

FOUNDATION REPORT

2016.2017





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MISSION AND VISION STATEMENT

About Us

The GBS|CIDP Foundation International is the preeminent global non-profit organization supporting individuals and their families affected by Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as multifocal motor neuropathy (MMN) through a commitment to support, education, research, and advocacy.

Our Vision

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

Support Education Research Advocacy

Our Mission

To improve the quality of life for individuals and families affected by GBS, CIDP, or related syndromes such as MMN by:

- Creating and nurturing a global network of volunteers, healthcare professionals, researchers and industry partners to provide those affected with GBS, CIDP, or related syndromes such as MMN with support and the most current available information;
- Designing and implementing public, medical, and professional education programs to increase awareness and improve understanding;
- Funding research through grants, establishing fellowships, and using other
 appropriate avenues to identify the causes of and discover treatments for GBS,
 CIDP, and related syndromes such as MMN;
- Structuring partnerships to engage in advocacy at the federal, state, and grassroots levels to advance our vision and mission with legislators and government agencies.





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

Dear Friends,

Thank you...Gracias...Merci...Grazie...Danke Sehr...Arigato...Do Jeh... Daw-Dyeh to our GBS|CIDP family from all over the world. Mere words cannot express how grateful we are for enabling us to live the mission of this organization. This year your support has empowered us to:

- Present three one-day regional conferences
- Host seventy-five US Chapter support group meetings
- Re-design our website
- Invite 15,000 friends to join a Walk & Roll event
- Advocate on Capitol Hill for patient protections on healthcare reform
- Grow our Center of Excellence program to 39 Centers around the world
- Fund research in Zika- related GBS
- Fund our grant program to over \$3,000,000 in funding for research
- Develop a 17 member Global Medical Advisory Board with the world's top Neuro-muscular specialists

Although the past year has kept us busy, we remain committed to our mission to why this organization started- to help the patient.

The description of our logo really tells our story. It represents disorders that for a period of time, paralyze an individual and devastate a family. The three (blue) squares represent the darkness, both physically and socially that encompasses the patient's world. The light (green) square represents hope and recovery and arrival back into light. We are that square!

On the pages that follow, we tell the story of the many activities and projects, which have defined our year that make the light of hope and recovery possible. Above all, you are the core of all we do. As we recognize our supporters, be assured that your presence is your true gift to us and we are grateful.

Together we have much to share and many to serve.

My best to all,

Lisa

Lisa Butler
Executive Director

FINANCIALS

Endowment Summary

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 \$700 million.

As the endowment has grown from \$250,000 to over \$7 million 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.

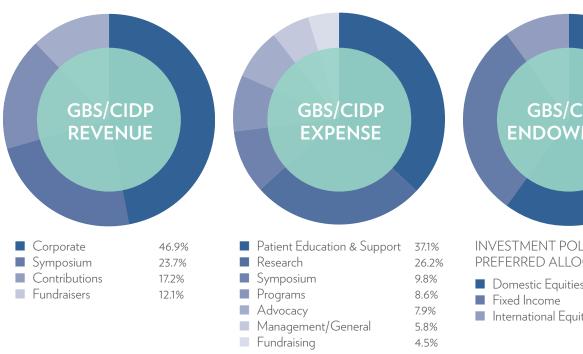
In an effort to minimize costs, the endowment utilizes low cost exchange traded funds and individual, high quality bonds. The exchange traded funds allow for the creation of a well-diversified portfolio and the individual bonds seek to provide stability and income required by the Board.

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, utilizing short term investments to protect from the adverse effects of rising interest rates. The aggregate portfolio is managed to focus on Total Return, protecting principal while trying to achieve reasonable levels of growth.

GROWTH OF GBS/CIDP ENDOWMENT

2006	\$250,000
2007	\$750,000
2008	\$650,000
2009	\$800,000
2010	\$2,800,000
2011	\$3,000,000
2012	\$3,500,000
2013	\$5,500,000
2014	\$6,000,000
2015	\$6,300,000
2016	\$7,200,000



Domestic Equities	0070
Fixed Income	30%
International Equities	10%

Support

"Serving members and building a community"

Creating and nurturing a global network of volunteers, healthcare professionals, researchers and industry partners to provide those affected with GBS, CIDP, or related syndromes such as MMN with support and the most current available information; And here is how we are doing it:



72 Chapter Meetings projected in 2017, an increase of 18% from 2016



140 volunteers nationally and 200 worldwide



20,000 members were invited to Chapter Meetings in 2017



1,500 new members nationally and **400** internationally received services since January 1, 2017



44,000 members in U.S., **6,000** members internationally



4,000 new patient inquiries answered annually



100,000 newsletters mailed annually



"Our chapter meetings are a place and time to let it all go and be embraced"

"A chapter meeting is a time we come together to learn from one another"

"Being a liaison is the most selfless, compassionate call to duty that I can perform"

