

# Guillain-Barré Syndrome

## SUPPORT GROUP NEW ZEALAND TRUST

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### NEWSLETTER MARCH 2011

***If undelivered please return to:***

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## **Editors Note**

It hardly seems possible that Christmas has been and gone and Easter is looming on the horizon along with our own Conference the following weekend.

We had another successful coffee morning here in the BOP in mid January. It was good to see a couple of new faces plus the “regulars”. I hope to organise another one mid June, once the kiwifruit season (or silly season as we prefer to call it) has been and gone.

I want to thank everybody who has sent in articles for the newsletter over the past year. It has certainly made my job a lot easier. I desperately need some new stories from members, so please put pen to paper and send it in. If you have any suggestions for articles you'd like to see in the magazine please let me know and I'll do my best to find and print it.

To those of you who live in Christchurch please accept our heartfelt sympathy. We hope that you and your families are safe and can soon begin to rebuild your lives.

**Chris**



## **Presidents Paragraph:**



I never fail to be impressed by those who do hospital visiting. It a cornerstone of our organisation and patients and families really appreciate it. It has been uppermost in my thoughts recently as two people I had been visiting did not recover. Most people who are afflicted with GBS/CIDP recover but it is a sad reality that a small proportion die.

On a brighter note I am looking forward to the fifth Annual Conference being held here in Wellington. I'm looking forward to it for a number of reasons: meeting patients, caregivers and family members coping with GBS/CIDP reminds me that every journey through this disturbing malady is a personal one. We may have the same medical condition but we experience it in intensely personal ways. The conference always refreshes my understanding about GBS/CIDP and provides me with up to date knowledge to share with others. I also enjoy meeting again stalwarts who come to every conference because they want to support the organisation and they want to share their experience with others. The meeting, greeting, sharing, learning, exchanging, understanding and goodwill that surrounds the conference are priceless. I hope everyone who can will make an effort to be there. You will not be disappointed.

In a nutshell, the conference brings the 'family' together and it is unique in this regard. There is no other conference in New Zealand which focuses on GBS/CIDP and which seeks to provide some understanding to bewildered patients and families.

As I write this piece me ears are tuned to the tragedy unfolding in Christchurch following the damaging earthquake. My heart goes out to people there but also to families in other places anxiously waiting to get accurate information. I'm also reminded about how little we really know about the extreme forces of nature. We know a great deal but not everything so on-going research is essential. A bit like GBS/CIDP, we know a great deal but not everything that is why on-going research is needed and that is another reason to come to the conference and hear about the latest research. In the meantime just reflect upon the strength of the human spirit in sickness and in natural disasters.

**Bob Stothart**



## Secretary's Jottings

What a chapter of natural disasters seems to have befallen this country in the last few months! Sat up here in sunny Nelson it is difficult to imagine the sheer scale of the distress and heartache suffered by the Christchurch and Greymouth populations as they struggle to deal with the events that have befallen them but – as Mayor Bob Parker commented in one of his many television reports - even amongst all these dark clouds there are rays of sunshine and for us it has been to marvel at the stoic resilience of New Zealanders in dealing with situations that would floor most people.

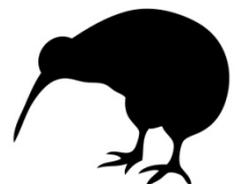
On a personal level the “arrival” of GBS was an unexpected disaster for most of us and we know just what a long uphill battle it was to get back to how we were and maybe we will never get back to that point but the rays of sunshine were there as well like finally being able to do up the buttons on your shirt or drink your wine from a glass rather than a straw! As I write our local group are keeping their collective fingers crossed for our friend Jon Anda who is in the midst of his stem cell treatment in the USA in an attempt to beat his particularly nasty form of GBS – we wish him all the best.

Thank you to all of you that have renewed your membership – I am slowly working through the pile of receipts forwarded by our Treasurer but with a full programme of ticky tours for our UK visitors underway progress is a little slower than I might wish – please bear with me - your membership cards will arrive shortly!

Elsewhere in this newsletter is the formal notification about the AGM and I shall be sending out the appropriate papers to financial members by the end of the month. If you can't make the meeting in person please do take the time to complete the Proxy Form. Like all AGM's a lot of the business is “boring stuff” but it also provides a forum for you the members to let your Board know how you would like to see the Group develop and where we could improve on present performance. There is no monopoly on good ideas and constructive criticism is always a good reminder that we can all “do better”.

***As always take care***

***Tony***



## **A Personal Encounter..... ERIKA IS WALKING AGAIN!**

*This article was sent to us by a family in Oklahoma America who like many families here under went all the same fears, challenges, lows and highs that we have experienced.*

Eleven year old, Erika Taylor went home sick from school on January 3, 2005. This was the first day back from a two week Christmas break and she had been looking forward to seeing all of her school friends. Erika went to the doctor with an ear infection and started antibiotics on that Monday. She went to school on Tuesday. That night, January 4<sup>th</sup>, she started throwing up. She stayed home from school the next day and complained that her feet hurt. She rested all day. On Thursday she stayed home again from school. This time she could hardly walk. She continued to throw up. Medicine was called in to help with the vomiting. On Friday she was taken back to the doctor. At this point she could not walk at all on her own. The tests showed that she probably had a virus and it made her very weak. The family doctor contacted the parents on Friday afternoon and suggested that they take her to the Hospital Emergency Room so that she could be examined by the Pediatrician on call.

