

# Guillain-Barré Syndrome

## SUPPORT GROUP NEW ZEALAND TRUST

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## NEWSLETTER JUNE 2012

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

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## Medical Advisory Board

### Dr Gareth Parry

ONZM, MB, ChB, FRACP

Professor Emeritus, Department of Neurology,  
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### Dr Suzie Mudge

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Senior Lecturer/Senior Research Officer  
Health and Rehabilitation Research Institute, AUT University

### Dr Chris Lynch

Neurologist and Neurophysiologist at Waikato Hospital  
Honorary Senior Clinical Lecturer at the Auckland  
Medical School Waikato Campus

### Dr Pralene Maharaj

Pathology Registrar ADHB  
And Trainee in Pathology with the Royal College of  
Pathologists Australasia  
Member of GBS Support Group since contracting GBS in  
2006

### Dr Dean Kilfoyle

Neurologist Auckland City Hospital  
Auckland District Health Board

### Dr. Annette Forrest

ICU Consultant  
MBChB, BPharm, Dip ag & Vet Pharm

## Board of Trustees

Bob Stothart	John Davies
Ken Daniels	Don Martin
Tony Pearson	Maria de Cort
Peter Scott	Chris Hewlett
Dr John Podd	Meike Schmidt

### Introducing Meike Schmidt our new Trustee

My name is Meike Schmidt-Meiburg. I live with my family on a dairy-farm in Waitakaruru.

I got GBS in December 2005 and spent 10 weeks in Waikato Hospital, where I met another GBS-patient. Knowing I was not alone, was a key to my recovery.

I tribute my recovery to:

- daily visits of my husband plus 1 of our 3 children (and receiving their cuddles).
- the iron will to get better and beat GBS.
- visits of my ConTact C.A.R.E colleagues and receiving little treatments each time.
- the good care received in Waikato Hospital.

I would like to share how I got better and provide informational support to community members and sufferers of this illness.



## UNFINANCIAL MEMBERS

The Trust has, like all businesses, been examining its costs to see where savings can be made.

We have found that we currently are sending newsletters to 130 people who are not financial members of the Trust.

Each newsletter costs 96c to print and with postage (60c) makes a total of \$1.56 a copy or \$6.24pa. This rises from 1 July 2012 to \$6.64, with the increase in postage that's a total cost of \$863 pa. for those 130 magazines.

**THEREFORE THE SEPTEMBER 2012 NEWSLETTER WILL BE THE LAST ONE UNFINANCIAL MEMBERS WILL RECEIVE.**

It currently costs only \$10pa to be a member and receive the newsletter as part of your subscription.

Those NEW MEMBERS who join before the end of this financial year (30/11/12) will be deemed to be financial until 30/11/2013.

A membership application form is enclosed for those identified as having never belonged to the Trust.

For those members who have not paid their 2011/12 subscription you have a **RED UF** on your address label and a membership application attached to your newsletter. Please ignore this if you have paid your subscription in the last week.

We look forward to receiving your application and/or payment

*Peter Scott*  
*Treasurer*

## **Editors Note**

The AGM has come and gone. Thanks to those who came and gave your support to the Group. Commiserations to the two locals who got lost en route and didn't quite make it.

When Jenny first started this wonderful group it was her intention that the newsletter would be free to anyone who wanted to receive it. Sadly as time has gone on and production costs increased the Board has had to discontinue this service. Our Treasurer has more on this in the newsletter.



A small group of us met in Wellington to discuss upgrading our website and with the help of Web Master Ben Chapman we think we have the tools to do this. Lil Morgan will be undertaking a lot of this work which we hope to have completed later in the year.

Our Facebook site has been rather quiet of late. If you have problems joining the group I suggest you email Maria de Cort, our Publicity Officer as she was able to achieve what was impossible for me when a member was having trouble joining the group.

There is lots of reading in this edition of the magazine. Thanks to all the Medical Professionals who so willingly provided me with material when I asked. Thanks also to those who sent me their stories. Sorry that they could not all be published this time round, but they will be in the near future so don't despair.

Remember if there is anything in particular you would like in the magazine please let me know.

Keep on putting your best foot forward.

**Chris**



## **Presidents Paragraph:**

Following a very successful AGM in the warm but wet Mt Maunganui, hosted by Chris Hewlett, planning is now well underway for the next national conference to be held in Wellington 26-28 April, 2013. Members of the recently established Medical Advisory Board will be attending and will comprise an Expert Panel at the end of Saturday to answer questions from the floor. The Medical Advisory Board has multiple skills so bring your questions to that forum for up to date, informative answers. The conference, the only one of its kind in New Zealand, it is our shop window. There will be a special forum for the training of hospital visitors and this will be repeated at future conferences. An open invitation is out for all people interested in this crucial activity.

The conference is a great place to renew friendships, to share experiences (grim and rewarding) and a place to gather new knowledge about the complexities of GBS and CIDP. Start saving now to be there. We have done everything possible to keep the costs to an absolute minimum (\$100 for full registration and \$80 for Saturday only).

I have been visiting a very sick GBS person in ICU in Wellington Hospital and I was struck by the dedication of his wife to visit him every day (coming in from the Hutt Valley) and it reminded me how vital the carers are in the rehabilitation of GBS and CIDP patients. We all need the expertise of the specialists but the love and support of those near to us is critical for a sound recovery. To all our carers and hospital visitors Bravo.

Keep being well.

