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## Guillain – Barré Syndrome Support Group New Zealand Trust

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### NEWSLETTER December 2016



*If Undelivered Please Return To:*

Chris Hewlett  
51 Killen Road  
RD 2  
KATIKATI, 3178

|                             |                                   |   |  |
|-----------------------------|-----------------------------------|---|--|
| <b>Patron</b>               | Hon. Steve Chadwick               |   |  |
| <b>President</b>            | Doug Young                        | 87 Mona Bush Road, RD 1, Invercargill, 9871 | Ph (03) 230 4060<br>Email: <a href="mailto:deyoungs@xtra.co.nz">deyoungs@xtra.co.nz</a>          |
| <b>National Coordinator</b> | Tony Pearson                      | P.O Box 21, Mapua, 7005                     | Ph (03) 540 3217<br>Email: <a href="mailto:tonypearson@xtra.co.nz">tonypearson@xtra.co.nz</a>    |
| <b>Secretary</b>            | Tony Pearson                      | P.O Box 21, Mapua, 7005                     | Ph: (03) 540 3217<br>Email: <a href="mailto:tonypearson@xtra.co.nz">tonypearson@xtra.co.nz</a>   |
| <b>Treasurer</b>            | Peter Scott                       | P.O. Box 4162, Palmerston North, 4442       | Ph: (06) 357 8436<br>Email: <a href="mailto:peterscott@clear.net.nz">peterscott@clear.net.nz</a> |
| <b>Newsletter Editor</b>    | Chris Hewlett                     | 51 Killen Road, RD 2, Katikati, 3178        | Ph: (07) 549 0931<br>Email: <a href="mailto:chrispy57@gmail.com">chrispy57@gmail.com</a>         |
| <b>Publicity Officer</b>    |                                   |   |  |
| <b>Medical Advisor</b>      | Gareth Parry<br>ONZM.MD.FRACP.ChB |   |  |
| <b>Web Site</b>             | <b>Support</b>                    | <b>Education</b>                            | <b>Research</b><br><a href="http://www.gbsnz.org.nz">www.gbsnz.org.nz</a>                        |

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|---|--|
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# Board of Trustees

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## Banking Woes from the Treasurer

1. On the 21 November someone deposited a sum of money into our bank account. Unfortunately we have no idea who it is actually from. The details we have it was internet banking from a Westpac Britomart account reference is Freedom Hair or K Cameron. If that was you please, or you know who it was please let the Treasurer know ([peterwscott@gmail.com](mailto:peterwscott@gmail.com)) otherwise it will be treated as a donation.
2. A deposit was received from a Don Croucher in early December. We have no one of this name in our records, so if anyone knows him please get him to contact the Treasurer so we can add him to our mailing lists etc.



## Editor's Note

Hi everyone

*"I love deadlines. I like the whooshing sound they make as they fly by"* (quote from Douglas Adams) and that seems to be very much me. Despite my best intentions of having the magazine out early I seem to have reverted to my usual trick of leaving it to the last moment. I can't even blame those who send regular contributions as they were in hand very early in the piece. Thank goodness for a wet weekend so I am compelled to stay indoors and create.

It was very sad to hear of Bob Stothart's passing. He has been such a tremendous supporter of our group along with his wife Margaret. He will be sorely missed by us all.

It has been good to see that Auckland and Hawkes Bay have enjoyed a pre Christmas get together as did our BOP/Waikato group. I hope that this continues in the New Year. I know our group has just flourished in recent times and it is so great to hear how much everybody enjoys meeting and talking to others who have been down the GBS/CIDP track. To me that shows just what a positive effect contact with the support group can have on sufferers and their carers.

We have the Conference entry form in this newsletter. To prevent our Treasurer having a coronary can you please get your entry in asap. I know it is the "Kiwi" way to leave things till the last moment, and I am very guilty of that, but it does make it hard for the organisers.

The Group has a fund available to assist people who wish to attend the conference but may find it a bit more than their budget allows. This is treated in the strictest confidence and anyone wanting information and or assistance please get in touch with either our Secretary or Treasurer. We would love to have as many as possible attend, even if it is only for the very busy and full Saturday.

