“It’s Only Rare...Until It’s You”
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*Deceased
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.

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.
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.

![GBS/CIDP Revenue](chart1)

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corporate</td>
<td>46.9%</td>
</tr>
<tr>
<td>Symposium</td>
<td>23.7%</td>
</tr>
<tr>
<td>Contributions</td>
<td>17.2%</td>
</tr>
<tr>
<td>Fundraisers</td>
<td>12.1%</td>
</tr>
</tbody>
</table>

![GBS/CIDP Expense](chart2)

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Education &amp; Support</td>
<td>37.1%</td>
</tr>
<tr>
<td>Research</td>
<td>26.2%</td>
</tr>
<tr>
<td>Symposium</td>
<td>9.8%</td>
</tr>
<tr>
<td>Programs</td>
<td>8.6%</td>
</tr>
<tr>
<td>Advocacy</td>
<td>7.9%</td>
</tr>
<tr>
<td>Management/General</td>
<td>5.8%</td>
</tr>
<tr>
<td>Fundraising</td>
<td>4.5%</td>
</tr>
</tbody>
</table>

![GBS/CIDP Endowment](chart3)

<table>
<thead>
<tr>
<th>Year</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>$250,000</td>
</tr>
<tr>
<td>2007</td>
<td>$750,000</td>
</tr>
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<td>2008</td>
<td>$650,000</td>
</tr>
<tr>
<td>2009</td>
<td>$800,000</td>
</tr>
<tr>
<td>2010</td>
<td>$2,800,000</td>
</tr>
<tr>
<td>2011</td>
<td>$3,000,000</td>
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<tr>
<td>2012</td>
<td>$3,500,000</td>
</tr>
<tr>
<td>2013</td>
<td>$5,500,000</td>
</tr>
<tr>
<td>2014</td>
<td>$6,000,000</td>
</tr>
<tr>
<td>2015</td>
<td>$6,300,000</td>
</tr>
<tr>
<td>2016</td>
<td>$7,200,000</td>
</tr>
</tbody>
</table>

INVESTMENT POLICY

PREFERRED ALLOCATIONS

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domestic Equities</td>
<td>60%</td>
</tr>
<tr>
<td>Fixed Income</td>
<td>30%</td>
</tr>
<tr>
<td>International Equities</td>
<td>10%</td>
</tr>
</tbody>
</table>
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

GSB/CIDP Foundation International
U.S. VOLUNTEERS

- Volunteers

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

BIRMINGHAM, UNITED KINGDOM
University Hospitals of Birmingham

BUENOS 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

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

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
University Faculty of Medicine

PARIS, FRANCE
Groupe Hospitalier Henri Mondor, Universite’ Paris Est

PHILADELPHIA, PA
Perelman School of Medicine at the University of Pennsylvania

PHOENIX, AZ
Barrow Neurological Institute

PHOENIX, AZ
Phoenix Neurological Associates

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, Toronto General and Western Hospitals

WARSAW, POLAND
Medical University of Warsaw

WELLESLEY, MA
Saint Elizabeth’s Medical Center
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 pain-management 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 Symposium’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 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 non-profits 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 & Electromyography 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 neuromyopathies.

4 pillars of Health Care Reform

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

Maintain basic patient protections in ACA reform/replace 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 billion.
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 Foundation 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.

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.

Mary Collins
William Cooper
Gloria Cote
Edwin Cridland
James Crompton
James Cronie
William Curry
Donald Dahlin
Myron Daniels
Joan Decker
Rochelle Demo
R. Kenneth Doehman
Abby Dolliver
Betty Donelson
James Drue
Excell Duncan
David Eckstein
John Elligers
Ronald Ellis
Mark Erminger
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Joann Fenton
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Evelyn Force
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Linda Ginsgras
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Caroline Morrison
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Beverly Neunerfeld
Donald Nevers
Josephine Nicolosi
Beatrice Nilsen
Nancy Nurnberg
Susan O’Brian
Cynthia Newell Oliver
Milton Orenstein
Carolyn Palmer
Ronald Pawasarat
Robert Peterson
Matthew Pinto
Debbie Pimper
Richard Pimper
Robert Polis
Robert Prestwich
Jane Prou
Thomas Reland
Vivian Rothschild
Marlyn Rothstein
Helen Rummelburg
Lorraine Rumore
Ann Santafasci
Patricia Sartidi
John Schilke
Shirley Schleimer
Wienert J. Schuler, Jr.
L. E. Schultz
Elizabeth Schultz
Betty Stafford
Brian Stahl, Ph.D.
Robert Stanley
Pamela Stein
Joel Steinberg, M.D., Ph.D.
Bryan Storm
David Sullivan
Barbara Sotta
Marlyn Tedesco
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Walter Welling
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Elizabeth Widdifield
Marjorie Wichins
Edna Wilken
William Willetter
Midge Winchger
Vincent Wyles
Jim Yaffon
Rowland Yeo
Lois York
Helen Zasadny

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. Benson
Ellen Burr
K. Robert Doerrman
Ruth Elster
Carolyn Fairman
Jeffrey Fihn
Gladys Fortune
Estern Hayden
Susan Huebschman
Douglas Johnston
Monice Joy Porot
Ronald Root
Anne Travala
Kassandra Ulrich
Chris Zaal
“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, you with my good leg! I’ll fight you with my good leg!”

