

2018.2019

SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY





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MISSION AND VISION STATEMENT

About Us

The GBS|CIDP Foundation International is a global nonprofit organization supporting individuals and their families affected by Guillain-Barre' syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related conditions through a commitment to support, education, research and advocacy.

Our Vision

Every person affected by GBS, CIDP, or related syndromes will have access to early and accurate diagnosis, appropriate treatment, and knowledgeable support services.

Our Mission

We improve the quality of life for individuals and families affected by GBS, CIDP, and related conditions. Our unwavering commitment to the patients we serve is built on four pillars: support, education, research and advocacy.

- We **support** patients by nurturing a global network of volunteers, healthcare professionals, researchers and industry partners to provide them with critical, timely, and accurate information;
- We **educate** doctors, clinicians, patients and caregivers to increase awareness and understanding;
- We fund **research** through grants, establishing fellowships and other appropriate avenues to identify the causes of and discover treatments;
- We **advocate** at the federal, state, and grassroots levels to educate policymakers and help them make informed decisions that benefit our patient community.

Support
Education
Research
Advocacy





Dear Friends,

I congratulate each and every one of you for joining and supporting this remarkable 39 year journey of hope and healing. Our path in 2018 and 2019 has lead us to groundbreaking progress in support, education, research and advocacy for the GBS, CIDP and variant community. It is our great pleasure to inform you of all the new initiatives and achievements of the Foundation and to remind you that each step was inspired by you, our wonderful community of patients and caregivers! The stories shared throughout this report come from the newly launched Advocacy Action Center and remind us how important it is to come together as a community for a shared goal. This year, we were empowered by your support to achieve the following goals:

- **Launching** our first patient-reported registry, currently over 1000 patients enrolled!
- **Transforming** our Walk & Roll Program to Walk & Roll for **Research**, Raising \$150,000 in 2018 (Goal 2019=\$200,000)
- **Growth** of program from 3 to 4 one-day Regional Conference serving over 600 patients in total
- **New** online advocacy portal : The Advocacy Action Center where we have received over 200 constituent letters to date
- **Increased** advocacy efforts on Capitol Hill with over 100 in-person meetings with Legislators in support of a Medicare Home Infusion Bill
- **Record breaking** attendance of 575 at 2018 Symposium with 22 Specialists including sub-specialties like our new “ZenDen!”
- **Investing in Research** through our ever-expanding Walk & Roll program with over 2,000 Walkers in 2019!
- **Expansion** in Centers of Excellence to 49 centers worldwide
- **Live Online** Educational Programming
- **Incorporation** of new International Chapters (Hungary and Denmark)
- **Responding, supporting, educating** over 150 patient inquiries per month across the globe!

*As we recognize
our supporters,
be assured that
your presence
is your true gift
to us and we
are grateful.*

I am reminded, as I write these words – **transformation, growth, expansion** – of how far we’ve come, and of the incredible power of a small, dedicated group of caring and determined individuals. And I hope that the following pages offer a close-up view of the current culture and future vision of the Foundation. Please know that we are here for you; your stories inspire, empower and drive us to respond with all that we can! I hope that you are inspired to join us and see how far we can go.

In gratitude,

Lisa

Lisa Butler, *Executive Director*

FINANCIALS

Endowment Summary

Over the past ten years, the endowment has grown from \$800,000 to \$8,000,000 through generous contributions, bequests and portfolio performance. The Board's fiduciary focus has always been on managing risk within the portfolio while striving to fulfill the mission of support, education, advocacy and research.

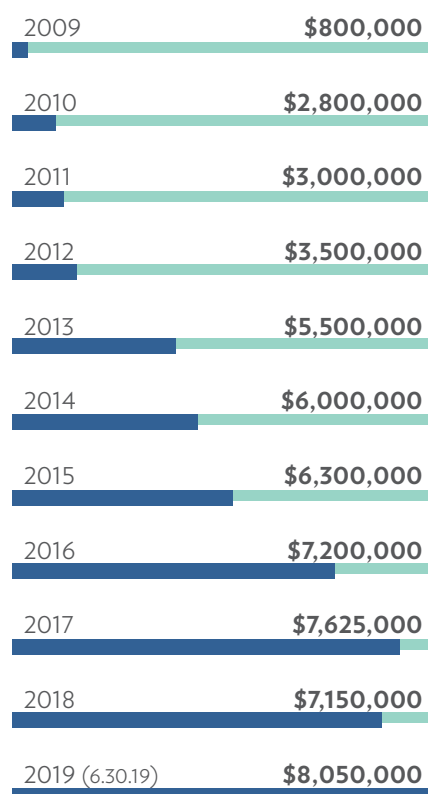
In an effort to minimize costs, the endowment utilizes low cost exchange traded funds and individual, high quality bonds. The exchange traded funds allow for the creation of a well-diversified portfolio and the individual bonds seek to provide stability and income required by the Board.

As fiduciaries, the Board seeks to limit spending to no more than 4% of the aggregate portfolio. The Investment Policy Statement provides guidance to both current and future Board members, with preferred allocations of: 60% Domestic Equities, 10% International Equities and 30% Fixed Income.