**Bob**



## Secretary's Jottings

I am on notice that Chris has a very full Newsletter this time round – so fore shortened ramblings from me!!

Having done my duty as a good ex Brit and watched nearly 4 hours of the Queen's Diamond Jubilee celebrations last evening I went to bed, rather smugly, smiling about the awful cold wet weather those resident Brits were having to endure at the start of their summer – compared to the superb sunny and warm days we were having down here in Nelson – well all that changed today and we are swamped with rain, temperature down to 9 degrees and worse on the way – that will teach me!! A bit like my first encounter with CIDP – rather more worrying to start with but survived and quite quickly back on my feet again and feeling pretty good about things – until No2 bout arrived and knocked me down again 100 days later – I learned my lesson and was ready for session No3!!

Just one new case of GBS down this way in the last month or so – over in Blenheim – I hope to catch up this coming weekend. Of course contact made via Google – no one in the Wairau Hospital thought to mention us during the month she was a patient!! Just what do we have to do to get the message through?!

On a happier “Marlborough” note Vivienne and I completed our half Marathon last month – a lovely day out with no serious after effects apart from my celebratory attempts to put a dent in the Sauvignon Blanc surplus in the area! If all our sponsors pay up we should be able to swell Peter's coffers by something a little short of \$300 in the coming weeks. Photo attached – if Chris has space to print.



My memory jogger on subscriptions has been well supported – thank you for continuing your membership – it is the primary source of the Group's operating funds and without your support we could not continue the work of the Group.

May was GBS awareness month worldwide and us here in Nelson thought we would do our bit and following Chris' Tauranga example have a get together. I'm not sure that we have impacted global awareness of our mission but we all enjoyed a coffee and muffin and a good old “chin wag”. Again photo attached for Chris to include if space permits.

Forth coming events?? – The Neurological Society Brain Day in Nelson on Saturday 7<sup>th</sup> July – we shall have a GBS stand there – if you are local pop along and give us your support. Annesbrook Church Stoke 10.30 onwards.

Enough for now

As always take care and **Get Better Slowly** if you ain't already 100%

Tony



*Getting it together in sunny Nelson*

# Report on the Proceedings of the 2012 Annual General meeting

Some 20 or so members turned up to support the meeting held in Tauranga at the end of April and enjoyed a lively meeting and some great food organized by Chris and her team.

The formation of the Group's Medical Advisory Board was formally welcomed and marks a BIG step forward in the Group's recognition and accreditation progress with the medical fraternity. The 2013 Conference venue was confirmed at the Brentwood Hotel in Wellington on 26/27/28 of April – it promises to be a busy and informative few days.

The development of a nationwide Hospital Visitors network is probably the biggest programme and challenge the Group has embarked on for a long time. Background policy and operational rules are being prepared and the first "gathering" of those interested in joining this important arm of the Group will be held at the 2013 Conference.

Jenny has stepped down from the Board of Trustees but remains our mainstay as National Co-ordinator. Her place on the Board has been filled by Meike Schmidt a life member of the Group from the Thames area. Otherwise the membership of the Board remains unchanged although Bob has signaled that he intends not to seek re-election as our President when his term of office expires at the Conference and AGM in 2013. Whilst maintaining adequate funding levels to support the Group's operation is of serious concern to the Board it was decided that in these tough economic

times the subscription levels should remain unchanged but as suggested by members present the Board need to keep this under review. Peter's Accounts were accompanied, as usual, by an unqualified Audit Report and whilst the year to last November showed a few thousand dollars deficit his shrewd financial management of our reserves means we can plan ahead for our next operational year and Conference with some degree of financial security.

Lil Morgan, having sorted out the unexpected accommodation upset in her and Bill's life, was welcomed back as our website Co-ordinator and has set about the task of invigorating our website with gusto – the process will take a month or so – but prepared to be surprised when you log on to the "new" site!

Whilst noting with sorrow the passing of our "Founder member" Dulcie Antill our President Bob was delighted to advise her husband Ronnie that the AGM had unanimously voted that he be invited to become an Honorary Life member of the Group.

If you would like a copy of the Draft Minutes of the AGM do please contact me

Tony Pearson – Secretary to the Board.

## Attendees at the AGM



*Zelda Menzies*



*Bob Stothart and Ken Daniels*



*John Podd*



*Margaret Stothart & Mrs Stephenson*



*Chris Hewlett*



*Tony Pearson*



*Maurice and Kath Vickers*



*Terry Watton, Gordon Stephenson and Meike Schmidt*



*Bill and Lil Morgan*



*Peter and Robyn Scott*

# **Annual Report of the President 2012**

## **Introduction**

I am pleased to present this report as I am acutely aware of the important work members do in visiting patients in hospital and the positive effect that those visits have. Many people contribute to make the support group function as an effective organisation and it is a privilege to work as the president.

## **Obituaries**

It is with sincere sadness that I record the death of Dr Lindsay Haas. Lindsay was a supporter from the formation of the organisation and he was particularly helpful in the planning of conferences. His wise advice will be sorely missed. Sadness too surrounds the death of Dulcie Antill. It was Dulcie's brush with Guillain-Barre Syndrome that led her sister Jenny Murray to establish this support group. Dulcie served several years as a Board member. Long time supporter and worker for GBS sufferers, Bill Fraser passed away during the year. He will be a real loss in the Christchurch region.

