

The Communicator

Providing Strength Through Support

Working for a future when no one with Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as MMN suffers alone and that everyone has access to the right diagnosis and the right treatment, right away.

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We are pleased to announce our **Perfect 100 Score** via **Charity Navigator!**

The GBS|CIDP Foundation has earned perfect scores for its *Financial Health* and its *Accountability & Transparency*. Those two scores then translate into a perfect 100 point overall score. Less than one percent of the thousands of charities rated by Charity Navigator have earned perfect scores!

http://www.charitynavigator.org/index. cfm?bay=search.summary&orgid=10284



CHARITY NAVIGATOR Your Guide To Intelligent Giving

14th International Symposium

Registration materials are enclosed for our 14TH INTERNATIONAL SYMPOSIUM SEPTEMBER 22ND - 24TH, 2016 SAN ANTONIO, TEXAS

Register Today!

GBS CIDP

Patient Story

By Aledawi Figueroa

My name is Aledawi Figueroa, but everybody calls me Widy. I am from Isabela, Puerto Rico. I'm currently 34 years old. I am happily married with my husband, Obeth Soto. We have 2 children, Alanis Valeria, who is seven, and Obeth Julián, who is one year old. I studied Business Administration, majoring in Industrial Management and Human Resources. After I finished college I continued studying Education, which is my passion, concentrating in Special Education.

I love personalized instruction so I founded Smile Again Learning Center Corporation in 2005. Here we offer tutoring, English and Spanish courses, test prep reviews, among other services. I love spending time with my family, reading and helping others. I've always worked with youth groups in church and together with my husband we give motivational talks to groups and couples. My favorite quote is "what is darkness for you today can be light for others tomorrow"; meaning that no matter how hard you're having it today, you can be sure that your experience will help someone tomorrow.

This is exactly what GBS confirmed in my life. In November 2013, my family and I were living a dream come true. I was finally pregnant with my second baby, this time a baby boy. Alanis had asked for a brother ever since she was able to talk and her prayers had finally been heard. We were all excited because the pregnancy was going perfect.

In February 2014, 18 weeks into my pregnancy, my hands and feet started feeling numb and tingly. I texted my doctor and she said it could be from water retention due to pregnancy. But a couple of days later symptoms started getting worse, my tongue started feeling tingly, as well, and I could no longer walk on my own. That's when I fell to the ground while taking some pre-baby pictures with my family.

At this point my husband knew that it wasn't water retention and we called the

continued on page 3

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Please Welcome Our New Staff Members

Walk & Roll Coordinator

Jessica McManus started with the foundation in January 2016 as the Walk & Roll Coordinator. She has a BA in Business Administration from the University of Hartford and has worked for the past six years in marketing and events for the legal services industry. Jessica brings her experience in volunteer work and event management to her role and is excited to help bring the Walk and Roll program to life while raising awareness of GBS-CIDP. She looks forward to connecting with patients and families affected with GBS and CIDP.



As a Philadelphia native, Jessica enjoys spending time with her family and friends, and can most often be found staying active, practicing yoga, and baking.

Community Engagement Coordinator

Gil Marder came to the foundation in May 2016 where he happily enjoys partnering with the foundation's talented, dedicated volunteers to support the diverse GBS|CIDP community. A nonprofit professional whose professional experience includes significant volunteer, program and event management, Gil is committed to supporting and progressing the foundation's critically important work to help people with GBS, CIDP or one of its variants.



A Philadelphian and Temple University graduate with a BA in English, Gil's passions include poetry, baseball,

Roman history and a healthy lifestyle. His greatest pleasure is being with his wife, Joanne, daughter, Julia and two cats, Lightning and Mini Meow.

Director of Development & Marketing

Rick Yanchuleff began his career in consumer advertising as a graphic designer/art director. After 15 years in corporate medical marketing, he shifted his career into non-profit marketing and development serving the blind and vision impaired; marginalized Christians in the Middle East and North Africa; women experiencing crisis-pregnancy; survivors of sex trafficking and sexual exploitation; and presently, individuals suffering from rare auto-immune deficiencies.



Rick's career history aligns with his personal goal of improving the quality of life for others.

