



GBS/CIDP
*Foundation
International*

**Guillain-Barré Syndrome and
Chronic Inflammatory
Demyelinating Polyneuropathy**

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

***Teen/Young Adult
Handbook***

*A publication of the
GBS/CIDP Foundation International*

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Arielle had GBS in 2006 at age 13. She is willing to share experiences that others might not understand. To have a teenager GBS'er pen pal, write, call or e-mail to Arielle.

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DEALING WITH GBS AND CIDP

So you've just found out that you have Guillain-Barré Syndrome (GBS) or Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). Most likely you have never even heard of these conditions before and don't know what to expect. Don't worry, that is the purpose of this book - to teach you things you need to know about GBS and CIDP.

You need to remember that you are not alone when you face these disorders. Even though GBS or CIDP have become a part of your life it does not have to be the center of it. This book has been written to help you work with your doctors, nurses, therapists and parents to learn how to manage GBS and CIDP, gain control, and become an independent person at an important point in your life.

Managing a Disorder

Three things are necessary to manage this neurological disorder: They are:

Knowledge - of how your disease affects your body

Skills - to take care of yourself and to talk to your doctor about your disorder

Plans - about dealing with your own feelings and how to cope with your condition

The goal of this book is to help you master these skills.

What is GBS?

Guillain-Barré (Ghee-yan Bah-ray) Syndrome is a disorder of the nerves outside of the brain and spinal cord. Some of the characteristics of GBS include the quick onset of weakness and, often paralysis of the legs, arms, breathing muscles and face. GBS is the most common cause of quickly acquired paralysis in the United States today.

GBS usually begins with weakness and/or abnormal sensations in the legs and arms. GBS may also affect muscles in your chest, face and eyes. At some point you will probably have to be in the hospital. Sometimes the muscles that you use to breathe get weaker, and a machine is used to help you breathe. GBS can affect people in different ways. Some people hardly have any symptoms, while others can become very ill.

Most people recover, but it may take time. Sometimes months of hospital care is required, and it is hard to tell what type of recovery people might make. The majority of patients return to a normal lifestyle within around six months.

What Causes GBS?

The cause of GBS is not well understood. Most cases come after a sore throat, cold or diarrhea. Some believe that the body's immune defense system of antibodies and white blood cells are triggered by the infection into damaging the nerves. This would lead to weakness and the abnormal sensation. These are believed to be possible causes of GBS.

How is GBS Diagnosed?

Most of the time the symptoms that you have, along with going to the doctor, are enough to show that you have GBS. That quick onset of weakness and those abnormal sensations are common. To really be sure and confirm if you have GBS, the doctor will administer a lumbar puncture. This is when the doctor inserts a needle into your lower back and takes a sample of the fluid that surrounds your spinal cord. This test may help to determine whether you have GBS. A doctor might also test your muscles and nerves to see if they are working the right way. Both of these tests will give the doctors a clear idea if you have GBS.

How is GBS Treated?

At first, GBS might be unpredictable. Because of this, most newly diagnosed patients go to the hospital. The goal is to make recovery as fast as possible. Most patients after a hospital stay are candidates for a rehabilitation program. This will help you learn how to use your muscles as your nerves get back to working correctly.

Treatments of GBS

Hospitalization:

Patients are hospitalized because symptoms come rapidly and can worsen quickly. Many patients are in Intensive Care and can be hospitalized for up to a month or longer. During a hospital stay doctors might perform a variety of tests to find out what is really going on. Some of these tests are painful, but it is important to know that every one of them is being done to help you.

Plasma Exchange:

Plasma Exchange is when blood is removed from the body, the liquid part is separated and the blood cells are returned to the body. This procedure is used to shorten the course and eliminate the severity of GBS.

IVIg:

IVIg is a plasma product formed by taking antibodies from about 20,000 donors and mixing them together. These have proven effective in several immune system disorders, including GBS. IVIg therapy is when gamma globulins are administered intravenously in order to reduce the severity of an attack. These globulins are proteins naturally produced by the immune system.