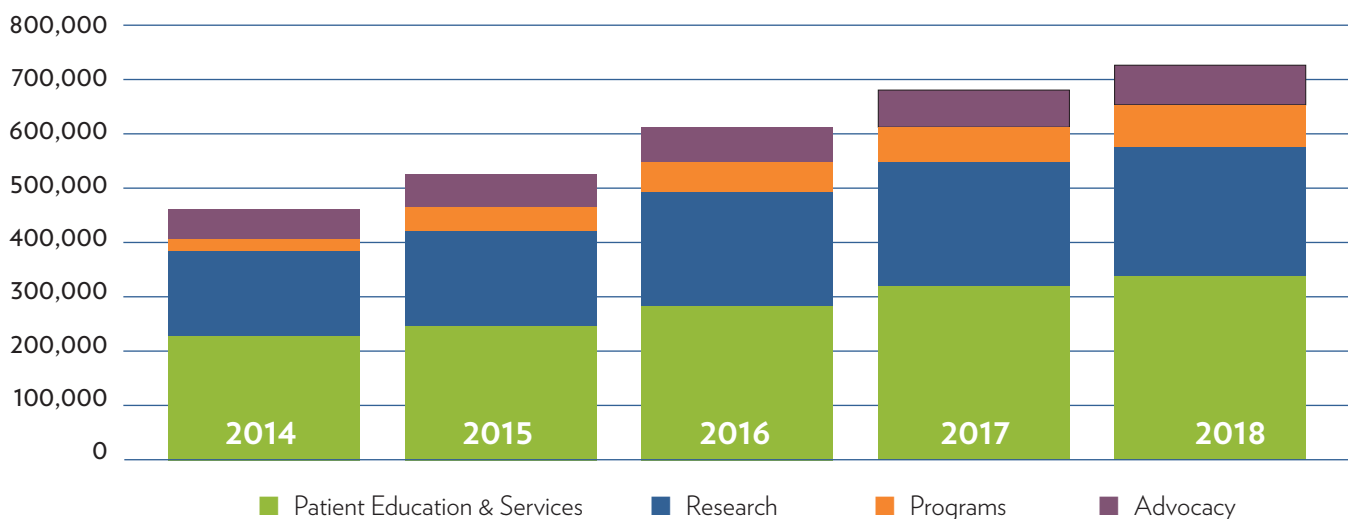
The Domestic Equity allocations are spread across large, mid and small companies. The Fixed Income allocations focus on capital preservation. The aggregate portfolio is managed to focus on Total Return, protecting principal while trying to achieve reasonable levels of growth.

Since 1999, Doug Swope, CFP® has been assisting The Foundation in the prudent management of the endowment assets. Doug's brother, John, was diagnosed with GBS in 1998. During Doug's 25 year career, he has been with industry leaders Merrill Lynch & Smith Barney, and in 2009 he and his father co-founded registered investment advisory firm, Stillwater Capital in Wayne, PA. The firm currently has 550 clients and manages over \$775 million.

GROWTH OF GBS/CIDP ENDOWMENT



EXPENSE ALLOCATION



Support

“It was truly our pleasure to attend the Foundation’s regional conference. Keep up the fantastic work! You all make a great difference in the lives of many.”

—Caroline Biagi (parent of CIDP patient)

Serving patients with GBS, CIDP or variants such as MMN, with the most valuable and up-to-date information and support is our top priority. Here’s an at-a-glance look at how it’s done:



103 Chapter Meetings Worldwide



232 volunteers in **49** countries



45,000 members including patients, caregivers, friends and medical professionals



49 global Centers of Excellence



\$4 million in research grants since 2006



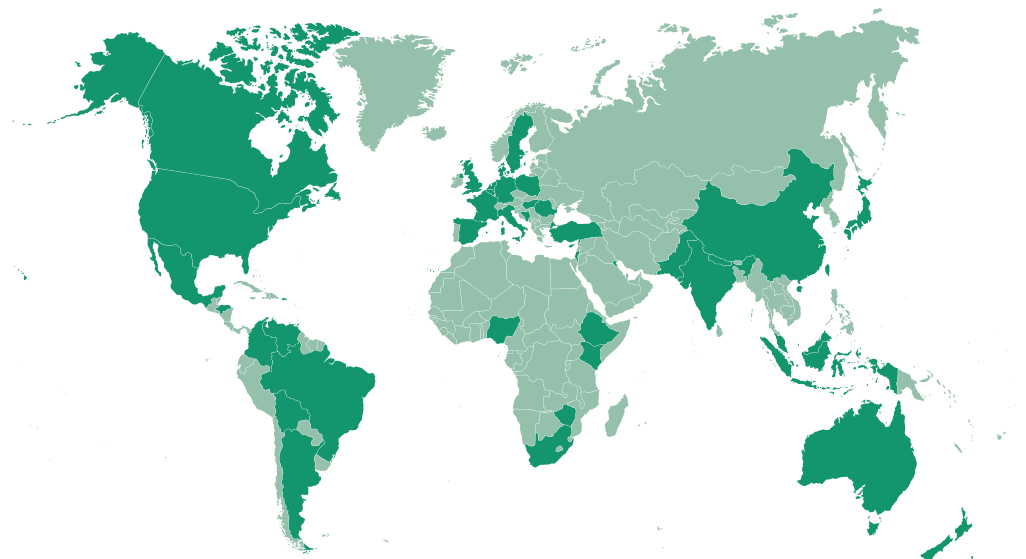
FOUNDER ESTELLE BENSON NAMED 2018 NORD HONOREE FOR ABBEY S. MEYERS LEADERSHIP AWARD

In May of 2018, The National Organization for Rare Disorders (NORD) honored Founder, Estelle Benson, and the work of the GBS|CIDP Foundation International with the Abbey S. Meyers Leadership Award.

“Abbey Meyers, NORD’s founder and first president, agrees. “During my time as president of NORD, many rare disease support group leaders would call us about administrative problems they were experiencing. I would tell them to call Estelle Benson because she understood the basic rules of effective leadership,” she says. “For Estelle, leadership was not telling people what to do; she actually made them want to do it.”

WE ARE AN
INTERNATIONAL
FOUNDATION
AND HAVE MANY
VOLUNTEERS
THROUGHOUT
THE WORLD

■ Volunteers



Support

8 New Centers of Excellence in 2018 & 2019

Our Global Medical Advisory Board has set standards for what they consider to be excellent medical centers for the diagnosis and treatment of GBS and CIDP. 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.” There are currently 48 medical facilities worldwide, that have been deemed GBS|CIDP Foundation International Centers of Excellence.

