GBS | CIDP
Foundation International

Summer 2014

The Communicator

Providing Strength Through Support

PHYSICIAN REFERRAL UPDATE

In our effort to maintain a physician referral list for patients, we welcome recommendations of those doctors from your area who are competent and treat patients who have GBS, CIDP, MMN, and variants.

To submit names, contact Lisa Butler in the Foundation office: Lisa.Butler@gbs-cidp.org

SYMPOSIUM UPDATE

See pages 13-17

Please update your contact information to make sure we have your current email address.

Your information will not be shared with anyone outside the Foundation

Contact us online at
www.gbs-cidp.org
or by emailing
info@gbs-cidp.org

Visit us on Facebook
www.facebook.com/gbscidp

Ken's Korner

This issue of the *Communicator* typically highlights medical articles and comments from experts in the fields of GBS, CIDP and MMN. In an effort to update you on all that is happening, we are sharing medical news with other Foundation news! This year you will find articles on pain in GBS, immune globulin and pregnancy, and IVIG dosing. We are also featuring several workshops that are offered as part of the **13th International Symposium** along with a brief biography on the presenters. Many of the doctors who are presenting are members of our Medical Advisory Board. You will also read about Laura Dodd who has had CIDP since the age of twelve and now is an accomplished country singer with a song in Country's Top 40! We are honored to announce that Laura will be performing at our Symposium! Our planning for the Symposium continues (see article, page 13). We hope you will join us in Orlando.

The Foundation just released notice for the Benson Fellowship in Neuromuscular Neurology. We are proud to report that we have twenty-eight applicants for this unique opportunity to attract young residents into the field of neuromuscular study. We hope to announce the recipient at the Symposium.

In April, the Foundation hosted a booth at the American Academy of Neurology conference where we had the opportunity to meet many new doctors. Most importantly, we were able to continue to educate and to spread the Foundation's message to attendees at the event.

On May 1st, a group of sixteen Foundation staff, Regional Directors, Liaisons, Board members and patients travelled to Capitol Hill for the GBS|CIDP Foundation's Advocacy Day. We met with nineteen Congressional Offices and their staffs. We hosted a congressional luncheon briefing which featured Katrina Gwinn from the National Institute of Neurological Disorders and Stroke, Millie Birr from the American Association of Neuromuscular and Electrodiagnostic Medicine, Dr. Carol Lee Koski, our own Medical Director and Jim Crone who shared his journey with CIDP. Several members from the House and Senate attended the lunch.

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We take this opportunity to thank ***CSL Behring*** *for their support in making this newsletter possible through an unrestricted educational grant.*

CONTACT US
International Office
The Holly Building
104½ Forrest Avenue
Narberth, PA 19072

1.866.224.3301
1.610.667.0131
Fax: 1.610.667.7036

www.gbs-cidp.org
email: info@gbs-cidp.org

Ken's Korner

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In each meeting we were able to tell a patient's story, educate about neurological conditions, inform about the Foundation and our mission, and conclude with requests for action which included the following:

To Advance Medical Research: Support from Congress to provide the National Institute of Health (NIH) with at least $32 billion in Fiscal year 2015.

To Improve Patient Care:

- Cosponsor and advance the bipartisan Patients Access to Treatments Act. (H.R.460)
- Reach out to the center for Medicare and Medicaid Services (CMS) and to raise concerns over the deep cuts to the reimbursement rate for neurological diagnostic tests (EMG and NCS).
- Raise concerns with CMS over an interim rule allowing private insurance to prohibit acceptance of third party premium payments made by charitable organizations.

Many House and Senate Congressmen will be in their local home offices in August. This is the perfect time to visit your Representative. Contact Lisa Butler at the Foundation office for details.

In July we will be represented in Düsseldorf at the Inflammatory Neuropathy Consortium. Although we have been "on the move," we are always here for you. We appreciate your continued support. Please let us know what we can do for you!

Ken Singleton
Executive Director

A Plan for Giving: Remember the GBS|CIDP Legacy Circle!

By naming the Foundation in your will or trust, or as a beneficiary of a retirement plan, you won't affect your current cash flow, and you can change your decision at any time. No gift is ever too small. We welcome you to make your future gift in honor or in memory of a loved one.

For more information about becoming a member of the GBS|CIDP Foundation Legacy Circle contact Ken Singleton, Executive Director: 610-667-0131 or ken.singleton@gbs-cidp.org.

On a Roll With Walk and Roll 2014!

The **North Central New Jersey Walk and Roll** held in Bernard's Township, New Jersey, kicked off the Walk season on May 4th with a huge success for patients of all ages and their families! The Walk, with over 120 Walk and Rollers, was a great day of fun, friendship, refreshments, and festivities.

As one walker described the day, "It was old friends getting together who had never met before," meaning patients and families had the opportunity to share their experiences with inflammatory neuropathies with others who had similar stories to tell! Many new friendships mark each Walk and Roll, and North Central New Jersey was no exception. Special thanks go to Sue Salzmann, the North Central event chair, and to all the Walk and Rollers and supporters of the event.

We are looking for both walkers and volunteers for all walks. New walks are already being scheduled for the 2015 Walk season.

We are also seeking volunteer support for the following areas:

Dallas, TX	New York, NY
Chicago, IL	Washington, DC
Seattle, WA	Los Angeles, CA
San Francisco, CA	San Diego, CA

If you are interested in helping to expand the Foundation's reach and would like to volunteer for or participate in a Walk and Roll, please contact Bob Nelson at (610) 667-0131 or by email at bob.nelson@gbs-cidp.org.

Locations currently scheduled for the 2014 Walk season include:

Rome City, IN ~ June 6, 2014
Philadelphia (Delaware Valley), PA ~ Sunday, June 22
Pittsburgh Area, PA ~ September 13, 2014
St. Louis, MO ~ September 13, 2014
Boston, MA ~ September 20, 2014
Atlanta, GA ~ October 18, 2014
Orlando, FL ~ November 1, 2014

IGOS

IGOS is an on-going project: International Guillain-Barré Outcome Study

We are very proud to announce that together we have reached an important milestone in IGOS!

It was only last November that Dr. Zhahir Islam/Badrul Islam from Dhaka, Bangladesh, enrolled patient number 250. Now Professor Satoshi Kuwabara from the Chiba University Hospital, Chiba, Japan, has enrolled **patient number 500! Congratulations!**

On the right you will find an overview of the inclusions being at the half way point of the study. Participants are from all over the world.

We would like to thank everyone again for their continuous support.

