



# Foundation Report



SUPPORT

EDUCATION

RESEARCH

ADVOCACY



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# VISION & MISSION STATEMENT

## GBS|CIDP Foundation International

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 grass roots levels to advance our vision and mission with legislators and government agencies.

GBS|CIDP Foundation International  
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# PRESIDENT OF THE BOARD OF DIRECTORS - Santo Garcia

Dear Friends of the Foundation,

When you've finished reading this report I want you to be inspired to take action!

Across the globe the GBS|CIDP Foundation International has worked tirelessly on behalf of all whose lives have been affected so profoundly. In the past year we have funded research in Australia, The Netherlands, Canada, England, Scotland and the United States. We've expanded our network of liaisons and global volunteers into Central and South America, Africa and Southeast Asia. There are now twenty-four Centers of Excellence for those in need. Scientists, liaisons, patients and their families from all over the world and pharmaceutical partners came together in Orlando for the 13th biennial symposium like "friends meeting for the first time." We laughed; we cried; we asked questions; we learned; we hugged. And, we promised to see each other again in 2016! In April we marched through the halls of the U.S. Congress on behalf of those in need of financial assistance, to petition for increased NIH funding and to advocate for the men and women of the military who are disproportionately affected by GBS. Because of your generosity we can fund two dedicated three-year fellows. If it sounds like we've squeezed a tremendous amount of action items into twelve months it's because we have. We are on a mission. We are deliberate and decisive. At no point have we lost focus. Not once have we lost momentum.

We need you! We need 2016 to be bigger and better than any of our past thirty-five years. I'm sure you are asking yourself right now, "What can I do to help those like me?" "How can I make a difference?"

Here are some suggestions:

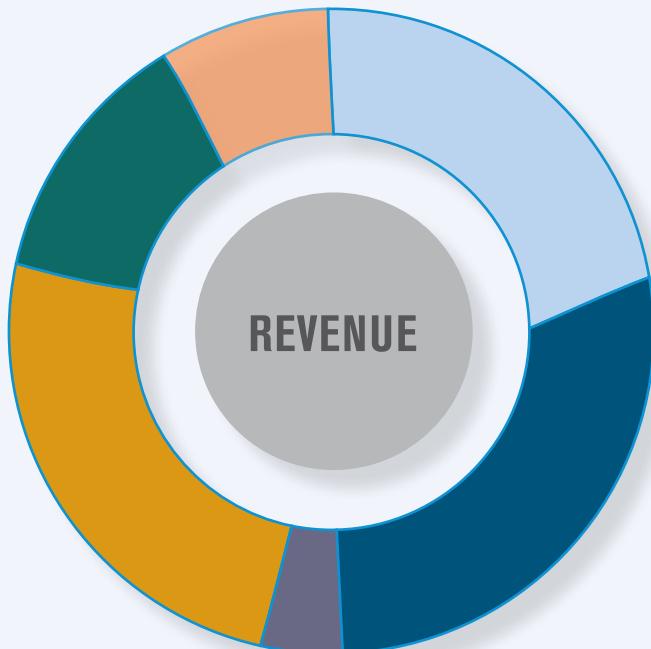
- Attend a chapter meeting.
- Write to your congressperson.
- Ask if your employer matches donations
- Come to one of our Walk & Roll fundraisers. Organize a Walk & Roll.
- Become a "Point of Contact" and visit newly diagnosed patients in the hospital.
- Let us know about your special skills/talents that you would like to share.
- Make a contribution to the foundation: Work, Wealth or Wisdom

We'd love to see you, where will you be in 2016? You give us meaning and purpose and for that we are genuinely grateful. It is an honor to serve you.