Subs are also due again, and the form on the back page of this newsletter. The funds from this allow us to print the newsletter and provide other information and support to GBS/CIDP patients around the country. Your continued support is very much appreciated.

Wishing all the very best for the festive season.

Chris

### Correspondence Received

I was wondering if anyone else in the support group has CIDP plus cramp/ fasciculation syndrome ? I would be keen to communicate with them if possible

Cheers

Marion Wood –

Contact Marion at: [marionawood@gmail.com](mailto:marionawood@gmail.com)



### Interesting Reading

The following link was sent in by Dr Robert Gregory

<http://www.news-medical.net/news/20161209/Researchers-show-how-common-bacterium-in-improperly-cooked-chicken-triggers-GBS.aspx>

## Presidents Report



Welcome to all our new GBS Society newsletter readers. There has been a lot of activity within the organisation over the last three months.

Starting with tragic news of the death of Bob Stothart in early November. Bob was an early committee member of the GBS Society with Jenny. As can be seen in the tribute to him in this newsletter he was an amazing character, whose advice and experience will be sorely missed by our organisation.

Our sympathies go to his wife Margaret and family.

I extend my thanks to those of the Board who attended his Funeral in Wellington.

Looking back, Havelock North's gastro experience appears to have abated, leaving 2, possible 3 GBS affected people. We are not aware if our local carer support group have been asked to assist although every effort was made to inform local GP's of our organisation.

The good news is for this publication, it appears to have been circulated around some District Health Boards internal staff information systems. It was great to receive personal feedback about it from a nursing friend who commented on it.

As we all know, getting the message that we actually exist to the right people within the hospitals is one of our greatest ongoing challenges.

Another issue we have considered over the last 6 months is the use of the GH Jones Memorial Fund towards research for a pain relief drug for GBS / CIDP sufferers, which is another article in this newsletter worth looking at.

Looking forward to the 2017 conference in Rotorua, early May will soon roll around, so I encourage all of those wishing to attend to register as early as possible to assist us with the accommodation and general organisation of this important event in our calendar.

As the festive season is upon us I wish you all a safe and happy Christmas / New Year with family and friends.

Regards to you all.

Doug Young  
President.



Auckland GBS Coffee Group had their third meeting for the year, 2pm 20th November at Hobsonville, enjoying afternoon tea, getting to know a new member and learning more about each other's encounter with GBS or CIDP.

**Left to Right:** Nola Neas, Lorraine Ledger, Sharon Dixon and Eileen Jacobsen



## Secretary's Jottings

They say bad events come in three's – First we have the *Campylobacter* outbreak in Hawkes Bay, then we lose a stalwart of our Group Bob Stothart and now the earthquake. I suppose for many of us "The Donald" could prove to be yet another disaster but that's for the future.

I guess I am surprised, but also relieved, that the potential GBS knock on consequences of the contaminated Hawkes Bay water do not appear to have materialised and whilst there is still no news, at least to my knowledge, of the cause the crisis does appear to be under control if not over.

They also say the Gods vent their fury when a great warrior dies – well the heavens certainly let rip for Bob's funeral. We arrived – after a delayed flight from Nelson – to join the queue into Old St Paul's signing the attendance book in driving rain and gale force winds and got home the next day (via Auckland!) after an abortive attempt to land at Nelson the previous evening and an enforced stay in Wellington overnight. But I wouldn't have missed the funeral for anything. The church was packed with over 200 family, friends and long - time colleagues – as well as a good attendance from the Group – our President having travelled the furthest from Invercargill. Vivienne and I and, I think, the other members of the Group at the funeral were amazed to learn of the extent of Bob's activities, skills and interests and the impact he had on the development of Physical Education in this country – a truly remarkable man. As for the earthquake – all I can say is that having moaned a lot about the amount and cost of the steel our Engineer insisted we put into the re-build of our property in Mapua I am now thankful that we did so. We sure rocked and rolled (half the place is on piles) but no serious damage. I hope the same was true for all of you –our hearts must go out to those so badly affected in Kaikoura and surrounds and as we GBS'ers well know the stoicism shown by so many of those interviewed on TV can mask serious emotional stress that may continue for a very long time after the bricks and motor have been rebuilt.

