



GBS/CIDP Foundation International

Serving patients of GBS, CIDP and Variants with support, education and research

Guillain-Barré Syndrome • Chronic Inflammatory Demyelinating Polyneuropathy

Spring 2010

The Communicator

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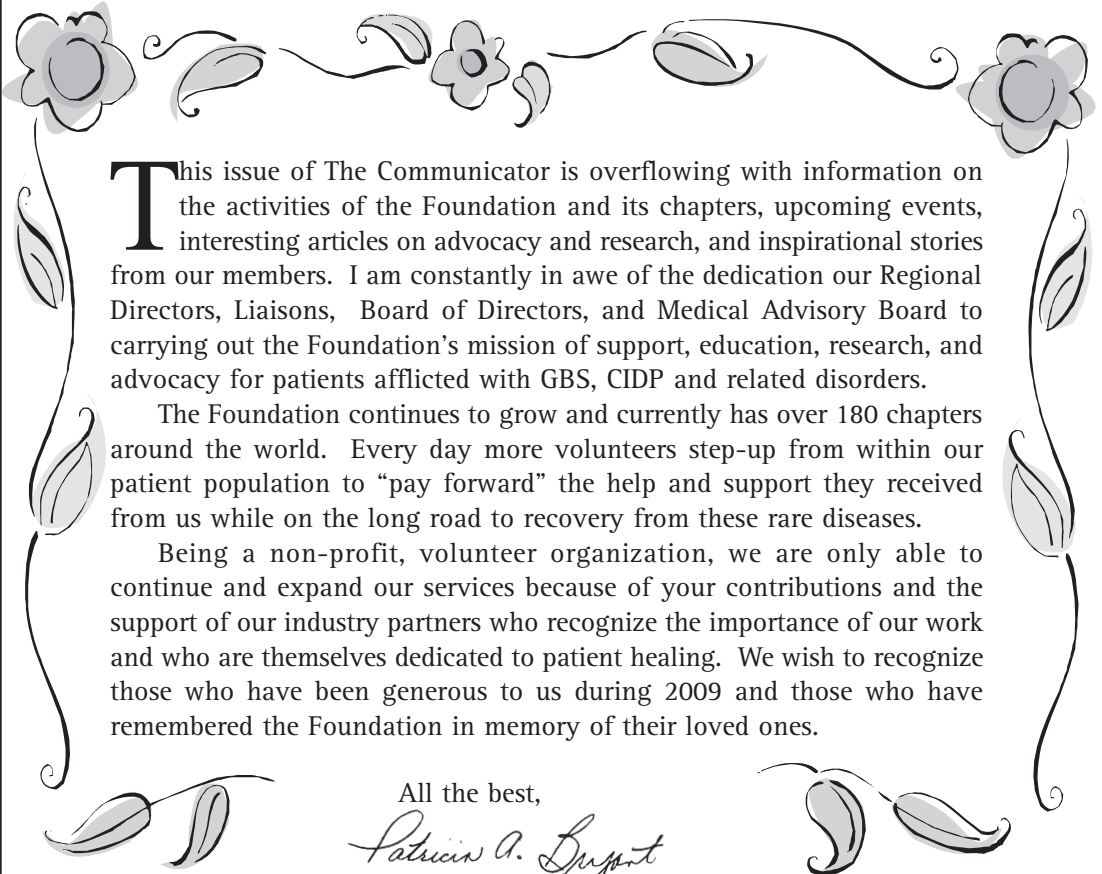
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This issue of The Communicator is overflowing with information on the activities of the Foundation and its chapters, upcoming events, interesting articles on advocacy and research, and inspirational stories from our members. I am constantly in awe of the dedication our Regional Directors, Liaisons, Board of Directors, and Medical Advisory Board to carrying out the Foundation's mission of support, education, research, and advocacy for patients afflicted with GBS, CIDP and related disorders.

The Foundation continues to grow and currently has over 180 chapters around the world. Every day more volunteers step-up from within our patient population to "pay forward" the help and support they received from us while on the long road to recovery from these rare diseases.

Being a non-profit, volunteer organization, we are only able to continue and expand our services because of your contributions and the support of our industry partners who recognize the importance of our work and who are themselves dedicated to patient healing. We wish to recognize those who have been generous to us during 2009 and those who have remembered the Foundation in memory of their loved ones.