Update IGOS worldwide per 8 May 2014

	Country	Centers	IRB+ centers	Inclusions
1	UK	20	20	88
2	USA	40	40	83
3	Bangladesh	2	2	58
4	Denmark	5	5	47
5	Italy	19	11	43
6	Netherlands	19	15	40
7	Spain	10	10	38
8	Germany	6	6	27
9	Argentina	10	7	22
10	Japan	8	6	17
11	Canada	11	3	12
12	Malaysia	1	1	9
13	France	8	2	7
14	Belgium	8	3	6
15	Taiwan	1	1	2
16	Australia	8	1	1
	Total:	**176**	**133**	**500**

Immune Globulin and Pregnancy

By Leslie J. Vaughan, RPh
Senior Vice President of Clinical Services, NuFACTOR Specialty Pharmacy

While the medical community believes the benefits of IG therapy outweigh the risks during pregnancy, dosing adjustments may be needed for immune-deficient patients.

Many patients who are prescribed immune globulin (IG) therapy have concerns about whether the drug is safe during pregnancy. While there is no definitive answer to this, pregnancy is listed as a precaution for IG. For instance, WebMD states that "during pregnancy, this medication should be used only when clearly needed." Of course, IG is clearly needed by immune-deficient patients, as well as many autoimmune disease patients. The good news, then, is that most physicians believe IG is safe during pregnancy, and that its benefits outweigh its risks. In addition, there are many case reports of patients being treated with IG with no adverse effects to the fetus.

Benefits vs. Risks

Upon a medicine's approval, the U.S. Food and Drug Administration assigns it one of five pregnancy categories that indicate the potential of a drug to cause harm to the fetus if used during pregnancy (Table 1). Each category outlines whether clinical studies have shown any potential risks of the drug during pregnancy. IG falls under category C, which means that either no animal or human studies have been conducted or animal reproduction studies have shown drugs in this category to have an adverse effect on the fetus, but there are no well-controlled studies conducted on humans to date. IG's potential benefits may warrant its use despite potential risks.

The current belief in the medical community is that IG therapy is safe during pregnancy. But, the decision to continue to infuse IG during pregnancy is one that should be made with the treating physician, and it should be based on a risk-benefit analysis. A standard risk-benefit analysis considers all the benefits of using a medication and weighs those benefits against the risks of potential adverse events that may be caused by the medication. For women who are pregnant, the risk-benefit analysis should consider both the benefits of the medication and the risk of adverse events to both the mother and the developing fetus. For IG, the risk-benefit analysis should also include the risk of stopping the medication. For example, someone being treated with IG for an immune deficiency may be at increased risk of developing serious infections if IG is stopped during pregnancy. Ideally, a patient with a chronic condition being treated with IG or any other drug should discuss pregnancy with her physician well in advance of becoming pregnant. This will allow for the development of a solid treatment plan to support both the mother and the baby during pregnancy.

IG Dosing

Currently, there is no specific protocol published for IG therapy during pregnancy. According to Dr. Marc Riedl, associate professor of medicine in the division of rheumatology, allergy and immunology at the University of California, San Diego, "it's well-recognized that IgG trough levels will fall in the second and third trimesters due to placental transfer, blood volume and weight gain." So, he says it is advisable to begin checking the trough levels of those with an immune deficiency during the second trimester and to make dose adjustments to keep IgG levels well within the normal range. And, toward the end of gestation, it may be necessary to increase the frequency of the infusions. "In my experience, antibody deficient patients do very well during pregnancy with these relatively simple measures," says Dr. Riedl. For patients with autoimmune conditions, IgG trough levels aren't a valid test for determining the correct dosing adjustments. Instead, the best indicator is to assess the specific symptoms related to the condition prior to pregnancy with the goal of maintaining the patients' symptoms at the same or improved levels. If during the course of pregnancy the patient declines clinically, the physician may consider a modest dose increase to regain control. According to Dr. Todd Levine, director of the department of neurophysiology at Good Samaritan Hospital in Phoenix, Arizona, he adjusts the IG dose for autoimmune disease patients only if symptoms get worse. Otherwise, he keeps his patients on the pre-pregnancy dose throughout gestation.

Case Studies

Several studies conducted in the past have assessed the safety of receiving IG during pregnancy. Most of these articles are small case studies of patients who were receiving IG for a chronic condition prior to becoming pregnant, and continued to receive IG during the course of their pregnancy. And, each of the studies found it was safe to continue IG therapy with no adverse events noted for the mother or the baby. Three of these studies focused on patients with common variable immune deficiency who were treated with IG during pregnancy and whether dose adjustments were needed. The common result from each

Table 1. U.S. Food and Drug Administration Pregnancy Categories

The FDA-assigned pregnancy categories as used in drug formularies are as follows:	
Category A	Adequate, well-controlled studies in pregnant women have not shown an increased risk of fetal abnormalities.
Category B	Animal studies have revealed no evidence of harm to the fetus, however, there are no adequate and well-controlled studies in pregnant women. or Animal studies have shown an adverse effect, but adequate and well-controlled studies in pregnant women have failed to demonstrate a risk to the fetus.
Category C	Animal studies have shown an adverse effect and there are no adequate and well-controlled studies in pregnant women. or No animal studies have been conducted and there are no adequate and well-controlled studies in pregnant women.
Category D	Studies, adequate well-controlled or observational, in pregnant women have demonstrated a risk to the fetus. However, the benefits of therapy may outweigh the potential risk.
Category X	Studies, adequate well-controlled or observational, in animals or pregnant women have demonstrated positive evidence of fetal abnormalities. The use of the product is contraindicated in women who are or may become pregnant.
NA	FDA pregnancy rating not available

of these studies found dosing adjustment was necessary during the course of the pregnancy to keep IgG trough levels at pre-pregnancy levels. The need for increased dosing in the late second and third trimesters is thought to be due to plasma volume expansion. The studies also found that babies born to immune deficient patients who continued IG therapy during pregnancy had adequate IgG levels after birth, whereas babies whose immune-deficient mothers were not treated throughout pregnancy had slightly lower birth weights and presented with lower IgG trough levels. The studies did note, however, that low birth weight babies did develop normally and did not have any long-term impact.

Communication Is Key

While there are no current studies directed at testing the safety of IG treatment during pregnancy, current practical experience has found IG to be safe and effective, and the benefits of IG therapy are believed to outweigh the risks. However, each patient is different. Therefore, close communication between the patient, the IG prescriber and the Ob/Gyn physician throughout the pregnancy will allow for timely dose adjustments when necessary.

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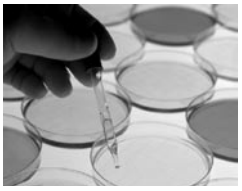

The PATH Study - CIDP Treatment with Subcutaneous Immunoglobulin (IgPro20)

By Dr. Orell Mielke, MD, Global Clinical Program Director
Therapeutic Area Inflammation/Pulmonology Global Clinical Research and Development, CSL Behring

CSL Behring is currently recruiting patients for the PATH study, an international clinical trial designed to evaluate the effectiveness of IgPro20 compared with placebo in the treatment of chronic inflammatory demyelinating polyneuropathy (CIDP). The study will also look at the safety and tolerability of these doses.