Bob's passing now leaves us with two vacancies on the Board. A recent Nelson based member Dr. Matt Peacey has, with Gareth's support, put himself forward as a member of the Board. After reviewing his experience and background the Board has decided to co-op Matt onto the Board. Matt will come up for election at the AGM in May to confirm his appointment. Matt is currently Research Manager at the Nelson-Marlborough Institute of Technology and is working with Gareth and others on new research into GBS related issues one of which is reported on separately in this Newsletter.

BUT we still need **another** member to "step up" and **NOW** is the time – with the Conference and AGM in May next year there couldn't be a better time to come onboard and have a say in the structure of both these events and the future direction of the Group. It is a responsible job but not onerous and – as a lot of Americans are currently realising – it's no good moaning about the outcome of events if you didn't stand up and be counted beforehand!

I enjoyed the last Newsletter but am left puzzled by the picture of Chris and Marty at the Arctic Circle – where was the trailer with all your clothes and personal stuff?? – surely you can't travel all that way with just what's in the panniers?? (*Yes everything is in the panniers, including tools, spare parts etc. The beauty of motorcycle travel is you learn to pack VERY light.*). It was also good to read Bruce Kennedy's story, particularly with his daughter's comments alongside. I loved the bit about the notice pinned to the sheet "Please wake me I would love to see you" – I recently went to Nelson Hospital to visit a friend who had broken his hip and had a replacement – when I got to his room his eyes were closed so I whispered to his roommate – "Tell David I will call back later when he is awake" – and this disembodied voice came from behind the screen – "no you won't I'm awake now!" – anyway a good tip for Carer's in future! Conference is coming – details elsewhere – but I hope that as many Hospital Visitors as possible can make the Workshop on Friday afternoon – it won't be a "lecture" – from me or anyone else - but a chance to pool our experiences and ideas to help us provide a better service in future. If you think you might like to join our "Happy Band" (and we particularly need to increase our South Island numbers) come along as well and make yourself known. It's a job that does require commitment and it's not always convenient but a quick chat to any of us will confirm just how rewarding it can be to see the difference you can make to a new sufferer and their supporters who are often confused and depressed by the situation they find themselves in when GBS comes visiting.

Lastly the next Neurological Foundation Brain Day will be held in Auckland on March 25 2017. Whilst we were unable to make a showing at last event our presence at previous events have been a significant success in publicising the Group's existence. If you can spare an hour to help man our "stall" please let me know and if there is sufficient support we can again make an effort to attend.

As always take care and if you ain't there yet continue to GBS (Get Better Slowly)

Best regards and see you in May 2017 at Rotorua

**Tony**

## Obituary : Bob Stothart: 11.10.34-2.11.16

Bob was 82 years young when he passed away! Far too soon in the minds of all of us. He retained his sharp and incisive mind to the end and just a few weeks before his death he was active in planning the 2017 conference with Gareth.

Bob was President of the GBS Support Group from 2006 to 2013 – but a member of the Board long before that and was an early member of the Group back in 96/97 when Jenny started things off.

Bob contracted GBS in 1979 and it was six months before he could get back to work and even then, he was in a wheelchair. He was hospitalised after a period of several months' deterioration during which he admitted he "resisted" aid – only giving up driving his car when he had to use a pair of pliers to turn the starter key!! (the slow deterioration would classify Bob as having CIDP rather than GBS but the distinction between the two closely related conditions was not widely recognised in those days). Bob's treatment was steroid injections with "a rapid and dramatic effect" – but even so full recovery took a long time and a lot of effort and perseverance.



Recounting his experience in a Listener article back in 1979 – and in typical Bob fashion - he says *"I learnt about myself but more particularly I learnt about the disabled. I am convinced that as a principle the disabled should have a much greater say in the management of their own everyday affairs and most disabled people wish to be treated normally", particularly in interpersonal relations"*

He couldn't have been more correct the new Disability Strategy for New Zealand, currently being finalised and to which our Group has made representations, reflects just those principles.

He was a firm hand on the management tiller – responsive to suggestions but determined if he felt his way was the right one. An interesting comment made by one of his many long-time friends at his funeral was *"yes, Bob was on many Boards and Committees – but he really only liked being the Chair of them"*.

