebsa/**

U. S. Department of Health & Human Services – Provides a health center locator & low cost care by state. **findahealthcenter.hrsa.gov/Search_HCC.aspx**

U. S. Department of Health & Human Services – Provides insurance information, healthcare laws, etc. **www.healthcare.gov**.

U. S. Department of Health & Human Services – Provides information on the state managed Children’s Health Insurance Program (CHIP) that provides free or low-cost health coverage for children up to age 19. **www.insurekidsnow.gov**.

Wheelchair Net – This a website of the University of Pittsburgh . It provides information/resources for living, managing and enjoying everyday life using a wheelchair. **www.wheelchairnet.org**

The following are links to many catalogues for aids and products for disability patients & caregivers

Access Unlimited (Mobility Issues-Home & Car) - A commercial source for products that allow easy access to any vehicle, from cars and vans to trucks and SUVs. Access Unlimited products are available from over 400 dealers worldwide. - **www.accessunlimited.com**

AMeds (Home health care products) 866-802-6337 - AMeds is a division of Claflin Medical Equipment Company (CME). This commercial site offers a selection of disability and medical equipment for home health care. - **www.ameds.com**

Arthritis Supplies (daily living aids for bathing, sitting & standing, dressing, mobility, etc.) - **www.ArthritisSupplies.com**

Care Giver Products (home medical supplies for people with varying physical needs - useful tools, appliances, equipment, and rehabilitation products) - **www.CareGiverProducts.com**

Full of Life (fitness, health aids, hobbies & gifts, household helpers, mobility, personal care, & therapeutic) - **www.FullOfLife.com**

Gimp on the Go (Traveling information for the disabled) - www.gimponthego.com

Gold Violin (Independent living aids from arthritis, diabetes, foot care, hearing, incontinence, memory loss, mobility, pain relief, plus size, poor circulation, rehab & recovery, sleep aids, and vision) - www.goldviolin.com

Make Life Easier (broad selection of products in the categories of housewares, health & personal care, laundry & cleaning, travel & auto, tools, and garden) - www.make-life-easier.com

Mobility Aids (mobility aids & accessories for wheelchairs, scooters, walkers, transfers, canes, crutches & safety alarms) - www.Mobility-Aids.com

North Coast Medical (Provider of rehabilitation, assistive, and splinting products; adapted utensils, assistive devices, disability aids, products for the handicapped, and adaptive daily living aids.) - www.ncmedical.com

Patterson Medical (Provider of rehabilitation, assistive, and splinting products) - www.pattersonmedical.com

Pride Mobility (scooters, chairs, and ramps) – www.pridemobility.com

The Wright Stuff (adapted utensils, assistive devices, disability aids, products for the handicapped, and adaptive daily living aids) - www.WrightStuff.biz

Vehicle mobility (disability products and services such as handicap vans, mobility van rentals, wheelchair accessible service and repairs, home stair lifts, or disabled driver hand controls) - www.betterlifemobility.com/Mobility-Products/Disabled-Driver-Equipment



CHAPTER OPERATION

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WALK and ROLL for GBS/CIDP

This activity is a departure for our organization because our support group chapters were never intended to be fundraising arms of the organization. However, we have been so impressed with the success of local walk-a-thons that we want to nationalize the concept to maximize our visibility. We are calling these events “*Walk and Roll for GBS/CIDP.*” If you are interested in holding a *Walk and Roll*, the information provided here will assist you.

Purpose(s):

- To strengthen Awareness Day/Month (May)
- To increase the public’s awareness of GBS, CIDP, MMN, Miller Fisher, and their variants
- To raise funds to carry out the Foundation’s mission

Over the past couple of years there have been fewer Awareness Day meetings held during the month of May. Awareness Day/Month helps both the lay public and healthcare professionals to become acquainted with GBS, CIDP, MMN, Miller Fisher and their variants, and to help them understand symptoms and treatment options. Additionally, while Foundation expenses are growing, sources of income are not. One way to address both of these issues is to make the *Walk and Roll* a more exciting, visible event. An Awareness Day meeting could be held either before or after the Walk, or even on a different date.