AMSTERDAM, THE NETHERLANDS

Academic Medical Center (AMC),
University of Amsterdam

SYDNEY, AUSTRALIA

University of Sydney

BALTIMORE, MD

The John Hopkins University School of
Medicine and The John Hopkins Hospital

BARCELONA, SPAIN

Hospital De La Santa Creu I Sant Pau

BELGRADE, SERBIA

University of Belgrade Clinical
Neurology Clinical Center of Serbia

BIRMINGHAM, UNITED KINGDOM

University Hospitals of Birmingham

BUENO AIRES, ARGENTINA

Argentina Hospital Britanico

BUFFALO, NY

The University at Buffalo School of
Medicine and Biomedical Sciences,
State University of NY

BURLINGTON, VT

University of Vermont

CHARLOTTESVILLE, VA

University of Virginia

CHICAGO, IL

The University of Chicago

COLUMBUS, OH

Ohio State University – Wexner
Medical Center

DALLAS, TX

The University of Texas
Southwestern 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

The University of Kansas Medical Center

KARNATAKA, INDIA

National Institute of Mental Health
& Neurosciences

LONDON, ENGLAND

King's College Hospital

LEUVEN, BELGIUM

University Hospital, Saint Luc,
University Louvain

LONDON, ENGLAND

MRC Center for Neuromuscular
Disease, National Hospital for
Neurology and Neurosurgery

LOS ANGELES, CA

Cedars-Sinai Medical Center

LOS ANGELES, CA

The University of CA – Los Angeles

NEW ORLEANS, LA

Louisiana State University

MALAYSIA

University Malaya Medical Centre

MILAN, ITALY

Milan University, Humanitas
Clinical and Research Center

MINNEAPOLIS, MN

University of Minnesota Medical Center

NASHVILLE, TN

Vanderbilt University Hospital

NEW YORK, NY

Columbia University

NEW BRUNSWICK, NJ

Rutgers, Robert Wood Johnson
Medical School

ORANGE, CA

University of CA-Irvine

OSAKA, JAPAN, KINDAI

University Faculty of Medicine

PARIS, FRANCE

Groupe Hospitalier Henri Mondor,
Universite' Paris Est

PALO ALTO, CA

Stanford Neuromuscular Program,
Stanford Healthcare

PHILADELPHIA, PA

Perleman School of Medicine at
the University of Pennsylvania

PHOENIX, AZ

Barrow Neurological Institute

PHOENIX, AZ

Phoenix Neurological Associates

RICHMOND, VA

Virginia Commonwealth University

ROCHESTER, MN

Mayo Clinic

ROTTERDAM, THE NETHERLANDS

Erasmus MC University Medical Centre

SAN FRANCISCO, CA

California Pacific Medical Center

SALT LAKE CITY, UT

University of Utah

SEATTLE, WA

University of Washington

TAMPA, FL

University of South Florida

TORONTO, ONTARIO, CANADA

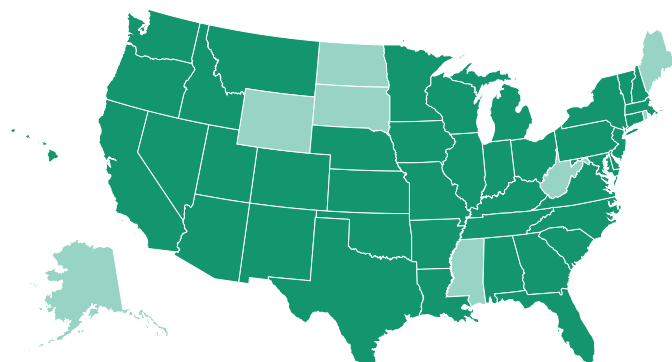
University of Toronto, Toronto
General and Western Hospitals

WARSAW, POLAND

Medical University of Warsaw

WELLESLEY, MA

Saint Elizabeth's Medical Center



U.S. VOLUNTEERS

■ Volunteers

Education



Four Regional Conferences

In spring of 2019, one-day regional conferences in Princeton and Colorado Springs brought together a combined 250 attendees including local physicians, patients, caregivers and loved ones for a day of sharing, learning and connecting.

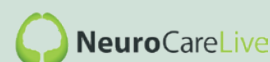
Our medical presenters on March 9th at the Princeton, New Jersey Regional Conference included Steven S. Scherer, MD, PhD, Professor of Neurology at Penn Medicine along with Shan Chen, MD, PhD, Neurologist at Robert Wood Johnson University Hospital. On April 9 in Colorado Springs, Colorado, our team of medical presenters included GMAB member David Saperstein, MD, Neurologist at Phoenix Neurological Associates, and Dianna Quann, MD, Neurologist and Professor at University of Colorado. Both GBS|CIDP medical teams presented the latest in GBS|CIDP research as well as “What to Expect” after a GBS or CIDP diagnosis, and an interactive “Ask the Experts” session with specific questions from attendees.

Additional topics presented at both conferences ranged from breakout sessions for patients based on their specific condition, insurance and advocacy, social work and your circle of care, adaptive living devices for the home, caring for the caregiver, and various sessions on current treatments available.

Two more one-day regionals are scheduled in Indianapolis (September 7th, 2019) and Boston (October 5th, 2019).

Live Online Series for Patients & Medical Professionals

In 2018, GBS|CIDP Foundation International partnered with Platform Q for Live Educational Programming. Three live online educational programs (NeuroCareLive series) were produced to help patients and caregivers, physicians, and medical employees in a hospital setting to better understand the rare condition of GBS|CIDP and variants. Members of the GBS|CIDP Global Medical Advisory Board, along with other specialized physicians, patients, and the Foundation's Executive Director, Lisa Butler, participated as presenters and panelists, answering questions from viewers in real time. Over 300 viewers on average logged on to the live events, and nearly 1,500 viewers have since viewed the recorded programs.