Bob's funeral was a testament to his community involvement and learning of the extent of his influence in physical educational development in this country was a revelation. Right from the early days when he was part of a group of Scouts sent to the UK in 1951 for the Commonwealth Games and throughout his academic career Bob was at the forefront of new ideas and directions. The love of his life – after his wife and family – was, I think, skiing and he derived much pleasure from teaching his grandchildren to ski in his treasured Tongariro National Park.

Bob wrote numerous articles, both academic and in popular journals and several books and was – we were advised- something of a cartoon producer. Certainly, my English grammar and spelling (never my strong point) was kept in line in my Secretarial offerings for his approval!

Bob was married to Margaret for 57 years and during that time they travelled extensively and none of us need reminding of the unfailing support she gave him at all our get togethers. Margaret's children and grandchildren are there to support her in the years ahead as we will.

One of Bob's virtues that was highlighted on his memorial Order of Service was "arguing" but as Gareth said – *"I always thought of it as lively discussion but he always had a well thought out position and could defend it with passion"* – that's our Bob!!

A lovely, gentle man and a genuine contributor to the well being of this country. You will be greatly missed by many Bob – including your GBS Group friends.

Tony

## **Presidents Introduction to Research Study**

The following article by Gareth Parry and Eric Buenz is to inform the Groups members about the research we have decided to provide financial support for.

All GBS / CIDP sufferers know how painful the disease can be at various stages, and the pain relief offered during hospitalization often seems to be ineffective at times. (I felt like my very bones were aching not just the muscles, whatever pain relief they put into me didn't seem to make a lot of difference at the time?)

The fact that the research proposed involves a common New Zealand native stinging nettle, which may have compounds within it possible providing pain relief is especially appealing.

However without researching the plant and scientific results attained from it, there will be nothing gained for our people.

The combination of the availability of the GH Jones Memorial Fund interest money, the purposes for its use under the Trust deed, and the research being carried out in New Zealand by our own people with some specialist support from the USA. All leads to the decision to provide what support we can.

Hence the committee's decision to support the application for funding of this project .

We encourage members to donate to the support group so we may continue to support promising research of this type.

Regards  
Doug Young  
President.

## **Urtica ferox**

*Urtica ferox*, commonly known as Tree Nettle, or ongaonga in Māori, is a nettle that is endemic to New Zealand. It is sometimes known as "Taraonga", "Taraongaonga" or "Okaoka". [Wikipedia](#)

**Scientific name:** *Urtica ferox*

**Higher classification:** Nettles



# ***A potential novel treatment for neuropathic (nerve) pain in Guillain-Barre syndrome (GBS) and chronic inflammatory demyelinating polyneuropathy (CIDP)***

## ***Gareth Parry and Eric Buenz***

### ***Nelson-Marlborough Institute of Technology***

Neuropathic pain occurs in about 40% of patients following an attack of GBS and in patients with CIDP. Neuropathic pain results from damage to the nerve fibers carrying painful nerve impulses following a physiological painful stimulus such as a burn or a cut. Inflammation of the nerve, as is seen in GBS and CIDP, damages the pain fibers and leads to abnormal pain. In GBS the pain may persist for years or decades after the acute attack. In CIDP, the ongoing inflammation and nerve damage causes ongoing pain. Pain may persist even when the weakness caused by GBS has recovered or when successful treatment of CIDP has induced remission.

Neuropathic pain can be severe and is often cited by patients as the most disabling aspect of the disease. It is almost always located in the feet and sometimes in the hands but can extend to other body parts. This pain is difficult to treat and the available drugs that are used often have disabling adverse effects. Opioid drugs like morphine and its derivatives are certainly effective, but the effect wanes with time and the need for increasing doses can lead to addiction. Antidepressant drugs such as amitriptyline, nortriptyline and venlafaxine can also be effective, independent of their antidepressant properties, but have many side effects that limit dosage and, therefore, effectiveness. Similarly, anti-epileptic drugs, particularly gabapentin, can help, but their effectiveness is limited by adverse effects. All three of these classes of drugs can cause fatigue, cognitive impairment and sedation and patients often find the adverse effects bother them more than the pain. Unfortunately, anti-inflammatory drugs such as paracetamol, naproxen and ibuprofen are seldom helpful, even at very high doses.