Physical Therapy And Occupational Therapy:

Physical Therapy (PT) and Occupational Therapy (OT) are very important in patient's recovery. Some people need more than others, but in the end PT/OT is what will help you get stronger. PT/OT and regular exercise are needed throughout the recovery period to strengthen the weakened muscles. The therapy program can be made to fit your specific needs.

What is CIDP?

CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) is a rare disorder of the nerves outside of the brain and spinal cord. It is characterized by weakness that may increase over time. It is caused when the covering of the nerves (called myelin) is damaged. The weakness usually occurs over two or more months.

What Causes CIDP?

The body's immune system which normally protects it thinks the myelin is not supposed to be there and attacks it. What starts this process is not clear. Some patients are found to have abnormal proteins in their blood, and these may start the damage.

How is CIDP Diagnosed?

The patient with CIDP usually has trouble walking, which gets worse over a few months. Patients can experience tingling or other weird sensations if the myelin that surrounds the nerves that controls your senses is damaged. A physical examination will usually show the loss of reflexes, such as the knee and ankle jerk. An evaluation by a neurologist will often include an electrical test, called a nerve

conduction electromyography study. It may show slowing of conduction of electrical signals or blocked conduction. These findings are often seen in CIDP. A lumbar puncture is taken to analyze the spinal fluid and will typically show elevated protein which may help confirm the diagnosis.

How is CIDP Treated?

Treatment of CIDP is somewhat of an art. If a patient shows good improvement with an initial treatment but again shows weakness, the treatment may be repeated or another therapy may be tried. Several treatment options are available for people with CIDP.

Prednisone:

Similar to protective anti-inflammatory corticosteroids that are normally made by the body, prednisone may be used as an initial treatment for several reasons. It often improves strength, can be conveniently taken by mouth and is inexpensive.

IVIG:

High dose intravenous immune globulins (IVIG), are protective blood proteins obtained from healthy volunteers and can be readily given through an arm vein. For more information on IVIG look to the earlier section on treatment of GBS.

Plasma Exchange:

(PE), or plasmapheresis, is when some of the patient's blood is removed and the blood cells are returned without the liquid plasma portion of the blood. It may work by removing harmful antibodies contained in the plasma. For more information on plasma exchange look to the earlier section on treatment of GBS.

Working With Your Doctor

When people go to the doctor they expect the doctor to make them better. They don't always realize that in order to get better they have to play an active role in the recovery process. When you have GBS or CIDP you will need to work with your doctor.

Your doctor will need you to do three things:

- Take your medications as directed and let your doctor know about any side effects
- Solve any problems that could keep you from taking your medication
- Keep track of any symptoms you have and report them to your doctor

By following this guideline, you can both work together to create a good treatment plan. Sometimes people also do not believe that medications will make them better, or make the symptoms go away. It usually takes awhile for medications to work, so you have to give it time.

Coping With GBS and CIDP

The teen years are definitely a difficult time to deal with a rare disorder! At a time when it's normal to be concerned with how you look, it can be hard to feel different. All teenagers who have an illness want to lead a "normal" life where they don't need medicine, have any limitations, or have to take care of themselves in any special way. This is perfectly normal. Teens who have learned to manage their illness feel so healthy and strong that they wonder whether they need to keep up with treatment and follow their doctor's orders.

Not taking care of your body can lead to problems. Tell your doctor how you feel. Talk about what you'd like to be doing and can't, and see if there is anything you can work out. This is all part of taking more control and becoming a player in your own medical care.

Getting adjusted to living with an illness takes time, patience, support and the will to learn and participate. People who deal with unexpected challenges often find an inner strength they might not have known was there before.

School and Friends

School can be a tough place for someone who is sick. One thing that might help is not hiding anything and let your peers know what is going on. You could talk to your class, or tell a teacher or a parent. Tell them that GBS and CIDP are not contagious at all, that you don't know how you got it and that you will get better. It is important for you and your friends to talk about your illness and help them to understand it. You may find this personally therapeutic as well.