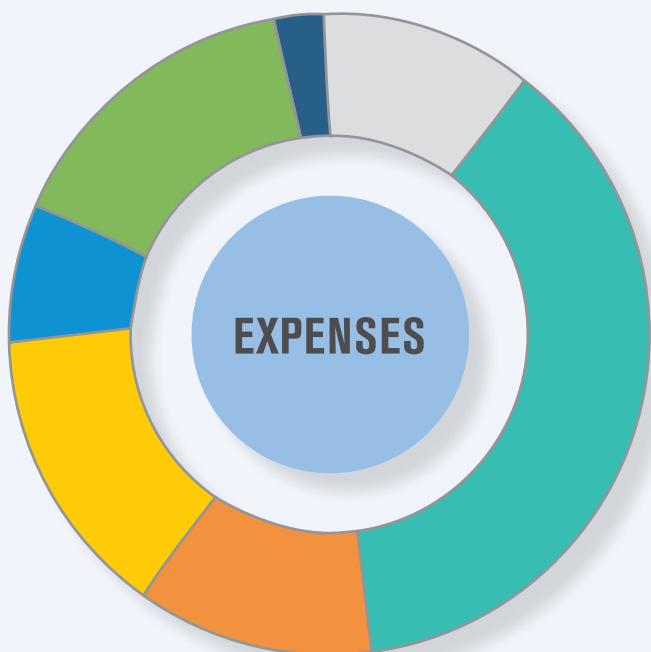
Santo



# FINANCES



- Individual Contributions 22.4%
- Corporate Contributions 27.7%
- Fundraisers and Special Events 6%
- Symposium 23.1%
- Endowments 11.5%
- Investments 9.3%



- Management 10.4%
- Research 37.5%
- Patient and Chapter Support 11.7%
- Education 15.9%
- Fundraising 6.1%
- Symposium 15.9%
- Advocacy 2.5%



## SUPPORT

- The Foundation office receives over 100 inquiries for new information, WEEKLY.
- We have 105 US Liaisons and 43 US Points of Contact. To date in 2015, we have had over 65 chapter meetings across the country.
- We have 58 global volunteers in 47 countries around the world.
- We invite over 24,000 patients and caregivers to Chapter Meetings annually.
- In addition to our paper newsletter, we now send our “eCommunicator” to over 16,000 people worldwide.
- On Facebook, we see over 3,000 hits weekly and have over 7,300 “likes.”
- We are currently creating a database of patient-referred medical professionals. This is in addition to the 250 recommended neurologists already in our database.
- We have 24 Centers of Excellence around the world.

# EDUCATION

We are committed to providing patients, families, and medical professionals with the most current and relevant information possible.

In 2014 we re-launched our website in an intuitive, user-friendly format. Our homepage now features our latest news, an events calendar, and the amazing stories you have shared. We recently added a section on our homepage which highlights newly added material. We also added pages on variants such as multifocal motor neuropathy (MMN) and anti-MAG peripheral neuropathy.

In October 2014 we hosted our 13th (and largest ever) International Symposium in Orlando, FL with over 600 people in attendance. This symposium featured separate tracks for GBS, CIDP, and MMN patients. Additionally, we had thirty healthcare professionals present twenty-nine sessions and workshops.

Also in 2014, we produced 5 informational videos on the following topics: adult GBS, pediatric GBS, CIDP, MMN, and our Centers of Excellence. All are available for viewing on our website.

We continue to publish *The Communicator*, our quarterly newsletter, which always includes relevant medical articles, many written by our own Medical Advisory Board. In July 2015, we introduced our first digital newsletter, *The eCommunicator*, which allows us to communicate with our members more frequently in an eco-friendly manner.

In cities across America the Foundation sponsors an informational workshop called “Managing your CIDP” that outlines the history, diagnostic protocols, and treatment strategies of CIDP.

Our professional partners are critical to us as we endeavor to share the most relevant and current information. These relationships include:

NORD: National Organization of Rare Disorders

PNS: Peripheral Nerve Society

IgNS: Immunoglobulin Nursing Society

PPTA: Plasma Protein Therapeutics Association

AANEM: American Association of Neuromuscular & Electrodiagnostic Medicine



# RESEARCH

In the past 11 years, the GBS|CIDP Foundation has dedicated more than \$2,000,000 towards sponsoring over 30 research grants! We fill an important need in the GBS, CIDP, and related disease research arena by offering seed money for research that may lead to NIH funded projects. Annually, grants are reviewed by our Medical Advisory Board and then recommended to the Board of Directors for final acceptance.