He holds a degree from Pennsylvania College of Art and Design, Lancaster, PA; a BA in communications from Lebanon Valley College, Annville, PA; and an MA in advertising from Syracuse University, Syracuse, NY.

Rick resides in Lancaster County, PA and enjoys spending time with his grandchildren, baseball, and driving his Miata on the weekends.

Disclaimer Information Questions presented in the GBS|CIDP Newsletter are intended for general educational purposes only, and should not be construed as advising on diagnosis or treatment of Guillain-Barré syndrome or any other medical condition.

Privacy Policy In response to many queries: Intrusive practices are not used by the GBS/CIDP Foundation International. It does NOT sell its mailing list nor does it make available telephone numbers! The liaisons are listed in the chapter directory with their permission. We are proud that none of our members has ever been solicited or sent materials other than those concerning GBS, CIDP, and related related syndromes such as MMN. We respect your privacy.

From the Executive Director

Dear Friends,

Seeing is believing! Being Executive Director for the past few months has been quite an experience. I am overwhelmed with pride as I see the activity in the office as our staff (some of whom are featured in this issue) carry out our four pillars with a myriad of activities!

Every day we can find meetings being planned, Walks being organized, reporters being informed, research grants being reviewed, and patient needs being answered just to name a few. The most touching was the response we received from total strangers inquiring about the Patient story from our last Communicator. There was an out-pouring

of concern, offers to visit the patient and contact the family who was so moved by all of this. This is the essence of why we exist, and I can't thank you enough! This also shows how carefully the newsletter is read by the thousands who receive it!

And now, for the event of the year- our next symposium! I look forward to seeing you September 22-24, 2016 in San Antonio, Texas. pride as I see the activity in Electronic registration is now open on our web site or you can also complete the form in this newsletter and mail it to us! The response to date is at an all-time high. We offer something for everyonepatients, caregivers, friends and medical professionals in addition to the history and charm of San Antonio!

I am overwhelmed with the office as our staff carry out our four pillars with a *myriad of activities!*

Looking forward to meeting you personally in San Antonio, I am, as always, here for YOU!

Lisa Butler Executive Director



continued from page 1 **Patient Story**

doctor. She asked to see me the very next day and called in a neurologist and I was diagnosed with GBS. I got treated in the hospital with immunoglobulin and was transferred to a rehab center. I couldn't be given any pain killers because I was pregnant, so I went through it all with the help of God, my family, my friends, prayers from many, many people, and my set goal to be able to walk when my baby was due in July 2014.

After many therapies and exercises, most of them in a pool in order not to put pressure on the baby, I was able to walk and hold my baby when he was born. It was a tough journey but I've always felt that it was a blessing from God. I have faith that God has a purpose for everything and that everything happens for a reason. With this life-changing experience I have been able to help many people, some with GBS syndrome and others that are facing tough challenges in life, and I hope to be able to help many, many more.



CONTACT US International Office The Holly Building 104¹/₂ 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

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



The third theme concerned the knowledge level of

participants at the beginning of their illness and the desire

that they had for additional information from caregivers

and other resources. Participants had no knowledge of the

illness and utilized multiple methods to learn more about it

after being diagnosed. Participants wanted members of the

Nurse Researcher, Dwayne Hooks, PhD, APRN, FNP-BC, NEW-BC, AAHIVS, FACHE, Has Interest In Better Understanding Patient's Experience With Guillain-Barré Syndrome

revious research has revealed that nursing care has been inconsistent and that nurses do not have an understanding of the special needs of the GBS patient. These issues lead to unnecessary stress and discomfort for patients and families. It is important that nurses have the knowledge and resources necessary to provide the highest level of care possible to GBS patients. A nursing researcher, Dr. Hooks, wanted to better understand the patient's experience with moderate to severe hospitalized Guillain-Barré syndrome patients in order to frame potential recommendations for improvement in nursing care guidelines, health policy, and education. Dr. Hooks' qualitative study allowed him to interview fourteen individuals about their experience with moderate to severe Guillain-Barré syndrome. These participants were from eight (8) states representing

primarily states located within the southeastern part of the United States. Seventy one point four (71.4%) percent of the participants were female and 28.6% were male. Ages of participants ranged from 19 to 79. All of the participants were hospitalized anywhere from 5 days to 405 days.