It can be hard to explain to people what is going on, even to your classmates. They may not understand. They might just think you're faking, or that it's really not that bad. That is just how kids are. They don't understand and probably never will. Most of the time it is even hard for parents to understand how their kids feel. If your parents can't understand, how can you expect understanding from your friends? By explaining your problems you can open up to your friends and help them understand how you are feeling. If you don't

want to tell your friends to their faces, you can get your parents to talk to their parents. That way they can talk to your friends and explain it to them. It definitely is hard, and hanging out with friends may not be as easy but it is important to make the extra effort without pushing yourself too hard physically, mentally or emotionally.

Bringing it all Together

So now you know what GBS and CIDP are, and after reading this booklet you should have a pretty good idea of what you are up against. While it might sound scary you should not be afraid. Even though dealing with GBS and CIDP is tough, the knowledge you now have will help you get through. Just keep in mind that the road ahead of you will be a tough one to travel, but once you have made it down that road you will be a stronger person. We hope this booklet will help you to better understand some of the issues that teenagers and young adults face when dealing with GBS and CIDP. You now have what it takes to deal with GBS and CIDP. From this point on it is up to you to decide how you walk down the road that is in front of you.

GBS/CIDP FOUNDATION INTERNATIONAL

GBS/CIDP Foundation International is the only voluntary, nonprofit organization that provides support to patients of GBS/CIDP and their families, awards grants to researchers and offers education to the lay and professional communities.

Our Mission Statement

To improve the quality of life for individuals and families worldwide affected by GBS, CIDP and variants by:

- *Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support and reliable up-to-date information.*
- *Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.*
- *Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.*

The Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy Foundation International was founded by Robert and Estelle Benson as a means of helping others deal with GBS. Since it began in 1980 this grass roots effort has become an international organization with over 25,000 members in more than 160 chapters on five continents.

The Foundation provides printed information, educational opportunities, sponsors worldwide meetings, lectures and support groups, hosts the bi-annual GBS/CIDP International Symposium and encourages new findings by awarding grants for research.

The organization continually raises awareness by exhibiting at neurological conferences all over the world, by direct mail, by personal contact with hospitals, emergency rooms and physicians, and through their quarterly newsletter "The Communicator."

The following pages contain some "real life" experiences by teenagers. We thank them for sharing with past, present and future teens what they went through and helping to give the hope and optimism that helps GBS/CIDP'ers get through the episode.

LETTERS

Hello,

My name is Stephen Owens. I am currently 17 (will be 18 on November 14, 2008). I live in Metairie, Louisiana, just outside New Orleans. I am currently a senior at Archbishop Rummel High School. In January 2006, I was diagnosed with Guillain- Barre Syndrome. This illness was very tough for me as I am a very active person. I run track and compete in the high jump, so my legs are pushed to the limit every day. At the beginning of my sophomore season, I was doing conditioning drills, as the first month of the season is non-stop running. I noticed I was very short of breath and could not keep up with everyone else. Within the next few days, I noticed my left big toe became numb.

I paid no mind to it. As the days passed, I noticed the rest of my toes were becoming numb as well, and eventually my tongue became numb. I went to my ENT doctor, who could come up with no diagnosis other than the flu. After about 4 days, I was unable to move. I found it hard to breathe. After a few days, I went to East Jefferson General Hospital. They ran blood tests and once again, said it must be the flu that was making me feel weak. Well by now my face was becoming weak. My eyes could no longer focus as my vision became blurred. My mom then decided to make me an appointment with a neurologist at Children's Hospital in New Orleans. So on January 12, or at least I think that's the date, I went in for what I thought was just a routine doctor visit. I went into the ER and had a consultation with a doctor named Stephen Deputy. He asked me a number of questions and decided that I should take a nerve conduction test to see what it was that had plagued me. I took the test, which was extremely painful. Dr. Deputy then said he wanted to perform a spinal tap on me. Luckily for me, he had an emergency patient that needed to be tended to. I got switched to a doctor named Ann Tilton. She felt that a spinal tap was not necessary and after consulting me decided that I had Guillain- Barre' Syndrome. Obviously, as a 16 year old, I had never heard of this and had no idea what was tearing me apart. She explained what it was, but I couldn't pay attention. I was too mesmerized by the fact that something was actually seriously wrong with me. I hardly ever got sick. I'd never even had the flu. The part that really got to me was when a nurse came in and told me I would