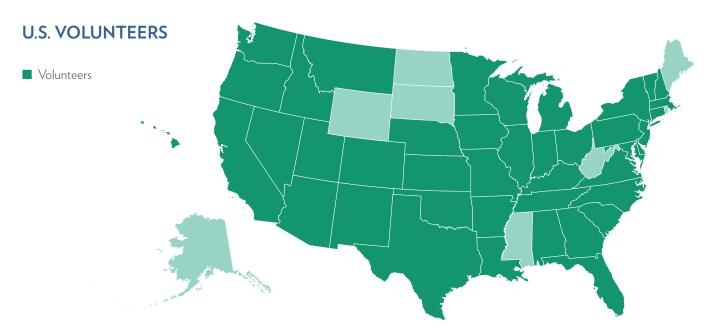
"Being a volunteer is being a light of hope"

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

■ Volunteers



Support



Centers of Excellence – 2017

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

BIRMINGTON, UNITED KINGDOM

University Hospitals of Birmingham

BUENO AIRES, ARGENTINA

Argentina Hospital Britanico

BUFFALO, NY

The University at Buffalo School of Medicine andBiomedical Sciences, State University of NY

BURLINGTON, VT

University of Vermont

CHARLOTTESVILLE, VA

University of Virginia

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 (UTHeath)

KANSAS CITY, KS

The University of Kansas Medical Center

LONDON, ENGLAND

King's College Hospital

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

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

ORANGE, CA

University of CA-Irvine

OSAKA, JAPAN, KINDAI

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PARIS, FRANCE

Groupe Hospitalier Henri Mondor, Universite' Paris Est

PHILADELPHIA, PA

Perleman School of Medicine at the University of Pennsylvania

PHOENIX, AZ

Barrow Neurological Institute

PHOENIX, AZ

Phoenix Neurological Associatess

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

TAMPA, FL

University of South Florida

TORONTO, ONTARIO, CANADA

University of Toronto, Tornonto General and Western Hospitals

WARSAW, POLAND

Medical University of Warsaw

WELLESLEY, MA

Saint Elizabeth's Medical Center

Education



Symposium

We were honored to share a spectacular weekend in San Antonio last September with 500 patients, caregivers, and friends old and new from South Africa to North Pole, Alaska and everywhere in between.

Our Biennial Symposium is our hallmark event, with our first being held nearly 30 years ago in 1988. While the structure will never change, we did decide to take a new, fresh approach on curriculum! Our focus was on "Life After Diagnosis" with sessions covering alternative therapies, mindfulness, and painmanagement just to name a few. We hoped that these would provide a whole approach for our patient base and complement our scientific sessions, led by our incredible Global Medical Advisory Board.

Also new this year were our Physician One on One's – a private, fifteen minute dialogue with one of our Global Medical Advisory Board physicians. Members were able to sign up in advance for these meetings, and based on the overwhelming response, we look forward to offering these sessions for our next event.

We also hope that you had a little fun! Our themed receptions; a Texan Style Hoedown to welcome you all and a Closing Fiesta with our big announcement – the location of our 15th Biennial Symposium!

SAVE THE DATE

15TH INTERNATIONAL SYMPOSIUM

The GBS|CIDP Foundation International invites you to join us for our 15th International Symposium on November 1st-3rd, 2018 at the Hilton San Diego, Mission Bay in San Diego, California!

This Symposium will be an incredible opportunity to learn about GBS, CIDP, and variants from leading medical experts in the field, to meet other patients and families, and to have fun! Stay tuned for registration information.

Regional Conferences

You asked and we listened!

NEW IN 2017 – Regional Conferences! Brand new to our Foundation! A little spirit of a chapter meeting and a taste of a symposium – these one-day conferences brought together local physicians, members, caregivers and loved ones.

Happening in the Symposia's "Off Years," we will host these conferences in different locations all over the country.

In 2017 we traveled to Fort Lauderdale, Baltimore and Chicago, and the response was outstanding! Our speakers included our Global Medical Advisory Board as well as local physicians and our sessions maintained our "Life After Diagnosis" theme. The curriculum included insurance, zika virus updates, Physical and Occupational Therapy, and more!

Thanks to the incredible turn out, it's safe to say that these conferences will be here to stay. We look forward to visiting new cities in 2019!

Research

Grant Awards given by the GBS|CIDP Foundation International

2016

FILIP EFTIMOV, MD, PhD THE NETHERLANDS

ICOS, predictors of treatment response (ICOS-PREDICT)

CRISTOFORO COMI, MD, PhD **ITALY**

Assistant Professor of Neurology Department of University of Piemonte Orientale

Development of a Tolerogenic vaccination for Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

KATHRIN DOPPLER, MD **GERMANY**

Effect of Anti-Contactin-1 Antibodies on DRG Neuron

HELMAR C. LEHMANN, MD **GERMANY**

Department of Neurology University Hospital of Cologne

Loss of Schwann cell plasticity in CIDP: A central role for GM-CSF

KEVIN O'CONNOR, MD, PhD **UNITED STATES**

Defining the contribution of B cells to CIDP pathogenesis

PROF. EDUARDO **NOBILE-ORAZIO ITALY**

An Italian Multicenter Network for the diagnosis and therapy of chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) and of its variants Proponent