In an attempt to circumvent the many adverse effects of these systemic medications, researchers have investigated topical application of medication to the skin in the region of the pain. Capsaicin is the chemical that causes the hot taste of chili peppers. It has been shown to attach to the nerve fibers in the skin and studies have shown that it can deaden neuropathic pain in conditions such as diabetic neuropathy and shingles. However, the effect is weak and short-lived so most patients abandon its use after a few months. Thus, there is a need for treatments of neuropathic pain that are effective without being limited by annoying and sometimes serious adverse effects.

The NZ native stinging nettle (ongaonga or *Urtica ferox*) is familiar to any New Zealander who spends time in the bush. Contact of the skin with the plant causes intense stinging or burning which subsides over minutes to hours. When there is extensive exposure, as the pain subsides, it is replaced by numbness which can last days. The nature of this reaction strongly suggests that the plant contains a compound which attaches to nerve fibers in the skin initially causing the pain but then temporarily suppressing activity in these same nerve fibers causing the numbness. This indicates that it has potential to provide benefit in patients with neuropathic pain. We at the Nelson-Marlborough Institute of Technology (NMIT), in collaboration with the Mayo Clinic in America, have shown that high concentrations of an extract of the ongaonga plant can affect nerve cells grown in a test tube. The molecule that causes this effect on nerves cells is entirely unknown but could be a new therapeutic agent for chronic neuropathic pain. It may seem paradoxical that a chemical that damages nerve cells could be useful in treatment of pain arising from nerve damage but many therapeutic chemicals are known to be therapeutic at low doses but toxic at high doses. We therefore plan to explore the therapeutic potential of the ongaonga toxin in more detail in the test tube to determine the molecule that might be used as a therapeutic agent. This scientific work is the first step to eventually a study in experimental animals and ultimately humans.

This research has been partly funded by a generous grant from the NZ GBS Support Group and we are enormously grateful to all of the members of this group who have donated funds to the organization.

## GBS A PERSONNAL ENCOUNTER – Simon Wyatt

My experience goes back to late March 2012. I was a detective in the NZ Police at the time (28-years-old), and had just returned to work after a week off sick with a gastro illness. I was working a late shift in West Auckland. About half-way through the shift I was taking a statement from a witness in Massey, after the discovery of a clan lab operation. I recall feeling pins and needles in my right calf muscle. At the end of the shift, at 10:00 pm, I walked to my personal vehicle parked outside the Henderson Police Station and was limping. I remember thinking it was strange - I was young and fit and hadn't done anything to aggravate it. So I told myself I'd sleep it off and the next morning I'd wake up feeling normal again. How I was *wrong*. The next morning, I got out of bed and fell on my arse, my legs having given way, feeling as though I had heavy weights strapped to each of them. I also found that I couldn't wiggle my toes. Obviously, I knew something terrible had happened to my body, and called my father to assist.

We ended up at the local GP's, where I told the doctor about my gastro illness and showed him the limitations I now had with the movement of my toes. Looking back I felt as if he didn't really 'listen' to me and take me seriously. He merely told me that it was likely dehydration and cramp from the gastro illness, and that if it got worse to give him a call. We listened to his advice and my father took me back to my parent's house. Feeling frustrated at the lack of answers and knowing something was wrong with my body, I ended up on Google. I typed in 'loss of movement in toes after infection'. The first search result I looked at was about GBS (which I had never heard of). I started reading the symptoms and found myself ticking off symptoms as I went along: pins and needles, weakness, clumsiness, loss of movement of body parts. It also included the words 'Treat as a medical emergency'. My father took me to the local hospital, where I told the nurse at the counter my Google-assisted diagnosis. I was asked to wait, while people with sports injuries - broken noses, sore wrists were being given priority. After about 2-3 hours of waiting we finally saw a young doctor who 'listened', made some phone calls and then shipped me off to Auckland Hospital where I was eventually diagnosed with GBS by a neurologist that night.