On Saturday, January 8<sup>th</sup>, Erika could not walk or even raise her arms. She was totally paralyzed! Erika was taken to the local hospital to find out what was going on. Dr. Ellis, the pediatrician, checked Erika's reflexes and she had no response. He diagnosed her and ordered a transfer to The Children's Hospital in OKC, OK. The parents drove to the hospital not knowing what to expect and how severe the diagnosis was. The doctor had written GUILLAIN BARRE on the note. What in the world was that? The parents had never heard of it. They were informed that Erika would need a Lumbar Puncture. (This is also known as a spinal tap.) The parents tried to stay calm. They knew that Erika would have to endure a lot of pain just with the spinal tap. The nurse informed Erika's parents that they could probably forget this school year. The nurse explained that Guillain Barré Syndrome would mean that Erika would have to learn to walk again and it was a long recovery process if she fully recovered. The parents were devastated yet hopeful to know that there was a good chance for recovery. After four tries for the spinal tap in ER, Erika was admitted to the 6<sup>th</sup> floor Pediatric Intensive Care Unit. The second try for the spinal tap on the 6<sup>th</sup> floor was a success. Erika at this point could not walk, barely could talk, and she was having trouble breathing. The doctors informed them that Erika more than likely did have the Guillain Barré Disorder. An article from the internet stated that 1 in 100,000 people are affected with this disease. Also known as GBS. (Guillain Barré Syndrome) This could be caused from a viral or bacterial infection. There have also been articles that suggest that an immunization or influenza vaccine could also cause a person to develop GBS. Still unsure of the severity, they started calling family and friends and asking them to pray for Erika.

By Monday, January 10<sup>th</sup>, Erika felt like she was going to die. She knew if that happened she would, "go to Heaven to be with JESUS". Her parents were devastated over her feelings. They informed Erika that GOD was not through working on her and that GOD had more plans for her. It was the disorder that was affecting her ability to breathe on her own. Her parents had been informed that this would be a possibility with the GBS diagnosis. The GBS symptoms start by the eating away at the lining of the nerves of the feet. It goes from the feet and works its way to the head. This will sometimes affect the ability to breathe. Erika was placed on a ventilator on Monday morning to help her breathe easier. This left her with the inability to talk.

Erika's dad, Brian, came up with a list of words so that Erika could nod her head at the words listed. This was the only way to communicate for 16 days. This was their only way of knowing what was hurting or bothering Erika. Some words were added along the way. The alphabet was also used to spell out what might need attention. Her parents joked that trying to understand that her arm pit itched was tough to figure out. Erika's mom and dad took turns staying up with Erika 24 hours a day to make sure she did not need to be suctioned in her tube or needed a fan or wanted to turn on her side. It was a very difficult time. However, Erika was able to keep her smile even while she was sick and miserable. Lying flat on her back for 18 days was not easy on a girl that had always been active and full of life.

## **ERIKA IS WALKING AGAIN!**

A treatment called Plasmaphoresis was started. Plasmaphoresis is performed by removing the whole blood from the body and processed so that the red and white blood cells are separated from the plasma. The blood cells, without the plasma, are then returned back into the body. This is done to help reduce the duration and severity of GBS. This was performed every other day for five treatments.

Erika stayed calm once she knew that she was going to get better. Once the breathing was affected then the disease started exiting the body from the head and going back to the feet. The doctors conducted a nerve test to find out the severity of the case. The test results showed that Erika had a very severe case of GBS. They could not, however, give a definite time line for recovery. Each case is different and the time it takes to recover can vary from one patient to the next. Most studies have suggested that the recovery could be anywhere from six months to two years. The parents were reassured in knowing that there is a 95 % survival rate and the majority of the cases completely recover.

The outpouring of prayers, letters, phone calls, visits, and love offerings were enormous. Cards from all over the United States were sent to the hospital. The hospital volunteer auxiliary knew where Erika's room was from all the cards and flowers being delivered. Erika's room was covered in cards and dolphin posters. She and her 5<sup>th</sup> grade teacher, Kayla Moore, will forever share a special bond. Her teacher visited every week-end. Her class brought something special each week, including a home-made video of commercials the students had created. The prayers were felt and answered. Erika was taken off the ventilator on Wednesday, January 26<sup>th</sup>, and she could finally breathe on her own again. The feeding tube was left to help in giving her the nutrients she needed to regain her strength. The doctors felt they should be just as aggressive as the disease was with Erika so they started another treatment. Intravenous immune globulin (IVIg) was given for five days. This is a plasma product formed by taking antibiotics from about 10,000 donors and mixing them together.