be moved to a room where I could get treatment, and that I would be there for at least 4 days. I absolutely hated this because it caught me so off guard. I didn't even notice that my mom had brought my clothes in a bag when we arrived at the hospital. I can actually remember the first thing that I said when they explained the recovery process. I said "Am I going to be able to run track this year?" It was crazy to be thinking about that, but when you love doing something that much, it hurts for someone to tell you that you're paralyzed.

The nurse gave me an IV and started to treat me with gamma globulin. I would be on cycles for at least 4 days. I went straight to the ICU where I could be monitored around the clock. I hated it in there more than anything else. It was a cramped area and I was in the corner in a makeshift room. I was surrounded by little kids. I felt so bad because right in front of my bed was a 6 year old who had just had open heart surgery. I thought I didn't belong in there with them. After 2 days in the ICU, I went to a private room, where I met and talked to what seemed like a hundred doctors, some neurologists, some therapists. They each tried to explain what was going to happen to me and how to cope with it.

I can remember all I really wanted was to be with my friends. That was probably the hardest thing next to not being able to run track. Every day I hoped that my friends would show up and visit me. They actually came the first day I was in the ICU, but they were not allowed in because they weren't family. This was pretty depressing. On the 4th day in the hospital, three of my friends came. It was great. We laughed at stupid stuff and joked around like we always do. It made me feel like I was getting better just being around them.

The day after my friends came, I sat up for the first time on my own. It felt great. I was actually making progress, and faster progress than the doctors thought I was capable of making. It felt great. And since that day I have been moving forward.

After being able to sit up, I started physical therapy. It was so tedious to have to learn to walk again, but I was ready and willing to go through it. It took time, but I could walk again (with the help of a walker of course).

I got out of the hospital after 9 days of non-stop tiring therapy. Going back home felt funny. The day after I returned home, my friends and I went out (with me in a wheelchair) and just hung out like we always did. It was probably one of the best nights I've ever had.

I knew the transition back would be hard, especially the one to

school. After about 3 weeks of being home, I started going to school again. I had missed 2 months, but luckily my teachers understood and let me just pick up with where everyone else was as it would be impossible to make up all that work. Track season was actually still going on. Every day after school I went and hung around the track. Just being there made me happy.

I went to physical therapy twice a week. Although it wore me out, I loved going. Every time I went I could see progress made. I realized that with the progress I was making, I might be able to make the track season and get to jump. This motivated me even more.

I was soon able to start jumping. The only problem was that I wasn't able to jump nearly as high as I used to. This got to me. I got to jump in 3 meets that year. In all of them I would be too tired to jump more than 10 or 11 times. It was so frustrating to go from one of the best to one of the worst. My coach told me that the best thing was that I was actually jumping just weeks after being paralyzed. Soon everyone was telling me this. Although I was still angered by my lack of success on the track, I was happy to see the success I was making in my recovery.

Now, it's almost 2 years later, and I am obsessed with fitness. I work out every day and love to run. I still do track and am even better and stronger than I was pre-Guillain-Barre'. My experience actually has inspired me to pursue a career in medicine.

Everyone affected with this disease will tell you, it's horrifying. I can't go through a day without thinking of my experience. But, if there is one good thing that came out of the disease, it was that I have become a better person. I have a much higher respect for life than I ever have. I thank God every day when I get up that I can move and stay active. Also, I have an enormous respect for my family, as they were there with me for the whole ride.

So that's my story. Sorry if it's more than what you wanted, but I didn't want to leave anything out. Thank you for running the foundation that means so much to me and I'd love to play a part in it with you.