I spent approximately 5 weeks in hospital, another 5 weeks in rehab, before commencing an outpatient programme. At my weakest, I couldn't walk, and was so weak I couldn't open a packet of crisps. I lost a lot of muscle, had to learn how to walk again, but was grateful that I never ended up in Intensive Care or had paralysis extend to the upper half of my body. Today, I have recovered to the extent that I can work (albeit, with a slight limp at times) but still have difficulty moving my toes and standing on them, so cannot run properly just yet. I have since left the NZ Police and now work as an investigator for the Serious Fraud Office (SFO).

Early in my hospital stay I was devouring a lot of crime fiction; my favourite genre (probably a given based on my chosen work). It was at this time that I thought I needed a goal, a sense of purpose to work towards. A sense of purpose, I feel, is vital. Especially in such dour and life-changing circumstances such as this. A young, fit man, living the dream as a detective, now crippled. The goal I gave myself was to write a book - a murder mystery novel using my past experience and my investigative skills to create an authentic product based locally in West Auckland - the place I grew up and policed.

So I went about the task (daunting as it seemed at the time) to write a book, using my time over the next three years after work hours (after having returned to work on a gradual basis), and on weekends. The book has been finished and is now in bookstores nationwide (including Whitcoulls and Paper Plus). On its first week (week ending 29 October 2016), *The Student Body* topped the bestseller list for NZ fiction, and is still currently sitting in the top ten. I have dedicated the book to survivor's of GBS and to others facing hard times through serious illness. The book helped me in so many ways with my recovery. I hope this story may help someone out there (or more than one person) who may be in a similar situation that I was in. I want to emphasise to them that they can and will rise up and defeat it. Don't let GBS bring you down and eat away at you. The mind is a powerful thing; remember you're in control of your mind and your emotions, and sometimes there is a silver lining (mine was discovering my passion for writing). I know for one, times can be extremely difficult, but it is through these trying times we learn most about ourselves and about what we really value. Never give up.

# GBS A PERSONNAL ENCOUNTER – Simon Wyatt

Continued....

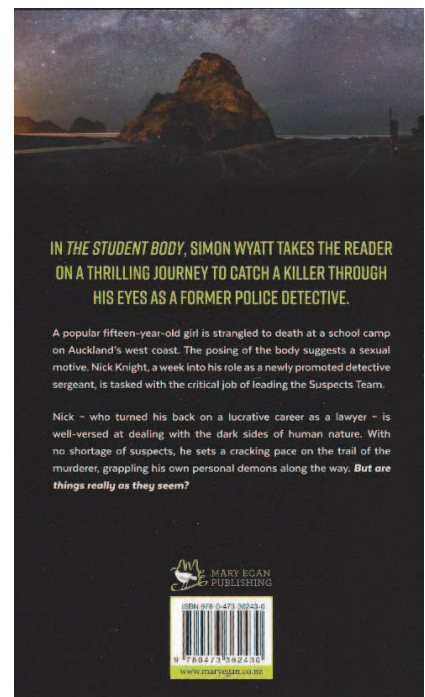
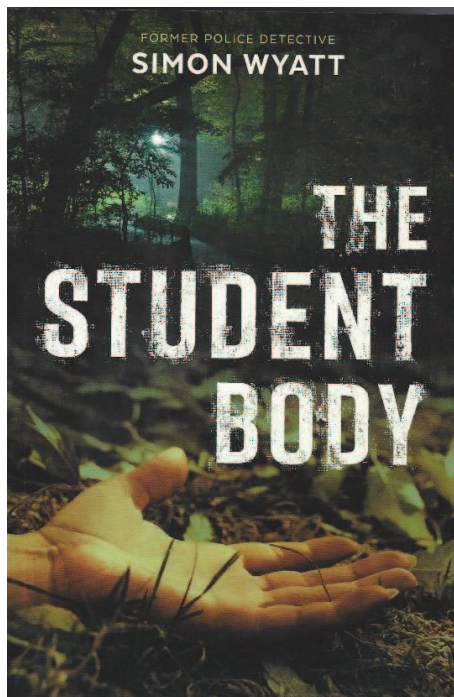
I would like to thank immensely the staff at both Auckland Hospital (Neurology) and Rehab Plus for the way they went about helping me through my journey. I was rather impressed with the way they went about the difficult work they do. It was in a friendly, courteous, respectful and informative manner, and I will never forget it. It is very much appreciated.