JULIA WANSCHITZ, MD **AUSTRIA**

Analysis of antibody responses against nodal/paranodal antigens in an Austrian cohort of patients with Guillain-Barré Syndrome

2017

RAFFAELLA LOMBARDI, MD **ITALY**

Probing the role of skin biopsy in CIDP,nodo-paranodopathies

UMAPATHI THIRUGNANAM, MD **SINGAPORE**

Sr. Consultant Neurologist

Flavivirus and arbovirus associated GBS in South. East Asia

GANG ZHANG, PhD **UNITED STATES**

Enhance peripheral nerve repair by modulating macrophage subsets

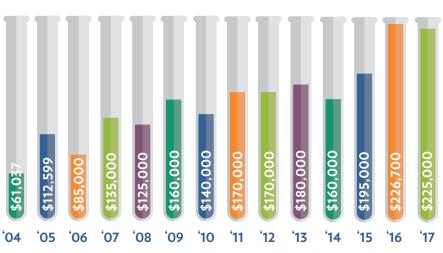


\$150,000 Foundation Fellowship in 2015, 2016, 2017.

DR. RUTH HUIZINGA, *Rotterdam, The Netherlands*. High innate responsiveness to microbial triggers predisposing to GBS: identification of genetic causal variants

GRANT AWARDS GIVEN BY THE GBS CIDP FOUNDATION INTERNATIONAL FROM 2004-2017





Advocacy

Foundation Hill Day

20 advocates participated in **26** legislative visits for 2017.

100 Foundation members of Grass-Roots Advocacy group.

DOD PRMRP

 Guillain-Barré Syndrome is now listed as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP). Military service members, particularly those stationed abroad, are at a higher risk for infection. Two-thirds of GBS cases occur following an infection and most commonly these infections include gastroenteritis or respiratory tract infections; two prevalent illnesses amongst those that frequently travel abroad.

The Foundation supported other related nonprofits by attending PSI, AANEM and PPTA Hill Days

- Patient Services, Inc. (PSI) Hill Days are about supporting patient's
 access to premium assistance, giving Hill offices the patient
 perspective and advocating for the importance of these programs.
- We have worked with American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) to assist in rooting out the fraud in the EDX testing field. These fraudulent factors have an adverse effect on patients and ultimately lead to misdiagnosis.
- We advocated with Plasma Protein Therapeutics Association (PPTA) giving the patient voice in discussions about the necessary access to therapies and the need for cost effective therapies.

PSI's 3rd party premium bill

- Some insurance plans are exploiting a loop hole to discriminate against rare/costly conditions. Many legislators and patients are unaware this is happening (and surprised it can happen).
- Congress can fix the loop hole and Health and Human Services (HHS) could simply clarify the rule.
- A new bill by Rep. Kevin Cramer (R-ND) will be introduced in September which the Foundation supports.

Report Language

- National Institutes of Neurological Disorders and Stroke The Committee supports progress of increased research in GBS and CIDP
- National Institute of Allergy and Infectious Diseases (NIAID) is working on hosting a State of the Science conference for autoimmune neuropathies.



4 pillars of Health Care Reform

The Foundation focuses on the following elements of health care reform:

Maintain basic patient protections in ACA reform/repeal proposals.

- Maintain pre-existing condition discrimination prohibition.
- Allow young adults to stay on their parent's insurance until age 26.
- Limit lifetime and annual caps on insurance coverage.
- Limits on out-of-pocket costs for patients.

GBS|CIDP Advocates including CIDP patient and staff member Kelly McCoy participated in a broad community effort led by the Cancer Society visited Senate offices and explained to them the harm that would have occurred without basic patient protections through the repeal and replace debate.

NIH Funding

The Foundation continues to request increased funding for National Institutes of Health FY2018 ask of \$36 billon.

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 Asbury Sue Baier William Beam Estelle Benson Garrett Bergman Calvin Bright Ellen Burr Edwin Cridland K. Robert Doerhman Mariorie Downey Debra Harvey Ernest Hayden Marilyn Horan Susan Huebschman Jerry Jones Joe Maas Louis T. Mazawey Ralph Neas Cynthia Newell Oliver Helen Rummelsburg Patricia Schardt Lawrence Stern Jack Swope Davol Tedder Marilyn Tedesco Anne Travalia Paul 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.