Sincerely,
Stephen Owens

October 10, 2007

Samantha Cunningham
London, England

At the age of 17 I woke up and was unable to move from the bed where I lay. My face had “dropped” the day before and I was unable to move my face normally. I had Glandular Fever and was really ill – not being able to move may just be stiffness I thought. I tried to move out of bed – but I couldn’t – none of my limbs were working and I began to panic. I shouted for my mum and to my horror no real sound came out. An ambulance was called and I was taken to a near by hospital who told me it was a virus and sent me home – on returning home I worsened to the point that my eyes were not working and I could no longer blink or see. I was then sent to a different hospital where I deteriorated very quickly – even so they could not figure out what was wrong with me. The nurses at the hospital would try to get me out of bed and make me walk – I would collapse in a heap – my body did not work. I had various scans and tests and a lumbar puncture and eventually they discovered I had Guillain Barre Syndrome – that meant nothing to me at the time – I couldn’t see, or blink, I couldn’t move my face, talk or swallow – I was frozen perfectly still and finding it harder and harder to breathe. Imagine being trapped in a body that doesn’t move – in so much pain that you want to shout, only you can’t shout, you can’t do anything because you’re completely paralyzed from the head down – its unimaginable. I got much worse before I got better. I had my body flushed with medicine and stayed in the hospital for what seemed like an eternity. It was a Specialist Neurological Hospital and the staff absolutely saved my life, in every sense that someone can be saved. At times I would just lay there in so much pain that I wished to just die – to fall asleep and never wake up – with a tube to breathe and a tube to feed me it didn’t feel like much of a life and sometimes I wanted to give up – if I couldn’t move or talk or see then what was the point, I thought. One morning I woke to blurred vision – with an excitement words cannot describe I tried and tried to move my limbs until suddenly my left arm shot up in the air – “This is it” I thought – “I’m doing it. I had heard the doctors tell my mum that I would never be able to walk again and would more than likely be wheelchair bound indefinitely. “I’M SEVENTEEN!!” I thought. I don’t want a bloody wheelchair. “If I can’t walk now I’ll make myself

walk.” From that moment on I felt hopeful – if I could move one arm then I could do anything at all. Slowly parts of my body regained movement and I had Physio Therapy to learn how to walk again, which is one of the hardest things anyone could ever do. “Take it SLOWLY”* I would wait until the nurses were busy – get in the wheelchair they provided me with – wheel myself to the upper floor of the hospital – get OUT of the wheel chair and practice walking. Every time I fell down, I got back up – and believe me, I fell! “Get up Sam, WALK Sam” I’d think in my head with more determination than I had ever felt in my life and more fear than I had ever experienced. I got better and better. The right side of my face still shows signs of paralysis but that’s a small price to pay considering I recovered in every other way. Now when things get tough I think – “When you fell down – you got back up...” and for someone who couldn’t even stand properly that took strength. In comparison everything else seems easy to achieve – so every time I fall – I just pick myself up and carry on. People don’t need to know what you’ve been through in life, as long as overcoming terrible circumstances leaves you with hope then that’s more than enough strength to get through anything. That’s a massive lesson to learn at just 17, but I thank God every day for showing me what I can do if I have the will to do so. This is dedicated to everyone who has had or still has GBS. My thoughts and prayers are with you always.

Hi,

My name is Paige Brusso and I'm 19. I was 17 when I was diagnosed with CIDP and it was my senior year in high school. I am now in college and it has been a real struggle trying to just live my life as normal as possible. In high school my boyfriend carried me onto the dance floor at our senior prom and at graduation my English teacher had to help me up onto the stage. After undergoing Plasmapheresis, several surgeries, and now IVIG I am going to college and trying to obtain a job for the first time since I became ill. The one thing that helped me cope with my illness was trying to live my life as normally as possible. I still went on vacation, I still went to college, and I still hang out with friends. I also have an amazing support system. It was immensely hard at first being paralyzed but now I'm living life to the fullest and I go to the gym everyday (which is a huge accomplishment.) There are still a lot of struggles to come in my future regarding my illness but I feel like I'm prepared for anything with a positive attitude and a great family.