All the best,

Patricia Bryant

Our Foundation Continues to Grow

We welcome the following new chapters and liaisons:

- Richard Barbour - Lititz, Pennsylvania
- Yvonne Bishop - Blue Springs, Missouri
- John Lever - Seattle, Washington
- Joyce Kennedy - Fayetteville, Arkansas
- Lee Ann Gooseman - Auburn, Washington
- Margee McKenna - Warren, Ohio
- Les Skolnik - Syosset (Nassau County), New York
- Alejandra Pérez del Real - Madrid, Spain
- Khaizan Sharizad Binti Ab. Razak - Malaysia
- Japan CIDP Support Group - Tokyo, Japan

We take this opportunity to thank **CSL Behring** for their support in making this newsletter possible through an unrestricted educational grant.

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Letter to the Editor



1/22/10

Dear Ms. Bryant,

Enclosed, please find our dues for \$25.00. My husband, Bill, contracted GBS in June of '08.

A wonderful lady came to the hospital to visit him and to help us with help and answers to our many questions. Her name is Ginger Crooks. She is the director for the GBS Chapter here in St. Louis, MO. She gave us a book and helped us so much.

Bill was paralyzed from his waist down. He works very hard with walking our neighborhood, first with a walker and help and now with a cane. We are so thankful for what he can do. He will be 86 this year and walks daily.

Thank you so much.

Bill and Ann McDaniel
St. Louis, MO

GBS & CIDP PATIENTS - Alert

The Foundation's advocacy efforts on your behalf have intensified in light of the expanding financial difficulties and issues being faced by GBS and CIDP patients who rely on IVIG treatments. Reductions in reimbursements and cuts by Medicare, Medicaid, and an ever growing list of third party insurers has resulted in our patients having a reduction in or denial of treatment. In order for us to be able to effect change we need your help. In meeting with federal and state legislatures and insurance providers we need to be able to provide statistics and evidence of the financial and clinical hardships these cuts in coverage are causing patients.

We need your help! If you are experiencing a reduction in treatment, being denied coverage, have capped out, or have no insurance, please share your story with the Foundation either by email at info@gsb-cidp.org or mail your story to:

GBS/CIDP Foundation International
The Holly Building
104 1/2 Forrest Ave., Narberth, PA 19072

Note: It is important to include your contact information.

Letter to the Editor



To Whom It May Concern CIDP Foundation:

I'm sending a heartfelt thank you for your newsletter and helping us connect with an organization that helps our family relate to CIDP and how to deal with it.

Cabrina was struck with CIDP in 2003 at the age of 10 and we knew she was ill but had no idea what she had. Not able to do her ballet, tap or gymnastics anymore, we knew something was wrong. After searching for an answer for a period of over six months she was misdiagnosed with Dermatomyositis, after a muscle biopsy which returned negative. We ran more tests. Cabrina was in and out of the hospital and had numerous testing and was unable to lift a spoon or walk without falling. That year she missed over 70 days of school. She was finally diagnosed with CIDP. Upon the diagnosis we were unsure on how to treat her illness and we tried all of the treatments such as Plasma Pheresis, steroids and finally found a doctor at the Mayo Clinic in Rochester who specializes in treating CIDP and has studied this illness with his father for years.

Through this treatment we have our daughter back and she is now established and has a normal life as a teen. She graduated middle school and was on National Honor Society.

She is a junior and is on the Principal's Honor roll this semester. She has found her love in theatre and has been in over seven plays. She was in a Christmas play in 2009. She has shown our family that overcoming an illness can be done with the love and support of your family along with an open mind and a positive attitude. We thank the GBS/CIDP Foundation and staff for your support. I was never able to take the time to write and thank you because of all the time spent with helping our daughter get to this level.

With thanks and gratitude, Susan and Cabrina Gomez



Please check with your local chapters for information on planned activities.

The 4th Annual GBS/CIDP 5K

The 4th Annual GBS/CIDP 5K in Charlotte, North Carolina is taking place on Saturday, May 1, 2010. Thanks to the hard work and excellent planning of Hannah Blanton, our North Carolina liaison, and her outstanding team of volunteers, this event is turning out to be bigger and better than ever. If you are in the Charlotte, NC area please join me for a great day and an important cause. You can register on line at www.gbs-cidp.org! I am looking forward to walking with you!

Pat Bryant

Not able to be in North Carolina?

Show your support by your sponsorship. Just go to the home page of our website to make a donation and take a virtual walk with us.

New this year!