GBS|CIDP SYMPOSIUM



We are pleased to announce the 2020 patient symposium will be October 1-3, 2020, at the Hilton Mark, Alexandria, VA. There will be a DC Walk & Roll on Sunday, October 4. The event will be preceded by a Patient Advocacy Day on Capitol Hill. More information will be shared this fall at gbs-cidp.org. We hope you can join us.

2018 BENSON VOLUNTEER AWARDS

Benson volunteer awards were given to four of our passionate volunteers by none other than Founder Estelle Benson herself. These dedicated volunteers best represent the mission pillars of the organization. Included in the roster were Board of Directors member and Regional Director Jim Yadlon, for his unwavering commitment to **SUPPORT**, GMAB member Dr. Richard Lewis for his determination to **EDUCATE** patients worldwide, GMAB member Dr. Kazim A. Sheikh for his innovative spirit and dedication to **RESEARCH**, and Liaison, Hill Day Advocate and Walk & Roll Chair, Tonya Charleston, for her passion and persistence in the area of patient **ADVOCACY**.

Education

Communications Corner

Efforts towards marketing and communications were enhanced in 2018 and 2019. We revised our mission and vision statement, expanded our social media outreach, and gave a refined brand look to our library of resources and communications materials in an effort to increase overall reach and impact. We have also integrated our website contact forms with our database management system to streamline our workflow, and ensure accuracy in donation tracking and patient record keeping. Additionally, we have incorporated a new CMS system to ensure continual and consistent messaging in all programmatic and news-related email communications and social media posting. Please contact the office if any of your contact information has changed!



A 30th Celebration to Remember

It was the best of all worlds in November of 2018 at the International Patient Symposium in San Diego where a record-breaking 575 attendees gathered for 3 days of GBS|CIDP patient support, education, research, and advocacy. Attendees included patients, caregivers, presenters, sponsors, and our international circle of friends from around the globe including France, Canada, Australia, Japan, Germany, Italy, Mexico, Nepal, the Netherlands, England, Trinidad & Tobago.

Our San Diego Welcome Walk kicked off the Symposium with a burst of energy, warmth, and friendship. Over 300 participants gathered for a one mile walk to the Symposium opening reception. Sponsors of the event cheered patients from the sidelines and the spirit of hope and camaraderie grew stronger with each step. Keynote Speakers were Dr. Richard Lewis and TV actor and GBS survivor, Michael Coleman.

“We are at the Symposium for the first time. It has only just kicked off but it has already been such an amazing experience for our family. Thanks to all who make these meetings possible, so we can connect with others and learn!”

—CHARLENE COWELL



CLINICAL VISITS & EXPERT GUIDANCE

During the symposium, over 65 patients were able to meet for 15 one-to-one discussions with some of the top neurologists in the world. And if more questions arose after their meeting, there was ample opportunity to ask during our 4 “ask the experts” breakout sessions followed by expert-led sessions on emotional health, PT/OT, best practices for IVIG, integrative healthcare, guidance on sexual health issues for women, promising new therapies for GBS, and transformational topics and tips for coping with physical and mental stress.

Symposium sponsors included CSL Behring, Grifols, Kedrion, Shire, PPTA, NuFactor, Soleo Health, RMS Medical Products, Accredo, NeuroCareLive/PlatformQ, Brivoa, Kroger and Diplomat Pharmacy.

Research

Grant Awards given by the GBS|CIDP Foundation International

2018

ELISABETTA BABETTO, PhD

Research Assistant Professor
The Research Foundation for
SUNY on behalf of U. at Buffalo

Targeting Wallerian-like degeneration
in GBS mouse models

**LUANA BENEDETTI, MD, PhD
AND LUCILLA NOBBIO, PhD**

University of Genova, ITALY

Sphingomyelin dosage in GBS/
CIDP patients: biomarker validation
in a multicenter, prospective study

**PAOLO RIPELLINO, MD,
NEUROLOGIST**

Neurocenter of Southern Switzerland

(IGOS) in Switzerland: a deeper
look into HEV-induced GBS

LUIS QUEROL, MD, PhD

Hospital de la Santa Creu i
Sant Pau, Barcelona

Disease-specific Biomarkers In
Inflammatory Neuropathies

**LAURA ZAMBREANU,
MD, MRCP**

National Hospital for Neurology
and Neurosurgery, UK

Intravenous immunoglobulin and
intravenous methylprednisolone
as optimal induction treatment
in CIDP (OPTIC trial)

2019

KARISSA GABLE, MD

Duke University

Pathogenic Th17 cell pathology in CIDP

**EDUARDO NOBILE-ORAZIO,
MD, PhD**

Milan University, IRCCS Humanitas

A randomized controlled trial with
Rituximab versus placebo in patients
with chronic inflammatory demyelinating
polyradiculoneuropathy (CIDPRIT).