## **Thanks**

To all members who have visited hospitals to comfort GBS and CIDP people the thanks of all of us are accorded to you without reservation. Your sensitivity and consideration is priceless, greatly valued and worthy of our admiration.

Other people are deserving of our sincere thanks, in particular, Jenny Murray who volunteers her time to service the network and to comfort patients and families coming to terms with this upsetting and frightening condition. Professor Gareth Parry has been a leading academic at the University of Minnesota. He has a demanding workload but he is readily available to answer complex medical questions and to provide wise guidance and support for us. His re-location in Nelson presents us with an added advantage and we have benefited from his wise advice. Tony Pearson (as always) provides us with a fully professional level of secretarial support and advice.

Other members (of the Trust) contribute in other multiple ways: looking after our money, keeping records and legal issues in line, responding to emails and generally providing the benefit of their experience for the advantage of the GBS/CIDP fraternity: Peter Scott, John Davies, John Podd, Don Martin, Chris Hewlett, Maria De Cort, Ken Daniels.

Special thanks too to Steve Chadwick our Patron. Her on-going support and sincerity is greatly valued by all who have worked with her.

## **Jenny Murray**

Jenny has indicated that she does not wish to remain a member of the Board and will formally resign at this AGM. She will however, carry out her duties as our National Coordinator. We owe an enormous debt of gratitude to Jenny originally for setting up the organisation but especially for her role as National Coordinator. In this role Jenny has been the epitome of discretion and a wonderfully helpful person as often bewildered patients or caregivers make initial contact. Jenny has received a QSM for her services to Guillain-Barre people. Thank you again Jenny for all you have done and will continue to do for other people.

## **Numbers**

Currently we have 254 members (with 80+ of those members hovering to pay). The number fluctuates as some people, upon recovery from GBS/CIDP do not wish to continue their association with the support group. Other members renew their contribution and renew their commitment to provide services to those who develop the illness.

The Newsletter is distributed to about 400 recipients on a regular basis. The Newsletter is an important component of our operations and contributions are always welcome. Thanks to Chris Hewlett who produces the cram-packed "newsy" Newsletter on a regular basis.

## **Conferences**

The bi-annual conferences (2003, 2005, 2007, 2009, 2011) have been highlights in the work of the support group. Gathering great speakers and listening to inspiring stories of bewilderment and eventual recovery along with the meeting and greeting, networking and socialising are incredibly valuable.

# **Annual Report of the President 2012 *continued...***

## **Medical Advisory Board**

Dr Parry has led the establishment of a Medical Advisory Board comprised of experienced professionals in neurology, physiotherapy and rehabilitation. This group will be extremely valuable as we consolidate our position as a support group.

## **Sponsorships**

In these difficult financial times I have to report that we have lost the sponsorship of the Taranaki Savings Bank due to changed criteria. The ARA Lodge continue to help us with their annual grant of \$1250 for which we are most grateful. Sponsorship was received from the Lottery Board \$2650-00 for support for our conference and we thank the Lottery Board for their assistance. We have however, received the benefit of work by Cath and Morris Vickers in organising a theatre evening and raising \$300.

We are always of course on the lookout for appropriate sponsors. Clearly there are on-going opportunities for members to raise money for the organisation in creative ways so seize the initiative and make a contribution. All efforts greatly appreciated including receiving the Newsletter by email.

## **Hospital Visiting**

The Board is planning a training programme for hospital visitors. We hope to clarify this in the near future and to have training available at the 2013 conference and AGM in Wellington.

## **Challenges**

All small organisations face challenges and we are no different. We face the following challenges:

- maintaining membership
- maintaining quality services to those in need
- maintaining a financially sound organisation
- gathering sponsorships to extend our services
- planning strategically for future change.

Your elected representatives will be confronting these issues, and others, as they arise during the coming year.

Trustees serve for a specified term and my term of office will expire at the AGM in Wellington in 2013. I give notice that it my intention to retire at that point. I have an unshakeable belief that all organisations flourish and benefit from change and refreshment.

Thank you again for the privilege of serving as your president.

Bob Stothart



*Attendees at the AGM*

# **My GBS Experience - Shock Horror - Our Granddaughter has GBS!!**

Towards the end of the October school holidays we had one of those call we all dread – Olivia our ten year old granddaughter has been rushed to Rotorua Hospital, cannot walk, has a terrible headache and aching limbs. Immediately there are visions of meningitis, rheumatic fever etc.

Our daughter is a teacher and cannot easily take time off. She and her husband make some arrangements to take turns at the hospital. Our older granddaughter Amy phones us and is in tears because she does not know what is happening. Everyone is in panic mode. We decide that Granny Peggy has to go to Rotorua and be at their home to help while the parents are back and forward to the hospital.

The hospital staff perform a multitude of tests. The doctors are not sure what is wrong with Olivia and work hard at trying to solve what is causing the problem. The symptoms could lead to many different possibilities. Olivia's eyes start to lose focus and she has difficulty reading. Olivia is put onto a number of prayer chains here in New Zealand and elsewhere.

Eventually she is sent to Hamilton to have further tests. The young pediatrician at Waikato Hospital thinks that he has an idea what is wrong and organises a test for Guillain-Barré Syndrome. The tests show that she has contracted GBS and the pediatrician advises immediate treatment. She is so thin because she cannot keep her food down and we call her the "Biafran kid".