Finally, I'd like to donate 10 copies of my book to the *Guillain-Barré Syndrome NZ Trust* to be given away to any mystery/thriller readers out there recovering from GBS.

Simon Wyatt

***On behalf of the NZ GBS Support Group the Board would like to thank Simon for his very generous offer. Ed.***

*If you would like a copy of Simon's book please contact Tony Pearson, contact details on the cover page of the magazine.*



## **A Personnel Encounter – Lyn Stuart**

My GBS experience starts four years ago in June 2012 with an idyllic holiday in Rarotonga. I had a bad stomach bug a few days before we left but was determined to make the trip. Luckily I had recovered but was tired when we flew out. We only had 5 days but made the most of the time and spent lazy days on the beach and exploring the island. A couple of days before we were due to return I noticed that it was difficult to squeeze out the kitchen sponge but thought no more about it even though the problem didn't go away. Looking back I was also a little unsteady on my feet at times but put that down to still being tired after the tummy bug. On returning to Auckland we had a connection to make for our flight back to Christchurch and I remember wondering why I couldn't keep up with my husband Allan walking from the international terminal to domestic. Usually we walked at much the same pace.

Back home and back to work. I had timed the holiday to be back on deck a week before the June annual balance to complete the annual financial statements for the NGO I worked for. Monday was naturally very busy at work so the problem with my weak hands was put aside, but by Wednesday it was apparent that something was really wrong as I almost collapsed at work. Allan picked me up and we went to my GP. She was right on the case, told us that she thought it could be GBS and that I should collect a few things and go straight to Ashburton hospital.

I stayed overnight at Ashburton while being assessed and that night the pain started. I would ache all over and only movement eased it. I was still mobile but my hands were quite weak so next day I was transferred to the neurology ward at Christchurch hospital. There was some confusion about a GBS diagnosis as apparently I didn't fit the classic symptoms. Therefore it was two weeks in Christchurch before I was given the plasma treatment that was supposed to bring about an immediate benefit. During the time in Christchurch I was experiencing a deep aching pain every night but felt better during the day. The only way to alleviate the pain was to walk the ward for half the night as the only pain relief was Panadol. Also during this time my legs were getting weaker to the extent that I couldn't get up off the toilet by myself even with a raised seat. Once I was upright I could walk slowly and felt more stable but even that was becoming a problem. At one consultation with a doctor, he asked me to crouch a little as if skiing and the result was a collapse to the floor much to his surprise and the entertainment of others in the ward.

Immediately on completing the last plasma treatment I was loaded into an ambulance to return to Ashburton with an assurance that I would come right fairly quickly. So back to ward one at Ashburton and more assessments there. A couple of days later I hadn't noticed any improvement but was told that I should be able to go home soon. Shortly after that I collapsed while getting to the toilet even though I was using a walker and this upset me because I felt weaker not stronger. The doctors still expected me to be able to go home and ordered a physiotherapist to test my ability on stairs. I failed miserably, able to go up with lots of help but just collapsed when going down. Obviously I wasn't getting better and in fact was much worse.

My new home was ward six at Ashburton hospital and I say home because it that was the case for the next eight weeks. At that time Ashburton was taking an overflow from Christchurch and the ward was full to capacity with Christchurch people who had a variety of issues from stroke victims to people with fractures in transit between Christchurch hospital and Burwood rehabilitation. There were also some local people with a variety of issues. I got to know several of them and watched their progress with interest as I was going backwards instead of forwards. The only improvement was on the pain front as I was prescribed a cocktail of drugs which prevented pain from surfacing. The physiotherapists were amazing and I was given all the assistance I needed but was still deteriorating to the extent that it was a real effort to roll over in bed and sitting up to eat involved complicated manoeuvring, sometimes resulting in getting stuck not able to get my legs over the side and not being able to push up from balancing on my elbow but I always made it in the end as mealtimes helped to break up the day. Even so I lost about 5 kgs which was probably due mostly to muscle wastage. Early on I was taken to the toilet by means of a gutter frame with a nurse holding me up by a waist belt, the problem with that was although I could balance on my upper arms, my hands wouldn't hold if I started to collapse. Later I was introduced to a wheelchair and slideboard system which gave me much more independence.