On Friday, January 28<sup>th</sup>, Erika was moved to the third floor and the feeding tube was removed. The special attention that was given by the PICU floor was greatly missed. Erika was now being seen by the Physical Therapists and the hard task of trying to move her body was about to begin. The slightest movement of her body resulted in excruciating pain. She was miserable. It was a helpless state for the parents for they were unable to make the pain go away.

Erika was transferred to The Children's Center where she would start her rehabilitation process. It was like starting over to learn to feed, clothe, and walk by herself. She was determined to prove all of the doctors and past articles wrong. Her strong will helped to surpass all of the predictions as to the time-frame of recovery. She continued to fight for a quick recovery.

With the hospital stay at 25 days, her parents expected at least a two month stay at The Children's Center. Erika never gave up. Neither did her strong support system. The cards, prayers, phone calls, visits, and special gifts continued. Most of all, it was GOD answering the prayers of so many concerned people. People who were unknown were placing the eleven year old girl on their prayer chains. Even e-mails of concern were sent. Children from their local church even realized the power of prayer. The experience will last forever as will the love and faith that GOD will help to overcome what obstacles are faced.

Erika stayed at The Children's Center for 23 days. The treatment received was wonderful. The Christian atmosphere was outstanding. GOD'S presence could definitely be felt. Erika had to learn to walk again. She had mentioned to her grandmother that she was going to walk for her on her birthday. As her grandmother, Nona, turned the corner on February 19<sup>th</sup>, Erika was on a walker and walking toward her. Her personal goal had been met. What a wonderful birthday present. She still had one more goal to accomplish and that was to be strong, able to leave the center, and return to school. Her heart was hurting to be with her classmates and home in her own bed. She commented to the doctor after a long week-end of friends visiting that she was going home that week. (Friday to be exact.)



## ERIKA IS WALKING AGAIN!

She was ready to go home. Her rehabilitation goals were accomplished. Erika was eating, dressing, and walking by herself. Erika came home from her ordeal on February 23, 2005. The doctor had commented that the last patient with GBS spent four months in the hospital and four months in the rehab center. Here Erika was home in 48 days. Nothing short of a miracle! The excitement of actually coming home was unexplainable. The church and the school marquee announced that Erika was coming home. What a testimony to be walking again.

Erika managed to keep up with her school work while being home schooled during her illness. She made the all A's Honor Roll for her strong determination to not get behind on her school work. What a wonderful accomplishment.

Erika has always been one to volunteer to help others. Her class had discussed the idea earlier in the school year to participate in the OKC Memorial Kids Run Marathon. Erika was determined to make it home before the run. This year, through all of her difficulty, Erika will be one of the participants in the OKC Memorial Kids Run Marathon. She plans on completing the run, alongside her classmates, without the use of a wheelchair.

### UPDATE



We are celebrating our sixth year since my daughter had GBS. She was 11 yrs old at the time and was on a ventilator for 16 days while staying in the hospital for a month and rehab for a month.

Erika is now a junior at Antlers High School in Antlers, OK. She still has signs of muscle weakness in her ankles and joints but is determined to play softball. She has such a strong will and refuses to let any signs from her GBS ordeal get in her way of living life to its fullest. Erika will be 18 years old in July and plans to spend her birthday by skydiving. She plans to go to college and become a physical therapist.

We are thankful that you have such an informative website for people to search information regarding this horrible disease

*In October 2010 Erika was one of 50 students selected to serve on the 2010 – 2011 Oklahoma State Superintendents Student Advisory Council. Congratulations Erika and thank you for sharing your story. (ed)*

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## Interesting Information on Your Blood Type

*According to a Japanese institute that does research on blood types, there are certain personality traits that seem to match up with certain blood types. How do you rate?*

Does Your Blood Type Reveal Your Personality?	
<b>TYPE O</b>	You want to be a leader, and when you see something you want, you keep striving until you achieve your goal. You are a trend-setter, loyal, passionate, and self-confident. Your weaknesses include vanity and jealousy and a tendency to be too competitive.
<b>TYPE A</b>	You like harmony, peace and organization. You work well with others, and are sensitive, patient and affectionate. Among your weaknesses are stubbornness and an inability to relax.
<b>TYPE B</b>	You're a rugged individualist, who is straightforward and likes to do things your own way. Creative and flexible, you adapt easily to any situation. But your insistence on being independent can sometimes go too far and become a weakness.
<b>TYPE AB</b>	Cool and controlled, you're generally well liked and always put people at ease. You're a natural entertainer who's tactful and fair. But you're standoffish, blunt, and have difficulty making decisions.