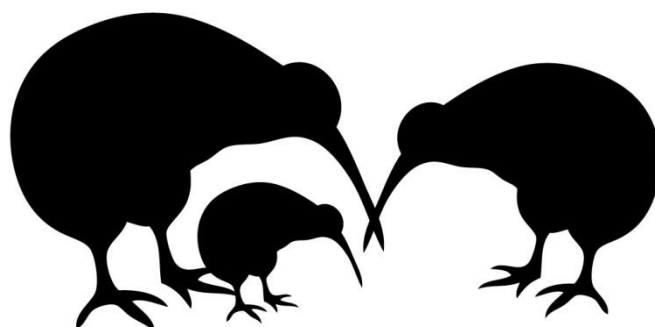
What on earth is GBS? Never heard of it. Visits to the internet show that it is well documented and was first found by the doctors after whom it was named in 1916. The descriptions on the internet make your hair stand on end and we all start to wonder if she will be a cripple or even die! The only re-assuring statement we could find is *"Approximately 80% of patients have a complete recovery within a few months to a year; although minor findings may persist"*.

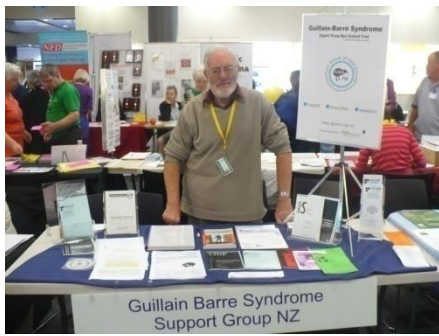
The treatment was started and we all prayed that she would start to recover. A high spot while she was in hospital was a visit from Prime Minister John Key. Even better is that this was reported in the newspaper and Olivia's name was mentioned. Granny spent many hours with Olivia both in hospital and then at home. Every book that could be found and was suitable was read by Granny. Eventually when Olivia's eyesight improved I lent her a small netbook (PC) to use while sitting in bed and this was also a great help to recovery. She improved reasonably quickly and around this time we found that there is a worldwide support organisation with a branch in Tauranga. We even found others who had the disease. It was also re-assuring to talk to others who had been through all the trauma themselves. We appreciated the local newsletters which made it all seem more normal!

Olivia returned to school but with the proviso that if she did not feel well then she should quickly tell the teacher. She had one brief relapse and went to hospital but was quickly discharged. She is now almost back to her old cheeky self and has regained most of her weight.

The experience makes you realise how precious life is and the importance of living each day and having faith in God. We are also thankful for the superb people who staff the hospitals in Rotorua and Hamilton.

*Richard Evans - Olivia's Grandfather*





## Brain Day 2012

By John Davies

Auckland Brain Day 2012 dawned bright, fine, and cool, not only was it on St. Patrick's Day– March 17<sup>th</sup>, but also on the same day as the Wellington Brain Day.

Not only is this an important day for the Neurological Foundation and those involved in Brain Research, but it also gives the opportunity for Community and Support groups to come together under the one roof, to demonstrate and inform the wider public on services available to them if and when they are inflicted or recovering from the many lesser known, unusual, or rare medical problems associated with the brain or neurology in general.

For the last two years Brain Day has been held in Auckland in the Owen Glenn Business School at the University of Auckland. An ideal location where all the various exhibits can be held on one large floor, with separate areas for experiments and demonstrations to be given for all ages under the watchful eye of the “experts.” Lectures are also delivered in the adjacent lecture theatres.

This year there were forty-two stands – manned by volunteers, many of them “victims” of the neurological problems that they had themselves encountered. So the words and advice given was “straight from the horse’s mouth” so to speak. They ranged from Epilepsy; Parkinsons; Essential Tremors; Post-Polio; Autism: ADHD: to give just a few examples.

This year our GBS Support Group Stand was manned by Margaret and myself, since our helpers from previous years - Maurice and Kath Vickers, had decided to leave us to our own ends whilst they enjoyed themselves on a cruise around Australia and all points east.

It was to be a long day, leaving home at 0730hrs, with the days’ events supposedly beginning at 0900hrs, and concluding at 1630hrs. Even before I had finished setting up the stand people were starting to arrive – as early as 0815hrs. With our original GBS Banner being used at the Wellington Brain Day, I was left with a bit of a dilemma as to how we could advertise our presence, however, with the original art work given to me by Maurice; the aid of a ‘friendly’ graphic artist and printer; and using a photographic lighting stand, I was able to come up with a table top version of the original. This proved to be ideal as many of the large Banners had to be placed behind the tables where only half the Banner was on view, whereas ours was fully visible.

The official opening time of 0900hrs was ignored and the public streamed in. It was a steady procession all day long, and Margaret and myself didn’t have too much time to our-selves, even having lunch on the run. Our ever faithful ‘fount of all knowledge and help’ - Jenny Murray, had supplied us with sufficient printed material to hand out to those who were really interested. However, having learned from the previous Brain Days, I was very reluctant to put too much on display. There were always the ‘tyre kickers,’ those individuals who collected material for collecting’ sake, and then there were the genuinely interested folk. So Margaret and I rationalised and saved where we could.

We enjoyed the company of medical students, nurses, doctors, physiotherapists, professors and specialists, and many young children who couldn’t even pronounce Guillain - Barré – neither could many adults. It was rather disappointing that no one else who had either suffered from GBS, or been associated with GBS, took the opportunity to share their experiences with us or the people in general, that is apart from Meike Schmidt and her son, who had travelled up from Waitakaruru in the Waikato for the day. It was a great pleasure to meet and talk to them both for the first time.