Sieglinde Abendroth Anne Ackerman James Adair Louis Adams Jose Ameijide Richard E. Anderson Kathleen Antonucci Jorge Arroyave Arthur Asbury Joan Athey Gregory August Sue Baier Nancy Bailey Verna Bain Charles Bauer Harold Becker Estelle Benson Mitchell Benson Carla Bernav David Beymer Philamaine Biffle Barbara Blankenship Hannah Blanton Maureen Bozicevich Ann Brandt David Brooks Bettie Brown Mark J. Brown, M.D. Audrev M. Brucker Carol A. Brusseau Joyce Brykman Gloria Burke Ellen Burr Barbara Butler Lisa Butler Marcelle Callens Tonya Charleston Edna Cicerelli Frances Clark Marilvn Clark Luey Clough

Mark Cole

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Anna May High Charles Mayberry Enrica McCann James McCarthv Thomas McCullum Lila McKay Carol Mensching Tom Metzler Ann Millar Rose Mitchell Virginia Molenaar Caroline Morrison Anneliese Nathan Ralph Neas Beverly Neuenfeld Donald Nevers Josephine Nicolosi Beatrice Nilsen Nancy Nurnberg Susan O'Briant Cynthia Newell Oliver Milton Orenstein Carolyn Palmer Ronald Pawasarat Robert Peterson Matthew Pinto Debbie Plimmer Richard Plimmer Robert Polis Robert Prestwich Jane Priour Thomas Reiland Vivian Rothschild Marlyn Rothstein Helen Rummelsburg Lorraine Rumore Ann Santarlasci Patricia Schardt John Schilke Shirley Schleimer Wernert J. Schuler, Jr I E Schultz Elizabeth Schultz Betty Stafford Brian Stahl, PH.D. Robert Stanley Pamela Stein Joel Steinberg, MD, PhD Bryan Storm David Sullivan Barbara Szitta Marilyn Tedesco Jon Toumev Joseph Tremari Kassandra Ulrich John Wagner LaVon Wankum Hans Wehl Kenneth Wells W.H. Werling

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Vincent Wyles

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Rowland Yeo

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Edna Wilken William Willever

Kenneth Marx

Michael Mattia

Legacy Circle

The Legacy Circle recognizes individuals who have named the Foundation as a beneficiary in their Estate plans and have named the Foundation as a beneficiary in their will, charitable gift annuity, charitable trust, or similar vehicle. All individuals who have included the Foundation in their estate plans, and have made their intentions known are invited into membership in the Legacy Circle.

Louis Adams Estelle L. Bensen Ellen Burr K. Robert Doerhman Ruth Elster Carolyn Fairman Jeffrey Fihn Gladys Fortune Ernest Hayden Susan Huebschman Douglas Johnston Monice Joy Poirot Ronald Root Anne Travalia Kassandra Ulrich Chris Zaal

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CRYSTAL

"It didn't occur to me that there was anything major going on until it effected my hands and feet constantly. When I was finally diagnosed, I know this sounds weird. but I was relieved. I was actually more worried that he wasn't going to find anything. Even when he did diagnose me, I didn't have the full picture. He said 'Well it's CIDP and I'll see you in a few weeks when you start IVIG' and I had to go home and look it up myself. I knew my life had changed. I knew going forward it wasn't going to be the same.

With treatment, it hasn't gotten me to where I want to be, but I'm better than I was. Some things get better and some things will get worse with CIDP – it's fluid. It's constantly changing. It's the randomness, it's the not knowing.

My hope is a cure #1. If not, my hope is to be the best Crystal I can be with this. Do you know Monty Python and the Holy Grail? The scene with the Dark Knight? "Come over here I'll kick you with my good leg! I'll fight you with my good arm!' That's going to be me! I'm the Dark Knight, and no matter what this disease does to me I'm going to work through it and try to help people."

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Karen Jones John Jones Debra Jones

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Doris Jones Joan Jones Jenna Jordan



RAY

"I developed a stomach virus and gradually became weak. I knew that something was wrong. I drove to the nearest hospital where they evaluated me and I was told to go home and take liquids and bedrest. The next day I just plopped on the floor. I went to another hospital where I was given a spinal tap and I was diagnosed with Guillain-Barré Syndrome.

I felt so alone because I didn't know anyone else who had GBS.

I received an invitation from my local volunteer and he invited me to one of his meetings. I went there and was able to see the support the Foundation provides."

Louise Kass

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Nandini Moran

Mark Moreno

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Muriel Morisev

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Stephen Noel

Sandra Nogosek Jeanine Nolan Debbie & Rick Nolte Megan Norman Edwin Norman Michael Normington Roy Norris Kathleen Northrop John Noval Brvan Nowlin Louis Nuechterlein Chad Nunamaker Lisa Nunes Jasen Nunes Nancy Nurnberg Gerald Nvari Eva Nyari Norman Nye Adam Nystrom Jolynne O'Banion Greta Obereiner Julian Oberman Susan O'Briant Jack O'Brien Maria O'Brien Richard O'Brien Mike & Briana O'Brien William O'Brien Robert O'Brien Eleanor O'Brien Tara Ocello Rosa Ochoa Todd Ochsner Arlene O'Connell Edward O'Connell Karin O'Connell Timothy O'Connell John O'Connell C. Jackson Grayson Jr., PHD

and Carla O'Dell, PHD Alec O'Doherty Denise O'Donnell Maureen O'Driscoll Mildred Oglesby Vincent & Monica O'Grady

Ada Ojeda Sheena Ojeda Mary Frances O'Kane Ruth O'Keefe Mary Olden Arline Olim

Gerald McIntyre



CORBIN

"I had this tingling in my feet. That morphed into numbness in my legs. I just thought I was stressed and tired and busy. Then I realized I was weak, I was struggling to take a carton of milk out of the refrigerator. I had numerous tests and was told I had this odd thing called CIDP.