## Interesting Information on Your Blood Type

Blood Type and RH	How many People Have It in NZ
O+	38%
O-	9%
A+	32%
A-	6%
B+	9%
B-	2%
AB+	3%
AB-	1%

## Blood Types You Can Receive

If Your Type Is:-	You Can Receive							
	O-	O+	B-	B+	A-	A+	AB-	AB+
AB+	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
AB-	Yes		Yes		Yes		Yes	
A+	Yes	Yes			Yes	Yes		
A-	Yes				Yes			
B+	Yes	Yes	Yes	Yes				
B-	Yes		Yes					
O+	Yes	Yes						
O-	Yes							

## Donating Blood After GBS/CIDP

*I emailed the NZ Blood Service and asked them what their policy was. Below is the reply I received from Dr S Ghosh, Transfusion Medicine Specialist.*

“At present we accept donors with a history of Guillain-Barré Syndrome who have fully recovered and off treatment for two years or longer. We do not accept blood donations from those who have a recurrence of the disease and / or require regular treatment.”



## Helping Children Cope by Maria De Cort

When my husband Roy was hospitalised mid-last year and diagnosed with GBS one of the many things whizzing around in my head in those crazy first few weeks was concern for how to help our three-year-old daughter Megan cope with it all. It was a very unsettling time for her but she amazed us with her resilience and maturity that at times seemed beyond her years. We tried a number of things to help make it all less scary for her and, with not knowing what sort of time frames we would be looking at, to help bring some sort of normality to her life.

I thought it might be helpful to share some of these ideas, activities and coping strategies in the newsletter in case someone else is in a similar situation with a young child coping with a close relative's illness.

- As well as keeping a diary myself, which I could later share with Roy, I started a scrapbook for Megan. We took photos at home and at the hospital with Daddy and I would write little "stories" by them for her. I also included pictures of things we would see at the hospital (cut out from a useful booklet we found in the hospital cafeteria) so I could explain some of the machines, people, etc. Megan would add to the book with pictures she'd drawn and would take it up to share with Daddy sometimes. We also made scrapbook pages to add to the learning journal she has at pre-school so she could show them to her teachers and share how she was feeling with them.



- We would make sure Daddy's locker was never without stickers, colouring-in books or sweets for good little visitors and a few times I bought presents for Megan and stowed them away and we told her that the nurses had helped Daddy pick out a special present for her for helping out Mummy at home. One of the special gifts Daddy gave Megan during his first week in hospital was a book called *Hugless Douglas*. It turned out to be a really good platform for us to invent special new hugs – such as the finger hug – we could use as Daddy's paralysis spread.

- We made good use of our local Toy Library. The first week Daddy was in hospital I got Megan out a doctor's kit bag and she set up our lounge with all her dollies laying in beds like Daddy in his room on Ward 28 and set about doing her "rounds" looking after them. We also hired a few DVDs that had hospital themes and it gave us a chance to talk about lots of things and made the hospital less scary when we visited as it had become familiar from our time in its animated equivalents! As a surprise for Daddy a few weeks into his hospital stay when he was quite low I hired a doctor dress-up outfit for Megan and we arrived for our visit with Dr Megan ready to administer some big doses of TLC.



- The nurses on Daddy's ward were really great too. On one of her first visits to see Daddy a nurse transformed a surgical glove into a balloon with a big smiley face on it. Many of the nurses also let Megan help do some of Daddy's "obs", eg putting the thermometer in his ear or putting the alligator clip on his finger which made her feel very important and like she was having an important role in making Daddy better.



- Megan noticed how many of the nurses had really cool name badges and when I found out that a lady in Timaru had made them I got my parents who live there on to ordering Megan her own nurse badge. We made a big deal out of it being a reward for how she was being such a good visitor and nurse's assistant.

- One thing we did, which was as much for Roy as it was for Megan, was making a special effort to keep some of the favourite parts our daily routine in place, such as bedtime stories. We would have an early dinner then get Megan dressed in her PJs and drive up to the hospital (lucky we live just a 10 minute drive away from public) so she could snuggle on Daddy's bed for a story. She slept better on those nights – they were some special moments to witness as she would snuggle in close and tell him how much she loved him and missed him.



- One thing which kept Roy "sane" was listening to the radio and downloaded music and comedy shows on iPods our friends lent him and kept continually stocked up. One of our friends has a recording studio at home and, as a surprise for Daddy, Megan and I popped around one evening and recorded her singing a few songs for Daddy and loaded them on to an iPod for him to listen to.



## Links to Disability Services

Following on from the article for Care Givers in the last magazine Donald Martin provided these links to an on line library which is free and open to all. It has information on a number of disability related issues, including orthotics, wheel chair use, pain management and other topics relevant to GBSers CIDPer and MFers etc.

<http://www.ccsdisabilityaction.org.nz/Support/LibraryampInformationServices/tabid/77/Default.aspx>

<http://www.ccsdisabilityaction.org.nz/> or Library and Information Services form the home page

## Physio Help Available

If you need extra physio help and live in the North Shore area or New Plymouth these physio therapists would be pleased to offer you there expertise.