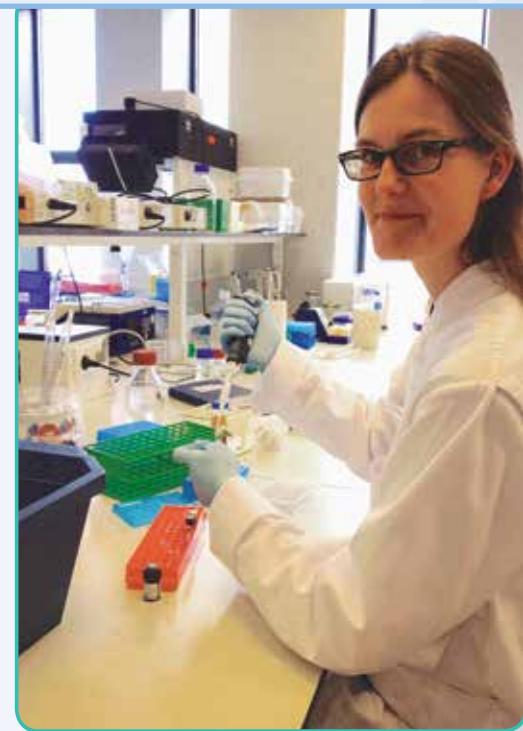
In 2014, we awarded our first Benson Fellowship for Neuromuscular Research to Dr. Ruth Huizinga. Dr. Huizinga aims to understand the causal relationship between preceding infections and anti-neuronal antibodies.

In 2015, we awarded our first Mazawey Fellowship to Dr. Marielle Pruppers. Dr. Pruppers is researching anti-MAG peripheral neuropathy, a rare CIDP variant. This fellowship was established by Louis T. Mazawey JD, a patient, to further understanding, diagnosing, and treating Anti-MAG.

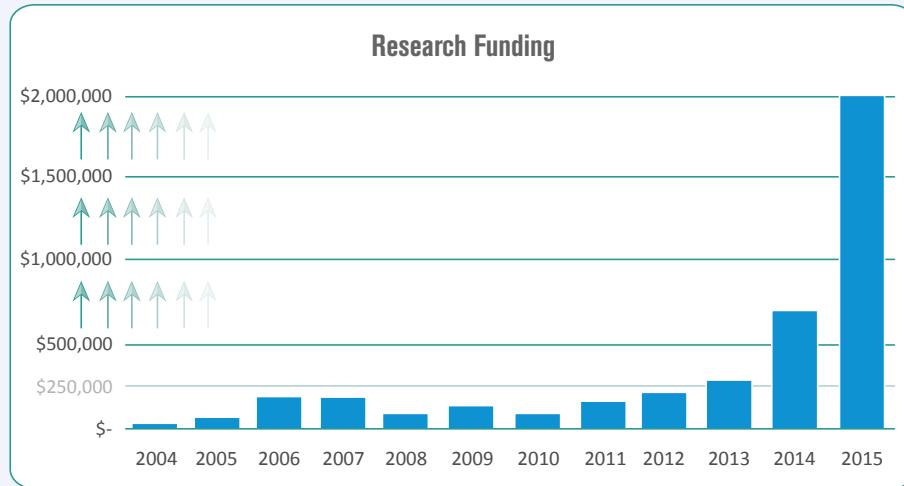
Other 2014 grants involve the following:

1. Led by Dr. Isabel Illa at De La Santa Creu in Barcelona, this study looks to identify different genetic subgroups of CIDP.
2. In Bangladesh, where the incidence rate for GBS is much higher than the global average, Dr. Zahirul Islam and his team are working on developing new outcome measures for GBS patients in low-income countries.
3. At the University of Chicago, Dr. Betty Soliven is investigating how different types of immune cells contribute to disease severity in CIDP patients.
4. Dr. H.H. Lopez in Argentina is attempting to better understand the signaling pathway involved in neuron growth inhibition.

The Foundation has also supported the International Guillain-Barré Outcome Study (IGOS), the largest and longest prospective trial designed to collect extensive data in a systematic manner from patients affected with GBS. This study involves over 200 medical centers in more than 20 countries. As of this publication, over 1,000 patients have enrolled!



Ruth Huizinga in her lab isolating white blood cells from a patient with GBS.



# ADVOCACY

2014 marked the second year of the Foundation's organized efforts with advocacy. Together with our partner, Health and Medicine Council of Washington, DC, we have a targeted approach to improve the lives of patients by informing and influencing policymaking processes through individuals and organizations in DC.

We seek to educate the legislators making decisions which affect the Foundation's community. In 2014, we participated in our second annual Capitol Hill Day with 15 constituents making 20 visits on Capitol Hill. We followed in 2015 with a group of 30 making 40 visits.

We have rewritten the advocacy pages on our website and have a newly formed Advocacy Action Committee made up of leaders from our volunteer community who participate in quarterly advocacy activities. We need our voice to be heard! The following are some of the initiatives we are currently supporting:

**Accelerating Biomedical Research Act** (S. 318/H.R. 531): seeks to systematically increase funding for the National Institutes of Health, which will expand research portfolios on various conditions (including GBS, CIDP, and MMN).