A head count was taken for the day, with a total of over three thousand in attendance. At times it was like Eden Park when the All Blacks were playing. All in all it is a worthwhile exercise for the GBS Support Group to have a stand at the Brain Day, where we can show that we exist as a Support Group; explain the syndrome; let people know how we can be of service to them; and above all inform them that GBS is not the end of the world for them, but that they can, and in ninety-five percent of cases, return to normal life. I like to think that I am a reasonable example of that.

We now look forward to continuing the work that we do, next year and well into the future.



*Margaret and an interested youngster.*

## ***Obituary: Dulcie Antill***

Sadly, on 14 March 2012 Dulcie Antill passed away suddenly. Dulcie was diagnosed with GBS in 1997 and it is because of this fact that the Support Group we now know was formed. Dulcie was my sister and lived here in New Plymouth as I do, and I saw her go through the various stages until she returned to a fairly normal life once again.

Shortly after diagnosis Dulcie was airlifted to Waikato hospital where she could be on life support 24/7 until she could breathe unassisted again, then returned to Taranaki Base Hospital for rehab. It was a long and difficult journey for her as many of you who have 'been there, done that' will know.

Dulcie died peacefully in her sleep. Her husband Ronnie and family were very grateful for the cards and messages received at that time from the GBS members. The family asked that donations go to GBS at the funeral and that has been forwarded to Peter to bank.

When GBSFI learned of Dulcie's death a huge bouquet of flowers arrived at my door with a card from Estelle Benson. That was a lovely thought and such beautiful flowers. Thank you Estelle and GBSFI.

*Jenny Murray.*



## **Obituary :**

## **Janet Gregory**

*On 12<sup>th</sup> March 2012 Janet Gregory passed away. She was the partner of Bob Gregory, one of the founding members of the GBS group.*

In late August 2011 Anne (partner) and I visited our dear friends Janet and Bob Gregory who had recently moved from Palmerston North to Buderim, a beautiful little town about an hour's drive North of Brisbane, Australia. On one of our many sightseeing trips with Janet and Bob we visited Eumundi, a small settlement about 30 kms North West of Buderim. It was market day in Eumundi. From our first day in Buderim, Janet had complained of a severe pain in one of her arms. She was in pain when we arrived at the market. As we walked around, we heard the shouts of a young woman in distress. Moving towards the commotion, we came upon the distressed woman. She had a baby with her and she was very, very drunk. Janet immediately raced ahead to break up a small group of people around the woman. Janet found her a chair and comforted her for what must have been the best part of 2 hours as the police tried to sort things out. I will never forget the distress I saw on Janet's face, the anguish in her voice, as the young woman was carried away. We did not know it at the time, but the severe pain in Janet's arm was the harbinger of a serious and fatal illness.

The pain was ignored as Janet tried so very hard to protect and comfort this inebriated young woman. For those who knew Janet well, her behaviour at Eumundi would have come as no surprise; merely typical and quite predictable. She was so kind, so caring, and so willing to help anybody in need, strangers and friends alike. Janet passed away on March 12, 2012 suffering from an incurable and aggressive form of cancer. Her daughter, Mary, wrote a very moving tribute to her "Mum" saying that Janet took people into her house and into her heart with all the love and kindness imaginable.

Naturally, Bob held a special place in her heart. Bob was a senior lecturer in Psychology at Massey University for over 25 years. Twenty-odd years ago, he began to get sick. He suffered from fatigue, exhaustion, and drop foot – familiar symptoms too many readers, no doubt. At the time, though, it took a full year before Bob was diagnosed with GBS. Bob says that he was "so fatigued without reason or rationale... I must have been very hard to live with." But Janet was always there for him and over the next decade as he slowly recovered.

Janet had her own successful career as a lecturer in Human Development and Health in the Faculty of Education at Massey University, a career that paralleled Bob's. Prior to these New Zealand experiences they had lived and worked at many different places in the USA. A real highlight in their lives was the 15 months spent living among the Kastom people of Vanuatu. Their field work and experiences there provided fuel for many joint publications in academic journals.

Janet's concern for the weak and vulnerable was especially intense when it came to children. She was acutely aware of the needs of children exposed to abuse and neglect. She was a member of the International Society for the Prevention of Child Abuse and Neglect (ISPSCAN), presenting research papers at several of their international congresses in Australia and S. Africa. In New Zealand she worked tirelessly to improve the mental health and well-being of infants. To her satisfaction, and without a doubt one of her greatest achievements, she co-founded a new organisation: The Infant Mental Health Association of New Zealand ([www.imhaanz.org.nz](http://www.imhaanz.org.nz)).

Janet will live on through these achievements, but she will be sorely missed by those of us who knew her personally. We are comforted knowing that this world, in so many ways, is a much better place for her impact on it.



# Guillain-Barre syndrome (GBS) – How does it affect you?

*This is the second in a series of 5 articles on GBS, written by Dr. Gareth Parry which will give a general overview of the disease.*

GBS is an acute paralytic illness caused by an immune (inflammatory) attack on peripheral nerves as outlined in part 1 of this series. Any disease that affects the peripheral nerves is called a neuropathy. Nerves control 3 important functions; they mediate sensation, control strength and also control autonomic functions. These include functions such as heart beat, blood pressure, sweating, over which we have no control and those over which we have only partial control, such as bowel and bladder function. All of these functions are affected to some extent in GBS.