Prior to the walk on May 1st there will be a Carolina Art Soirée, an exhibition of regional artists benefiting the GBS/CIDP Foundation International. It will be held on April 29th from 5:30 p.m. to 9:00 p.m. in Charlotte. For more information please visit the "News and Events" section at www.gbs-cidp.org.

My Story



Francine Benatti Furtado

My story begins almost five years ago, on a Friday morning in June 2005. At the time, I was fifty-nine years old and had awakened to prepare for my work day, having worked at the same employer for forty years and was looking forward to the weekend off. To my dismay I was experiencing something very unfamiliar, for example, numbness, tingling, and pins and needles in both my hands and feet. Well, off to work I went thinking this was a pinched nerve or whatever. At the end of the day with this strange feeling still there, I remember going home, taking two aspirins and getting right into bed.

However, when I woke up the following morning, the condition worsened, and I went straight to the emergency room at North Shore Hospital, Nassau County, New York. I was never one to run to a doctor, but I knew something was “not right” because this strange feeling was getting worse by the minute.

After a blood test, EKG and brain scan, the doctors sent me home, saying that my potassium was low. The next morning, same symptoms were worse, so I went back to the emergency room and the team of neurologists told me that it must be something neurological and to come back on Monday for a CAT scan. Well, when I woke up on Monday morning and tried to get out of bed, I could not walk. Panic set in.

I went right back to the emergency room and the doctors scheduled an EMG test, which indicated that this may be a case of Guillain-Barré Syndrome....which neither I, nor anyone in my family had ever heard of. Next step was a spinal tap which confirmed the diagnosis. Luckily, I had such an incredible team of doctors monitoring me; they placed a shunt in my shoulder and started plasmapheresis immediately. Five days of treatment was very hard to tolerate as the condition worsened, but I was not about to give up.

After one week of treatment, I was transferred to Glen Cove Rehabilitation Center. Unfortunately, within a few days and unable to stand on my feet, the doctors decided to send me back to the hospital for IVIG (intravenous immune globulin) treatment which lasted for five days. Within the week, I was practically paralyzed from the neck down.

After the IVIG treatment, I went back to Glen Cove

Rehab in very bad condition, unable to feed or dress myself. Basically, I was dependent on aides to care for me from morning til night. I began intense physical and occupational therapy for the next two months in severe pain. Emotionally and mentally, I was a mess. This was a very frightening and depressing state for me to be in, and I never thought I would recover well enough to take care of myself again. I cannot say enough about the professional care, patience, therapy and support that I received at Glen Cove Rehab. Thankfully, after two months, I was sent home (yippee!!) with a walker as my new vehicle for getting around. I continued outpatient physical therapy near my home for three days a week for about a year.

Today, I am walking on my own, driving my car and thankful for every day I am up on my feet and able to care for myself. What a blessing. I will never take anything as menial as brushing my teeth for granted. My illness was a complete nightmare for me, my husband and our families.

I cried constantly but would never give up. To anyone suffering from GBS be conscientious about your physical therapy and know that you will recover!

My most amazing inspiration came to me while in North Shore Hospital right after my diagnosis was confirmed. My sister looked up GBS on the internet and called the local New York Chapter Liaison and told her about my case. She no sooner came to visit me, walking into my room and introducing herself to me....”Hello Francine, my name is Patricia Bryant and I had Guillain-Barré and I want you to know that you will recover and be okay.”

That same Patricia Bryant is our current Director of the Foundation and I am honored to call her my friend and tell you that she was the reason I fought to recover. Patricia visited me a second time and inspired me physically, spiritually and emotionally. God bless her. She is the reason I am writing this to all those who have been afflicted with GBS or had a family member who suffered from this disease. Have faith, be strong and never give up.

On a happier note, I retired (never stepped foot back in my office after that Friday in June) and life is good once again. I have some residual effects, but I am no longer dependent on anyone to take care of me. There is a light at the end of the tunnel. Remember, when one door closes another opens. ■

Disclaimer Information Presented in the GBS/CIDP Newsletter is intended for general educational purposes only, and should not be construed as advising on diagnosis or treatment of the Guillain-Barré Syndrome or any other medical condition.

Privacy Policy In response to many queries: Intrusive practices are not used by the GBS/CIDP Foundation International. It does NOT sell its mailing list nor does it make available telephone numbers! The liaisons are listed in the chapter directory with their permission. Our CIDP and Miller-Fisher Groups share names only after a signed permission slip is received. We are proud that none of our members has ever been solicited or sent materials other than those concerning GBS. We respect your privacy.