**American Cures Act** (S. 289/ H.R. 2104): seeks to systematically increase funding for all medical research programs and activities across the federal government (including the Veterans Administration and the Department of Defense).

**The Patients' Access to Treatments Act** (H.R. 1600): seeks to ensure patient access to innovative treatments by reducing high out-of-pocket expenses associated with coinsurance requirements through private insurance plans.

**Part D Beneficiary Appeals Fairness Act** (S. 1488/H.R. 2624): allows Medicare Part D participants to have relief from high out-of-pocket costs for innovative treatments by allowing beneficiaries to formally request an exception from cost-sharing requirements.



*Our Hill Day group on the steps of the Capitol!*

# Report of Donors 2014-2015



## 1. 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.

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## 2. 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.

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### 3. 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. Legacy Circle members will be recognized.

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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: Chairing 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 the events they lead.

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# Special Event Fundraisers

**Ofir Brzinov:** Sold GBS|CIDP Awareness Bracelets

**Shane Sumlin:** Held a community movie night, inviting families to get together to raise awareness and watch a movie together at a local auditorium

**Brenda Wieckhorst:** Sold GBS|CIDP Awareness Bracelets

**William Shirey:** Unable to “Walk and Roll”, William planned to “Sit and Stay” with his annual sit in.

**Lizz Russell:** Planned a fashion show, donating proceeds from design sales

**Holly Cannon:** Organized a Golf Outing, as well as a Basketball Free Toss competition at the local high school

**Thomas Segur:** Gathered family and friends to run the Brooklyn Half Marathon in honor of the Foundation

**Pamela Wilson:** Held a community retail event, donating % of store sales to celebrate her store’s 1 year anniversary

**Julie Bell:** Organized a “twist” challenge, putting her spin on the Ice-Bucket Challenge

**Jason Zenk:** Planned a “Blue Jean Day” at work, where employees paid to dress down for a “charitable Friday”

**Catherine Showerman:** Organized a Tractor, Motorcycle, Truck and Car Show in honor of the Foundation

**Renee Canfield:** Designed and sold custom GBS|CIDP T-shirts

**Stephanie Stamatelos:** Sold GBS|CIDP Awareness Bracelets at work

**Emily Fruik:** Wine and Cheese Night

**Will Johnson:** Held lecture on Miller Fisher Syndrome at his Rotary Club

**Ellen Zschunke:** Planned a “Blue Jean Day” at Lower Moreland Twp School District

**Hugh Williams:** Run 52 5k races in one year

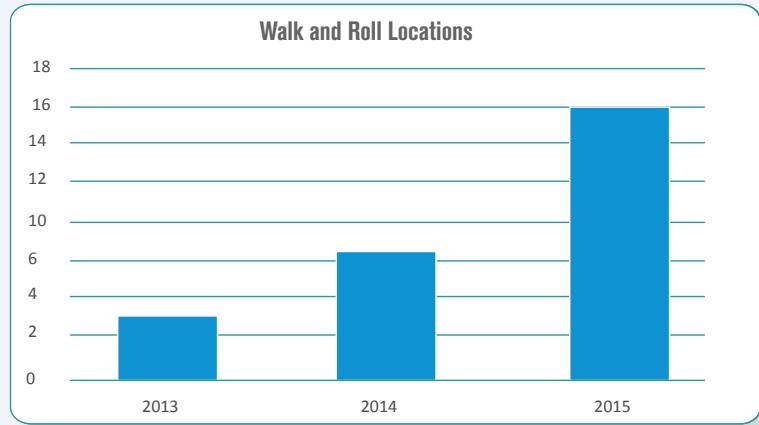
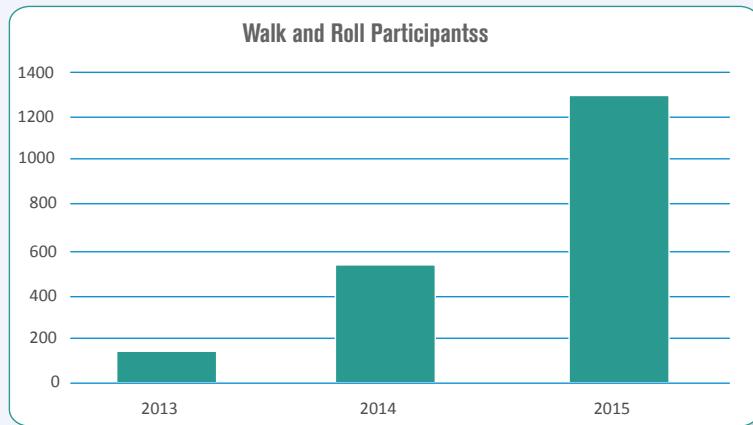
**Miranda Harper and Gina Davis:** Organized Charity Swim Meet to raise awareness