Intravenous immunoglobulins (IVIG), steroids and plasma exchange are recommended treatment options for CIDP, although only one IVIG has received official marketing approval. IVIG have to be administered by intravenous injection (through a needle inserted in your vein). In contrast IgPro20 is a subcutaneous immunoglobulin (SCIg), which means that it can be administered by injection under the surface of the skin. It may, therefore, offer another treatment option for CIDP, possibly allowing patients to administer the medication at home, or wherever and whenever it suits them, and to integrate the treatment into their daily routine.

What does the study involve?

The study is made up of 4 different periods that all together will last about 52 weeks. The study doctor will decide if you are eligible to continue in the study at the end of each study period.

1. **Screening period**
   In the Screening period you will attend a screening visit where some medical assessments and a blood draw will be done. The study doctor will use the results of these tests to decide if you are eligible to participate in the study.
2. **Withdrawal period**
   Some patients do not need the same amount of IVIG throughout their treatment of CIDP, and some may not need IVIG anymore because they are in remission. The purpose of the withdrawal phase is to find such patients before treating them with the study drug. To do this the study doctor will stop your IVIG treatment and closely monitor you to see if your symptoms get worse. If your symptoms do not worsen, you may not need IVIG anymore or only a reduced dosage.
3. **Re-stabilization period**
   You will quickly be treated with IVIG again as soon as the study doctor confirms that your symptoms do get worse. In this case you will continue in the study and receive IVIG over a period of 10 to 13 weeks to improve your symptoms.
4. **Subcutaneous (SC) treatment period**
   For the final period of the study, you will receive either the study drug IgPro20 or placebo as weekly subcutaneous infusions over 25 weeks. The study team will teach you how to do the subcutaneous infusions at the beginning of this period, after which you can do the weekly infusions yourself.

To make the comparison between IgPro20 and placebo as fair as possible, this study is "double blinded." This means that neither you nor the study doctor will know which treatment you are taking. The study doctor will closely monitor your symptoms during this period. If there is any sign that your symptoms get worse, you will again be given IVIG and will stop with the study.

Who can take part?

To be eligible for the study, patients diagnosed with CIDP should:

- have had repeated treatment with IVIG (≥ 4 infusions) within the last 9 months prior to enrollment.
- have had an IVIG treatment during the last 8 weeks prior to enrollment.
- be ≥18 years of age.

Patients with any of the following are not eligible to participate:

- Any polyneuropathy of other causes, any other disease (mainly neurological or chronic orthopedic) that has caused neurological symptoms or may interfere with treatment or outcome assessments
- Severe diseases and conditions that are likely to interfere with evaluation of the study product or satisfactory conduct of the study
- History of thrombotic episodes within the 2 years prior to enrollment
- Known allergic or other severe reactions to blood products including intolerability to previous IVIG

I am interested in volunteering in a study, who do I contact?

We are always looking for volunteers to participate in our studies. If you are looking to volunteer or want information about a study site near you, please contact the study team at clinicaltrials@cslbehring.com

Where can I find more information about taking part in the study?

To find out more information about the study and where we are currently recruiting patients, you will find this information published on the US website www.clinicaltrials.gov.

Ongoing Research Measures IVIG Dosing Efficacy for CIDP Patients

By Brian Cleary, Marketing Manager, AxelaCare Health Solutions

Patients being treated for CIDP with IVIg soon will benefit from new technology in clinical trials to help doctors monitor therapy and precisely adjust medication doses as frequently as needed.

An ongoing trial called GOOD SHEPARD (Outcomes Database for Specific Home Infusion Evidence, Patient Care and Research Data) is being conducted in numerous academic medical centers and in private physician practices in states where its sponsor, AxelaCare, is licensed to perform home infusion. The trial will enroll 1,500 patients and is expected to take five years.

GOOD SHEPARD is designed to measure patient outcomes from AxelaCare's CareExchange home IV infusion and outcomes system for delivering immunoglobulin (IVIg) for treatment of CIDP. Initial data has shown there is a significant association between IVIg dosage and treatment outcomes and that the new technology enables clinicians to readily track patient data to monitor response to treatment and titrate immune therapy, if necessary.

"Many rare and complex diseases, and the medicines that treat them, lack robust research data to support physicians in formulating the most effective care plans. So far in a small number of patients, we are learning that CareExchange is a valuable tool that can generate a broad database for measuring outcomes of IVIg therapy," said neurologist Richard Lewis, M.D., Cedars Sinai Medical Center. "The technology can collect meaningful, objective outcomes measurements to follow patients after clinical interventions with intravenous immunoglobulins."

According to John Ney, M.D., neurologist, University of Washington Medical Center, the technology generates evidence-based guidance physicians need to make treatment decisions for their CIDP patients. "The data collection and validation process offers the most practical and insightful information to practicing clinicians as well as build data sets with specific research objectives in mind," Ney said.

In the trial, CareExchange is allowing investigators to measure treatment outcomes by collecting quality of life, physical status and disability assessments in patients with peripheral neuropathies. The standard of care for IVIg therapy provides limited outcomes data, and physicians usually adjust doses during patient visits every three to six months. There is an unmet need for reliable and more timely outcomes data to help determine therapeutic responses to IVIg therapy.

Thus far in the study, the data analysis shows that the mean change from baseline in seven outcomes metrics was highly dependent on dosing. Patients treated with low and medium doses showed poorer outcomes and the high-dose group had improved mean outcomes from one to three months. The high dose-group showed improvement in every outcomes measurement; and there were significant improvements in grip strength, fatigue severity; and neuropathy limitations. In the low dose group, every outcomes measurement worsened after three months.

"The data clearly show a strong association between IVIg dosage and patient responses, and that the CareExchange technology can collect meaningful outcomes data following clinical interventions with intravenous immunoglobulins. This will help physicians formulate and adjust treatment strategies," said Jeffrey Allen, M.D, a neurologist at Northwestern University's Feinberg School of Medicine. "We anticipate further studies will provide insight regarding the optimal IVIg initiation dose, maintenance dose, and infusion frequency."

For more information please contact Brian Cleary at bcleary@axelacare.com.

A Patient's Story: Laura Dodd

The old adage "when life gives you lemons, just make some lemonade" has been a byline for Laura Dodd almost her entire life. At the young age of 12, Laura was diagnosed with a rare neurological disorder, CIDP. The result was several years traveling from a wheelchair, to a walker, to using a cane and finally "standing on my own two feet" as expressed in one of her original song compositions. To combat her illness Laura has regularly scheduled intravenous treatments. In addition to the medicinal routines, Laura incorporates daily workouts and exercises to improve her overall welfare.