Advocacy Report on HealthCare Reform

“The trouble with the future is it ain’t what it used to be!” said Yogi Berra.

How true! How painfully true when witnessing recent events surrounding healthcare reform.

While attending a meeting in Washington on February 17th, 2010 Patricia Bryant and I listened to three invited guest speakers give us their latest take on the status of healthcare reform. Since many of their comments were off-the-record I won’t identify them by name but I will tell you their current positions; a Health Policy Director from the National Conference of State Legislatures, a Health Counsel person from the House Committee on Energy and Commerce and a Senior Policy Advisor from the House Ways and Means Committee.

The “hill” is staffed with some of our nation’s brightest, and enthusiastic people who are extremely knowledgeable, who love our country and our political process, are dedicated to their bosses and very comfortable in their influential jobs. Knowing that helped me because the messages delivered by all three presenters were both disappointing and depressing. You felt like you were left little choice but to accept their pessimistic, personal forecasts because they are front line people in-the-know!

The experts, a vast majority of them, were reporting that Health Care Reform has stalled, and restarting the debate may be next to impossible. Even the recent White House Health Care Summit, though it included top Republican figures, became more a photo opportunity and platform for media sound bites more than a real chance at reconciliation.

No matter what your political preference, we can all agree that the healthcare reform process has been anything but bipartisan. And the question remained, “Will this current Congress ever be able to resolve our other serious issues like job creation, controlling our budget deficit and on and on and on?” As the brilliant comedian Gilda Radner said, “It’s always something!” Many say it’s time our elected officials acted American first; Democrat, Republican, or Independent second.

Now we move on to Sunday, March 21, 2010. Widely viewed as dead two months ago, the Senate-passed Healthcare Reform bill cleared the House on a 219-212

vote and was signed into law by President Obama on March 23, 2010. The bill will expand Medicaid coverage for the poor to cover people with incomes up to 133 percent of the federal poverty level with childless adults covered for the very first time. Medicare prescription drug provisions gradually close the “doughnut hole” gap. Beginning in 2011, seniors in the gap receive a discount on brand name drugs, initially 50 percent off. When the gap is completely eliminated in 2020, seniors will still be responsible for 25 percent of the cost of their medications until Medicare catastrophic coverage kicks in. Proudly, your Foundation alongside other patient support groups advocated directly and repeatedly to members of Congress calling for these very changes including elimination of lifetime insurance caps which also is part of this bill’s reform provisions! I can only offer my sincerest thanks to all of you that made phone calls, wrote emails and letters in support of your Foundation’s efforts. In what seemed, at times, to be a frustrating series of events, proved to make a difference. We did not get everything we were asking for, therefore our good work must continue in earnest.

While it may take months to sort out how this bill will specifically affect GBS/CIDP patients and families, the Foundation will be ramping up our advocacy efforts aimed at defining those components of the bill which will have the greatest impact on managing your health care issues. I’m not just referring to federal issues because state issues are just as important, at times more so, as we will see in the months to come. A major component of our 2010 plans includes calling upon many of you to participate and supercharge our Foundation’s grassroots efforts at the state level. To help you we have to clearly identify and qualify the appropriate issues, map out the engagement strategies, then provide you with the right set of tools to get the job done professionally and effectively. Before I provide more comment on the subject here is some interesting data from the experts at the Kaiser Family Foundation. These are results of a late 2009 public opinion survey. Match these results against how you would have responded.



In the past 12 months how did you respond to increases in healthcare costs?

- 34% skipped dental or medical checkups
- 26% did not refill their prescription
- 22% skipped recommended medical tests or treatment
- 17% cut their pills in half

Ranking Elements of Reform:

- 79% said design affordable health insurance plans for all
- 71% said insurers must cover pre-existing conditions
- 69% do not want to see an increased budget deficit
- 68% want to eliminate the Medicare donut hole

Economic Priorities for President & Congress:

- 45% - Help business keep or create jobs
- 33% - Help unemployed afford health insurance coverage
- 31% - Help states cover healthcare needs of low income families
- 27% Cut taxes for the middle class

Please send me an email at ed.gdula@gbs-cidp.org if you would like a copy or link to the entire presentation.