**M. Cohen Designs:** Designed and sold bracelets to raise awareness





The Walk and Roll for GBS|CIDP is a signature walk designed to increase public awareness and to raise support for the mission of the GBS|CIDP Foundation International.



## In Your Words

*"God bless you for all your work!"*

*"I was diagnosed with CIDP in June of 2014. It's changed my life so much. But I have wonderful friends and family who are incredibly supportive. I hope these donations are used to bless people with CIDP. God Bless and thank you for everything you do for us"*

*"What an amazing walk! Lots of great stories, wow! Looking forward to 2016"*

*"It was a lot of fun having the Walk and Roll in OKC this year! Thanks for helping me through it!"*

*"I'm so happy the walk went so well. Thank you for all of your help, I'm looking forward to working with you again."*

*"Thank you for your time towards this cause. It was a great experience for my son"*

*"The abundance and quality of information you have provided will assist them and their son in making further testing and treatment decisions. God bless you and your organization for all of the work done on behalf of those suffering and living with GBS|CIDP and their families!"*

*"I think it was a terrific day and we feel so blessed to meet others who have walked this journey. Thank you for all you did!"*

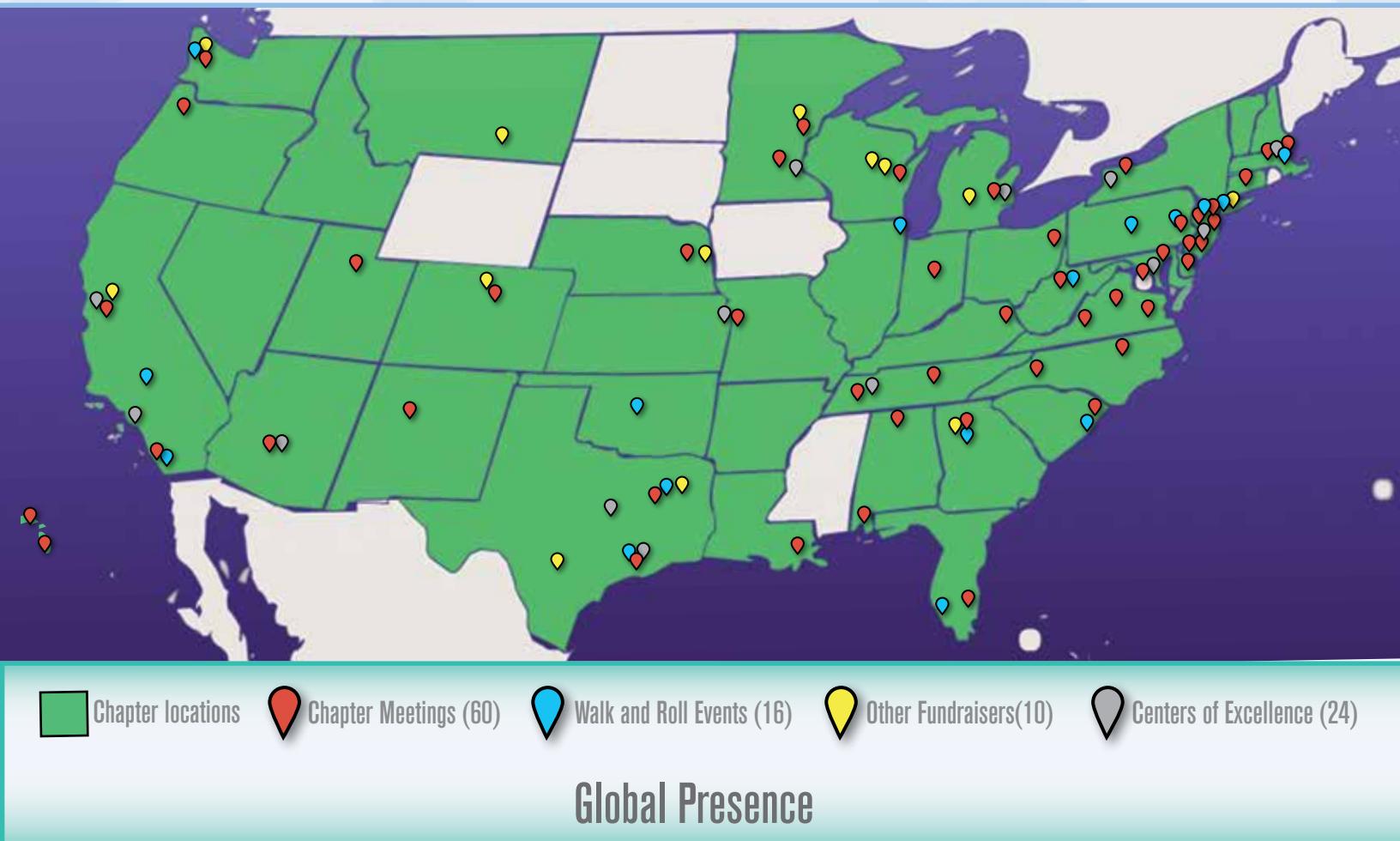
*"It is a great comfort to know that your organization exists for patients with rare conditions and that you are able to provide support and information worldwide."*