Laura's vocal and stage accomplishments are quite a few. Some of her more recent performances include the Washington, DC, mall venue for the 100-year celebrations for the Girl Scouts of America, theatrical and vocal performances at the JFK Center for VSArts, the Strathmore in Bethesda, MD, for the Disability Coalition, the lawn of the White House for the Miracle League annual game, as well as many more not listed here. An independent film director in Denver, CO, has included 3 of Laura's original song works in 2 of her films and 1 documentary.

Born and raised in a small Alabama community, Sand Valley, Laura now resides with her husband Joe in Jasper, AL, with part of the time being spent in her small home in Nashville, TN.

When asked about her disability, Laura explains, "My family encouraged me from day one to make this trial a positive one, to grow and become all I have dreamed of. My dreams have always been big," Laura says while smiling, "but my 5 foot 3 inch frame is dreaming its way to the world renowned stages, Carnegie Hall, Grand Ole Opry, and many, many more. Music has truly been the very best medicine for my journeys in life."

Pain in Guillain-Barré Syndrome

By Gareth Parry, MD
Department of Neurology University of Minnesota Minneapolis
Member Medical Advisory Board

Guillain-Barré syndrome (GBS) is a disorder in which the dramatic nature of the paralysis overshadows all other features. Pain is not given much attention but is an integral part of the disease; in some studies, pain has been reported in more than 80% of patients. It has been my experience that pain is frequently underappreciated and undertreated by physicians. At one extreme, I have talked to patients who have been told that they cannot have pain because pain does not occur in GBS. Pain may occur during the acute phase of the illness and may even predate the onset of the weakness or it may occur during recovery and rehabilitation.

Because of space limitations, I will not discuss the emotional pain; but close attention to anxiety and depression in both patients and their loved ones is a critical part of overall management of GBS. Nor will I discuss the pain which may occur during the rehabilitation process.

Pain during the acute phase of the illness

Pain may be the first symptom of GBS or may develop together with the weakness. It typically is located in the region of the spine and the upper parts of the limbs. For example, there may be pain between the shoulder blades, in the low back and buttocks or around the hips and shoulders.

The pain is often difficult to describe but tends to have an aching or cramping quality. There may be stabs of pain with movement. It is not at one clearly localized point but is somewhat diffused and seems to be deep in the body rather than on the surface. It is usually no more than a nuisance but may be severe, particularly in patients with rapidly progressive and severe paralysis.

In such patients, who may be on a ventilator and unable to communicate easily, it is very important to ask specifically if pain is present. This is the most neglected type of pain seen in GBS since the doctors are concentrating on the life-threatening aspects of the disease. However, when severe it may cause dangerous heart irregularities and changes in blood pressure and aggressive treatment with strong analgesics such as morphine may be needed. Care must be taken with the use of these narcotics in patients with reduced respiratory function since they may cause respiratory failure. If the patient is already on a ventilator there is little cause for concern. This pain may resolve rapidly during treatment with plasmapheresis. It also improves with steroids such as prednisone.

It is also important to realize that immobility causes pain which can be alleviated by frequent turning and passive movement of paralyzed limbs so experienced high quality nursing is very important.

Pain during recovery

As recovery from paralysis progresses, the pain discussed above usually subsides but may be replaced by a different type of pain. This new pain tends to be localized in the lower part of the limbs, particularly in the feet. The pain is less often of the aching/cramping quality and is more burning, stabbing or shooting. It may be associated with marked sensitivity to touch so that even the light touch of the bedsheets is perceived as pain. It is also exacerbated by exercise and weight-bearing so it may interfere with rehabilitation. This is called "neuropathic pain" and it responds rather poorly to narcotic analgesics although they should still be used in severe cases.

Best responses are seen with certain antidepressant drugs such as amitriptyline (Elavil) and nortriptyiine (Pamelor) or with anticonvulsant drugs like gabapentin (Neurontin) and carbamazepine (Tegretol). High doses are usually necessary and response may not be immediate. In my experience, the most common cause of failure of these drugs is that the dose is not high enough and is not used for long enough. Most patients will experience side effects if the drugs are used in sufficient doses to relieve pain but the benefit should outweigh those side effects.

Another problem is patient expectations; treatment is expected to reduce the pain but will seldom abolish it. If a patient is expecting to be pain free and there is only a 50% reduction in pain intensity that will be regarded as a treatment failure and yet that is about the best that can be expected. Nontraditional treatments such as acupuncture may also help. Neuropathic pain also subsides with time but may persist for months or years and occasionally some pain may persist permanently.

In summary, pain of some degree occurs in most patients suffering from GBS and may occur at any stage of the illness. It is frequently ignored and usually is undertreated. Fortunately, in most patients it is mild and, even when severe, it usually improves spontaneously or with treatment.

Thirteenth International Symposium Update

We hope you will join us in Florida this fall!
The Symposium takes place from October 30–November 2, 2014.

This Symposium provides a unique and exciting opportunity for patients, caregivers, physicians and experts to interact. The program consists of large group general workshops which will be focused on GBS, CIDP, and MMN. You may select the right one for you! Also featured will be smaller workshops offering practical information and teaching valuable skills.

Attendees will learn about every phase of GBS, CIDP, MMN and variants from diagnosis, treatment, and care to rehabilitation, coping skills, emotional issues, and the latest in research.

Come and meet your GBS, CIDP, and MMN family of fellow patients and caregivers!

HOTEL INFORMATION

Disney's Coronado Springs Resort celebrates the character and traditions of the American Southwest and Northern New Mexico. From one-of-a-kind networking opportunities with colleagues to a magical vacation experience with family and friends before or after the Symposium, to simply finding time to relax and unwind, this is a destination which offers something for everyone.

The Symposium room rate is $125.00 per night plus tax (single or double). Disney has created a custom website just for Symposium attendees.

Go to the following website to book your stay:

http://www.mydisneymeetings.com/gbscidp2014

You can also book your reservations by phone at (407) 939-4686 and state that you are with the GBS|CIDP Symposium.

After Monday, September 29, reservations may be subject to a higher rate and will be based on availability; so book your plans NOW!

AIRPORT/TRAVEL INFORMATION

Disney provides free transportation to and from the Orlando airport via the "Disney Magical Express." This service picks you up and takes you from the Orlando International Airport to the Coronado Springs resort, while the luggage service delivers your bags to your room. Disney will also assist with departure through the Resort Airline Check-in Service and return transportation to the Orlando International Airport.