During the health care debate your Foundation has sent numerous, personal letters and emails to the highest ranking majority and minority leadership in both the House and Senate as well as letters to various committee leadership. On several occasions Foundation leadership made personal visits to staff members on the "hill" to express our (your) concerns. We continue to offer our opinions and recommendations to pending legislation in Nebraska, California, Hawaii, Minnesota, New York, New Jersey, Pennsylvania, Florida, and South Carolina. As I pointed out earlier the issues highlighted were pre-existing conditions, portability of healthcare coverage, tier four pricing, early elimination of lifetime caps, broader coverage for the poor, and co-pays just to name a few. Remember, even with Federal mandates and provisions, the individual states can legislate their own version of these provisions which can be quite different and not always as generous in terms of coverage or coverage eligibility and costs. We will be watching each state very closely and will be advising you when to take action when necessary.

Copies of all of our correspondence to our elected officials and relevant committees will be available soon on the Foundation's new legislative section of our website mentioned below. Be looking for it!

CIDP Patient Survey - Be on the Lookout!

The Foundation will be conducting an important CIDP patient survey in the near future. Your participation is critical. Within the next month or two all U.S. CIDP patients registered with us will be receiving a survey in the mail. The survey is designed to provide data on the effectiveness of various treatment protocols in CIDP patients over a period of time, as well as your abilities and disabilities at various stages of treatment. It will also provide us with information that will be very useful in our advocacy efforts on your behalf. In the past the Foundation members' responses to surveys has been outstanding.

Please take the time to complete all the questions and return it to us by the stipulated due date. All responses are anonymous.



Without a doubt the United States remains seriously divided over healthcare reform with opponents of the bill vowing to take the fight to the polls in November. While the politics of the healthcare debate moves ahead our Foundation keeps moving closer to our goal of becoming a more efficient and effective grassroots advocacy Foundation with 2010 programs planned to produce a watershed of events. We are planning a Foundation Capitol Hill Day following the summer recess, an advocacy handbook, and the continued update of our incredibly user-friendly and comprehensive legislative alert section of our website at www.gbs-cidp.org.

Furthermore, I encourage every CIDP patient or caregiver who will be receiving a survey form from the Foundation in the near future to please respond. Embedded in the survey are some extremely important questions that relate to healthcare coverage and access to treatment. The information you provide will help us develop the most effective advocacy programs targeting the right audience on your behalf!

Keep smiling, be happy, and stay healthy!!

Sincerely,
Ed Gdula
Director of Advocacy



The Central Role of Patients' Own Voice: Helping Clinicians in Constructing Proper Outcome Measures for Clinical Follow-up Studies and Therapeutic Trials in Guillain-Barré Syndrome and Chronic Inflammatory Demyelinating Polyneuropathy

*Els Vanhoutte, Sonja I. van Nes, Catharina G. Faber, Pieter A. van Doorn, Ingemar S. Merkies**

From the: Department of neurology, Maastricht University Medical Center, Maastricht,

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Department of neurology, Erasmus Medical Centre Rotterdam, Rotterdam

The Netherlands

**Corresponding author: merki007@planet.nl*

In the last 2 decades, clinical trials have demonstrated the therapeutic efficacy of intravenous immunoglobulin in patients suffering from Guillain-Barré syndrome (GBS) and chronic inflammatory demyelinating polyneuropathy (CIDP). Despite this therapeutic intervention, many patients are still confronted with the chronic often disabling consequences of these illnesses. Over 50-80% of patients with GBS and CIDP may still suffer from chronic complaints like pain, fatigue, pins and needles or other sensory disturbances, and mobility problems that may last for years after having experienced the first symptoms of the disease. These symptoms may lead to a reduction in social functioning like performing a job, taking care of the family or doing leisure activities, and may lead to a reduction in quality of life expectation. Residual complaints like these should therefore be more important in future intervention studies aiming to ameliorate these complaints.

In the last decade, there has been an increasing awareness under physicians working in the inflammatory neuropathy field to include patients who have suffered from GBS and CIDP or one of their representatives in the development and design of new trials. It is believed that the contribution of patients is crucial in monitoring and guiding the proposed objectives of such studies and to determine whether the proposed objectives fit the needs of patients experiencing these illnesses.