Thanks for your time,

Paige Brusso

"Don't wait for the storm to pass, Learn to dance in the rain!"

February 2, 2007

College Essay
By Caitlin Vierra
Reston, VA

The voices of the doctors saying, “She may not make it through,” still echo in my head to this day. It felt so degrading when I had to resort to crawling on my bare elbows and knees. It was so hard to try to tell my mom that I could barely move, she made me crawl to the bath and lifted me up and I fell face first into the water. I immediately started to try and hold my tears back. That was the defining moment when my parents decided to take me to the hospital. My mother and father strapped me into my desk chair using my robe belt, and carried me down the stairs and into the car. My head couldn’t stay in place from the loss of nerve feeling, and I was exhausted from vomiting constantly and from the lack of nutrients. When we arrived at the hospital emergency room they first treated me for dehydration, then my family physician came in and had me transferred to Fairfax Hospital. Most people would like to remember an ambulance ride, but I was so drained that I felt as though I was in a dream, no, a nightmare. I don’t even remember being moved into my hospital room in the Intensive Care Unit (ICU). Even though I didn’t have feeling, I could still feel the pain of the IV’s being shoved into my arms and feeling the clear liquid sinking its way into my body. It was January 29, 2005.

As the week went on I became weaker and weaker as the loss of feeling moved up my body. Some nights I had a hard time breathing so the nurses put me on oxygen so I could sleep. I underwent extensive testing – MRIs, blood tests, and a spinal tap. The doctors were 5% sure that I had a sickness called Guillain-Barre syndrome (GBS). GBS is “a disorder in which the body’s immune system attacks part of the nervous system.” But in my case it started shutting down my entire nervous system. I was pretty strong emotionally until the third day when my friend Brittany called me. Then I broke down because she was so worried – no one had told her what had happened to me until that day. I had to get off of the phone because I was choking on my tears and couldn’t breathe. I had support from my friend Taylor who had a non-cancerous spinal tumor removed in 8th grade. She knew what I was going through, and it helped that she visited me every day she could. Lots of friends visited, including my swim mates, and gave me the strength to be myself again.

Because of the GBS and hospitalization, I missed the district swim meet where I was supposed to be swimming the 100 yard backstroke, my favorite. Swim team is always so much fun, and we always work together and treat one another like family. I wanted to show my team that I could be strong, thanks to their encouragement, and come back to make a stand for myself. I told myself that I couldn't stay this way. The doctors talked about putting me in a rehabilitation center for 4-6 weeks but I told them, "I am going to get out of here and go to my swim team banquet in two weeks." They said it was an unlikely goal but I never stopped hoping. I still couldn't feel my fingers or anything else. The muscles in my face made me look as though I had had a stroke but my mother still called me beautiful. I am as stubborn as can be, so when the doctors told me that I probably wouldn't make it to the banquet that's when I decided to prove them wrong.

I remember the first time I sat up in my hospital bed with excruciating detail. It's hard to comprehend that it would be hard to sit up, but after being unable to move from one position for two weeks and losing 20 pounds you can see how agonizing it would be. The nurse grabbed one side of me and my mom grabbed the other. They then began lifting me from my laying position into sitting. I had no feeling in my legs and arms, and yet during those moments the most insufferable pain shot through my entire body. All my muscles stiffened in an instant as tears streamed down my face. They quickly set me back into place so I wasn't in pain, but I wanted to walk again. About every hour I would try to sit up for a minute at a time. At first my mom always had to help me pull myself up then I found a way to do it on my own. I refused help from anyone. I wanted to get better and I knew I had the determination to do it! I began sitting on the edge of my bed and pulling myself into my walker. I then progressed into walking around in it for a short time. I was so happy just to move again, and I felt like I was ready to do anything I put my mind to. By the end of my hospital stay the doctors called me their "Star," since what I told them had come true – I was released in time to go to my swim team banquet. It was a sunny day on February 14, 2005 when I went home. That was the most majestic day of my life, and the greatest Valentines Day gift I could ask for. After school got out my friends all came over, and I showed off how I could use my walker. As the days went on I figured how to use the items around me – tables, counters, walls – to help me walk. I refused to use my walker most of the time.