The earliest symptoms are often sensory, mainly vague tingling or pins and needles in the hands and feet. Very rarely the first symptom is pain, usually located between the shoulder blades or in the low back but sometimes around the hips and shoulders; pain more commonly develops coincident with weakness. This early pain is a deep aching sensation and it almost always resolves within a few days. It is what is called nociceptive pain that results from inflammatory activation of normal pain receptors in the nerve sheath. It may be replaced later by a different pain as will be described below. At the time these initial symptoms develop a cursory examination by a general practitioner or emergency department physician is likely to be normal and these earliest and quite nonspecific symptoms are often dismissed.

Within 1-2 days the much more dramatic motor symptoms develop with rapidly evolving weakness while sensory symptoms resolve; persistence of prominent sensory symptoms should prompt a search for some other cause of the neuropathy. Weakness almost always affects limb muscles first and usually affects both proximal (closest to the body) and distal (farthest from the body) muscles. Legs are usually affected before the arms and this pattern led to GBS being called an ascending paralysis. In some cases weakness spreads to the face and throat muscles leading to slurred speech and difficulty swallowing. About 50% of patients are found to have facial muscle weakness but speech and swallowing are less frequently affected. About 25% of patients develop some difficulty with breathing but it is not always severe enough to need artificial ventilation. Weakness may be so mild that it does not limit activities or so severe that every voluntary muscle is paralysed, a

situation sometimes called the “locked-in syndrome”.

Autonomic involvement does not usually cause symptoms in the early stages of the disease. Occasionally there may be some dizziness when the patient stands from a lying position, rarely leading to brief loss of consciousness. Difficulty emptying the bladder is common but most patients are unaware of it because they usually have a catheter inserted. Constipation is also common but typically presents later, after a week or so. Abnormalities of sweating and skin colour may be observed but are seldom a cause of symptoms. A rapid heartbeat is very common and occasionally serious irregularities of the heart may occur, necessitating use of specific medications or even a cardiac pacemaker. Blood pressure may fluctuate wildly from very high to dangerously low but active treatment is seldom needed. Autonomic abnormalities are generally seen in patients with the most severe forms of the disease and always resolve with time, even when strength does not completely return to normal.

Weakness progresses over days to weeks but always stops within 4 weeks. There is then a plateau where neither progression nor improvement occurs, lasting for another few days or weeks and then improvement begins. While weakness affects proximal and distal muscles about equally, recovery always occurs first in proximal muscles. If there is to be residual weakness it affects the muscles of the hands and feet most severely. Once improvement begins it usually continues without interruption but about 5% of patients suffer a minor setback during the first few weeks of recovery. These relapses are never as severe as the initial attack and only occasionally need to be treated. Recovery is usually good with about 75% of patients fully recovering strength while the remainder are left with varying degrees of distal weakness.

Autonomic manifestations of GBS almost always resolve within a few weeks. When the patient first gets out of bed to begin the rehabilitation process periods of low blood pressure may occur, sometimes leading to dizziness and even fainting but eventually these symptoms resolve completely. Some difficulty passing urine and persistent constipation may also occur for several months, partly related to the neuropathy itself but autonomic effects are never persistent.

# **Guillain-Barre syndrome (GBS) - How does it affect you?**

Sensory symptoms are generally minor in GBS. The symptoms are present and the neurological and electrophysiological examinations confirm loss of sensation but the paralysis is so dramatic that it overshadows sensory loss in the great majority of patients. One exception to this general rule is pain. Pain at the time of acute paralysis or even preceding it has already been mentioned. More common is pain that emerges as the weakness is improving. This later pain is neuropathic pain; pain that arises as the result of nerve damage. It is most commonly described as burning, shooting or stinging although any pain symptom can occur. It is almost always restricted to the feet and, to a lesser extent, the hands. Probably about 50% of GBS patients have some neuropathic pain but the number in whom it is disabling is much smaller, probably no more than 15%. Patients who have severe nociceptive pain at the time of the original presentation are more likely to also have neuropathic pain during convalescence. Pain subsides over many months but is occasionally persistent for many years; even those individuals with severe, persistent pain usually improve to some degree. Another sensory symptom that is persistent and the cause of significant disability in incompletely recovered patients is imbalance.

Most people think of balance as being a motor phenomenon but even patients how make a complete recovery of strength may have problems with balance because the nerve fibres that transmit critical nerve impulses that allow us to be aware of the position of our legs when walking are quite susceptible to damage in GBS patients. This type of imbalance is typically worse in the dark or when the eyes are closed and also on uneven ground; patients say that they can "trip on cracks in the pavement".

Cognitive problems do not occur as a direct consequence of GBS but there may be problems with memory and concentration in patients who have been severely paralysed, probably as a result of being sedated in the intensive care unit (ICU). Oxygen lack to the brain may occasionally occur due to paralysis of the diaphragm or due to pneumonia or pulmonary embolism (blood clots going to the lungs) and this may affect cognition. Emotional problems including psychosis and later depression may also occur as a result of the illness but not as a direct consequence of GBS. Vision is rarely affected. The disease itself does not directly affect the brain or spinal cord except in extremely rare instances that are thought possibly to be due to antibodies attacking a protein that is present in both peripheral and central nervous system.

