



GBS | CIDP

Foundation International

Providing Strength Through Support

Fall/Winter 2011

The Communicator

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Message from the Executive Director



In my short time as Executive Director with the Foundation, one thing that stands out above and beyond all else is PASSION. Each person I have met cares deeply and genuinely for patients, family members, caregivers and the cause. I am honored to be in such a committed community. With over 29 years working with non-profits, I have a deep appreciation for dedicated and hard working volunteers and staff. Having worked in both the for-profit world and the not-for-profit world, I know that there is no greater reward than the opportunity to work with passionate volunteers

in an outstanding organization.

I am very excited about joining the Foundation at a time when we are planning for 2012. The year 2012 is going to be big for the Foundation. I encourage everyone to check out our new website www.gbs-cidp.org. What matters most is that we serve you better by keeping you up to date and engaged with what is happening with the Foundation. The site enhancements are designed to help you get what you need quickly and easily.

I recognize and appreciate that you made the Foundation a success this past year. In the coming year I commit to listen to your input as we shape the new site and expand the support it facilitates. Look for details in the future on the website and in your mail about the 12th International GBS/CIDP Symposium, October 26-28, 2012, in Fort Worth, TX.

In addition to checking out the new website, I have a favor to ask. Updating everyone's contact information will be the key to expanding and improving our communication. This update can be done by either calling the office at 866-224-3301 or by the web at www.gbs-cidp.org/members.

Thank you for your past support. I am eager to see how much we can accomplish together in the next year helping all people impacted by the disorders.

Best wishes during the Holiday Season,


Ken Singleton



*May your holidays be filled with peace, joy, and love.
A very Happy New Year to everyone.*

THE STAFF OF THE GBS/CIDP FOUNDATION INTERNATIONAL

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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Letters to the Editor

I was eight when I was diagnosed with GBS. I am 29 now, no wounds, no scars, no nothing. Back in 1990, I remember I woke up one day and I couldn't move my legs. My parents took me to a doctor but he wasn't able to determine what was wrong with my body. They thought I was joking. A few days later my symptoms got stronger. Numbness in my whole body (I kept telling my parents I felt like an army of ants was walking down my skin), my voice changed... I was definitely sick. Finally they took me to the emergency room, where some doctors, after a few exams, told them that I had GBS.

One day, one of the most difficult ones, my fingers got purple because my blood was running out of oxygen. The doctors said I needed a tracheotomy but my parents said they didn't want to see their daughter breathing through a tube. The next day, miraculously, the symptoms started to slowly disappear. I spent more than five weeks at the hospital. I had to learn to crawl again, then to walk again, jog again, write again, eat again, and today I'm a really and incredible healthy person. If you see me walking down the street, you couldn't tell I suffered from GBS! Even though I was a child and I can't remember most of what happened to me, I can assure you that the love and support of my family members were crucial.

*Marcela Estrada
of Columbia, South America*

In March of 2008 I was at my 6 year old son's Baseball game, playing catch with him, helping him warm up. I started to feel like I had pulled the muscles in the back of my legs, but just sat down to rest thinking nothing of it. Within a week, I had so much pain down my lower back, and legs that I went to see my doctor. She gave me some mild pain reliever, and home I went. The next day, I went to another hospital 42 miles away for a second opinion, received an MRI, and was told it was something in my neck. I received a neck brace and was sent home. The next day I woke up to the side of my face drooping. I was petrified! Back to my doctor who told me to go to the ER 42 miles away to see a nerve doctor. Within ten minutes of being in the ER I couldn't move, and I was in the most pain I have experienced in my life! They admitted me to the ICU. Thankfully the paralysis did not go higher than my stomach. Daily they would check my breathing, and run tests. After two weeks they finally diagnosed me with GBS. But I still did not know how I contracted it. I am so thankful for my husband, son, and mother, as they were there daily (driving 42 miles each way) to be with me. I had a lot of emotions, guilt being the first. How do you explain to a six year old what you yourself don't understand? And hearing that he is afraid his Mom is going to die? (Talk about a motivation to get better!) I slowly got better, went through rehab, and am now walking again. Although I still have problems with pain, and some numbness in my face, legs, and feet, I feel like a survivor! I am grateful every day for my family, and my strength that I have found through all this.