The last thing you think of, is a chronic illness. Until one day, you sit down with the doctor and they say 'I have bad news' and it's a shock. I know that surely, I'm not being knocked down by some 'alphabet disease' I've never heard of! So yes, it's only rare until it happens to you, and then it's very real."

Greg Olin Beth Oliva Ralph And Kat Oliva Vinny Oliva Willow Olivares Cvnthia Newell Oliver John Olivera Heather Olivo Joseph Olney Roy Olsen Nancy Olszewski Maribel Omlor Becky & Steve Omlor Michael O'Neil Donna O'Neil Dan & Lauren O'Neill Benjamin Onyango Gail Opel Gary Oradat Teresa Orandello Daniel Orcutt Milton Orenstein Trish Organ Robby Organ Carol Orr Jolynn Orth Marilyn Orthouse Don Osborne Judy O'Shea Raymond O'Shea Jan Osier Erik Ostbye Webster Otis

Jessica Overbee

Karen Overhoff

Linda Overstreet

Suzanne Owens

Nicole Owens

Marla Owings

Stephen Paar Charles Pace Gloria Pacini Patty& Thom Paddack Louise Paden Corina Page Dennis Pageler Donna Palaganas Tom Palaia Susan Palladino Bridget Palmer Carolyn Palmer Jean Palmeri Agnes Palumbo Juan Paniagua Bill Pannier Mary Panzarino Linda Paolano Janice Papalia Carlo M. Pappania Karvn Pappert Dorothy Paquin Helen Paris George Parker Harriet Parker Kristine Parker Samantha Parker Rebecca Parsons Jeffrey Paskar Nancy Pastre llene Patasnik Tom Pate Chirag Patel Shannon Patelczyk Nancy Patella Frank Patille Anna Patsel-Powell Bryan Patterson

Linda Paul

David Paulissen Wendy Paulo Carol Paulsen Michael Pavan Howard Pavane Ronald Pawasarat William Pawlak Todd Pawlowicz Angela Pawlowicz Martha Payne Donald Payne Raymond Payne Linda Payne Sharon Pazak Daniel Peacey Christina Peacey Donna Peacher-Hall Allie Peacock Melanie Pearce Jetty Heron and Laura Pearce Margaret Pearce Karen Pearson Cvnthua Peecher Todd Peeples Lynn Pelland . Wayne Pelletier , Miranda Pellett Linda Pelliccioni Vicki Pendergast Ed Penniman Lorraine Pennington Mark and Cindy Pennington John Pennucci Rachel Pensabene Mary Pepper Samira Perez Nancy Perlow John Perotta Yves Perrier Bryan Perry Mary Perry Michele Perry Don Pessin Kathaleen Petelle Johny Peter Virginia Peters Lori Peters Jessica Petersen Thomas Petersen Robert Peterson Pete and Kay Peterson Cathy Petriw Shawn Peyton Darla Pfeffer Maryann Pfenning Thomas Pfenning Maryann Phelps Charlotte Phillips Lorraine Philson Dolores Piccirilli Rose Pickens Lisa and Mark Piecha Patti Pieja John Pielemeier Darin Pierce Lloyd Pierce Dorothy Pierce Susan Piervin Daniel Piett Thomas Pike James Pinder Kathy Pinkston Juliette Pinkston Robert Pinney Robert Piorkowski Ragga Pischieri Evelyn Pisegna-Cook

Nancy Pitcherella

Mary Pittarelli

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Roslyn & Bob Pittsford Michael Platt Andrea Plesnarski Thomas Plewes Elizabeth Plewes Daphne Plummer Kathy Plummer Kathleen Plunkett Jo Poe Ronald Poedtke Stephanie Poett Monice Joy Poirot Roberta Polanco Rosaria Polizzi Richard Polster Movane Polzin Robert Pomeranz Kathie Pomykala Kathleen Popchak Adam Popchak Jean Poplin Patricia Porter Roy Porter Ted Portillos Jodi Pospeschil Mary Postler-Adelhelm Paul Pothier William Potter Ruth Potter John Potter James W. Potts Dawn Potts Nancy Powell Nancy Carole Powell David Power June E. Prance Dora Prato Cilla Prato Wesley Prato Maria Prato Nicole Prato Lynn Pratt , John Prell Frances Prenzler Theresa Preskar Richard Preskill Aviva Pressman Brian Pressman Elisabeth Preston Robert Prestwich Doris Preziosi Timothy Price Jennifer Prince-Moughan