**A. JUNG-JOON SUNG, MD,
MS, PhD**

Seoul National University College

Development of New Biomarkers
Using Immune Cells Profiling and
T-cell Specific Sequencing

BETTY SOLIVEN, MD

University of Chicago

Exploring possible role of TGR5 and
FXR in autoimmune neuropathy

**H.G. (RUTH) HUIZINGA, PhD
& BART C. JACOBS, MD, PhD**

Erasmus MC, University Medical Center

Neuromuscular ultrasound (NMUS)
parameters as diagnostic and prognostic
biomarker in chronic inflammatory
demyelinating polyneuropathy (CIDP)

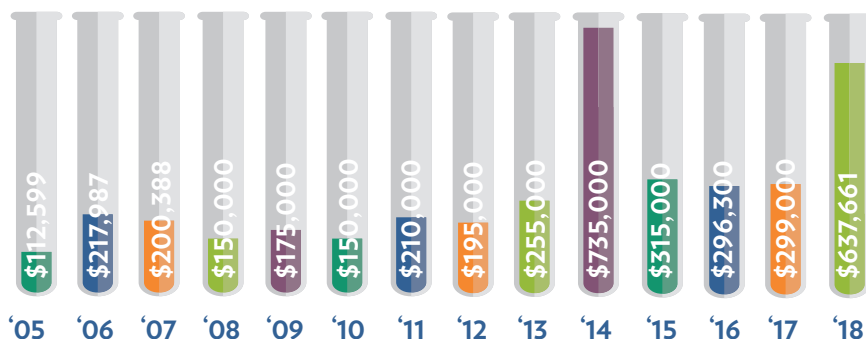
A New GBS|CIDP Patient Registry

On February 28, 2019, the GBS|CIDP Foundation launched its first patient reported registry for patients with GBS|CIDP or variants of the condition. Currently, **over 1,000 patients** have enrolled in the online Patient Registry. The Registry consists of patient reported standardized questionnaires that will allow healthcare professionals to access critical, **de-identified** patient data and a more in-depth understanding of the patient experience. This unique collection of data can be critical for the pursuit of medical advancements and development of patient resources.

IF YOU ARE A PATIENT, OR THE PRIMARY CARETAKER OF A PATIENT LIVING WITH GBS, CIDP OR A VARIANT OF THE CONDITION, WE ENCOURAGE YOU SHARE YOUR EXPERIENCE, ENROLL IN GBS|CIDP PATIENT REGISTRY AND PLAY A ROLE IN A BETTER TOMORROW FOR GBS|CIDP PATIENTS EVERYWHERE. GBS-CIDP.IAMRARE.ORG

RESEARCH INVESTMENTS

Grants, PNS Sponsorship,
IGOS, Benson Fellow



Advocacy



Advocacy Action Center

In May 2019, patients and caregivers were encouraged to be their own best advocate by joining a congressional letter writing campaign. Over 150 advocates wrote letters through the Advocacy Action Center, representing 37 states. Additionally, on May 23 — GBS|CIDP Hill Day — 32 advocates from all over the US joined Foundation Representatives on Capitol Hill to meet with 52 different Congressional Offices to ask for support of the Foundation's legislative agenda. During that same week, Congressman Blumenauer and Congressman Holding introduced the Medicare IVIG Enhancement Act, which is a bill that would create the demonstration project in Medicare Part B to allow CIDP and MMN patients to receive IVIG infusions at home through their Medicare Part B benefit. *The bill was given the number of H.R. 2905.*

Department of Defense Research Grant Fund Includes GBS on list for 3rd Year in Row

Advocacy efforts of the GBS|CIDP Foundation have influenced the US Senate to name Guillain-Barré syndrome as an eligible condition on the Department of Defense peer-review medical research program (PRMRP). The addition allows researchers access to compete for more than three billion dollars set aside for the program. The Peer Reviewed Medical Research Program, established in 1999, has supported research across the full range of science and medicine, with an underlying goal of enhancing the health and well-being of military service members, veterans, retirees, and their family members.

**FOUNDATION
GMAB MEMBER
KAZIM SHEIKH,
MD, AWARDED
DEPARTMENT
OF DEFENSE
GRANT FOR
STUDY IN
IMMUNE-
MEDIATED
NEUROPATHY**

PRINCIPAL INVESTIGATOR:
Kazim A. Sheikh, of Texas, University of Houston, Health Science Center, was awarded \$1,699,402.00 through the DOD PRMRP in (FY) 2017.

STUDY TOPIC:
Defining Final Common Pathogenetic Pathway of Endoneurial Inflammation and Nerve Injury in Models of Immune Neuropathy.



Advocacy

2018-2019 Advocacy at a Glance

Advocacy Priorities & Successes

Medicare IVIG Access Enhancement Act

- Introduced to 115th Congress – HR 4724
- Reintroduced with stakeholder input to 116th Congress – HR 2905
 - Current CoSponsors:

Rep. Earl Blumenauer	Rep. George Holding	Rep. Doris O. Matsui
Rep. G. K. Butterfield	Rep. Mike Kelly	Rep. David E. Price
Rep. Susan A. Davis	Rep. Robin L. Kelly	Rep. Terri A. Sewell
Rep. Dwight Evans	Rep. Elaine G. Luria	Rep. Adrian Smith
Rep. John Garamendi	Rep. Kenny Marchant	

NIH and CDC Funding Increases

- Two important federal agencies involved with research into GBS and triggers, CIDP, and variants. Due to the collective advocacy of like-minded groups, these institutions continue to receive funding increases to continue essential work

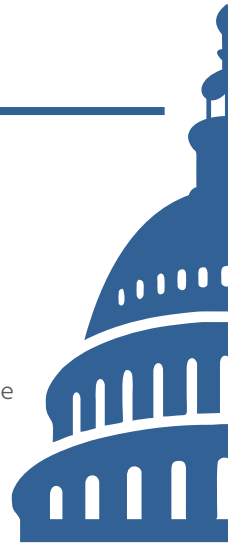
DoD PRMRP

- Because of grassroots advocacy, GBS continues to be listed as a condition eligible for study through the Department of Defense's Peer Reviewed Medical Research Program



HR 2905 Progress

We continue to work with the Senate Finance Committee and hope to introduce a Senate Companion during the 116th Congress



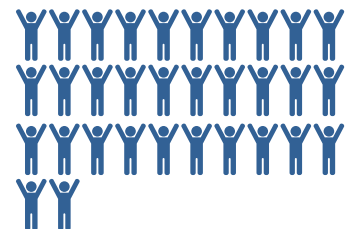
2018 HILL DAY

15 patient advocates participated



2019 HILL DAY

32 patient advocates met with 52 Congressional Offices



FIND OUT MORE

If you would like to find out more about our legislative agenda and learn how to get started with advocacy efforts, contact Advocacy Manager, Chelsey Fix, at Chelsey.Fix@gbs-cidp.org.