### North Shore:

[sue@neurorehab.co.nz](mailto:sue@neurorehab.co.nz)

Neuro Rehab Results **Ph:** 09-4806464

and website [www.neurorehab.co.nz](http://www.neurorehab.co.nz)

### New Plymouth:

[newplymouth@activephysio.co.nz](mailto:newplymouth@activephysio.co.nz)

Active Physio **Ph:** 06-7699992

and website [www.physio.co.nz](http://www.physio.co.nz)



# **Dystonia, Spasms, and Cramps** by Stanley Fahn

*Reproduced with permission from the NZ Neurological Foundation and Dana Alliance.*

*Many GBS sufferers I have talked to often complain of getting frequent painful bouts of cramp especially at night so I thought this article from the NZ Neurological Foundations Magazine might be of interest. Ed*

What dystonia, spasms, and cramps have in common are unwanted, involuntary, excessive muscle contractions. These symptoms may be manifestations of a larger problem, especially if they are persistent and widespread, or they may occur on their own.

## **Spasms and Cramps**

The term *spasms* is perhaps the least specific of the three. Spasms are typically brief contractions that can appear in any muscle in the body, with or without pain. They can be due to many causes, including a reaction to pain, such as when a muscle contracts to avoid pain. This is common when a person has a pinched nerve that causes pain when he or she moves; by contracting, the muscle prevents movement and thus prevents the pain. An example would be a painful herniated disk, which results in involuntary contraction of a back muscle to guard against the pain.

Spasms can be the result of irritated nerves; a common example is facial spasms when a blood vessel is pressing against a facial nerve. This condition has been given the name hemifacial spasm. A change in a person's blood electrolytes, particularly a reduction of calcium, can produce muscle spasms. Because the term *spasm* is rather general, people sometimes apply it to various twitches, tics, and other jerks they might encounter, although neurologists prefer to label these other muscle contractions by their distinctive names.

Muscle cramps are painful spasms. The most common occur in the middle of the night, waking a person from sleep. They usually involve the foot or big toe, and the pain is due to excessive shortening of a muscle. These are relaxed by stretching the muscle. Some of these foot cramps are due to decreased sodium in the blood, often from sweating in hot weather without taking in enough salt to make up for the loss. Intestinal cramps are also common. These result when the muscles of the intestines contract excessively.

## **Dystonia**

Dystonia is a neurological disorder in which a person experiences sustained muscle contractions, usually causing twisting movements and even abnormal posture. The involuntary movements can be slow or fast; when fast, they can resemble repetitive muscles spasms.

Dystonia can affect any of the voluntary muscles of the body. Most commonly the condition is confined to a specific body part, producing what is called focal dystonia. Focal dystonias are so common that many have been given their own names, including:

- torticollis (wry neck, or cervical dystonia)

- blepharospasm (blinking and closure of the eyelids)
- dysphonia (dystonia of the vocal cords)
- writer's cramp and musician's cramp (dystonia of the hand and arm)
- oromandibular dystonia (sustained jaw clenching or jaw opening)

But dystonia can also spread from one site to adjacent areas, or even the whole body (generalized dystonia). It is usually not painful, except when the neck muscles are involved.

Dystonia is due to a variety of diseases involving the central nervous system, particularly the deep nuclei in the brain. When this condition appears without a known cause or is due to a genetic abnormality, it is called primary dystonia. Several genetic types have been identified. Primary dystonias are not associated with loss of nerve cells—in other words, they are not degenerative disorders. They are more likely due to abnormal physiology in the person's nerve cells.

Secondary dystonias are the result of an injury to the brain, such as from trauma, encephalitis, strokes (ischemic, hemorrhagic), birth injuries and various toxins and drugs. Some degenerative

diseases of the brain can cause dystonia when they damage neurons in the deep nuclei. These include Huntington's disease, Parkinson's disease, Hallervorden-Spatz syndrome, and Wilson's disease.

A neurologist must determine the cause of a patient's dystonia. The presence of other neurological features on examination would suggest a secondary or degenerative dystonia, because primary dystonia is not associated with other neurological features besides the presence of dystonia and sometimes tremor. Gene testing for one of the primary dystonias is available. For many of the secondary dystonias, the diagnosis can be made on the

basis of a detailed history of an insult to the brain or exposure to drugs or toxins. Imaging of the brain, such as a magnetic resonance imaging (MRI) scan, is very helpful. The MRI scan is often abnormal in secondary dystonia and in dystonia due to various neurodegenerative disorders, whereas it is normal in primary dystonia.

Treatment varies, depending on what is appropriate for the condition, and may consist of oral medications, injections of medications into the contracting muscles to weaken them, or surgery involving the deep nuclei in the brain. When a person's dystonia is severe and disabling and medications

have failed to provide sufficient relief, doctors may employ a new technique: implanting electrodes that stimulate the deep nuclei artificially (hence the name deep brain stimulation). This treatment provides relief by neuronal depolarization—that is, blocking conduction of the signals causing the muscle contraction.