*"Thank you for the literature you have attached- your foundation is truly awesome and your support so very welcome."*

*"Praise the Lord. May God shower your team with endless blessings."*

*"Thank you for finally offering the Communicator in an email format! I would like all the funds raised to be used for research and not printing and mailing....I hope that you encourage all the newsletter recipients to go green."*

# Events Map



# JUMP IN! THE WATER'S FINE...

Picture yourself swimming the length of a pool. Arm-over-arm, each stroke pulling you smoothly through the water. Your strong legs are rhythmically beating the wake behind you into a splattering froth. You take a deep breath and...Stroke! 2,3,4...stroke! 2,3,4. You're as graceful as a dolphin but as fierce a barracuda. Each set of breaths, strokes and kicks propels you through the next ten meters. Faster, stronger, faster...faster...stroke! 2,3,4. "You're living your dream. You're going to win..Push! Push!," is the mantra pulsing through every cell in your body. You're exhausted but years of mental and physical training won't let you quit. Stroke 2,3,4 fifteen meters to go. Your chest expands, Breath! 2,3,4 ten meters, arms are burning, legs are kicking relentlessly. Five meters, three meters, one meter, reeeeach...FIRST PLACE!!



Two days later you get GBS and all your dreams sink to the bottom of the pool. Juan Castillo-Vazquez is a remarkable young man. His life, like yours, was sucked into a whirlpool of weakness, fatigue, paralysis, fear and despair. Juan is remarkable, like you, because that didn't stop him. He, like you, chose to rise up from the depths.

This past August, he flew to Toronto with the Cuban National Team to compete at the 2015 ParaPan American Games and BROKE THE WORLD RECORD for the 100 meter butterfly! Need we say more?

Juan swam *his* race in *his* lane, alone, but he trained and received support as part of a team. GBS, CIDP and other variants such as MMN have brought us together and we are now family. So, no matter where you are in your recovery process keep swimming and make some room because we're jumping in with you!



# WE ARE THE GBS|CIDP FOUNDATION STAFF

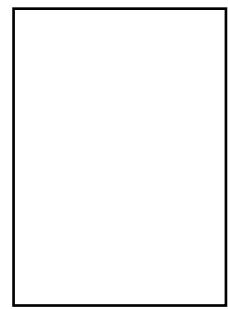


## AND WE NEED YOU!

...to come to a chapter meeting, give us a call and share the name of your local neurologist, rehab center, therapist or specialist to expand our referral list, participate in a Walk, or plan and chair a Walk in your area, create your own fundraiser, give us your email address so that we communicate electronically, participate in advocacy and send a letter to your Representative, plan to join us in San Antonio at symposium 2016, document and share your story so that we can share it on our website and publish it in our collection, make a donation in honor or memory of a special person in your life, remember us in your estate planning, and most importantly, give us a call and let us know what we can do for you!



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[Address Block Here]

# SAVE the DATE

## for the 14<sup>th</sup> International Symposium

*Featuring an entirely new curriculum*

The GBS|CIDP Foundation International invites you to join us for our 14th International Symposium on September 23rd-24th, 2016 at the Hyatt Regency in San Antonio, Texas!

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*

SUPPORT

EDUCATION

RESEARCH

ADVOCACY