The banquet day finally arrived. I put on a dress, my mom curled my hair and then helped me put on make-up so that I didn't look so ill. As we pulled up to the country club where the banquet was being held, my swim team captains came out to get me. They wheel chaired me into the room, surprising everyone. It felt amazing to see the people who cared for me again. One of our banquet traditions involves handing out paper plate awards. I didn't expect one but they awarded me the "Most Injured" award. I was so happy that I had gotten where I was that night. It was heaven on earth – just laughing and hearing jokes from friends.

Within a few days, I started with home tutoring and home physical therapy and soon started going to my sports therapist, Dallas, for physical therapy. Home schooling continued for 4 months. It was difficult trying to catch up since I was constantly tired and so far behind. But I was driven to be normal again, and to do well. I made it back to school for two afternoon classes by the end of the school year. I had gained 10 pounds back and was swimming again by June 2005. It helped to know that my friends and family always believed in me and never gave up hope.

Junior year though I faced many new challenges. I signed up for hard courses thinking I was 100% back to normal. I was wrong. Though the GBS seemed to have vanished, it left its prints on the person that I am today. I developed chronic fatigue syndrome, which left me exhausted during the school day. I refused to drop any of my classes or take easier ones. I thought that if I can get through being sick then I can make it through a school year without problems. I would wake up in the mornings and blackout while taking showers or start heaving. My doctor tested me for everything from adrenal gland failure and diabetes, to Lyme's disease. The seemingly endless tests all came out negative. I realized something had to be done. My mother contacted a specialist at Johns Hopkins in the middle of last year; we could not get an appointment until June though. He explained how rare (I'm a one in a million kid!!) and serious GBS is, and told me I need to be exercising constantly during the week to keep my stamina up, and to feel normal again. He also prescribed medication to soothe the painful misfiring of nerves that are still healing in my legs and face. Since visiting the doctor I have found daily life easier. I go to the gym almost daily and have much more energy to focus on my academics. My grades dramatically improved on my first interims this year.

I feel as though now I can achieve what I set my mind to. I am constantly reminded about how tough life is, yet I look at the good things. People don't seem to realize how much you grow up when faced with a critical hardship in life. Through the trials of life we gain inner strength, and with that we need to show people how to live to the greatest potential possible. I know who I am, I know who my true friends are, and I know what I want. I was given a second chance with my health, now all that I ask is that I have a second chance with my education to prove what I can truly accomplish.

Hi,

My name is Kristin Bueb, I live in Colorado and am 18 years old. I had GBS three years ago when I was 15. It all started about a week after I had gotten back from vacation during the summer. It started with a little bit of numbness and tingling in my legs, but nothing to keep me from going out to the movies with my friends. The next day when I awoke and stood up out of bed, it seemed like my hips weren't working and I had difficulty walking. It was my core muscles that were being affected at that point, I had trouble standing up from sitting, and it was a huge ordeal to get up off of the couch. This seemed so strange because the day before I was fine for the most part. By the time lunch time came around that day I couldn't swallow very easily, and I wasn't able to talk very loud either. By dinner I couldn't even swallow water. By the time I went to bed that night, once I was down I was down, and couldn't do anything to move myself in any way. After calling the doctor and being advised to take me to the hospital, my parents nearly had to carry me into the car, and then into the emergency room. I spent the next few hours undergoing the ever so pleasant lumbar puncture, and other neurological tests. The next morning I was admitted into the hospital, but they still couldn't formally diagnose me since I had just been to Europe, which opened up numerous other ailments. That whole day was another day of tests (another pleasant lumbar puncture included) and examinations by so many different doctors. The next day, when they decided to move me down to the intensive care unit just in case I stopped breathing...no more than 15 minutes after I was in my room did I stop breathing, and had to be put on a ventilator. They then formally diagnosed me with GBS and I was also put on IVIG. From then on the majority of my experience was a haze because I was on so many drugs. I saw occupational therapists to keep my motor skills up. After about four days, I was able to come off of my ventilator and rely on a bi-pap machine, sometimes during the day I only relied on oxygen. Within the next few days they took me off of my feeding tube, and I was able to have a soft food diet, and I started seeing a physical therapist. When I was then able to walk, guided by a nurse and a rolling chair, to the shower, and take a shower by myself (though it was a long one), they moved me back into the general admission. From then on I kept seeing therapists, only needed the bi-pap machine at night, and was doing extraordinarily better at this