President's Circle

In recognition of cumulative gifts reaching \$10,000 or more, President's Circle members demonstrate leadership in philanthropy. This group of leadership donors make financial commitments of gifts that enable the greatest impact for the Foundation. In appreciation for their gifts, President's circle members receive special recognition throughout the year.

Arthur & Carolyn Asbury
Sue Baier
William Beam
Estelle Benson
Mitchell & Bonnie Benson
Garrett Bergman, MD
Barbara Blair
Calvin Bright
Ellen Burr
Barbara Cressman
Edwin Cridland
Karen Crombie
R. Kenneth Doehrmann
Marjorie Downey
William Gaffney
David & Janice Haley
Joan & Nany Hanisco
Debra Harvey
Ernest Hayden
Mitchell Herbets
Marilyn Horan
Susan Huebschman
Margaret Hunt
Jerry & Annette Jones
Joe & Robin Maas
Louis Mazawey
Abbey & Jerry Meyers
Allen & Nany Minton
Nelufar Mohajeri
Ellen Moseley
Ralph Neas
Cynthia & Eugene Oliver
Helen Rummelsburg
Albin Rzeszotarski*
Crystal & Jai Sada
Patricia Schardt
Christine & Ron Sobchik
Lawrence & Rebecca Stern
Amanda Swope
Douglas & Jeanne Swope
Jack & Joan Swope
Davol Tedder
Marilyn & Louis* Tedesco
Richard Thomason
Anne Travalia
Paul & Janet Votze

1980 Society

In recognition of donors who have given more than twenty donations. Since its founding in 1980, the Foundation has relied on the generosity of friends to grow into the outstanding organization that it is today. The 1980 Society donors are the most loyal donors and play a significant role in the past, present and future of the Foundation. In appreciation for their loyalty, 1980 Society members will receive special recognition throughout the year.

Sieglene Abendroth
Anne Acerman
Charles Ackerson, PhD
James & Sue Adair
Louis Adams
Barbara & John Alessio
Aida Alfonso
Jose Amijide
Richard Anderson
Kathlee Antonucci
Jorge & Maria Arroyave
Arthur Asbury, MD
Carolyn Asbury
Joan Athey
Gregory August
Sue Baier
Nancy & Allan Bailey
Verna Bain
Charles Bauer
Harold Becker
Vona Benge
Estelle Benson
Mitchell & Bonnie Benson
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Carla & Laurence Bernay
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Philamaine & Franklin Biffle
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Barbara & Charles Blankenship
Hannah & Charles Blanton
Maureen Bozicevich
Wendy Bradley
Gerald Brady
Dorothy & Alfred Brandstatter
Ann & George Brandt
David & Nelda Brooks
Bettie Brown
Mark Brown, MD
Audrey Brucker
Carol & Fred Brusseau
Joyce Brykman
Gloria Burke
Ellen Burr
Lisa & Tom Butler
Barbara Butler
Marcelle Callens

Carol & Michael Ceci
Yi-Mei Chang
Tonya Charleston
Edna Cierelli
Frances Clark
Marilyn Clark
Luey Clough
Mark & Evelyn Cole
Mary Collins
Melissa & Scott Conger
William & Sadie Cooper
Bill Copeland
Gloria & Donald Cote
James Cottrell
Edwin Cridland
Evelyn Crompton
James & Jennifer Crone
William Curry
Eleanor Curry
Donald & Sigrid Dahlin
Myron Daniels
Joan Decker
Janice DeDora
Rochi Demo
Peggy Dettwiler
Pam & Michael Dobos
Abby Dolliver
Betty & Skip Donelson
Marjorie Downey
James Drue
Excell Duncan
George Eberhart
David & Lesly Eckstein
Laura Edwards & Seymour Siegal
John Elligers
Ronald & Caroline Ellis
Jean de Elorza
Shane English
Mark & Marsha L Ensminger
Margaret Epplert
Virginia & John Ertz
Richard & Constance Etherton
Ralph Feick
James Fels
Joann Fenlon
Barbara Fisher
Wendy Fisher
Mary Fluke
Evelyn Force
Shirley Frederick
Mary Ellen Friedlander
Leora Fuller
Susan Gabay- Laughnan
William Gaffney
Santo Garcia
Don & Patricia Garrison
Linda Gawthrop
Thelma Gifford
David Gill
Linda Gindt
Robert & Linda Gingras
Kathy & Ira Goldberg
Joan & Bernard Goldman
Marilyn & Steve Gordon
David & Lois Greer
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BARB E. Florida

I started with numbness in my big toes in 2005. I went through all the neurological testing, and my Neurologist thought it was MS. I sought several different opinions, and finally in 2012, after not able to lift my leg to brake and stop my car. I ran a red light and crossed Hwy 1 (over 6 lanes of traffic) in St. Augustine FL. By the grace of God, I almost got hit but didn't, and I didn't hit anyone. Mayo in FL diagnosed me with CIDP.

I tried a 5 day load dose of IVIG, but due to my out of pocket cost, I chose to hold off on more treatments. Finally in 2015, I was almost completely numb from the pelvis down, and my face and hands. I knew it was only a matter of time before I would be in a wheelchair. I started home infusions of IVIG. They helped immensely. Unfortunately, when I turned 65 and went on Medicare, I could no longer have home infusions, and I drive to FI Cancer Specialists to receive my IVIG. It cost 35% more than home infusions. I had a 20/80 co-pay, which was very expensive for one year. Also, it is so much more convenient to be in our own homes.