*Stanley Fahn is the Houston Merritt Professor of Neurology at Columbia-Presbyterian Medical Center in New York City. This article is part of a series on neurological conditions published by the Dana Foundation.*

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## **The 9<sup>th</sup> AGM: 0930am Sunday 1<sup>st</sup> May 2011. Brentwood Hotel Wellington**

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all financial members of the Trust by the end of March. Everyone is welcome to attend the meeting but only financial members are eligible to speak and vote at the meeting

Members who are unable to attend the meeting may nominate a Proxy to vote for them, either our President Bob Stothart or another member of their choice.

Nominations for membership of the Trust Board are always welcome and should be lodged with the Secretary as soon as possible but no later than Thursday 28<sup>th</sup> April. Nominations should be signed by the candidate who will need to be, or become, a member of the Trust and supported by a Proposer and Secunder who must also be members, together with a brief C.V. of the candidate. If no nominations are received prior to the meeting the Board may accept oral nominations at the meeting.

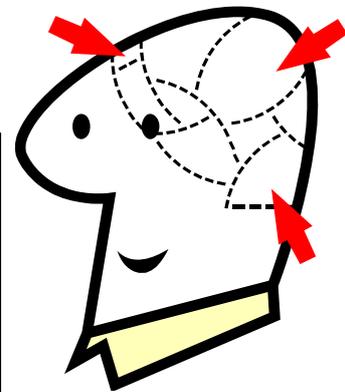
If you have any questions about the forthcoming AGM please direct them to:-

**The Secretary:** Tony Pearson

**Ph:** 03 526 6076

**Email:** [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz)





### What is Brain Awareness Week?

Brain Awareness Week (BAW) is a global campaign to increase public awareness about the progress and benefits of brain research. Brain Awareness Week also aims to increase community awareness of the potential for improving the long-term health of the brain through lifestyle changes and risk-reduction strategies. The Dana Alliance, based in New York, founded BAW 15 years ago, and continues to administer the campaign alongside the American Society for Neuroscience. For one week every March, Brain Awareness Week unites the global efforts of over 2,200 universities, hospitals, patient groups, government agencies, schools, service organisations and professional organisations in 76 countries in a week-long celebration of the brain.

**F**or the sixth year running, the Neurological Foundation is proud to be the key sponsor of the global initiative *Brain Awareness Week* in this country.

From Monday 14 March through to Sunday 20 March 2011, the New Zealand public can hear and share the science of the human brain from many of New Zealand's top neuroscientists, neurologists, neurosurgeons and neuropsychologists during the biggest-ever programme of Brain Days and regional public lectures. This year we are adding Christchurch to our list of Brain Days, and providing free public lectures in new areas such as Invercargill, Queenstown, Rangiora, New Plymouth, Wanganui, Gisborne and Pukekohe. In total there will be five Brain Days (Whangarei, Auckland, Wellington, Christchurch and Dunedin) and 14 regional public lectures.

A new era of discovery has been emerging in the field of brain research since the turn of this century, and New Zealand's scientists and clinicians, among the best in the world, are harnessing their incredible knowledge to unearth the mysteries of the brain and gain insight into the devastating disorders that can affect it. Our stellar speaker line-up includes scientists and clinicians from nearly every university and District Health Board in the country and boasts many whose research has made worldwide headlines. From lectures such as "*Understanding how the brain can be repaired after stroke*" to "*The past, present and future of Alzheimer's disease therapies*" this year's Brain Awareness Week offers an excellent opportunity for

members of the public to tap into some of the best brains and hear about their incredible work in the laboratory and clinic.

Below we have provided a list of 2011 speakers and topics, and our dedicated Brain Awareness Week website [www.brainweek.co.nz](http://www.brainweek.co.nz) features more in depth information about each lecture or event, including times and venues. The full and comprehensive Auckland Brain Day programme is also featured on the site – last year's event was the highest-attended (globally) in the history of Brain Awareness Week, so we look forward to beating the record again!

Our sincere thanks to all speakers who are taking time out of their very busy schedules to travel and speak, and to our partners, the Centre for Brain Research, University of Auckland; Parkinson's Auckland; the Tiaho Trust, Whangarei; Alzheimer's Wanganui; Victoria University of Wellington; the Van der Veer Institute for Parkinson's and Brain Research, Christchurch; Wakatipu U3A; the University of Otago and all of the participating community support groups.

Auckland Brain Day and Auckland public lectures are generously supported by the Ted and Mollie Carr Endowment Fund proudly administered by Guardian Trust. (Guardian Trust logo here)

The Napier public lecture is generously supported by the Dowdall Trust, administered by the Public Trust.