Chris Rowles of Hamilton, Montana

On September 7, 2011 my five year old daughter, Emma Rae, called me from the top of the stairs, "Mommy my legs hurt, and my head hurts from the sun." She had been battling a cold since the first week of school so I feared she had meningitis. I rushed her to our pediatrician's office. With strep ruled out, I proceeded to take her to the ER where after a buffet of tests we still had no definitive diagnosis. After three days of severe pain, hypertension, double vision and increased weakness/paralysis, a new neurologist was obtained and the diagnosis of GBS was made. Not a minute too late for her airway was severely compromised at this point. We transferred to another hospital where a second spinal tap was done the super high protein level assured our doctor that it was indeed GBS. Finally, we had our answer. As a mom and a health care professional I knew in my heart that something was terribly wrong. After five days in the PICU/five more on the pediatrics floor our next step was aggressive physical therapy. We transferred to Primary Children's Hospital in Saint Louis City on September 20 where her hard work paid off. After ten days she walked to my husband at the airport when we arrived home. She has just completed her first full week back to kindergarten. She is amazing and an inspiration to all!

Raelene Scheidler of Henderson, Nevada

Disclaimer Information Questions presented in the GBS/CIDP Newsletter are 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.

Patricia Blomkwist, Board Member, Honored by Queen Beatrix of the Netherlands



Patricia Blomkwist, in the presence of Queen Beatrix, received a "Crown" on September 30th at the 55th anniversary of the Princess Beatrix Fund Jubilee Symposium entitled "Ensure Independence" held in Utrecht, Netherlands. The "Crown" was presented by Laetitia Griffith, President of the Fund, and is an award for individuals or organizations that have done exceptional work for people with neuromuscular disorders. For her dedication over the past two decades Patricia Blomkwist received a "Crown."

Since Patricia Blomkwist was struck by Guillain-Barré Syndrome, she has been working with dedication to help people with this disease. In addition to her role as a Board member for the GBS/CIDP Foundation International, she is active in the group Guillain-Barré Syndrome of the Association of Neuromuscular Diseases Netherlands and maintains many international contacts. In addition, she regularly appears at the bedside of patients who may lose hope of recovery.

Princess Beatrix Fund Fundraiser in Rotterdam

A most unique fundraiser was held by the Princess Beatrix Fund on September 27th during which 57 people went abseiling from the Euromast in Rotterdam. Abseiling is a controlled descent by ropes from a steep pinnacle, otherwise known as rappelling in English. Pieter van Doorn, MD, of the Netherlands, a member of the GBS/CIDP Foundation International Medical Advisory Board, was the first to go down, joined by three people of his team. Two time GBS

survivor, Marianne van Mierlo, a member of the Netherlands support group, also participated. Ms. Mierlo was only one week shy of her 71st birthday when she decided to take the plunge as she abseiled from the crow's nest (331 feet high) of the Euromast which is 607 feet high. The proceeds of over €14,673.82 will go to Dr. van Doorn's research for GBS. Since the founding of the Fund in 1956, Queen Beatrix has been the patron of the fund. The Fund invests in scientific research and is committed to improving the quality of life of patients and their families. Over the past ten years the fund has raised over €25 million available for research.



On September 10th Ruth Elster and her husband Bob, in gratitude for her recovery from Guillain-Barré Syndrome, hosted an afternoon at their vineyard at Arrowhead Mountain in the Sonoma Valley.



Guests enjoyed a sumptuous lunch along with a wine tasting from the vineyard. Dr. Carol Lee Koski, renowned neurologist and member of the GBS/CIDP Medical Advisory Board made a presentation on the latest developments in the treatment of GBS and CIDP. Twenty one people attended, including Marilyn Tedesco, a GBS/CIDP board member and her husband Lou, and California liaisons Beverly Copeland and Russell Walter. The event brought in over \$1500.