(This letter is in response to our newly launched advocacy action center. Letters like these support the Foundation's advocacy agenda). Find out more: www.gbs-cidp.org/advocacy

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JAMES K. Maryland

I was diagnosed with CIPD in 2015 at the age of 70, a time of my life when I was still working full time as a pediatrician. Gradually, I had marked difficult ambulating, became fatigued and had to give up my private practice long before I planned.

Originally, I received IVIG treatments at home. A trained RN came to my condo 2 days per month and provided the necessary infusions. After a few months, Medicare informed me that they would not cover the treatments and I would be responsible for the entire cost of 400,000 dollars annually, so I had to stop infusions. About 6 months after appeals, I was approved to go to downtown Baltimore to Hopkins infusion center on 2 days every 3 weeks and sit in a so called infusion chair for about 5 hours including driving from the suburbs plus parking and walking about a mile to the center, this is about an 8 hour endeavor.

My story is unique, but there are thousands of other people with similar stories and struggles, so I hope that you will seriously consider becoming a cosponsor of H.R. 2905.

(This letter is in response to our newly launched advocacy action center. Letters like these support the Foundation's advocacy agenda). Find out more: www.gbs-cidp.org/advocacy

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Sue Jester
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PATRICIA M. Massachusetts

I was diagnosed with CIDP in 2013 at the age of 59, a time of my life when I was one year into my new profession managing my vacation rental property. I was misdiagnosed for 2 years when symptoms became more acute leading to a 7-month process to a confirmed diagnosis of CIDP. I turned 65 in February and now have infusions at a hospital where there are 10 different nurses who know nothing about me, my disease or even my particular medication. Prior to February I was home infused for 5 years by the same nurse who was one of my advocates and critical member of my Team.

When the IVIG wears off (2 1/2 weeks) I am at risk for falling (I've had 2 bad falls in 6 months) yet this is the exact time I am now required to leave my home, have someone take me to the hospital, infuse for 5 hours then have someone take me home. This is the time I should be in my home getting infusions just like I did for 5 years prior to turning 65!

(This letter is in response to our newly launched advocacy action center. Letters like these support the Foundation's advocacy agenda). Find out more: www.gbs-cidp.org/advocacy

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NANCY Di SALVO

Please join us in welcoming Nancy Di Salvo to the GBS|CIDP Foundation International Board of Directors! A tireless international volunteer for the GBS|CIDP community since 2013, Nancy has educated and supported numerous patients worldwide. Most recently Nancy held the very first chapter meeting in Italy, with over 50 attendees. Nancy brings a keen sense of cultural differences, combined with a friendly, hospitable and compassionate nature. We look forward to working with Nancy on continuing the mission of the Foundation and serving the GBS|CIDP community.

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Susan H. Smith	Rodney Steiger	Kevin Sullivan	Elizabeth Thirtyacre	Thomas Tudor	James Voeller
Teresa Smith	Gary Steigh	Lawrence & Josephine Sullivan	Sarah Thom	Carl Tufts	Mackenzie Voeller
Tracy Smith	Pamela Stein	Lisa Sullivan	Amanda Thomas	Luke Tullberg	Barbara Vogentanz
William Smith	Sherie Stein	Melanie Sullivan	Christine Thomas	Betrice Tunstall	Jessica Vogland
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Smith D'Auria	Debra Stemper	Carol Sulouff	Melissa Thomas	Andrea Tursi	York-Howell
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Kristina Smitten	Mariann Stephans	Arielle Sumits	Sarah Thomas	James Tuttle	Sreenath Vuske
Courtney Smothers	Daniel Stepp	Shane Sumlin	Susan Thomas	Christine Ulbricht	Sharmaine Waas
Judith Smoyer	Richard Stern	Jan Summers	Wallce Thomas	Steve & Debra Ulmer	Waccamaw Community
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John Snarr	Alyssa M. Stevens	Heidi Svenson	Corey Thompson	Aiko Umehara	Debbie Wade
Sneakpeak Prints	Brittany Stevens	Rebekah Svensson	Gary Thompson	UNUM Group	Robert Wagenmann
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Nancy Snedeker	Donna Stevens	Sandra Svoboda	Suzanne Thompson	Diane Urbaneck	Fred Wagner
Alma Snell	Catherine Stevenson	Jonay Swanson	Tammy Thompson	Stephanie Urena	Nancy & John Wagner
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JOSH BAER

Please join us in welcoming Josh Baer to the GBS|CIDP Foundation International Board of Directors! Josh Baer is Vice President of Equity Research at Morgan Stanley covering the Software industry, since 2014. Prior to that Josh held roles in investment banking, consulting, and trading at various financial institutions. Josh holds the Chartered Financial Analyst (CFA) designation, an MBA from NYU Stern School of Business, and a BSBA from Washington University in St. Louis. Josh had Guillain Barre Syndrome in 1996. After serving as the International Teenage Penpal for many years, Josh joined the Foundation's Finance Committee in 2015 and has served on the Board of Directors since 2018.