The findings of the study revealed five (5) major themes. First, participants described the manifestations of physical symptoms at the beginning of their illness, what they thought of these symptoms, and the subsequent progression of symptoms. Participants described the initial symptoms as "strange" or "odd" sensations or peculiar feelings. When participants initially started to experience symptoms, they tried to explain away the symptoms. Participants attempted to relate these symptoms to normal everyday activities and/or occurrences (such as a common illness, stress, or overworking). Most participants described the pace and progression of symptoms ranging from very quick onset to others who had a more prolonged onset. Pain and fatigue was also a major complication for participants.

The second theme centered around the attitudes and emotions that participants experienced during their course of illness. This theme illustrated the wide range of emotions that participants encountered; how having a positive attitude impacted mental well-being and was a useful coping strategy, how independence was desired, and how participants experiencing significant levels of personal disability still had concern for their loved ones well-being.

healthcare team to have more knowledge about the illness
 when directing and providing care to individuals with GBS.
 The fourth theme revealed the importance of peer
 contact. Participants commented on the value of being
 able to talk with an individual who had also been ill with
 Guillain-Barré syndrome. This provided the participants with

hope about recovery and the future. Participants described that information coming from an individual who had been through the illness is preferred over information coming from healthcare team members who had not actually been

ill with Guillain-Barré syndrome.

The last theme that emerged from the data was related to the general care that was provided. This theme revealed the impact that the lack of staff knowledge had on participants. In addition, this theme presented information related to the concept of personalized patient centered

care and communication with caregivers. This theme also illustrated the positive impact that accomplishing achievements has on participants. Dr. Dwayne Hooks will be attending the Symposium in San Antonio this September and will be able to share more about his findings.

These themes suggest that, generally speaking, healthcare team members, including nurses, do not have an understanding of the special needs of Guillain-Barré syndrome patients and that care is not consistent. Additional work and research is needed to enhance the patient's experience with moderate to severe Guillain-Barré syndrome. Implications are evident in the areas of practice, educational preparation of healthcare staff, health policy and future research.

If you have questions about this research, or if you would like to participate in future studies about the care provided to GBS patients, please contact Dr. Dwayne Hooks at jhooks6@kennesaw.edu. Future research will continue to focus on individuals who have recovered from GBS, as well as families and support systems, and professional and lay caregivers. A list of references for this article will be made available on request.

It is important that nurses bave the knowledge and resources necessary to provide the bigbest level of care possible to GBS patients



14th International Symposium

SEPTEMBER 22ND - 24TH 2016 - SAN ANTONIO, TEXAS



Have you registered for our 2016 Symposium yet??

You can register via our website, by mail (please tear out next page, complete both sides and mail), or by phone (call Kelly McCoy at 610-667-0131).

We have a jam-packed weekend planned for you! We are extremely excited to bring our members an all new curriculum for 2016, focusing on "Life after Diagnosis." We have already added some NEW sessions since we initially announced our curriculum in April, and we have some exciting news!

Introducing: One on Ones with our Global Medical Advisory Board!

Space is limited. We will be offering the opportunity for a group of our members to meet individually face to face with our world-renowned physicians for a private dialogue. Register now to be in the running for this amazing opportunity!

You MUST register for the symposium to qualify & members will be selected at random closer to the event date. If you have already registered please email <u>Kelly.McCoy@gbs-cidp.org</u> with your interest in this new feature.



Our event will be held at the Hyatt Regency San Antonio, located directly on the beautiful & historic Riverwalk.

123 Losoya Street, San Antonio, Texas, USA, 78205

- 16 Story Garden Atrium Hotel
- 8 Miles from San Antonio International Airport
- Across from the Historic Alamo
- Shops at Paseo del Alamo located within Hotel
- All Event space an easy elevator ride from your sleeping room
- Special rate for event \$155/night plus taxes & fees
- \$32 Round Trip shuttle to airport available through hotel(GO Shuttle)

Call today to reserve your room (hotel accommodations **not** included in conference registration cost) (210)222-1234 (you must mention GBS|CIDP for group rate)

Don't miss out on the local attractions! Visit the historic Alamo, enjoy an evening out on the Riverwalk, sight see the vibrant architecture of the city & much more!