Reservations are required. Disney recommends that reservations for the "Disney Magical Express" be made at least 30 days in advance.

This can be done online:

http://www.mydisneymeetings.com/gbscidp2014

Or you may call: (407) 939-6244

You can also arrange your transportation by cab, at your cost, for approximately $60-70 one way.

DISNEY RESORT TICKETS

Disney offers an option for specially priced theme park tickets which are now available for purchase. All day and afternoon tickets are available.

Special tickets for a Halloween trick-or-treat Magic Kingdom event MUST be reserved and purchased in advance. There is limited availability for this event so if you are interested, make this reservation early!

Specially priced tickets are for Symposium attendees and companions and are valid for use on the Symposium dates and for a limited time before and/or after the Symposium as determined by Disney.

Purchases can be made online at:

http://www.mydisneymeetings.com/gbscidp2014

or by calling:
(407) 566-4985.

NOTE: Registration for the Thirteenth International Symposium must be made separately. Symposium registration can be made online via the GBS|CIDP website.

Online registration will be open by July 1 at: www.gbs-cidp.org/symposium

You will also receive a Symposium brochure in the mail later in July.

Preview: Thirteenth International Symposium Topics

In this June issue and in the September issue of the *Communicator,* we will feature some of the topics and highlight some of the presenters from our own Medical Advisory Board. We hope that this may inspire you to join us for this unique opportunity to meet our esteemed experts!

Diagnosis and Pathogenesis of GBS

By Dr. Bart C. Jacobs and Professor Nobuhiro Yuki

GBS is a devastating disorder that may occur in any person. The rapid onset, severity, slow recovery and uncertainty about the future have a major impact on patients and families. Doctors are confronted with sometimes difficult decisions about the accurate diagnosis and treatment. Specific treatments like immunoglobulins and plasmapheresis have improved the perspectives of patients, but still a majority of patients suffer from residual disability and complaints. How are physicians and researchers trying to improve this situation? Dr Jacobs and Professor Yuki will provide an update on the latest insights in the diagnosis, pathogenesis, and treatment of GBS. Extensive studies in large groups of patients show the diversity of GBS, which make early recognition by physicians difficult in some situations. Most patients develop GBS one to three weeks after specific types of microbial infection. These are usually quite common infections, which in only 1 of a few thousand infected persons results in GBS. In these susceptible people, molecular mimicry between micro-organisms and peripheral nerves causes an immune attack to their own nerves. Toxic antibodies and complement activation result in severe nerve damage and muscle weakness. These auto-antibodies are most abundant at disease onset, and disappear in a few months from the body. Nerves may then have the chance to recover and treatment with immunoglobulins and plasmapheresis may help to stimulate nerve recovery. Not all patients recover well after this treatment and at present this is still poorly understood. Recently, tools have been developed to predict in individual patients in an early stage of the disease the chance of a good or bad recovery. This provides the opportunity to develop strategies for personalized treatment, in which more potent treatments are given to patients that need it most. More research is required to cure all patients, and ongoing international collaboration between patients, basic scientists and clinicians is vital to get this done.

Nobuhiro YUKI, MD, PhD is a Research Professor of the Departments of Medicine and Physiology, National University of Singapore. He received his MD from Niigata University, Niigata, Japan, and completed his doctoral degree in Tokyo Medical and Dental University, Tokyo, Japan.

Since his first encounter with a Guillain-Barré syndrome patient in 1989 and having seen the poor outcome, he promised to dedicate his research life to clarifying the pathogenesis and to develop new treatments. He found that molecular mimicry between peripheral-nerve and microbial components is a cause of GBS. He showed that a complement inhibitor, which has been used for patients with disseminated intravascular coagulation other conditions, is effective for an animal model of GBS. Currently, his laboratory is interested in elucidating target molecules for autoantibodies in chronic inflammatory demyelinating polyneuropathy (CIDP) and also the development of new treatments for GBS and CIDP.

Bart Jacobs, MD, did his medical training and residency in Immunology and Neurology at the Erasmus MC. In 1997 he finished a Ph.D. thesis on the pathogenesis of the Guillain-Barré syndrome (GBS). Since 2003 he works as a staff neurologist at the department of Neurology and as a consultant and workgroup leader at the department of Immunology. Since 2008, he has been an Associate Professor of Neurology and Immunology at the Erasmus MC.

His research is focused on the epidemiology, clinics, pathogenesis and treatment of immune-mediated neuropathies, especially GBS. He has a special interest in preceding infections, molecular mimicry, anti-ganglioside antibodies, genetics, intravenous immunoglobulins and predicting outcome in GBS. He has initiated the International GBS Outcome Study (IGOS), a world-wide collaborative study from the Inflammatory Neuropathy Consortium, on the monitoring and prediction of the clinical course of GBS.

Dr. Jacobs is a Member of the Educational Committee Postgraduate School Molecular Medicine, Member of the Educational Committee Master of Science 'Infection and Immunity', and a Board member of the Dutch Neuromuscular Research Center. He is a member of the Dutch Society of Neurology, Dutch Society of Paediatric Neurology, Dutch Society of Immunology, Dutch Society of Glycobiology, International Society for NeuroImmunology, European Neurological Society, Peripheral Nerve Society, and Inflammatory Neuropathy Consortium.

CIDP

By Dr. Kenneth C. Gorson and Dr. Pieter A. van Doorn

Drs. Gorson and van Doorn will discuss the salient clinical features of CIDP, highlighting the important clinical symptoms, neurological findings, temporal patterns of progression, and diagnostic studies (including electromyography, spinal fluid testing, MRI imaging of nerve roots and nerve biopsy) that help establish the diagnosis.

There will be a brief review of various unusual clinical manifestations of the illness (so called "clinical variants") and discussion of the postulated mechanisms of the cause of the disease with an overview of the putative role of the immune system in the production of inflammatory nerve demyelination. Case studies may be used to illustrate the diagnostic challenges in the evaluation of CIDP patients.

Kenneth C. Gorson, MD, is Professor of Neurology in the Department of Neurology at St. Elizabeth's Medical Center, Tufts University School of Medicine, in Boston. Dr. Gorson has published over 60 original peer-reviewed research articles, book chapters and reviews pertaining to Guillain-Barré Syndrome, chronic inflammatory demyelinating polyneuropathy (CIDP), paraprotein associated neuropathies and various other inflammatory and immune mediated disorders of the peripheral nervous system. His clinical and research expertise extends to patients with neuropathies associated with diabetes, connective tissue disorders, cancer, inherited peripheral neuropathies, disorders of muscle, myasthenia gravis and amyotrophic lateral sclerosis. He has been a principle investigator in several clinical research studies, including experimental treatment trials for CIDP, diabetes, painful neuropathies and post-herpetic neuralgia. He has lectured widely to medical specialists and patient support groups on various topics in the field of neuromuscular diseases.