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Ambassadors

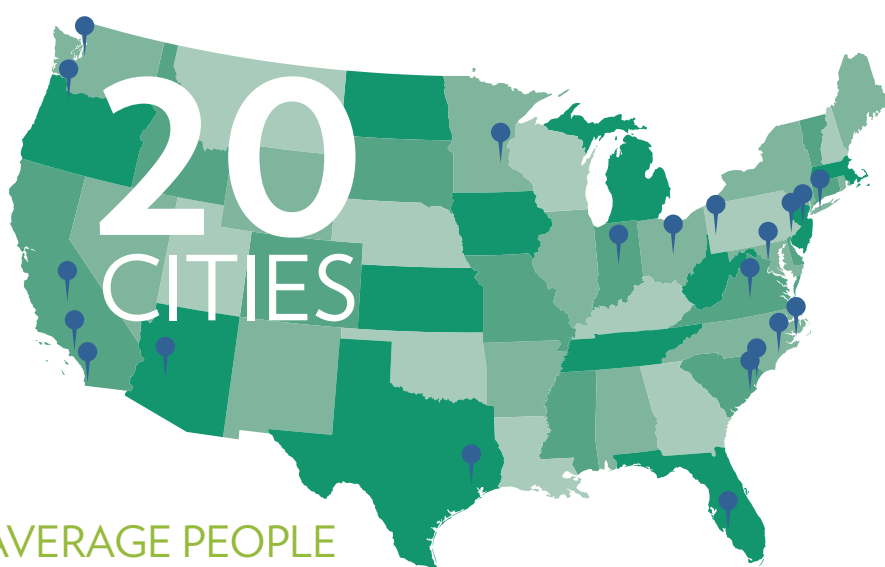
These Special donors give the gift of time and leadership. Ambassadors are individuals who have engaged the community in the name of the Foundation. This includes, but is not limited to the following: facilitating a chapter meeting chairing a Walk & Roll, Chairing a specific fundraiser and conducting an Advocacy event by making a Congressional visit. In recognition of their dedication to the Foundation, Ambassadors will receive special recognition for their leadership.

Bill Ansley	Megan Kaump
Susan Banchansky	Valerie Keller
Robert Bard	Matt LaRocco
Julie Bell	Ray Lopez
Estelle Benson	Merrilyn Macurak
Garrett Bergman	Dave Mayer
Yvonne Bishop	Megan McCulloch
Sheila Blaine	Glenn Miller
Betsy Blake	Kris Orlandi
Dennis Bosch	Brenda Perales
Wayne Bowyer	Michael Perales
Bruce Breneman	Michael Ring
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Jim Crone	Pat Schardt
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Sibylle DeRosa	Jack Sena
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Janice Dunkerton	Oli Smith
Rebecca Ferguson	Kristen Spaunhorst
Rick Forney	Roger Steck
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Robert Fuerstenau	Elizabeth Thirtyacre
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Lee Ann Gooseman	Kassandra Ulrich
Jonathan Gould	Rob Vasquez
Julia Grant	Kristy Vaughn
Caroline Grimes	Angela Whittington
Steve & Joe Hackett	Corbin Whittington
Wes Henrikson	Pam Wrobel
Misty Hernandez	Jim Yadlon
Mindy Hester	Russ Walter
Anita Joy	Kristen Weaver

Please note list may not be conclusive and we apologize if we have omitted a name.



33 WALKS



3,813
ATTENDEES
& COUNTING

9 AVERAGE PEOPLE
PER TEAM



\$300,000
RAISED FOR RESEARCH
AND COUNTING



WALK & ROLL
FUNDRAISING
PAGES CREATED

“

“I recently participated in Ohio’s Walk and Roll on 9/23/18, and was blessed by witnessing a beautiful group of people weaving their stories, challenges, determination, love, optimism together to provide a place where people arrived feeling alone – and left with a hearts filled with validity, understanding, community & family.”

Joanne Howard

CONNECT WITH US! @GBSCIDP



12,587
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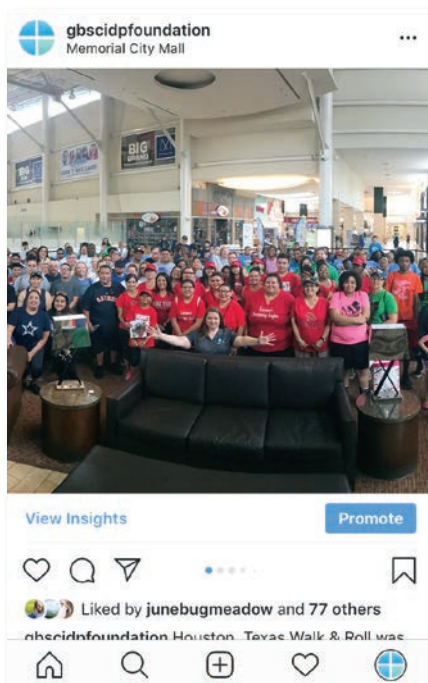
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WHY I VOLUNTEER

“

“A lot of what the Foundation offers is this patient to patient contact. It’s really a wonderful thing that I get to share my experience with other patients and it’s truly bonding because they really do need someone else that knows what they are going through. It changes everything.”

—JESSICA SCHEXNAYDER

“

“The Foundation events are all a matter of camaraderie and being able to talk about what’s going on their lives what’s worked for them. Teaching and learning from each other as patients is extremely important with a rare condition. I volunteer for the Foundation because I care about the patients and caregivers, that’s why I’m in it and I’ll be in it until I can no longer do it”

—RICK FORNEY

“

“There is nothing compared to connecting with a real-life person who’s been through it at the moment you are going through it.”

—PATRICIA BLOMKWIST-MARKENS

“

“After hearing the GBS or CIDP diagnosis, the patient-to-patient contact is so wonderful, so life changing, because in the outside world we are kind of alone. In the Foundation community we are not alone.”

—NANCY Di SALVO



GBS CIDP Foundation International Earns Coveted 4-Star Rating from Charity Navigator

For the 7th consecutive time, the GBS|CIDP Foundation International has earned a 4-Star Rating from Charity Navigator. The Foundation’s strong financial health and commitment to accountability and transparency have earned it a 4-star rating from Charity Navigator, America’s largest independent charity evaluator.

WELCOME TO OUR NEW INTERNATIONAL CHAPTERS!



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