The Inspirational Story of a Nurse Who Overcame a Tragic Illness

By Ruthann Devine, Account Manager, Crescent Health Care

Experiencing adversity is simply part of the human condition. This is a story about a woman, who when faced with the most tragic curveball of her life, rose to the occasion and didn't give up. Vulnerability is a sign of great strength. Pam Wrobel (our liaison in Greenville, South Carolina) happily shared her story from a place of humility and gratitude. She truly inspired me and I feel honored to know her.



June 27th, 1994 was the day that changed the trajectory of her life. Pam was a thirty year old operating room nurse on a neurosurgical team in a hospital in Greenville, SC and a new mom in a new home, with a seventh month old son and a husband on that infamous day. This day was like no other. She started having a "weird numbing sensation in her feet and the left side of her tongue." She went to work as usual and jokingly mentioned her symptoms encouraging her co-workers to diagnose her. By the weekend her symptoms were no joking matter as they had rapidly progressed. Intense pain radiated down the backs of both legs as well as her back and she suddenly had a feeling of impending doom. Something was wrong and she couldn't figure it out. Desperate for relief, Pam had a friend take her to the emergency room where she tried desperately to help the neurologist figure out what was causing these horrible symptoms. She told the doctor that she had been cleaning her new home over the weekend and wondered if perhaps the cleaning agents could have triggered this problem or perhaps she was bitten by a tick. Pam's attempts at a possible solution were dismissed and she was sent home with a prescription for Ativan to alleviate her anxiety. On July 5th she went to work still symptomatic with numb fingers and bone scans were done. July 7th Pam was having great difficulty with balance and was incredibly weak. One of the doctors she worked with told her to go to the lounge and he would check on her between patients. Upon doing so, he admitted her to the hospital immediately. Following many tests which included a spinal tap, he shared the words she'd never forget; "looks like it's going to be a long road ahead for you Pam." He told her she had GBS, and that she'd probably not be home before Christmas. Devastated, but determined to prove her doctor wrong, Pam worked overtime to regain her mobility. Debilitating pain, weakness and numbness advanced until she was essentially a quadriplegic on a ventilator. Continuous support from her mother and coworkers helped to keep Pam focused on overcoming all of her limitations. Nurses were hesitant to go in her room because they felt scrutinized by the constant stream of "professional" visitors. During her extensive hospital stay she received many infusions of IVIG and plasmapheresis, rehab with PT and OT

which included wearing AFO braces on her legs every 2 hours alternating with high-top sneakers, which she insisted on wearing. Foot drop was ultimately prevented. On October 21st Pam was discharged home to continue all of her therapies outpatient. Her progress paralleled her baby's; as he learned to crawl and eventually walk, so did she. In 1995 Pam was determined not to accept that this was as good as she'd ever feel and

consulted the NIH (National Institutes of Health) where federally funded research is done. She was given higher doses of IVIG which resulted in a major improvement in terms of her response to therapy.

Being a nurse and a patient gave Pam the ability to be her own best advocate. Pam reflected on the insensitivity and lack of common sense of one nurse who actually tried to give her pills as she suctioned her own secretions. She recalled the frustration the nurses felt with her because she insisted on wearing her AFO braces every two hours. As a patient, Pam said she had a heightened awareness in terms of tone, sincerity, and respect. She was at her most vulnerable place and couldn't believe the insensitivity of some caregivers.

Eventually Pam was able to walk again and thought she'd resume her position as an OR nurse but her job was no longer available. This turned out to be an unexpected blessing as she was placed in a pre-op position instead. The realization that she could be of service to her patients who were now awake and incredibly fearful and vulnerable, astounded her. Surviving GBS made Pam uniquely qualified to recognize the terrified look many patients have prior to surgery that says "I'm out of control and I'm falling into a black hole." Pam realized she could share her experience, strength and hope and really comfort her patients. The trauma that Pam survived enhanced her ability to relate to her patients in a profound way. She is known as "Angel Nurse" on her unit because she started the tradition of drawing an angel on the pillows of her patients.