To assess the effect of future interventions, we need good, valid and reliable scales that capture possible clinical changes related to for example a new drug that is being evaluated for its effectiveness. Traditionally, these outcome measures were constructed solely by experts in the field who selected some items to be assessed and provided each of these items with a set of logic response options like "unable to perform", "able to perform, but with difficulty", and "able to perform, without difficulty". Subsequently, the selected items were gathered, a sum of the scores obtained for each item was constructed, and the obtained values were then used to determine possible changes in time.

The traditional way of constructing a scale has numerous limitations which will not be detailed here, since these are beyond the scope of this writing. It should be stated, however, that the patient is scarcely, if ever, consulted in these procedures.

We believe that patients' voice should be more important in the construction of scales that will serve as vehicles to assess more properly possible changes in their clinical condition. Researchers with special interest in developing such scales should use their knowledge to capture the needs of those suffering from these disorders. Currently, great efforts are being taken by the Peripheral Neuropathy Outcome Measures Standardisation (PeriNomS) study group to reach the above-mentioned goals. The PeriNomS is an international collaborative study of 24 prominent centres in the field of inflammatory neuropathies. The PeriNomS group has presented a list of 146 daily and social activities (n=146 items) to a group of 280 patients who experienced GBS or who still have CIDP. This list of items was based on the World Health Organisation classification of daily and social activities. The data we obtained were subsequently exposed to a modern scientific method (called Rasch analysis). Using this method we succeeded in reducing the amount of items to the 24 most relevant ones. The constructed new scale, also called the Rasch-built overall disability score (R-ODS), is specifically designed for clinical follow-up studies and to be used in future therapeutic trials in patients with GBS and CIDP. The R-ODS includes the following 24 items: ability to read a newspaper or book, to eat, to brush your teeth, to wash upper body, to sit on toilet, to make sandwich, to dress upper body, to wash lower body, to move a chair, to turn a key in a lock, to go to the general practitioner, to take a shower, to do the dishes, to do the shopping, to catch an object, to bend and pick up an object from the floor, to walk 1 flight of stairs, to travel by public transport, to walk and avoiding obstacles, to walk outdoors < 1 km, to carry and put down a heavy object, to dance, to stand for hours, and ability to run. These items

are scored as 0 = unable to perform, 1 = able to perform, but with difficulty, and 2 = able to perform without any difficulty. Based on the obtained raw scores a better linear final score will then be calculated which can be used for further analyses. The technical parts of the construction of the R-ODS and its application have been presented at the last Peripheral Nerve Society congress in Wurzburg, Germany. The construction of this new scale has been made possible by the voice of those suffering from these illnesses and exposing it to modern scientific knowledge, which is quite different when compared to the traditional way of constructing scales. The first results of the application of the R-ODS indicate that this scale is more sensitive in detecting changes in the clinical condition of patients than the traditional scales used thus far, despite its simplicity. These findings are encouraging for future clinical studies.

The PeriNomS study group does more: its major objective is to present within two years a specific set of

outcome measures that can be used in future studies in patients with GBS and CIDP, which will include the best scales to assess aspects like weakness, sensory problems, daily functioning, social participation, and quality of life expectations. Our message will be to include the specific set of scales in all future studies in these conditions in order to be able to compare the results of interventions in different studies more appropriately. Our central aim was formulated at a workshop in 2004 where a representative of the GBS/CIDP Foundation International was also part of the discussing panel. The final results of the PeriNomS study will also be shared with the GBS/CIDP Foundation in the near future.

Last but certainly not least, this study has been made possible by the GBS-CIDP Foundation International, by providing the PhD fellows with a grant. We thank the Foundation for their generous support and all researchers in the field as well as the patients helping us to bring this study to a great end. ■

Foundation News and Events

Congratulations to the **United Kingdom & Ireland GBS Support Group** on the celebration of their 25th Anniversary. Their AGM Meeting will take place on April 17, 2010 in the U.K.

Foundation Chapter Meetings and Walk-a-thons:

- April 3, 2010 Boyd County Public Library – Ashland, KY
Liaison: Susan Kettel
- April 10, 2010 Bethesda Rehabilitation Hospital – St. Paul, MN
Liaison: Audrey Brucker
Speaker: Gareth Parry, MD
- April 11, 2010 Aston Gardens at Tampa Bay – Tampa Bay, FL
Speakers: Lara W. Katzin, MD and Ellen Eckelman, PT
- April 17, 2010 Grubb & Ellis – Fort Myers, FL
Liaison: Santo Garcia
- April 17, 2010 Palo Duro Senior Center – Albuquerque, NM
Liaison: Ann Lavezo
Speaker: Carol Lee Koski, MD
- May 2, 2010 Texas Scottish Rite Hospital – Dallas, TX (Walk-a-thon)
Liaison: Debbie Plimmer
Speaker: Sharon Nations, MD
- May 8, 2010 Fudrucckers Restaurant – Houston, TX (Walk-a-thon)
Liaison: Patsy Organ
- May 15, 2010 Webster Library – Webster, NY
Liaison: Barbara Amering
Speaker: Patricia Bryant – Executive Director, GBS/CIDP Foundation
- May 22, 2010 NeuroRehab and Balance Center – Centerville, OH
Liaison: Bill Werling
Speaker: Marcia Cox, MHS, OTR/L, SCFES

Detailed information about these meetings can be accessed at <http://www.gbs-cidp.org/news-events.htm>



Have you visited
our website lately?

Get up-to-date information
www.gbs-cidp.org

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*Your support is important to enable us to carry out
and expand the mission of the Foundation.*

We are grateful for all those who have supported the Foundation during 2009.

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A special "Thank you" to Samantha Lanier who organized and held a fundraiser for the Foundation in honor of her mother.

Disclaimer: Although The Foundation has made every effort to list all names of those who so generously donated during the year 2009, errors might occur. If we have omitted anyone, please contact us at info@gsb-cidp.org.

In Memoriam

We take this opportunity to thank families and friends for designating the GBS/CIDP Foundation as recipients of memorial contributions in memory of their loved ones who died during 2009:

Peter Alex, Jr.
Edith Baptista
Joan Borghi
Jack Caldwell
Shirley Capps
William Cassin
Donna DeMaria
Carol Rummage Eddleman
Sheryl D. Evans
Franklin Feld
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John Swope
Leonard Tesoro
Joseph Trinka
Ann Uebbing
Jack Walker
Kari Joseph "Buddy" Whitehead
Dwight Woods

Thanks Day

I awake in the morning now
With older and with wiser eyes
I open them and gaze outside
And check out brightening skies.

I twist my wrist and wiggle my fingers
And watch them move – the memory lingers –
Of when they were still
When I was ill.

I look outside and squeeze the hand
Of the one beside me, by best friend.

Who loved me through the worst of days
And loved me in the best of ways.

And think of beautiful sons and daughters always there.
Though they are there and we are here.
They were always there
A smile away from where I lay
When I was still.
When I was ill.

And one son came and sat by me. He knew I needed him.
The other's voice, 3000 miles. A gentle soothing hymn.

And dearest friends were there for me
Massaged my feet and scratched my beard
And laughed with me and stood by me
When I lay still when I was ill.

Now maybe today we'll catch a movie or take a hike
Or play a game or something else we like.

Brothers and sisters far away
Always in my heart are they.

Looking out the window lying in my bed
I greet the day and raise my head
Then pull these healing bones and muscles into action
Get dressed and smile with satisfaction

And look out of the bedroom window
before I go downstairs
have breakfast with the one I love and face the daily cares.

Thanks beautiful kids. Thanks dear grandkid(s).
Thanks cherished friends. Thanks my love.
And by the way.
Thanks sun. Thanks stars. Thanks moon and night

And day.

Rich Barbour (Thanksgiving '09)



GBS/CIDP *Foundation International*
 Serving patients of GBS, CIDP and Variants with support, education and research