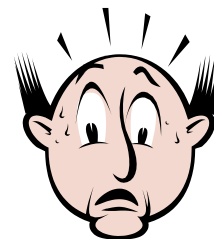
## ***My GBS Experience - An update by Arthur Bott***

I contacted G.B.S. on 20/10/2003 and thought you might like an update on my progress . I first noted there was something wrong with me when driving home from picking up takeaways for tea . As I drove around the corner I nearly side swiped a car and thought the power steering had gone in the car .The next morning I had to have my wife to help me out of my chair and even off the toilet. When hospitalised I managed to walk with the aid of a walker with wheels and did walks around the ward every 2 hours much to the nurses concern. I put that part of my getting back to rehabilitation as vital to my gaining strength and returning home after 12 days .I could not open milk tops or tabs of beer cans for some months and starting the mower was hopeless . I have only just managed to open screw bottle tops with my left hand lately - I'm right handed. I had to give up golf as hitting a ball far or throwing things is a no go with reduced muscles in my arms but I'm happy to say my snooker is still pretty sharp. At 75 years of age I count my blessings that I only had a light dose of G.B.S. compared to others in the Support Group and make do with reduced body strength. There is life after G.B.S.



# Nerve Conduction Study

If you have been diagnosed with Guillain-Barré syndrome you will very likely have had a Nerve Conduction Study (NCS) / EMG. You probably found this test rather strange and maybe a bit uncomfortable. So what was it all about?



## Why did I have this test?

NCS/EMG is a very important test in the diagnosis of GBS because in addition to the clinical features (your symptoms and the signs elicited on neurological examination) it provides some of the most specific information to confirm the diagnosis and rule out other conditions that can mimic GBS. Sometimes the clinical features and a typical NCS/EMG are all that are necessary to make a definite diagnosis. GBS causes demyelination of the peripheral nerve – a process where the myelin that insulates nerve fibers is removed. The loss of myelin impairs nerve impulse transmission and this results in numbness and weakness. There are only two ways to detect demyelination – nerve biopsy (a surgical procedure) or nerve conduction studies. Nerve conduction studies are superior in that multiple nerves can be assessed, the results are immediate and the procedure is safe without any long term complications.

## How does it work?

This is complicated. You probably remember being given small electrical shocks. These shocks stimulate the nerve underneath the stimulator. The nerve will then conduct its own electrical signal down to a muscle where the size and speed of the response can be recorded. Demyelination (see above) slows the speed of nerve impulse conduction and reduces the size of the response. These changes can be recorded by the computer and help confirm the diagnosis.

## What does EMG stand for?

Electromyography – the study of the electrical activity of muscles. EMG is the part of the test usually performed after the nerve conduction studies in which a small needle is inserted into a muscle. The needle acts as an antenna recording the electrical signals generated by your muscle. The signals cause a crackling/thumping sound through the computer speaker. This can provide information that supports or clarifies the first part of the test.

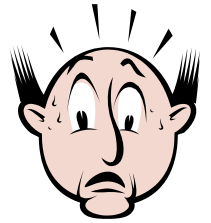
## Is it safe?

Yes, very. The small electrical shocks can travel only a very short distance in the body. The test is safe in pregnancy and in patients with pace makers or other medical devices. The shocks cause no lasting effect. The shocks are uncomfortable and can be frightening, especially for children, but once you know what to expect are usually quite tolerable. The EMG part of the test can cause bruising although usually less so than after a blood test for example. In experienced hands the risk of damaging nerves or other body tissues is extremely low.

## How much “juice”?

Most machines allow the doctor to select the amount of stimulus current – this is usually 10-30 milli amps but can go up to 100mA. The machine automatically adjusts the voltage depending on the skin resistance. A 10mA stimulus for most patients is felt as a light flick while 50mA is a definite twang. The stimulus duration is extremely short (one ten thousandths of a second). Some people are more or less sensitive to the shocks – in my experience professional electricians are particularly sensitised to the test (understandably so!). The shocks are significantly less powerful than a farmer's electric fence.

# Nerve Conduction Study



## Why didn't I have this test immediately?

NCS/EMG is a highly specialized test. It is not available 24 hours a day even in large hospitals and in smaller hospitals may not be available at all. A more important reason however is that it takes a few days after the onset of symptoms for the signs of demyelination to become detectable on the test. A test performed in the first few days may be falsely negative – i.e. give a misleadingly normal result. NCS/EMG is not mandatory to make a diagnosis of GBS and in smaller hospitals without ready access to this test the diagnosis can sometimes be made on a purely clinical basis. It is usually not necessary to wait for this test before starting treatment unless the diagnosis is in doubt.

## I was in intensive care – why didn't I have this test?

You might have had it done in the intensive care unit while sedated and unable to remember. You do not need to be awake for the nerve conduction tests.

## Does the test tell how bad the neuropathy is, or predict recovery?

Sort of. The information the test provides is very important for diagnosis but not so much for prognosis (predicting recovery). It provides some clues to the severity of the nerve damage but in general the clinical features (e.g. degree of weakness) are more reliable.

## Is repeating the test necessary or helpful?

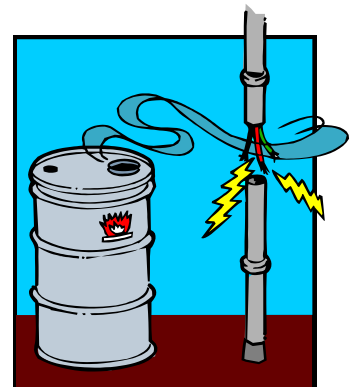
Usually not. As with the above question the clinical features are a more reliable means of following progress. Sometimes if the test is performed soon after symptom onset it may be falsely normal. In this setting a delayed repeat test might be needed.