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George A. Rafuse Reginald Ragland Anne Raker Maryann Rakowski Padma Ramanathan Sharon Rambera Marc Ramby Emma Ramirez Virginia Ramm Jessie Rampa Heather Ramsey Richard Randall Brian Randall James Randolph Marie Raney Janice Rankin Amy and Ken Rastelli Lvdia Ratcliffe Brenda Rau Daniel Ravinski Gerald Ray Robert Ray Nancy Ray Jacqueline Raynor Randolph A. Re Leah Rea John Ready Bob Reagle Diane Rebecchi Jeremy Rechtshaid Hestella Redic Stephen Redmon Peter Redshaw Bonnie Reed Thomas Rees Phyllis C. Reese Joyce Regina David & Patrice Rehm Kenneth Reid Jane Reid Thomas Reiland Victoria Reilly Mr. & Mrs. Herman Reimer James Reinarz Helen Reineking Ruth Reinermann

Rivka Reinman David Reisia Paul Reitman Zoe Rem Richard Rennel Lesha Renner Doug Renner Kim Rentner Theresa Resch Sandra Restino Laura Retzlaff Margot Reubens Jeremy Reus Jesse Řevicki Beth Reynolds Mary Reynolds Pat Rhoades Casey Rhoades Karen Rhoades Pat A Rhoades Richele Ricci Patricia Rice Chris Rice Charles Rice Shari Rice Samuel Rich Ruth Rich Robert Rich Danny Richard Thomas Richards Josey Richards A I Richardson Rebecca Richardson

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Norma Rogers Thompson H. and Jane D. Rogers Evelyn C. Rogers Ruth Rohde David Rohn Natalie Rohn David Rohrback Loretta Rolison Maricsa Roman Gabriel Roman David Roman James Roman Nelson Roman Jaime Roman

Allie, Mario And Via Rometo

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Russell Walter

Sandy Walters

Pauline Van Sickle

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BRENDA

"I thought it was a pinched nerve in my back. My left foot would go numb when I wore high heels. When I went to the neurologist, they did the nerve conduction study and other tests. I didn't fit any box neatly. So that is when I went to Johns Hopkins. He said that everything pointed to ALS. I have two sons that were in high school and all I could think about was 'Will I be around to see them graduate and have kids?" and I got angry. The last thing to try was IVIG; if IVIG worked then I did not have ALS and thankfully, it was working. I was then diagnosed with Multi Focal Motor Neuropathy.

It makes a big difference to have a place to go where people understand. I find myself continually telling people about the Foundation website so they can know about the Centers of Excellence and all of the other help they provide.

I'm in a place now where I have a new normal. I'm lucky because I have a treatment option, many don't. It's important to fund research to give us a chance."

Terri White Earl White Angela White Bernadette White Jerry Whitehead B. White-Spunner Valerie Whitfield Carol Whitley Chanon Whitman Roger Whitney Angela Whitt Gladys Whittenberg Corbin Whittington Brandon Whittington Regis Whittington Daya Whittington Lyndell Whyte James E. Wickert Elizabeth Widdifield Ralph Wiechert Raymond Wieczorek Douglas Wigton Lois Wildina Bob Wiley Martha Wilke Patty Wilkerson Harriet Will

William Willever Chris Williams Arlene Williams Melissa Williams Jimmie Williams Howard Williams Tom Williams Charles & Ivette Williams Todd Williams Judith Williams Glenda Williams Maureen Williams Bobby Williamson Steve Wills Cindy Wills Karen Wilson Gary Wilson Amanda Wilson David Wilson Diane Wingert Robert Wingert Ashley Winnett Tammy Wintermote Eugene R. Winters Christa Wirtz Johanna Wiseman Nedda Wiseman

Joanne Wolf Sheila Wolfe Jennifer Wolter Linda Wong Laureen Wood Kathy Wood Donald Wood Paul Woodard Lori Woodbury Kennard Woods Heather Woodward Zorina Woodward James Woodward Patricia A. Work Sandra Work Rodney Wray Shawn Wright Leslie Wright Linda Wright Mary Ann Wyand Casie Wyatt Joseph Wylen Vincent Wyles Karen Wynne Jola Xhunga Jim Yadlon Janet Yamron Rick Yanchuleff Alling Yancy Suzanne Yang Cynthia Yankowski Jack Yantis Caroline, Phyllis & John Jr. Yastrzab Robert & Candace Yates Stacy Yates Kevin Yates Bonnie Yeomans Larry Yepez Leslie Yerger Ray Yetvin Cheryl Yetz David Yocum Marlene Yoder Vicky York Courtney York Lois York Jane Young Lisa Young Tatum Young Timothy Young Helaine Young Wallace Young Warren Young Donald Young Somerset County Young Republicans Blake Zaal Chase Zaal John And Christian Zaal Ron Zaal Robert C. Zaccaro Kirsten Zajaczkowski Robert Zambito Paul Zanotto Dawn Marie Zarlingo Carol Zaun Ashley Zehler John Zeiger Jeraldine Zellers Dorothy Zellner Nadell

Wayne Wishart

Robert Witt

Edna Wittwer

Dawn Withstandley

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Elaine Wolbrom

Liam Wolf

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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.