I contacted Pam to see how I might support her efforts because in addition to being a pre-op nurse, Pam happens to be liaison for the local chapter of the GBS Foundation since 1996. Her responsibilities include providing support and hope to newly diagnosed GBS patients, facilitating walk-a-thons and support group meetings, as well as educating nursing students and physical therapists.

When asked if she could enhance her dual roles in any way Pam stated she would love to incorporate art into what she does for her GBS patients. She recalled how rubber stamping and playing the piano helped her regain her fine motor skills in her hands. She marvels at how much her angel pillows are valued by her patients.

Treatment of the Residual Effects of GBS with Dalfampridine

By Gareth J. Parry, MD,
Professor of Neurology, University of Minnesota
Member, GBS/CIDP Medical Advisory Board

The most common form of Guillain-Barré Syndrome (GBS) is acute inflammatory demyelinating polyneuropathy (AIDP). In this form of the disease inflammatory cells and antibodies attack the myelin sheath causing demyelination. There is always some accompanying injury to the underlying nerve fiber, the axon, but it is usually relatively mild. Repair of the myelin sheath (remyelination) is a quite rapid and effective process and results in near normal restoration of the ability of peripheral nerves to transmit electrical impulses. This is why AIDP usually makes an excellent recovery; 70%-85% of AIDP patients fully recover strength within a year or two of the initial attack. It is generally accepted that those patients who incompletely recover are those with more severe damage to the axon since axonal repair is a slower and less effective process. However, in some patients there is residual slowing of the speed of conduction of electrical impulses, the hallmark of incomplete repair of the myelin sheath, even years after the initial event. The degree to which this reduces efficiency of nerve and muscle function is not completely known. It is certainly possible that the residual fatigue that has been reported in up to about 80% of GBS patients could be related to incomplete remyelination reducing the efficiency of electrical impulse transmission. It is also possible that some component of any residual weakness and sensory loss could also be due to incomplete remyelination.

The chemical 4-aminopyridine (4-AP) has been shown to improve nerve conduction in the central nervous system (CNS) in experimental studies. It does so by blocking the potassium channel in the wall of the axon. In incompletely remyelinated axons the potassium channels are exposed and potassium leaks out of the axon, leading to loss of the ability of the axon to conduct the electrical impulses. 4-AP partially prevents leakage of potassium and improves nerve conduction. Recently, a sustained release form of 4-AP (known as dalfampridine or Ampyra), has been shown to improve walking in MS patients, presumably by blocking potassium channels and improving nerve conduction. Since MS is characterized by demyelination and incomplete remyelination in the CNS, it is plausible that dalfampridine may also help AIDP patients with residual weakness, sensory loss or fatigue due to incomplete remyelination and also patients with CIDP.

There are important differences between CNS and peripheral nervous system (PNS) myelinated axons. Firstly, the CNS remyelimates much less effectively than the PNS; it is possible that there is not significant potassium leakage in the PNS because the axons have more effectively remyelinated so that 4-AP might not, therefore, be helpful. Secondly, CNS axons need to transmit extremely rapid trains of impulses at rates of 100-300 impulses each second whereas PNS axons transmit at a much slower rate of 40-50. Thus, electrical impulse transmission in CNS axons is much more likely to fail and is more likely to benefit from 4-AP. Despite these caveats, there is a possibility that 4-AP in the form of dalfampridine could produce meaningful improvement in GBS patients who have incompletely recovered, particularly those in whom fatigue is the most disabling symptom. A clinical trial will be necessary to determine whether there is any benefit; the drug cannot be prescribed except for MS patients.

ROBERT BENSON RECEIVES AWARD

At the October 29, 2011

*Board of Directors meeting
Robert Benson was presented
with an award for his many years
of service to the Foundation
as the founding patient and as
a dedicated Board member.*



Robert Benson and Ken Singleton

SAVE THE DATE

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THE 12TH INTERNATIONAL GBS/CIDP SYMPOSIUM

will be held in

Fort Worth, Texas

October 26 - 28, 2012



www.gbs-cidp.org

Chapter Meeting Highlights

This fall was a busy time for chapters across the country. 21 support meetings were held since August – Hartford, CT (2), Dallas, TX, Minneapolis/St. Paul, MN, southwestern Virginia, Akron/Warren, OH, Indianapolis, IN, St. Louis, MO, King of Prussia, PA, Rochester, NY, Salt Lake City, UT, Raleigh, NC, Denver, CO, Atlanta, GA, Chicago, IL, Seattle/Tacoma, WA, Portland, OR, Charlotte, NC, Clearwater/Tampa, FL and Blue Springs, MO.