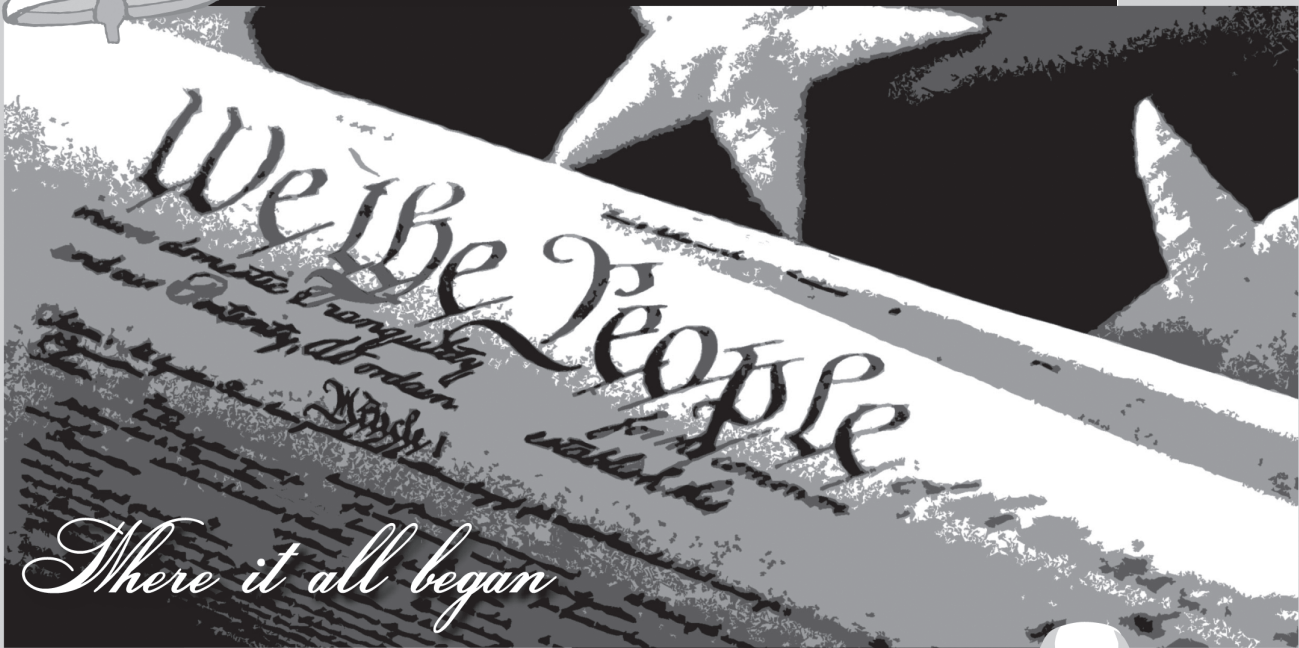
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2010

Guillain-Barré Syndrome • Chronic Inflammatory Demyelinating Polyneuropathy



The 11th International Symposium of the
 GBS/CIDP Foundation International
 will be held in King of Prussia

PENNSYLVANIA



NOVEMBER 5-7, 2010

★ 20 Workshops ★

★ State Night Dinner ★

★ **Special Guest Speaker: Loretta LaRoche** ★

Loretta LaRoche is an internationally acclaimed stress management and humor consultant whose wit, and irreverent humor, has, for over 30 years raised the humor potential in all of us. Loretta has starred in 7 one-woman PBS specials on humor and optimism (two of which received Emmy Award nominations), has authored and published seven books including: *“Relax, You May Only Have A Few Minutes Left,”* *“Life Is Not A Stress Rehearsal,”* *“Life Is Short: Wear Your Party Pants,”* *“Kick Up Your Heels Before You’re Too Short To Wear Them”* and her newest, *“Lighten Up.”*

★ **One-mile Walk-a-thon** (Valley Forge National Park) ★

★ Time to mix and mingle with others ★

★ **CME Program for Medical Professionals** ★

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DIRECTORY

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

- **"CIDP" Group**
For those having diagnosis of chronic inflammatory demyelinating polyneuropathy. Please identify yourself to the National Office in order to be put in contact with others around the country.
- **Children with GBS**
Call Lisa Butler • 215-628-2771
670 Penllyn Blue Bell Pike, Blue Bell, PA 19422
Son, Stuart had GBS at 5 1/2 years old
- **Children with "CIDP"**
For those children diagnosed with chronic inflammatory demyelinating polyneuropathy. A separate registry has been created. Please contact the National Office for details.
- **Group for Having GBS Two Separate Times**
Please call the National Office for contact with others.
- **Miller Fisher Variant Group**
Please call the National Office for contact with others.
- **Wheelchair Limited Group**
Please call the National Office for contact with others.
- **A Teenage Pen Pal Group**
Arielle Challander • 231-946-7256
4313 Shawn Drive, Traverse City, MI 49684
Email: GBSTeenPenPal@hotmail.com
Tracey Kennedy • Cell 303-746-4014
E-mail: traceynkenedy@gmail.com
- **Pregnant Women with GBS**
Robin Busch • 203-972-2744
264 Oenoke Ridge, New Canaan, CT 06840
Robin has offered to share her experience with GBS which came about during her pregnancy.
- **AMSAN Group**
Please call the National Office for contact with others.
- **The "Campy" Group**
Those whose GBS onset was identified as a result of the campylobacter bacteria. Numbers to be used for research purposes.