Complete the next two pages to register now!

See you in San Antonio!!



GBSICIDP Foundation International

Symposium Schedule

Thursday September 22nd 2016

- 12pm 5pm Lobby Registration
- 5pm-7pm Western Welcome Reception

Friday September 23rd 2016

- 7:00 Registration Resumes in Foyer
- 7:00 8:00 Continental Breakfast
 8:15-8:30 Morning Meditation
- Instructor: Pam Butler
- 8:40-8:55 Welcome Introduction Presenter: Lisa Butler & Santo Garcia
- 9:00-9:30 Keynote Speech Current Foundation Topics
 Presenter: Dr. Ken Gorson & Dr. Bart Jacobs
- 9:40-10:40 Managing Pain
 Presenter: Dr. Alejandro Tobon
- COFFEE BREAK CONCURRENT SESSIONS: (Please Select One)
- 11:00-12:00 Managing GBS Residuals
 Presenter: Dr. Richard Lewis
- 11:00-12:00 Teen Session Living with CIDP Presenter: Dr. Diana Castro
- 11:00-12:00 Vaccinations
 Presenter: Dr. John England
- ◆ 12:00-1:15 LUNCH
- Optional Sessions
- Yoga Session with Kristen Weaver/Sterling Yoga
- Hugh Williams Fifty Two Fives 'Why I Ran'
- Post Lunch Teen Activity Visit to the Alamo <u>CONCURRENT SESSIONS:</u>
- 1:20-2:00 Current Research GBS Presenter: Dr. Ken Gorson
- 1:20-2:00 Current Research CIDP Presenter: Dr. David Cornblath
- 1:20-2:00 Current Research MMN Presenter: Dr. Richard Lewis CONCURRENT SESSIONS:
- 2:10-3:00 CIDP "Stem Cell Transplantation: Treatment for CIDP by Rebooting the Immune System" Presenters: Dr. Richard Burt
- 2:10-3:00 Adaptive Equipment Presenter: To be determined
- 2:10-3:00 GBS Modified Therapies Research Annexon Presenter: Mario Saltarelli, MD, PhD, Chief Medical Officer
- 3:10-3:35- Kickoff Chair Aerobics Presenter: Santo Garcia CONCURRENT SESSIONS:
- 3:45-4:35 Sexual Health (Men)
 Presenter: Dr. Joel Steinberg & Santo Garcia
- 3:45-4:35 Sexual Health (Women)
- 3:45-4:35 CIDP Beyond IVIG & Steroids, Stem Cell Research, & More.
 Presenters: Dr. David Cornblath, Dr. Ken Gorson

Presenters: Dr. David Cornblath, Dr. Ken Gor

*Schedule is subject to change

- 3:45-4:35 GBS Protocols Instructor: Dr. Bart Jacobs <u>CONCURRENT SESSIONS:</u>
- 4:45-5:45 ASK THE EXPERTS GBS Presenters: Dr. Bart Jacobs, Dr. Ken Gorson & Dr. John England (Moderated by Dr. Carol Lee Koski)
- 4:45-5:45 ASK THE EXPERTS CIDP & MMN Presenters: Dr. David Cornblath, Dr. Kazim Sheikh & Dr. Richard Lewis (Moderated by: Santo Garcia)
- Members break for evening Dinner on own
- 7:00-9:00 Meet & Greet & Sweets