What would you be able to take away from a GBS/CIDP Support Group Meeting? Here are some recent comments from some of the meetings.

- "Thank you for these meetings. I really appreciate them and come home with something new. Keep up the good work."
- "Thank you for all who made this meeting possible. Very helpful to meet other GBS/CIDP patients – sometimes simple exchange of personal stories is the "medicine" we need. I hope the chapter keeps going."
- "Wonderful program, three of my patients from IVIG infusion suite came with their spouse and they all enjoyed the experience."
- "Great presentation – 1st time attendee."
- "Wonderful program, great information."
- "Good meeting, I learned a lot."
- "Thank you for all your hard work. It helps to know that I am not alone. I have been told that I am a "head case" and that there is nothing wrong with me. It helps to know that there are others."
- "This was my first meeting and I would definitely come back for another and bring more family members. I am grateful this exists and that everyone has taken the time to put so much effort into so many lives."
- "Very informative, glad I was able to attend."
- "This was a great presentation and a great chance to meet others with the disease. I am looking forward to more meetings. Thanks!"

Dr. Arthur K. Asbury Honored as "Citizen of the Year"

On October 28, 2011, the GBS/CIDP Foundation International awarded the "Citizen of the Year" award to Dr. Arthur K. Asbury, a member of the Medical Advisory Board. Two hundred people were in attendance at the College of Physicians in Philadelphia, including those from as far away as Paris, England, Netherlands and Israel. Among the Honorary Committee were Robert and Estelle Benson. Dr. Asbury was honored for his many contributions to medical education and our understanding of the limits and pathogenesis of Guillain-Barré Syndrome. \$250,000 was raised toward funding a Fellowship in Neuromuscular Neurology.



Don Gilden, MD



Estelle Benon



Carol Lee Koski, MD



Dr. Arthur K. Asbury



Austin Sumner, MD



Maryann Johnson, Richard Baringer, MD, Peter Johnson, MD and Professor Gerard Said, MD



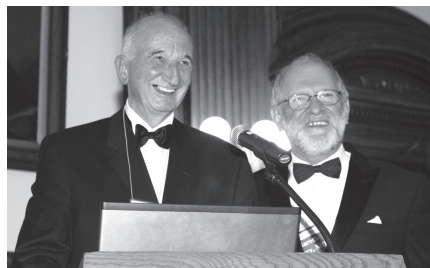
Dr. Asbury speaking



Ken and JoAnn Singleton with Santo Garcia



Patricia Blomkwist and Elizabeth Emerson, Esq.



Professor Gerard Said, MD and Gareth A. Parry, MD



Ralph Neas and Joel Steinberg, MD, PhD

From Therapist to Patient and Back Following GBS

By Lizbeth Albert, Roanoke, VA

On March 6, 2003 I went from being an ambulatory Physical Therapist to a bed-ridden Guilliane-Barré patient. The week before I had gone to the doctor due to back pain without a precipitating causation and I mentioned the recent numbness in my toes. His diagnosis: I had pulled a muscle in my back and the numbness was due to pressure on the nerves from increased muscle tone. He prescribed a muscle relaxant and bed rest. The muscle relaxant did not ease the pain but contributed to my falling down twelve steps. The numbness had increased which impacted my balance.

I was admitted to the hospital with a diagnosis of pneumonia which did not address the tingling numbness in my feet. After two days I was discharged with a prescription for an antibiotic and an appointment for a follow up chest x-ray. I called for a ride home, got out of bed, removed my clothes from the closet, washed off and went into the bathroom. When I tried to stand up from the commode I fell to the floor and could not move my arms and legs. A spinal tap revealed the diagnosis of Guillian-Barré Syndrome. My back pain continued to increase and its cause remained a mystery. Following many tests, x-rays and CT scans the pulmonary physician decided to perform a bronchoscope as fluid remained in the left lung. The procedure revealed malignant cancer in the left lower lobe.