Kathy Cooper
Lindsay Anna Cobb
Rosemary Cochran
Mrs. Reeves Cochran
Suzanne Cody
Gianna Coffman
Jeremy Cohen
Mimi Cohen
Hannah Cohen
Ethan Cohen
Denise Cohen
Carol Cohen
Jack Colantoni
Audrey M. Colavolpe
Caryl Cole
Morgan Cole
Mark Cole
Doreen Colletta
Betty Coleman
Elizabeth Coleman
Mgt Lonnie and Doris L. Collins
Frank Collins

Anna Columbus
Connie Comiter
Bt Communications
Susan Comrie
Tricia Comstock
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Gary Conrad
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Mary Alice Cooler
Laurel Cooky
Pamela Cooke
Margaret A. Cooley
Kathryn Coon
Kathy Cooper
Report of Donors 2016-2017

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Marylin Deak
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Ray Dean
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Regina Dearder
Joni Deardorff
Betsy Deering
Esther C. DeBra
Joan Decker
Jancie DeOra
Susan Deering
Diane DeFiore
Diane DelCampo
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Stacey Dematos
John Demberk
Rochi Demo
David DeMonte
Lisa DeNardo
John Denby
Barbara Denicola
Carl DeNico
Daxie Denson
Bea Dennis
Angela Dennison
Tina Depaulis
Frank DePrizio
Peggy Devitz
Nilesh Desai
Andrew Desmann
Peggy Dettwiler
Jerry Deutsch
Ruthann Devine
Frank Devito
Jim Devoy
Joe DeWitt
Debra Deweese
Shaffina Dhumre
Ronald Dias
David Diaz
Claude DiGraziano
Bonnie DiCostanzo
Donna DiDonna
Marilyn Dielmann
Pete Dieterle
Sandra Digiovanni
Christine Digiovanni
Claire Didugard
Michael Dillon
Jan Dillon
Julie Dillon
Misty Dimick
Mark Dinello
Darlene Dinerstein
Nicholas Dinunzio
Linda J. DiPietro
Jim Dismuke
Sandy Ditulio
Emily G. Dixon
Pam Dobson
Mary Lou Dobrydnia
Marie Doherty
Joan Dor
Roger Domborowski
Debbie Donahue
Ellen Donald
Kath Donaldson
Betty Donelson
Ellen Donnamurra
Mark Donnelly
Emily Donoughue
Martin Donovin
Joan Dooley
H. Kathleen Dooley
Elvira Dorcas
Marisa Dopil
Jeanette Doss
John Dougherty
Marla Doughty
Merrel D. Douglas
Donald Douglas
Wayne Downer
Martha Downey
Joanna Doyle
James S. and Evin Draeger
James Drako
Shaya Draper
Meg Drew
John Driscoll
Robert Drozd
Nicole Druga
Cruz Drummond
Larry Drummond
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Noreen Dubay
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Kara Dunford
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Cara Dunlop
Ronald Dunn
Linda Dunson
Stacia Durbin
Frances Durbin
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Anna Edwards
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Laura and Karl Edler
Nancy And Jim Eichman
Manlynn Eidler
Kathryns Eisendrath Rogers
Mark Eissert
Erin El Issa
Linda Elam
Melissa Eldredge
Vanya A. Elzondo Martinez
Marcia Elkins
John Elgarr
Jennifer Ellis
Craig Ellis
Jody Ellis
Ronald Ellis
Sharon Ellis
Verna Elly
Theresa Ethord
Russ Elde
William Embree
Carlene Embree
Elizabeth Emerson
Larry Emery
James Emison
Wendy Endelmand
David Endelman
Amelia Enidu
Holiday Eng
Elane Engelhart
Shane English
Shirley Entwistle
Charles Entwistle
Margaret Epplelett
Michael Epplelett
Scott Epstein
Thomas Erdich
Claudia Evers
Jennifer Erickson
Kate Erickson
Nicole Eitel
Virginia H. Ertz
David Ewert
Gary Erwin
Jennifer Estelman
Joanne Esparza
Ron Espey, RN
Ronny Erostog
Richard Etherton
Ellen C. Estk
Nicole E. Estle
Scott Evans
Robert Ewbank
Reginald Exton
Nancy Eytherson
Guastavo Ezquerra
Raymond Fabian
Desiree Fafouts
Grace Fahlscest
Elizabeth Farbrother
Anne Falk
Jack Faull
Morrison Family
The Harper Family
Molina Family
Vince Farace
Harriette Farber
August Farfalla
Chris Farmer
Deb and Charlie Farrell
Catherine Farrell
Maryanne Farrell
Lisa Fausnacht-Hill
Francis Faulkner
Gabriele Faust-Fischer
Ronald Fay
Stanley Fazzkas
Robert Fazen
Alain Fazzari
Amy Fedele
Tedd Fedele
Vincent Fehan
Daniel Feggstad
Kathleen Feigenbaun
Jean Feighner
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Edward Ferguson
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David Fisher
Wendy Fisher
Saul Fisher
Colville & Jan Fisher
Bill Fitzpatrick
Jen Flanagan
Bill and Carrie Flea
Archibald Fletcher
Diana Florence
Alex Flores
Adrian Flores