Dr. Gorson is an active member of the American Academy of Neurology (AAN) and the American Association of Electrodiagnostic Medicine, and serves on the subcommittee responsible for the selection of neuromuscular courses for the annual meeting of the Academy. He is also a Councilor for the Neuromuscular Section for the AAN.

In his teaching capacity, Dr. Gorson is Associate Director of the Tufts Neurology Residency Training Program and is responsible for reviewing applications and interviewing resident candidates, and supervises the daily academic activities of the Neurology resident trainees. He is also an integral part of the teaching staff for the neurology and medical interns and residents at St. Elizabeth's Medical Center and medical students from Tufts University School of Medicine.

Pieter A. van Doorn, MD, is professor of neuromuscular disorders at Erasmus University Medical Center in Rotterdam, the Netherlands. He coordinates the Neurology outpatient clinic and heads the neuromuscular branch. Dr van Doorn received his MD at Erasmus University, where he was trained in neurology and clinical neurophysiology. He started his research in immune-mediated neuropathies at the department of immunohematology at Leiden State University in the Netherlands. In 1990, he completed his thesis on intravenous immunoglobulin in chronic inflammatory demyelinating polyneuropathy (CIDP).

Dr van Doorn's main fields of interest are neuromuscular disorders, especially Guillain-Barré syndrome (GBS) and CIDP; and Pompe's disease, a muscle disease due to an enzyme (alpha-glucosidase) deficiency. He is pursuing studies that examine the relationships between antecedent infections, immune reaction/antiganglioside antibodies, and the effect of IVIg treatment. He is involved in studies on outcome measures and prognostic modelling in GBS and CIDP. Dr van Doorn has initiated and conducted several randomized controlled trials and surveys in GBS and CIDP, including the ongoing second-dose IVIg trial in GBS patients with a poor prognosis.

He is a member of the medical advisory board of the Prinses Beatrix Spierfonds and the GBS-CIDP Foundation International. Dr van Doorn is board member of the Peripheral Nerve Society (PNS), and chair of the Inflammatory Neuropathy Consortium (INC). He chaired the organisation of the PNS/INC meeting 2012 in Rotterdam.

Symposium Topics

Diagnosis and Treatment of MMN

By Dr. Jonathan S. Katz and Dr. Richard A. Lewis

What is so different about Multifocal Motor Neuropathy (MMN)? Isn't it just CIDP in disguise? What's conduction block have to do with it?

Come to the session on MMN and learn what makes MMN so unique. There's new evidence that will be presented that more strongly associates MMN with GM1 antibodies. We'll discuss why the disease is related to the Acute Motor Axonal Neuropathy (AMAN) form of Guillain-Barré Syndrome and that unlike CIDP and the Lewis-Sumner Variant, MMN is primarily a disorder of the conduction apparatus of the axon (Nodes of Ranvier) and not of the insulation (myelin).

Learn what we mean by conduction block. See some videos of normal nerve fiber conduction and nerve fibers that become blocked. We'll explain how this is important in understanding the disease.

Jonathan S. Katz, MD, is Director of Neuromuscular clinic at the California Pacific Medical Center, San Francisco. He attended college at the Johns Hopkins University in Baltimore, MD and medical school at Tulane University in New Orleans, LA. He completed neurology training at the University of Washington and neuromuscular training with Richard Barohn in Dallas, TX. Dr. Katz has written several papers on neurological diseases including work on the diagnosis and treatment of peripheral neuropathies including GBS. He has published a paper on treatment of GBS in children. Dr. Katz is currently interested in using artificial intelligence methods to analyze the diagnosis and treatment of diseases of muscle and nerve.

Richard A. Lewis, MD, works at Cedars-Sinai Medical Center, Department of Neurology. Dr. Lewis recently was Clinical Assistant Professor of Neurology at Eastern Virginia Medical School, Norfolk, Assistant Professor of Neurology at the University of Connecticut's Health Center, Farmington, and Assistant Professor of Neurology at the University of Pennsylvania School of Medicine, Philadelphia. He received a BS degree from Union College, Schenectady and a an MD degree from Medical College of Virginia, Richmond. In 2002 he received the AAN's Outstanding Teacher Award and was listed in Who's Best Teachers in America. In 2000 he was listed in Hour Magazine's Best Docs in Detroit, a result of a survey of area physicians and nurses. Dr. Lewis has published numerous articles and book chapters on neurological disorders and relevant issues, including Guillain-Barré Syndrome, and has been an invited speaker/faculty at various conferences and meetings. He is the recipient of numerous research grants, most currently from NIH and the Muscular Dystrophy Association.

Physical Therapy

By Santo Garcia

This year, the session on Physical Therapy will take on a new dimension with Chair Aerobics!

Strengthen your core! Tone your arms! Firm up your buns! No gym membership required!!

Grab a chair and a few minutes of your day and I promise you a workout that will make your muscles more toned, your joints more flexible and your body more ready to take on the day.

It doesn't matter how fit you are or if you've ever exercised before. Just you and a chair is all you need to sit your way to wellness. Sounds great!! No dumbbells or barbells. No belts, bands or steps. Just you and your chair, and you'll feel ready to take on the day.

Santo Garcia, MOT/L, diagnosed with CIDP in 2007, is a Master's level occupational therapist whose primary focus is providing home-based skilled intervention to individuals with neurodegenerative disorders, their caregivers and their clinicians.He is a graduate with high honors from the University of St. Augustine for Health Sciences, and continues the tradition of training future healthcare professionals as an Adjunct Professor at Hodges University's School of Allied Health.

In addition to his work near his home in Ft Myers, Florida, he travels nationally to share his experiences and strategies through continuing education courses he has created for practicing clinicians. His most recent venture is the founding of The Center for Neurologic Rehabilitation, an interdisciplinary journey from diagnosis to optimal recovery.

Symposium Topics

Since 2005, **James Romano** has served as the Director of Government Relations and Advocacy for Patient Services Incorporated (PSI). He worked with Dr. Dana Kuhn to develop the Government Relations Department at PSI. The department works to promote access to treatments and therapies for patients with chronic and catastrophic illnesses through public and private health insurance coverage.

James has spent his life advocating in the Plasma Community. He has three uncles and two cousins with hemophilia and he is the fourth generation in his family to advocate for the hemophilia community. In 1995, James began his career in advocacy lobbying for the Ricky Ray Hemophilia Relief Fund Act when he was 19 years old. After college, he worked on Capitol Hill for a Member of Congress for 5 years and at a health care lobbying firm where he represented the Hemophilia Federation of America (HFA) and Patient Services Incorporated (PSI).