Renee Richmond Chris Davis Rob Burton Jane Rosen Ariel Lasry Sue Salzmann Merrilyn Macurak Kristen Weaver Crystal Sada Jennifer Flary Brenda Velantzas Tonya Charleston Susan Martin-Gibbons Megan McCulloch Kristy Vaughn Lee Ann Gooseman Dani Sticka Matt LaRocco D William Ansley

Glen Barbour Robert Bard Richard Beukema Sheila Blaine Dennis Bosch Gail Buckingham Robert Burton Tonya Charleston Aaron Clarke Luey Clough Christopher Davis Bill Dendy Sibylle DeRosa Michael Engenlauf Windy Figueroa Jennifer Flary Rick Forney **Bob Furniss** Rose Gallegos Arthur Gause Dee Gause Joyce Gillespie Lee Ann Gooseman Linda Greco Brenda Hale Bridget Hamilton Mindy Hester Donna Holden Doreen Jackomin Jeff Jackomin Christina Jackomin Judi Jetson Anita Jov Megan Kaump Valerie Keller Joyce Kennedy Susan Kettel Sharon Klaschka Matthew LaRocco Jeanette Lawson Lisa Lochinski Raymond Lopez Merrilyn Macurak David Mayer Margee McKenna Tim McKenna Sheila Mota Sister Eleanor O'Brien Patsy Organ Kristina Orlandi Michael Ring Bill Robbins Amy Rollason Jon Schandler Patricia Schardt Jack Sena Gina Sharpley DanaWyn Sherman Victor Sheronas Ed Sward Marilyn Tedesco Bruce Throckmorton Jon Toumey Russ Walter Jo Ann Wettlaufer Pamela Wrobel Jim Yadlon

Joan Armstrong

Cheryl Auterio

Beverly Baker

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



WALKS

FROM JANUARY 2016 TO AUGUST 17, 2017



... & COUNTING!

"The 1st Seattle Walk & Roll was the first time I got to meet anyone else who had suffered from GBS. It was extremely moving to hear the stories and *experiences of many* others. As those who were with me at the time can attest to, mine was a scary and challenging experience. But the fact is, for me, it ended. For others the fight continues on."

Walk and Roll Participant



HONOR YOUR HERO

May is GBS|CIDP Foundation Awareness month! To celebrate, we asked our members to share their GBS & CIDP Heroes with us. Thank you to all who donated in honor of their hero this year. Look for the next opportunity to make a donation and honor your Hero during awareness month next May.



Anna Hamilton

My hero is my 10 year old daughter. She was diagnosed with Guillain-Barre right before her 3rd birthday (celebrated it in the hospital). She woke up one morning (a few days after having a high fever and flu symptoms) and said her legs felt funny. After a couple hours, she was walking funny. Took her to urgent care. They said she must have pulled a muscle, sent us home. Couple of hours later, she couldn't walk any more. Took her back to urgent care; doc said he had no clue what was happening. Sent us to Seattle Children's Hospital. After days of tests; cancer, spinal taps, etc. they finally diagnosed her with Guillain Barre. After plasma transfusions for 4-5 days she was sent home. She was supposed to start PT in a week and we were warned that she would be in excrutiating pain while her nerves healed. Within a couple of days at home, she was determined to roller skate again and she re-taught herself how to walk. Never complained about the pain... just slowly started pulling herself/walking around the house while holding on to things. The physical therapists were quite impressed with her and she never ended up needing PT. She is the strongest person I have ever known. She has absolutely no side effects. We were truly blessed with her recovery and survival.



Jim Yadlon

My GBS HERO is my caregiver and wife, Rachel. November 17 is a day that will be remembered in our lives forever. 43 years (1973) ago on this date,my wife, Rachel, and I went to the Englewood Hospital ER and for the next five weeks, I lay in the ICU, totally paralyzed. I want to attempt to tell our story through what I believe would be my wife's eyes. I can never truly understand how Rachel felt and thought during these weeks and months, but I will give it a try. I went down with Guillain Barre Syndrome. I was totally paralyzed including my diaphragm, unable to talk or communicate anything to anyone in any way. Rachel, my bride of three months and only 19 years old took over my life. The hospital that I was in did a pretty good job of keeping me alive. There was no IVIG or plasmapheresis in those days so keeping me alive was the only thing that could be done to make sure that I recovered. There were many decisions to be made during those days and Rachel made all the difficult decisions that affected my life.

The visiting hours in Englewood Hospital were brutal on a loved one. Rachel was only allowed in for five minutes every two hours. Rachel was also holding down a full time job. Rachel would come before work and visit and then again at lunchtime and then after work she would stay until midnight. This went on for five weeks. Her job was near the hospital, which was a small blessing. She worked for a Neanderthal of a man who had no empathy for our situation. He made crude comments to her and humorless jokes about my being ill. To make matters worse, while visiting me, she had to sit in a very small room and wait for the clock to hit that 55 minute before the hour mark.