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.”

Ray
“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.”
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 why I went to Johns Hopkins. I 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 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 Whitefield
Carol Whitley
Chanon Whitman
Roger Whitney
Angela Whitt
Glady’s Whittenberg
Corbin Whittington
Brandon Whittington
Regis Whittington
Daya Whittington
Lyndell Whyte
James E. Wickert
Elizabeth Widoffeld
Ralph Wiechert
Raymond Wieczorek
Douglas Wigton
Lori Widing
Bob Wiley
Martha Wilke
Patty Wilkerson
Harriet Will

Wayne Wishart
Dawn Withstandley
Robert Witt
Leslie Wittenborn
Edna Wittwer
Peggy Wojtowic
Elaine Wobrom
Liam Wolf
William Wolf
Joanne Wolfe
Sheila Wolfe
Jennifer Wolter
Linda Wong
Lauren Wood
Kathy Wood
Donald Wood
Paul Woodard
Lori Woodbury
Kennard Woods
Heather Woodward
Zorina Woodward
James Woodward
Patricia A. Work
Sandra Work
Rodney Way
Shawn Wright
Leslie Wright
Linda Wright
Mary Ann Wyand
Cassie Wyatt
Joseph Wylen
Vincent Wyles
Karen Wynne
Jola Xhanga
Jim Yadon
Janet Yanron
Rick Yanucheff
Alling Yancy
Suzan Young
Cynthia Yankowski
Jack Yantis
Caroline, Phyllis & John Jr. Yastrzabs
Robert & Candace Yates
Stacy Yates
Kevin Yates
Bonnie Yeomans
Larry Yepez
Leslie Yepper
Ray Yetvin
Cheryl Yetz
David Yocum
Marlo Yoder
Vicky York
Courtney York
Lois York
Jane Young
Lisa Young
Tatum Young
Timothy Young
Helene Young
Wallace Young
Waren Young
Donald Young
Somerset County Young Republicans
Blake Zaal
Chase Zaal
John and Christian Zaal
Ron Zaal
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Kirsten Zajciewski
Robert Zambito
Paul Zanotto
Dawn Marie Zarlings
Carol Zgir
Ashley Zeiber
John Zeiger
Jeraldine Zellers
Dorothy Zellen Nadell

Diane Zerilli
Judy Zhang
Jenna Zichtella
Hazel Ziebell
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Herbert Zimmerman
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Alan Zirkle
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John R. Ziko
Sasha Zikovic
Mariana Zlatinski
John Zolper
Bep Zonneveld
Joan Zorn
Anna Zoubberakis
Jeffrey Zyjeski

Ambassadors

These Special donors give the gift of time and leadership. Ambassador 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
Bob Burton
Jane Rosen
Arvel Lary
Sue Saltmann
Merryl Macurak
Donna Holder
Donna Holder
Sister Eleanor O’Brien
Patsy Organ
Kristina Orlandi
Michael Ring
Bill Robbins
Amy Rollason
Jan Schandler
Patricia Schardt
Jack Senna
Gina Sharpley
Dani Wynn Sherman
Victor Sharonas
Ed Sward
Marilyn Tedesco
Bruce Throckmorton
Jan Tomney
Russ Walter
Jo Ann Wettlaufer
Pamela Wrobel
Jim Yadon

Please note list may not be conclusive and we apologize if we have omitted a name.
WALKS
FROM JANUARY 2016 TO AUGUST 17, 2017

20 CITIES
1,281 FUNDRAISERS
188 TEAMS
30 WALKS
... & 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
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 excruciating 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. 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 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 guess I’m just getting older. 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.

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.
CONNECT WITH US! @GBSCIDP

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

Please join us in thanking our industry partners for their continued commitment to the Patient Community.