Typically thoracic surgery patients are ambulatory. Operating on a paralyzed patient is not the norm. Following the operation the surgeon told me that he had expected to remove a pea-sized tumor and found a soft ball sized encapsulated malignant tumor. He explained that had it not been found soon it would have burst out of the encapsulation and I would have had approximately one year to live. He had removed the left lower lobe which meant I escaped the ravages of radiation and/or chemotherapy.

As the motor control began to return to my legs I was transferred to a rehabilitation unit. Now I became the rehab recipient and began to experience what many patients feel. Exercises are boring and I hate counting to ten. You say I can trust you, you won't let me fall, but I don't trust

you. I don't want to stand or do therapy today, I'm tired. I promise I'll do more tomorrow/later. I am afraid and so tired. What if I can never walk again? What will become of me? Therapists are mean, they don't care or understand how I feel. I learned how frightening it is to transfer using a sliding board and to stand up when you know you cannot prevent yourself from falling. I experienced the true job of regaining the use of my body which I had taken for granted. At that time I was 63 years of age.

Three months after my admission I was wheeled to the hospital front doors. I asked the transporter to stop the wheelchair. I locked the brakes, stood and walked to the back of the wheelchair, unlocked the brakes and then joyfully pushed the wheelchair out to the car. I was determined to leave under my own power.

Home health came three times a week for two weeks which was all insurance would approve. The rest of my recovery was up to me. Daily I went to an athletic club and walked the track, went to exercise classes, worked on the strengthening machines and swam. On the treadmill I worked on balance and endurance on level and inclines while performing breathing exercises and I "pushed" myself. The hard work paid off. Today I walk on all surfaces without shortness of breath and the upper lobe of my left lung has expanded to fill the thoracic cavity.

Though able to retire early on disability I felt a strong desire/need to return to work. Fifteen months after I was stricken, using a single point cane for balance, I returned to work as an evaluating/supervising therapist and medical chart reviewer. Through exercise and constantly challenging myself I regained the strength, balance and confidence to return to work as a full time home health Physical Therapist.

Today, seven and one-half years after having been stricken with GBS, I continue to work in a long term care facility with an inner joy I did not feel before. My life is fuller and richer and I believe I have more internal understanding having been a PT patient. Guillian-Barré I believe saved my life and was a gift for which I am eternally gratefully.



"Update on CIDP" Coming to a Location Near You

The GBS/CIDP Foundation International will be hosting the first in a series of special meetings for CIDP patients only in Towson, MD on Saturday, January 28, 2012 from 10 a.m. to noon at the Towson University Marriott Conference Hotel. This "Update on CIDP" will help you sort out your diagnosis and treatment. The speaker will be Dr. David Cornblath, Professor of Neurology and Neurosurgery, Johns Hopkins University, and a member of the GBS/CIDP Medical Advisory Board. Look for invitations to these events throughout the year in a city near you.



GBS|CIDP

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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 with a diagnosis of chronic inflammatory demyelinating poly-neuropathy. 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 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.
- **AMSAN Group**
Please call the National Office for contact with others.
- **A Teenage Pen Pal Group**
Arielle Challander, 231-946-7256
413 Shawn Drive
Traverse City, MI 49684
E-mail: GBSTeenPenPal@hotmail.com
Arielle had GBS in 2006 at age 13. She is willing to share experiences that others might not understand. To have a teenage GBS'er pen pal, write, call or e-mail to Arielle.
- **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. We have many such cases and reassurance from someone who has gone through this is needed support.
- **Bereavement Group**
A group for anyone who has lost a loved one due to GBS/complications. Please contact: Bereavement Group at the National Office.
- **The "Campy" Group**
Those whose GBS onset was identified as a result of the campylobacter bacteria. Numbers to be used for research purposes.