*\* Please note there is no Grow your brain in 7 days website campaign this year – we are focusing instead on spreading the word about the wonders of neuroscience with this bigger public lecture and event programme. The campaign will return in the future.*

# **Insurance Cover – A cautionary tale!**

**By Tony Pearson**

By the time we arrived in New Zealand back in 2001 I had experienced three bouts of GBS and was a fully paid up member of the CIDP club. By then I knew the benefits of rapid IVIG treatment to halt the downward spiral of developing GBS and, being unsure at that time about just how quickly the NZ health system would be able to supply the necessary treatment should GBS return, - as I am sure it inevitably will at some stage –

I took out private health insurance with Southern Cross. Naturally as GBS was a “pre-existing condition” there was a three year waiting period before cover for it was accepted – but this duly passed without incident and my GBS came “on cover” in 2004.

A couple of years passed but in 2006 an unsolicited review of all our insurance policies by an independent Insurance Broker revealed the fact that my Southern Cross GBS cover was limited to a total expenditure of \$2000 !! – as you are all aware this would barely cover 30% of a 5 day IVIG treatment session and so was effectively useless. So I changed my cover to Tower whose limit was \$80,000 – much more comforting – or so I thought.

Again I had to wait for three years to bring my “pre existing condition” on cover but in 2009 Tower duly confirm GBS was covered.

However, in December of last year along with my renewal notice – and the inevitable notification that my premiums were going to increase- I received a 32 page - A4 size booklet advising the new terms and conditions that would apply to my policy with the covering letter asking me to “take the time to read the enclosed material” – so I did, all 32 pages of it!!

On page 26 clause 21 of the “What we will **not** pay for” section I came across the words:-

***Renal dialysis or specialized transfusions of blood, blood product, and derivatives***

And a warning bell rang in my brain. I wonder if this applies to IVIG and Plasmerpherisis (or Plasma exchange/PLEX)???????

To cut a long story short several letters to Tower have confirmed that under the new terms and conditions these fundamental GBS treatment options are now NOT COVERED under my policy (Hospital Cover Easy Care) so that the primary purpose of my taking out private insurance cover in the first place has been wiped out!

Vivienne and I are now trying to decide whether to continue cover – for the other “unknowns” but at nearly \$250 a month it’s a pretty big drain on pension resources!

**PLEASE take the time to look at the small print on your insurance cover – especially if it’s with TOWER – you may not have the peace of mind you thought you had!**



**My mind works like lightning, One brilliant Flash and it is gone.**

# NZ GBS SUPPORT GROUP Bi- Annual Conference



**Where:** Brentwood Hotel, Kilbirnie, Wellington

*There is a Brentwood Hotel courtesy car. A taxi ride is a short journey as Brentwood is close to the Airport.*

*Please specify if you require an accessible room i.e. wheelchair accessible and bathroom accessible when you book in.*

**When:** Friday April 29<sup>th</sup> 2011 to Sunday 1<sup>st</sup> May 2011.

Registration forms in this issue.

## **What's on:**

**Friday night from 5.30pm:** Wine and cheese, meet and greet

**Saturday from 9am:** Full day of interesting key note speakers including:

Professor Gareth Parry, neurologist at the University of Minneapolis, a distinguished New Zealander, and world authority on GBS/CIDP: he will make two presentations, one on up-dating us on recent developments and one on pain and fatigue.

Professor Ron Paterson, former Health Commissioner, and now Professor of Health Law at Auckland University: he will speak on patients' rights.

Lil Morgan and Ken Daniels will give a personal presentation's on their encounters with this perplexing neurological condition.

## **AND**

Ask the Experts Forum where conference goers can ask questions and seek answers.

Discussion groups where people can share and compare their own experiences with GBS/CIDP.

**Saturday Night:** Dinner and further chance to chat to fellow members

**Sunday Morning:** The AGM **9.30 am**

Stay and offer your thoughts and ideas on how we can provide more and better support to GBS/CIDP sufferers.

## **Press Release:**

### **International expert to give medical insights into rare disorder at NZ conference**

A world authority on Guillain-Barré Syndrome will headline a conference in the capital late April devoted to discussion around the rare disorder and its related neuropathies.

“Understanding Guillain-Barré Syndrome and CIDP” is the fifth national conference organised by the Guillain-Barré Syndrome Support Group of New Zealand. It will be held from 29 April to 1 May 2011 at the Brentwood Hotel in Kilbirnie, Wellington.

The biennial conference is for people with Guillain-Barré Syndrome (GBS) and its variants such as Miller-Fisher Syndrome, acute motor axonal neuropathy (AMAN) and others as well as patients with chronic disorders such as Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) and related disorders .

GBS is a rare autoimmune disorder, where the body’s own immune system turns on itself and attacks the peripheral nervous system causing temporary muscle weakness, sometimes to the point of severe paralysis, sensory loss and pain. Often triggered by a preceding illness, GBS has an incidence of 1-2 people per 100,000 or about 40-80 New Zealanders a year. CIDP is a chronic or ongoing neuropathy that closely resembles GBS.

Professor Gareth Parry, Medical Director of the Clinical Neuroscience Research Unit at the University of Minnesota who has studied GBS and its variants for the best part of four decades, will give two keynote presentations at the conference.