Rachel, I can never thank you enough for staying by my side and being my caregiver during those horrible days. We made it.



Jacy Roach

My hero is my son Grayson. Three years ago this month I was pregnant with him and starting having weird symptoms; falling down, dropping things, not able to walk and carry things. By July I was in a wheel chair and still had no diagnosis. Finally, in August, Dr. Maria Philip another hero and fellow mom, figured out that I either had GBS or CIDP. We decided that it would be best for the baby to hold off on treatment until after he came. We were all hopeful that after Grayson arrived I would be better and we could then decide what treatment was best. His birth was easy but 10 days later my symptoms got even worse and I could not walk, stand, or feed myself. I spent 6 days in the hospital and received 4 treatments. I came home and faced months of physical therapy to learn how to walk again. If I had not had my precious baby to take care of I think I might have given up. He made me realize the importance in fighting for normalcy and moving on.



Megan Bartlett Brien

My hero is my dad who rallied to walk me down the aisle on my wedding day. The week before my wedding, CIDP took over and he was unable to walk. He did a week straight of PLEX and physical therapy in hopes of walking me down the aisle. Moments before the doors opened for us to walk out, my dad said, "I don't think I can do this. If I fall, don't stop". Yet, he did it and walked me all the way down just as we had always dreamed of. A few weeks later, the disease took over and he was completely paralyzed and in ICU for months. Today, he has made a miraculous recovery, and he has really shown me that you cannot take anything for granted.



Rachel Macera

My hero is my 6 1/2 year old son. He was diagnosed with CIDP when he was 3. He has been getting IVIG infusion 2 days a month since. He is doing amazing, RAN a race this past weekend and came in 3rd out of 50+ kids who were his age or older. Before he was diagnosed he could no longer walk or hold anything in his hands.... this is a miracle and he is my HERO.



Rachel Gallery

My hero is my nephew Charlie who is too young to understand why. Like most people who are diagnosed with CIDP, I treated all of my initial symptoms as no big deal. During my first visit to a doctor, when my symptoms were tingling hands and feet, I was asked whether my job was stressful. I said yes. Things got worse but I was in denial. Why can't I run as fast or as far as I could last week? I quess I'm just getting older. Since when has it been so hard to turn the key in the ignition? Our car must be getting old. Why am I making so many typos? I must be overtired. And then it was undeniable. Why can't I ride a bike, open the drawers in my kitchen, lift my arms over my head, move my left hand, walk, stand up? As I was losing the ability to move and digest my food I became convinced that there was no way I was coming back from this. I didn't want to form words around that fear because I didn't want to scare my husband or my family and friends.

My nephew Charlie was 11 weeks old the day I was admitted to the hospital. We had spent the last week together doing more or less the same thing - lying around, being fed, and sometimes crying. With Charlie, I could say everything I was afraid to tell anyone else and he listened so intently, just sitting on my lap and looking at me with his beautiful blue eyes.

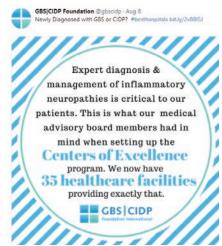
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Charity Navigator @ @CharityNav · Jul 19
.@CharityNav named 10 #charities #towatch incl. @JustDetention @gbscidp @eeisonline @BGCIndianRiver @ArthritisNRF bit.ly/2tFZq6a







Do you know we have an Online Support Group? Join the discussion with 2,500 other members today! *forum.gbs-cidp.org/forums/*

#mondaymotivation • #nationalnonprofitday • #besthospitals • #rarediseaseday



#FoundationFriday
 #gbssurvivor
 #foundationfriday
 #walkwednesdays
 #mondaymotivation
 #nationalnonprofitday
 #besthospitals
 #rarediseaseday

THANK YOU

Thank you for your support; let us be your light of hope and recovery.

IN THE YEAR AHEAD, WE INVITE YOU TO BE PRESENT WITH US. HOW?

- Attend a chapter meeting
- ✓ Write to your congressperson or senator
- ✓ Walk or support a Walk & Roll near you
- ✓ Create your own Fundraiser
- ✓ Share your story
- ✓ Ask if your employer matches donations
- ✓ Let us know of your special talents and skills
- JOIN US IN 2018 FOR THE 15TH BIENNIAL SYMPOSIUM IN SAN DIEGO
- ✓ Volunteer to visit and encourage patients
- ✓ Join the Card Alert group and send messages of hope
- Watch new videos and read about new research on our website
- ✓ Join our Forum conversations or Facebook page
- ✓ Recognize a person of influence with our "Honor your Hero" campaign
- ✓ Continue your generosity by making a donation

At any of these events, you will have the opportunity to meet people just like you who have similar experiences. You can walk away with new knowledge and empowered to take action in your new situation. When you are present with us, you belong to a community. Whether you are a volunteer, a patient, a care-giver, physician or supporter, you will always belong!













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