James has attained his BA in Political Science from Marymount University and his MA in Public Administration from George Mason University. Currently, he is pursuing an MBA from the University of Mary Washington. He currently resides in Fredericksburg, Virginia, with his wife Carolee and daughter Rachael, who he is training to be the fifth generation to advocate for the hemophilia community in his family.

Patient Services Incorporated

By James Romano

James Romano, from Patient Services Incorporated (PSI) will provide attendees of the Symposium with information regarding PSI and how it assists patients with CIDP. Patient Services Incorporated is a national patient assistance nonprofit charitable organization that offers financial assistance programs to patients with rare chronic conditions obtain the treatments and therapies then need to live as vital lives as they choose.

He will discuss how the Affordable Care Act assists patients with rare chronic conditions like GBS or CIDP. James will go through the positive and negative points in the law and plans to spur a robust question and answer session. He will discuss the importance of understanding your health insurance policy, looking at important concepts and terms-- even if you have government plans Medicare and Medicaid.

Finally James will discuss the future of Public Policy and Advocacy in the aftermath of the Affordable Care Act on a State and Federal level and will discuss areas that PSI is working in to continue to improve access for patients. Attending this enlightening session will make you a better health care advocate. Be ready to have your important questions answered.

Centers of Excellence

Our Medical Advisory Board has evaluated medical centers for the diagnosis and treatment of GBS, CIDP, MMN and their variants. Based on levels of expertise, available treatments, facilities, and research capabilities, these are the medical centers that we can unequivocally recommend as "Centers of Excellence.'' These institutions not only have clinical expertise and advanced training in electrophysiology, availability of testing facilities including neuropath that accurately evaluate nerve biopsies but are also involved in ongoing investigation in inflammatory neuropathy and clinical trials as evidenced in their publications.

If you feel your medical facility meets these standards, and would be interested in becoming one of our Centers of Excellence, please contact us. As noted there is a formal application and review process. We will pass the information along to our Medical Advisory Board members to process for consideration.

Current Centers Of Excellence

Amsterdam, The Netherlands - Academic Medical Center (AMC), University of Amsterdam
Baltimore, MD - The Johns Hopkins University School of Medicine and the Johns Hopkins Hospital
Boston, MA - St. Elizabeth's Medical Center
Buenos Aires Argentina - Hospital Británico
Buffalo, NY - University Of Buffalo School of Medicine and Biomedical Sciences
Dallas, TX - University of Texas Southwest Medical Center
Detroit, MI - Wayne State University Group/Detroit Medical Center
Duesseldorf, Germany - Heinrich-heine University Department of Neurology
Houston, TX - The University of Texas Health Science Center at Houston (Uthealth)
Kansas City, KS - University of Kansas Medical Center, Department of Neurology
London, England - King's College Hospital
Los Angeles, CA - Cedars-Sinai Medical Center
Los Angeles, CA - The University of California Medical Center
Milan, Italy - Milan University, Humanitas Clinical and Research Center
Nashville, TN - Vanderbilt University Medical Center
Paris, France - Groupe Hospitalier Henri Mandor, Universite, Paris
Philadelphia, PA - Perelman School of Medicine at the University of Pennsylvania
Phoenix, AZ - Phoenix Neurological Associates, Ltd.
Rotterdam, The Netherlands - Erasmus MC University Medical Centre
San Francisco, CA - California Pacific Medical Center
United Kingdom - Regional Neuromuscular Clinic, Queen Elizabeth Neuroscience Center, University Hospitals of Birmingham

The Foundation gratefully acknowledges the following Liaisons who have recently hosted Chapter meetings in their areas.

Hannah Blanton: Charlotte, NC
Jim Crone: Peoria, IL
Harriet Lion: Boyton Beach, FL
Ginger Crooks: St. Louis, MO
Everett Nichols: Raleigh, NC
Bruce Throckmorton: Pheonix, AZ
Rick Forney: Salem, VA
Bill Ansley: Columbus, OH
Jim Yadlon: Hamilton Square, NJ
Debbie Plimmer: Dallas, TX
Steve Smith: Newburgh, NY
Jon Toumey: Indianapolis, IN
Yvonne Bishop: Kansas City, MO
Jo Ann Wettlaufer: Spanish Fort, AL
Char Eggert: Elmhurst, IL
Estelle Benson: Philadelphia, PA
Judi Jetson: Asheville, NC
Sibylle DeRosa: New Windsor, CT
Noreen Reagan: Webster, NY
Joan Armstrong: Manlius, NY
Sherie Demple: Salt Lake City, UT

The Foundation thanks the following as they retire from service to the Foundation. We thank them especially for their years of dedication and service to the communities of the Foundation:

Raymond Smith, Beverly Copeland, Barbara DeFranco, Joanna Doyle, Kristen Bueb, Nancy Roberts, Doug Brondyke, Sherry Tudor, Doug Halsey, Sally Lowitz, Don Biron, Jerimy Schilz, Mars Gary, Robin Shanks, Anne Grace, Benn Barr, Larry Putlitz, Barbara Eastwood, Sherie Demple, Alain Bellacicco, Banu Anlar, and Jenny Murray

We welcome the following new Liaisons to the Foundation family:

Shane Sumlin: Shreveport, LA
Barry Mattison: Las Vegas, NV
Hansi Herzog: Waukesha, Wl
Wenesday Ketron: Jackson, TN
Barbara Brandt: Manassas, VA
Matt LaRocco: Washington, DC
Beth Morgan: Australia
Tony Pearson: New Zealand
Mia van Daalen: South Africa
Dr. (Ms) Can Ebru: Turkey
Ms. Hande Ucler: Turkey

Liaisons In The Limelight

Congratulations to the following Liaisons for their dedication, time, and commitment in serving the communities of GBS, CIDP, MMN, and variants!

Rick Forney: Salem, VA ~ In April, just a week prior to his Salem, VA, chapter meeting, Rick arranged an appearance on the local Roanoke, VA, Fox news program, "Day Time Blue Ridge." Rick was interviewed and shared his GBS story, information about the resources of the Foundation and its mission, and information about neurological challenges and awareness about his upcoming meeting!

Sharon Klashka: Wailuku, HI ~ New Liaison Sharon Klashka in Wailuku was presented with a proclamation on April 29 by the Mayor of Maui County. Sharon also appealed to the Governor of Hawaii for a State-wide proclamation, and just heard that he will endorse a state proclamation. In addition, Sharon has presented to two Kiwanis clubs to raise awareness. *(photo, page 19)*

Margee McKenna: North Central Ohio ~ On May 1 and 2, Margee represented the Foundation at the "Sharing the Vision...Shaping the Future" joint medical conference hosted by Nationwide Children's Hospital of Columbus. This was sponsored by the Association of Pediatric Hematology/Oncology Educational Specialists and the Association for Education of Children with Medical Needs. Margee and Bill Ansley organized and managed the booth for two days. *(photo, page 19)*

Bill Ansley: Columbus, Ohio ~ In March Bill presented a PowerPoint presentation to the Nationwide Children's Hospital. He spoke to pediatric neurologists and social workers. Later, Bill also presented to the Ohio State Medical Center.