Saturday September 24th 2016

- 7:00 Registration Resumes in Foyer
- 7:00 8:00am Continental Breakfast
- 8:00-8:15 Morning Meditation Instructor – Pam Butler
- 8:15-8:45 Kickoff Speech Zika Virus Presenter: NIH
- 8:50-9:40 The Power of Mindfulness Presenter: Penny O'Brien, MS
- > 9:30-11:00 Global Medical Advisory Board One on Ones
- COFFEE BREAK
 - CONCURRENT SESSIONS:
- 10:00- 10:50- Fitness Getting Moving Again
- 10:00- 10:50 Patient Financial Assistance Panel
- 11:00-11:30 Meet Fellow Patients!
- ✤ 11:30-12:45 LUNCH
- Optional Sessions
- Yoga Session with Kristen Weaver/Sterling Yoga
- Post Lunch Teen Activity Visit to the Riverwalk
- 12:55-1:20- Afternoon Chair Aerobics Presenter: Santo Garcia <u>CONCURRENT SESSIONS:</u>
- 1:30-2:20- Alternative Therapies Presenter: Dr. Terry Harville
- 1:30-2:20 Be Your Own Advocate Panel Presenter: Jim Crone, Dr. Joel Steinberg & Estelle Benson
- 1:30-3:00 Global Medical Advisory Board One on Ones CONCURRENT SESSIONS:
- 2:30-3:20 Emotional Issues Patients
- 2:30-3:20 Emotional Issues Caregivers Presenter: Lynn Kuttnauer, Ph.D.
- 3:30-4:20 Foot Care 101 Presenter: Dr. Jeffrey Gerland <u>CONCURRENT SESSIONS:</u>
- 4:30-5:30 ASK THE EXPERTS GBS Dr. Bart Jacobs, Dr. Ken Gorson & Dr. John England (Moderated by Estelle Benson)
- 4:30-5:30 ASK THE EXPERTS CIDP & MMN Presenters: Dr. David Cornblath, Dr. Kazim Sheikh & Dr. Richard Lewis (Moderated by: Dr. Carol Lee Koski)
- 6:30pm-9:30pm Closing Celebration Fiesta

Registration Information

Registration fee does not include travel or hotel accommodations. All on-site registrations will be subject to a \$25 fee.

Registration can be completed via our online form (<u>https://www.gbs-cidp.org/symposium/symposium-registration/</u>) or please complete all information below & return to:

GBS CIDP Foundation International c/o Symposium 104 ½ Forrest Avenue Narberth, PA 19072

(Please Circle Selection)

- Full Conference Price: \$150.00
 Covers all sessions, workshops, conference materials, box lunches, snacks, Thursday night Welcome Reception and Saturday evening reception. Does not include Friday dinner but we will have dessert at the hotel.
- Friday Attendee Price: \$50.00
 includes all sessions, continental breakfast and boxed lunch. Does not include dinner Friday.
- Saturday Attendee Price: \$75.00
 Includes all sessions, continental breakfast, boxed lunch and Saturday night closing celebration.
- Industry (Non Sponsor) \$400 Full Conference
- Teenager Full Conference (13-17 Years old) \$50
- ✓ Child Full Conference (up to 12 years old) \$0

First Name:		MMN Patient
		Miller Fisher Patient
		🗌 Teen
Street Address:		Child (up to 12 years)
Address Line 2:		
· · · · · · · · · · · · · · · · · · ·		□ Family/Friend
City:		🗆 Liaison
State / Province / Region	1:	Sponsor
ZIP / Postal Code:		()
Phone:		Medical Professional
		— ()
Email Address:		🗌 Other
Credit Card Number:		()
Expiration:	Security Code (CVV):	

To pay by check: Please make checks payable to GBS/CIDP Foundation International and return with registration information.

Affiliation:

- GBS Patient
- □ CIDP Patient

To complete information for more than one registrant please submit a separate sheet of paper. All participants must register separately.

For questions or to register via the telephone please call 610-667-0131 or email Kelly.McCoy@gbs-cidp.org

□ Please check if you are local and interested in volunteering opportunities at our event!

Advocacy Update

In February, Dr. Koroshetz and other leaders from NINDS met with Lisa Butler, Executive Director, and Dr. David Cornblath, Board member of the Foundation and Medical Advisory Board, of GBS|CIDP Foundation International in January and spoke about different opportunities for research and collaboration between the Foundation and NINDS. During the meeting, a State of the Science Conference was discussed and also there was concern about how to encourage younger investigators to apply for grants.

In April, Dr. Anthony Fauci and leaders from NIAID met with Lisa Butler, and Dr. Ken Gorson, Member, Global Medical Advisory Board, GBS|CIDP Foundation International in April to discuss the Zika Virus and how the Foundation and the agency can work together. Dr. Fauci spoke about the agency's response to Zika and the need for robust funding to help combat the spread of the virus. Dr. Fauci also discussed in detail possibilities to work with NINDS and NIAID to expand the research and understanding of the link between Zika and GBS.