## The Doctor said the shocks wouldn't hurt. Why did he/she lie?

There is huge variability in personal sensitivity to the shocks. Some patients find a 100mA shock only minimally uncomfortable while others find a 10mA shock unbearable. There are probably many factors that account for this. Patients with acute GBS often have nerves that are difficult to electrically excite and therefore require relatively larger shocks to get a recordable response. Conversely some patients have overly irritable nerves that may amplify or exaggerate the sensation of the shock. Many patients understandably also have a considerable sense of anxiety over the impending result of the test (and indeed much depends on it). A heightened state of anxiety also has a tendency to amplify neurological sensations.

So that is what NCS/EMG is all about – a seemingly strange and unique type of test but very helpful in providing that vital first step to recovery, a definite diagnosis.

Dr Dean Kilfoyle  
Neurologist  
Auckland Hospital



# **Rehabilitation for Guillain-Barré Syndrome - By Dr Suzie Mudge**

Once the acute phase of Guillain-Barré is over, rehabilitation becomes an important part of the recovery of function. Rehabilitation usually has broad aims of maximising your functional independence and facilitating the resumption of important life roles.

There are some key principles that underpin most of the things we do in rehabilitation. One of the most important components of learning a new skill is practice and regaining function is no exception. Practice and lots of it; generally the more you can do, the better. You will get better results if your practice is meaningful to you, in other words, practicing a task or activity is better than practicing an isolated movement. So you'll do better if you reach for that wine glass, rather than just reaching as a movement! It's also important for your practice to be challenging, so that you feel like you are working hard. A final point is that your practice should be specific. If a rugby player wants to get better at rugby, then they play rugby, not tennis. It's the same for you; practice each specific activity that you want to improve. These principles are universal and can be applied whether you want to improve anything from your walking to your speech.

One of the most common physical issues addressed in physiotherapy is weakness. Strengthening has long been the backbone of dealing with the underlying weakness in GBS, but recent research has been clearer about how hard you need to work when you are trying to make your muscles stronger. We now know you need a relatively high amount of load and a low number of repetitions for strengthening. Although there is little research specifically with people with GBS, almost every other neurological condition gets stronger with this kind of exercise with virtually no side effects. Care should be taken under certain circumstances, for instance if you are very weak or have a lot of pain, so we'd recommend that you exercise under the guidance of a health professional.



## **AIDS TO HELP GBS SUFFERERS**

Using a long handled Artists paint brush, I am able to moisturize my toes feet, ankles etc., No other way I can reach them so beautifully.

Cheers Carel Jost



# Something from the Kitchen



*These were a big hit at the AGM so for those of you who asked for the recipe here it is.*

*Thanks to Meike for sending it in.*

## CHOCOLATE BROWNIES

150 g butter or margarine  
1 cup baking cocoa  
4 eggs  
2 cups sugar  
1 teasp vanilla essence  
3/4 cup plain flour  
1 teasp baking powder  
1 cup white choc bits

Preheat oven to 160 degrees. Line base of a 27 cm x 18 cm x 3 cm tin with baking paper.

Melt butter/margarine and stir in cocoa, allow to cool slightly. Beat in eggs, stir in sugar and vanilla.

Sift flour and baking powder together. Add to mixture and stir until thoroughly mixed. Stir through white choc bits, turn mixture into tin.

Poke a few times with fork during baking, when it comes up too high.

Bake in pre-heated oven for 45-50 min or until just firm when pressed in the centre. Leave in tin for 20 min, then turn out onto a rack. When cold, cut into bars.

Dust with cocoa or icing sugar if desired.

For more recipes, have a look here: [www.bakers-corner.co.nz](http://www.bakers-corner.co.nz)



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## Great Lake Taupo Cycle Ride



Terry Watton would like to organise a team of riders to do this event and raise the awareness of GBS in New Zealand.

It is held in November, so if you are keen please contact Terry



**Contact Details:** Terry Watton

**Phone:** 07 862 6438

**E Mail:** paeroagardencentre@xtra.co.nz

# NOTICE BOARD

## Wanted

Have you made or found a device that helps with day to with other members.

Please send to the Editor.

E Mail: [chrispy57@gmail.com](mailto:chrispy57@gmail.com) or

Mail to Chris Hewlett

51 Killen Road, RD 2 KATIKATI, 3178



## Moving

or

### Changing your Email Server??

Don't forget to let the Secretary and/or Editor know your new details.



## Bay of Plenty Coffee Group.

**Next meeting:** Wednesday June 20<sup>th</sup> 10.30am

**Venue:** Villa Ridge Café – 528 Cambridge Road, Tauriko, Cambridge

## GBS BI-ANNUAL CONFERENCE 2013

Planning is well underway for this event. It promises to be one of our best ever with many interesting keynote speakers having been signed up to speak to us.

More details and a registration form will be published in the coming newsletters so in the meantime mark these dates on your calendar.

**FRIDAY 26<sup>th</sup> April 2013 to SATURDAY 28<sup>TH</sup> APRIL 2013**  
**Brentwood Hotel Wellington**

## Wanted - Urgently

Your personal story whether you be a sufferer or a caregiver we would love to hear from you.

Please send to the Editor.

E Mail: [chrispy57@gmail.com](mailto:chrispy57@gmail.com) or Mail to Chris Hewlett 51 Killen Road, RD 2 KATIKATI, 3178