Suggestions:

1. Inform the Foundation of your plans as soon as you have decided to run a *Walk and Roll*, and no less than two months before your event date. Provide the Foundation with contact information such as Support Group Chapter name, Coordinator for the *Walk and Roll*, telephone numbers, email address, etc.
2. Selecting a good site can have big impact on the success of the event. The ideal site will be accessible for *Walk and Roll* participants, have a relatively “flat” walking route, have accessible bathroom facilities, and have a pavilion or other structure available that can be used in case of inclement weather.
3. Check with local officials to determine what permits and approvals may be required. Determine if insurance is required (the Foundation will help with this).
4. Then send out a “save the date” to your group and people in your personal and social network that may have interest.

5. Businesses and organizations often contribute drinks, snacks, and other refreshments. Start making contacts early to request their support for the **Walk and Roll**.
6. Be sure to communicate to all who may have interest in the Foundation's mission and/or the event, that there are many ways to participate in the event. People can walk and contribute, contribute and not walk, sponsor people who participate, or even do a virtual walk online (see our virtual link on our To Donate page on our website).
7. When planning for your **Walk and Roll**, contact local running and bike clubs. Most are willing to help with most anything having to do with the walk.
8. This is a walk or a stroll. It is not a race. Be mindful of participants using walkers or wheelchairs.
9. Encourage supporters to donate online and have checks made out to the GBS/CIDP Foundation International. Walker contribution envelopes will be provided by the Foundation.
10. Use Form 1008, provided by the Foundation, to record donations. Ensure that the complete address is legible so that "Thank You" letters can be sent.

What the Foundation will do:

1. Provide all walk related materials and our **Walk and Roll** event manual.
2. Post your **Walk and Roll** information on our website, www.gbs-cidp.org.
3. Create a specific web page for your event, and a donation page for your event.
4. Supply mailing labels.
5. Create and distribute email communications about your event to Foundation members
6. Reimburse approved "walk-related" expenses. These need to be coordinated with the Foundation before funds are committed or spent!
7. Send a press package as requested. You can use the sample press release to help get the word out. Let the local newspapers and radio stations know where and when the walk is taking place. Most newspapers and many radio stations have a special community calendar feature that announces coming events.
8. Provide necessary insurance documents if required.
9. Provide you contact information for those who have organized successful "walks" in the past.

Centers Of Excellence

The Centers of Excellence were proposed as a measure to provide patients with diagnostic facilities through out the USA (and other countries) with expertise in inflammatory neuropathy. The patient may want a second opinion if they feel they are misdiagnosed, not doing as well as they have been told they should, or if there is no specialist in their area that is familiar with the diagnosis or management of inflammatory neuropathy.

This not a measure to provide total care or follow up but instead to give an expert consult that will evaluate their diagnosis and treatment regimen and provide that information as well to their local neurologist.

The centers will form a network of healthcare facilities to provide expert diagnosis and management of inflammatory neuropathies for patients who are unable to consult with medical experts in the field in their own communities.

The designated facilities are:

1. Academic Medical Center (AMC), University of Amsterdam – The Netherlands
2. California Pacific Medical Center - San Francisco, California
3. Cedars-Sinai Medical Center - Los Angeles, California
4. Heinrich-Heine University Department of Neurology - Düsseldorf, Germany
5. King’s College Hospital - London, United Kingdom
6. Perelman School of Medicine, University of Pennsylvania - Philadelphia, PA
7. Phoenix Neurological Associates/Banner Good Samaritan Medical Center - Phoenix, Arizona
8. Milan University, Humantis Clinical & Reseach Center - Milan, Italy
9. Saint Elizabeth’s Medical Center - Boston, Massachusetts
10. The Hospital of the University of Pennsylvania - Philadelphia, Pennsylvania
11. The Johns Hopkins University School of Medicine and The Johns Hopkins Hospital - Baltimore, Maryland
12. The University at Buffalo School of Medicine and Biomedical Sciences, State University of New York - Buffalo New York
13. The University of California Medical Center - Los Angeles, California
14. The University of Kansas Medical Center - Kansas City, Kansas
15. The University of Texas Health Science Center at Houston and The University of Texas Medical School at Houston - Houston, Texas
16. Wayne State University Group, Detroit Medical Center - Detroit, Michigan
17. Vanderbilt University Hospital - Nashville, Tennessee

Additional information about the centers and designation applications can be found on the Foundation’s web site: www.gbs-cidp.org.