point. The doctors were amazed because at this point I had only been in the hospital for just about two weeks, and they were considering discharging me.

I was discharged within the next couple of days, after they determined that my breathing and heart rate would be okay without monitoring. I didn't need any additional occupational or physical therapy. My case was a very short one, but a pretty bad one. While my lungs were collapsed after I had stopped breathing, I also contracted pneumonia, and my heart rate dropped so dramatically whenever I would sleep that I almost needed a heart monitor. I fortunately didn't have to deal with school while I went through this, but since I got out of the hospital only two weeks before school started, the doctors advised me not to go back to school for a few more weeks, or just take half days. I wanted to go back to school though, and didn't want to miss anything (although now I don't see why I was so anxious to go back to school...). I agreed to take one day off a week for a while, which only happened the first week of school. My teachers were very understanding though, and offered to let me keep a book in class and at home so I didn't have to carry them, because carrying a backpack was difficult. I also gave up auditioning for the play, because rehearsal would have been another few hours on my day. I also had to skip homecoming that year because there was no way I would make it through a whole night of dancing. I did start to push myself harder though. I got a job, joined a few more extra curricular activities than I was already in, and was out all of the time on the weekends.

When I had gotten home from the hospital and started to try to live my normal life, I realized that it just wasn't going to happen, nothing would be the same, but I didn't want to believe that. I was extraordinarily stubborn and believed that I could do anything. I was in major denial for about a year. The next summer when I had some down time to start thinking about that past year, I realized that my life would never be the same, and that I needed to slow it down if I didn't want to relapse, because I was always so fatigued, but denied that it had anything to do with my GBS. Once I entered my junior year in high school, I didn't do as much as I had the previous year. I didn't go out with my friends as much, but I didn't shut myself off completely from them. I was still working, I was involved in various extra curricular activities, holding leadership positions in some, and taking a few advanced placement classes in school, so I had to learn to compromise. If I was going to work a long shift, I wouldn't go out

that night, or if I did, I'd have people over to watch a movie. The one fall-back of this seemingly logical plan was that I never told anyone, not my parents or friends, that I had been having a hard time and I needed some time to slow down. Eventually my friends started getting mad at me when I wouldn't make it to parties on the weekends, or when I wouldn't plan something for everyone to do, since nobody wanted to plan things themselves. As a result of this, I then went into depression. School was getting harder, my friendships were getting shaky, and my parents were putting pressure on me to do better in school. I kept it all bottled up though, because I thought that I could handle it. I never told anybody, and to this day have only recently told my best friend. Eventually things settled down, and I realize now that you can't be afraid to ask for help. Life won't ever be the same, but I should be thankful that I can live life, and if I need a little help here and there, that's okay. I think if my friends would've known that I was just really tired and needed to take it easy, they would have been okay with that, they were very supportive of me the whole time I was in the hospital and afterwards, making sure that I was okay. My advice would be that you shouldn't be afraid to admit that your life has now changed. There are plenty of people there for you, just look at how many people come to visit you in the hospital or send you cards, or how your parents spend the night by your bedside. There are also a lot of us out here that have gone through the same thing and are always willing to share tips and experiences! Don't be afraid to take advantage of the people that love you, because they want to help! Life will eventually go on, I know it feels like it never will, and GBS is so scary and unfamiliar that you never know what to expect, but in the end everything turns out okay.

I hope this helps. I think this teen book is a great idea!

Thanks!
Kristin