NATIONAL INSTITUTE OF ALLERGY AND INFE



Dr. Ken Gorson, Chair of Global Medical Advisory Board, Dr. Anthony Fauci, Director of National Institute of Allergy and Infectious Disease, Lisa Butler, Executive Director

Chapter Meetings

Those looking to meet people with shared experiences who care have had plenty of opportunities in 2016 to attend a chapter meeting, grow their support network and learn about GBS, CIDP and its variants from experts in a range of fields. While everyone's personal situation is different, many share similar questions, concerns and desire to gain understanding and make sense of the often overwhelming challenges they face.

GBS|CIDP chapter meetings have offered just such a supportive, learning environment for thousands of patients, families and caregivers at more than 50 chapter meetings held so far in 2016 in the United States alone! Organized by dedicated GBS|CIDP Chapter Liaisons, who volunteer their own time to help people in their community, chapter meetings offer a welcoming place for patients, family members, caregivers, and others to make new friends, see old friends, share information and support each other.

If you would like to meet people in your area who care, learn more about your condition and gain access to valuable resources we can help! Be sure to check our community events calendar at https://www.gbs-cidp.org/take-action/ events/ to see a full list of upcoming events or contact gil.marder@gbs-cidp.org for information about chapter meetings in your area.



New Jersey chapter meeting



Southern Maryland, Virginia, and Washington DC multi-chapter meeting



Spring Update

"Old Friends Meeting For the First Time..."

The spring Walk & Roll season was a huge success with over \$100,000 raised and over 500 patients, caregivers, friends and family in attendance. With each walk we are closer to helping

to achieve our vision that every person who has been affected by GBS, CIDP, MMN or their variants has convenient access to early and accurate diagnosis, affordable treatments & dependable support services.

These Walks would not be possible without the enormous support of our Volunteer Chairs and their teams. We cannot thank them enough for their dedication & support. PLEASE CONSIDER JOINING US FOR AN UPCOMING WALK!

New Jersey: Basking Ridge ~ 6/12/2016 S. Carolina: Myrtle Beach ~ 9/10/2016 Pennsylvania: Pittsburgh ~ 9/17/2016 New York: Staten Island ~ 9/17/2016 Illinois: Chicago ~ 9/18/2016 Massachusetts: Boston ~ 10/1/2016 Washington, DC ~ 10/8/2016 Illinois: Indianapolis ~ 10/8/2016 Texas: Houston ~ 10/22/2016 Florida: Del Ray ~ 10/29/2016 Florida: Fort Meyers ~ 11/19/2016 California: Chico ~ TBD California: San Francisco ~ TBD Georgia: Atlanta ~ TBD Ohio: Columbus ~ TBD Pennsylvania: Philadelphia ~ TBD Utah: Salt Lake City ~ TBD Washington: Seattle ~ TBD



International Office The Holly Building 104 ½ Forrest Avenue Narberth, PA 19072-2215



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CHANGE SERVICE REQUESTED

Directory

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

Diagnosed with MMN? Contact: Dominick Spatafora dominck@dvsconsultants.com

Miller Fisher Variant Group

Please call the National Office for contact with others.

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 CIDP contact Holly Cannon whose daughter Hailey has CIDP. Holly.cannon@gbs-cidp.org

Looking for a 20-Something Contact? Contact: Kyle Van Mouwerik kyle.vanmouwerik@gbs-cidp.org

Teenagers with GBS and CIDP

We are launching a new online support forum for teens ages 12 to 18 to connect with one another, share stories, and support each other. This group is also open to teenage children of patients. Contact the office to find out how to join!

National Office: 610-667-0131

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.

Advocacy

If you are interested in advocacy activities on a federal, state, or local level contact the Foundation office to sign up!

Be sure to inform the International Office if you have been diagnosed with one of the following. This will add you to condition-specific communication.

AMAN AMSAN Anti-MAG Campylobacter GBS X2 Miller Fisher MMN