Shane Sumlin: Shreveport, LA ~ New Liaison, Shane Sumlin recently sponsored a unique fund-raising event for the Foundation. The event was a Family Movie Night and was the vision of a high school student. Family Movie Night became his senior project to raise awareness and community support. Over 200 people attended and donated over $6,000 to support the missions of the Foundation!

Lizz Russell: San Diego, CA ~ Celebrity Fashion Designer, Lizz Russell, hosted her annual "Cocktail and Couture" event. Lizz donates a portion of sales to the Foundation and this year celebrates 30 years as a GBS survivor by featuring a booksigning of her personal story, *I'm Smiling on the Inside.*

Elizabeth Smith, Baltimore, MD ~ Friend of the Foundation, Libby Smith recently published a children's book, *Twin Strokes* (published by Booklocker.com, available on Amazon). The book is dedicated to all Gullain-Barré survivors and Libby is donating a portion of sales to the Foundation.

Kind Kids *In Action!*

Ofir Brizinov: Edina, MN ~ In honor of her brother, Ofir sold GBS bracelets in her high school cafeteria at lunch time!

Hailey Cannon: Hardin, MT ~ For the fourth year, Hailey has helped organize a basketball free-throw event at her high school, all proceeds benefit the Foundation.

Kimby Hammands: Covington, GA ~ Kimby is the Co-Chair for the Greater Atlanta Walk and Roll. In addition, she has held bake sales to profit the Foundation. Kimby has also been interviewed on the local radio station and provided interviews to local newspapers to raise awareness.

Stuart Butler: Philadelphia, PA ~ Stuart, a high school Junior and GBS survivor, joined the Foundation for the day on Capitol Hill as the Youth Advocate for the Foundation.

The presentation of a proclamation in recognition of May as GBS Awareness month. From left to right: Fred Araki, Kana Seto, Patty Nelson, Mayor Alan Arakawa, Greg Ring, Sharon Klaschka and Patrick Ornellas.

Hawaii Proclamation

This was the first meeting of the Wailuka, Hawaii, chapter. The Mayor presented Sharon with the Proclamation and then briefly joined the meeting. This chapter plans to meet quarterly.

Liaison Vendor Booth

The GBS|CIDP Central Ohio Chapter operated a vendor booth at the "Sharing the Vision...Shaping the Future" Joint National Conference hosted by Nationwide Children's Hospital of Columbus. The conference was sponsored by the Association of Pediatric Hematology Oncology Educational Specialist (APHOES) and the Association for Education of Children with Medical Needs (AECMN). The conference was held on May 1-2, 2014, at the Sheraton Capital Square in Downtown Columbus.

I, along with Margee McKenna (Regional Support Director) organized and managed our booth for both days. The workshop had approximately 120 attendees from all over the country. We had many people stop by our display and ask questions about the Foundation. Even though the event was geared towards pediatric hematology and oncology, the main purpose was to support the educational needs for children who miss days of school. Many of the medical professionals also had children who suffered from GBS and had no idea our Foundation existed.

The attendees were supplied with pamphlets, pens, wrist bands, and local liaison points of contact for their region. I'm positive this was a great success for the Foundation but, most importantly, a positive direction for kids suffering from GBS and its variants.

Thank you for the opportunity and financial support in operating this vendor booth. I think medical workshops and conferences are untapped resources for getting our message out to the medical community.

William Ansley, Central Ohio Liaison

Charity Navigator

Charity Navigator, America's largest and most-utilized independent evaluator of charities, has awarded the GBS|CIDP Foundation International with the prestigious 4-star rating for good governance, sound fiscal management, and commitment to accountability and transparency.

Charity Navigator works to help charitable givers make intelligent giving decisions by providing information on more than five thousand charities nationwide and by evaluating their financial health. It calculates each charity's score based upon several broad criteria, including how much is spent per dollar raised, what percentage of funds goes to programs vs. administrative and fund-raising expenses, and the organization's long-term financial health. It then assigns a rating from one to four, with four being the best rating.

GBS|CIDP Foundation International is very excited and honored to receive this rating!

We Love to Hear From You!

Please send us your stories, "Letters to the Editor," and questions for the Medical Advisory Board.

Direct your inquires to Lisa Butler in the Foundation office at lisa.butler@gbs-cidp.org.

GBS | CIDP
Foundation International

International Office
The Holly Building
104½ Forrest Avenue
Narberth, PA 19072-2215

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DIRECTORY

Check the enclosed chapter directory and contact the chapter nearest you. In addition, our "subgroups" are listed below.

- **"CIDP" Group**
  For those with a diagnosis of chronic inflammatory demyelinating polyneuropathy. Please identify yourself to the National Office in order to be placed on the CIDP list for special mailings, etc.
- **Children with GBS**
  Lisa Butler, 610-667-0131
  GBS-CIDP Foundation International
  Email: lisa.butler@gbs-cidp.org
  Son, Stuart had GBS at 5 1/2 years old
- **Children with "CIDP"**
  For children diagnosed with chronic inflammatory demyelinating polyneuropathy. A separate registry has been created. Please contact the National Office for details.
- **Group for Having GBS Two Separate Times**
  Please call the National Office for contact with others.
- **Miller Fisher Variant Group**
  Please call the National Office for contact with others.
- **Wheelchair Limited Group**
  Please call the National Office for contact with others.
- **AMSAN Group**
  Please call the National Office for contact with others.
- **A Teenage Pen Pal Group**
  Arielle Challander, 231-946-7256
  4313 Shawn Drive
  Traverse City, MI 49685
  Email: ariellegiggles@gmail.com
  Arielle had GBS in 2006 at age 13. She is willing to share her experiences so others might understand. To have teenage GBS'er pen pal, write, call or e-mail Arielle.
- **Pregnant Women with GBS**
  Robin Busch, 203-972-2744
  264 Oenoke Ridge,
  New Canaan, CT 06840
  Robin has offered to share her experience with GBS which came about during her pregnancy. We have many such cases and reassurance from someone who has gone through this is needed support.
- **Bereavement Group**
  A group for anyone who has lost a loved one due to GBS/CIDP complications. Please contact: Bereavement Group at the National Office.
- **The "Campy" Group**
  Those whose GBS onset was identified as a result of the campylobacter bacteria. Numbers to be used for research purposes.