One talk will be an overview on pain and fatigue in GBS. “These are very common but much under-appreciated features of GBS and CDIP,” says Professor Parry, who will also touch on a potential new treatment for fatigue his research team hope to study soon.

In his other talk he will explain more about what inflammatory (autoimmune) neuropathies are and discuss some specific examples that have been come to attention in recent years. These include paraproteinemic neuropathies and multifocal motor neuropathy (MMN), which Professor Parry himself can lay claim to discovering and is actually called Parry’s syndrome in some parts of the world. Professor Parry will also review experimental treatments for these disorders.

Professor Parry is a New Zealander whose trip to the United States in the 1970s to study “for a couple of years” turned into a 30-plus year career there. “I arrived in the US at a the time of the 1976 swine flu vaccination program that caused a mini-epidemic of GBS and was at the heart of some of that research, which got me interested in the area.”

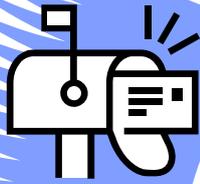
Professor Parry has written two books on GBS, one for neurologists and one for patients. He is GBS NZ support group’s medical advisor and is on the medical advisory board of the GBS/CIDP Foundation International.

His longstanding interest in finding more effective and safe treatments for CIDP sees him currently collaborating on a study of subcutaneous immunoglobulin administration to treat CIDP and MMN. He also hopes to get a project started on the use of a new drug – dalfampridine – that could potentially improve function in GBS patients who have not completely recovered, particularly those with fairly good strength but persistent fatigue. The drug has been proven to improve physiological function in nerves in multiple sclerosis and Professor Parry believes it should have a similar benefit in GBS.

The 2011 GBS/CIDP conference is open to current and former GBS/CIDP patients, and their families and caregivers. It will also appeal to neurologists, physiotherapists, occupational therapists, nurses and general practitioners. The conference, which will be officially opened by Labour MP Steve Chadwick, Patron of GBS New Zealand, includes a keynote presentation on patient’s rights by Professor Ron Paterson, professor of health law and policy at the University of Auckland and former Health and Disability Commissioner (2000-2010). There will also be presentations by former patients, an experts’ forum with Q & A time and group discussion sessions.

For more information or to register visit the GBS NZ Support Group’s website at [www.gbsnz.org.nz](http://www.gbsnz.org.nz)

# Notice Board



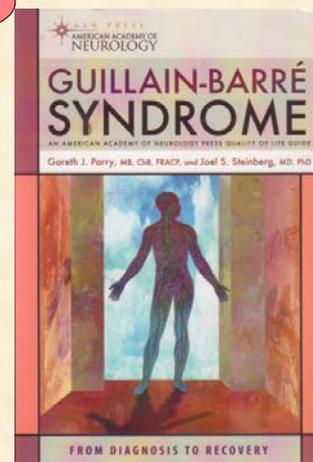
Want to receive your magazine by Email?  
Just email the Editor and your colour copy will be on its way.

The GBS/CIDP Foundation International's magazine is now available online. Anybody who wants access to this magazine can get it online at:  
[www.gbs-cidp.org](http://www.gbs-cidp.org)

## UK Facebook Support Group

Lil has set up a support Group on Facebook under the section 'common interest and health and well being'. If you are on Facebook join up and start some discussion going.  
Guillain-Barré/CIDP Support Group

More Personal Stories Wanted For Publication Please. Email or Post to the Editor



Jenny now has a new stock of Gareth and Joel's book.  
**Cost \$35 plus p&p**

Written in an "easy to read and understand" format for the layman, it covers a wide range of topics including symptoms and diagnosis, caregiver guidelines, rehabilitation and much more.

If you or any of your family members want a greater understanding of GBS then I strongly recommend this book.

# REGISTRATION FORM

**Guillain-Barré/CIDP Conference April 29/30 1 May 2011**

**Name**.....

**Address**.....

.....

**Phone**.....

**Email**.....

Please enclose Registration fee with this form and post to:

Tony Pearson, Skylark Ridge  
113 Weka Road, Mairiri, RD2  
Upper Moutere, Nelson. 7175

\$100.00 full registration

\$60.00 for Saturday only

\$50.00 for second person in a family

\$30.00 for full-time students

\$40.00 conference dinner. This is optional

Conference fees \$.....

Dinners \$.....

TOTAL \$.....

Make cheques payable to Guillain-Barre Syndrome Support Group and cross Not Transferable

Reserve your own accommodation at the Brentwood Hotel, 16 Kemp Street, Kilbirnie, Wellington:  
Phone 04 920 0440 and quote the Reference Group number 70912 to obtain the GBS special rate.  
(\$135.70 per room).

You will need to specify any disability requirements.

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If you are a first time attendee, please tick here.....

The conference fee covers venue hire, the Wine, Cheese and Chat session, the morning and afternoon teas, lunch on Saturday, postage, travel expenses for speakers and other administrative costs. It does not include the Saturday dinner.

We have worked hard to keep costs to an absolute minimum.