## **A Personnel Encounter – Lyn Stuart** *continued*

Of course my work was a real issue and my boss had to hire a temporary replacement who was thrown in at the deep end to try to work out what needed doing. Not an easy job as mine was a sole charge position and I had developed the systems over a number of years. Luckily she was able to come in to see me a couple of times with a long list of questions and I still seemed able to think reasonable clearly. Wendy was just one among a number of people that I am very grateful to for helping me through the whole process. My husband, workmates, family and friends were also very supportive and even staff at the library would select books to be sent to me.

Following the second plasma treatment I started to see an improvement in strength and continued to improve to the extent that I was able to progress to using a gutter frame without assistance then lastly a walking frame. At home a ramp was planned and the bathroom fitted with a swivel seat over the bath/shower. We also had to remove the toilet door and replace it with a shower curtain temporarily to allow me to back into the toilet using a walker. These modifications were only needed for a couple of months as I continued to improve and by October I could once again drive after a test run on a quiet back street. I had returned to work on a half day basis and went from sharing my job with the temp to taking over again completely in time to produce our annual accounts so by November the progress I had made was such that I could operate much as usual.

To most people it appeared that my recovery was complete but there are still some things that are an issue. The first is debilitating foot and leg cramps at night which meant I spent many nights walking the hallway trying to get to a point where I could go back to bed. This was a problem until about a year ago and an article in the GBS magazine suggesting Amitriptyline 10 mg for pain led me to mention this to my GP. She said that if GBS was causing cramp the Amitriptyline may help and this has proved to be the case. I have been taking this for twelve months and can't imagine being able to do without it as if I miss a night the cramp usually returns the following night. I also get a burning sensation on the top of my feet, cramp in my hands with fingers sticking out at odd angles and my leg muscles flicker a lot. This is worse after exercise but this too has lessened somewhat since taking the medication. Tiredness is hard to quantify and at age 68 I am not too sure how much GBS has contributed to this. I find that exercise is essential to prevent stiffness and maintain endurance and I sometimes use walking poles to aid stability on rough ground but mostly don't have to make concessions to any remaining symptoms. This May my husband and I made a trip to Europe, taking in some bucket list items including Badminton horse trials and driving through Wales, Ireland & Scotland, a few days in London then Paris on the way home and I was able to enjoy it all without any problems.

One of the strange things about this GBS experience is that once I knew what was wrong with me I kept coming across people I knew who also had GBS. Two acquaintances in South Canterbury, one young man working with my husband, one woman who was in hospital with me had it some years ago, plus someone I had worked with previously was diagnosed after me. Of these, two still had major visible symptoms, one had left the area so I'm not sure and the other two appeared perfectly fine. I wonder how many of us with some lingering issues are in the 80% fully recovered category as far as the medical profession is concerned. I know that my GP regarded me as fully recovered but four years on that is almost but not quite true.

Lyn Stuart



## Waikato/BOP Christmas Get Together



**Back Row:** Meike Schmidt-Meiburg, Glenda Ryan, Barry Deed, Ken Ardern, Grant McKay, Rex and Karen Soppett

**Middle Row:** Judy Deed, Julia Ardern, Fran McKay

**Front Row:** Chris Hewlett, Jan Gribble, Yvonne Powell, Emma and Phil Wolfe, David Powell

## HAWKES BAY CHRISTMAS GET TOGETHER

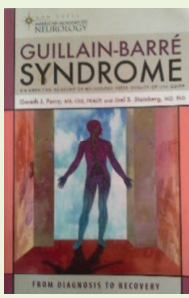


*A good turnout in the Hawkes Bay. Those attending were:*

*Bil and Lil Morgan, Jenny Ackroyd, Jeff and Beverley Whittaker, Dean and Mandy ?, David and Julie Meyer, Shona Taylor, Eddie Odwyer and Kathy Eggers*



# NOTICEBOARD



New Stocks of this easy to read and enlightening book are now available. If you would like to purchase one contact:  
Chris Hewlett:  
[chrispy57@gmail.com](mailto:chrispy57@gmail.com)  
Or  
Tony Pearson:  
[tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz)

## PUBLICITY OFFICER WANTED

We are looking for someone who would like to take on this role.

If you think you have what it takes please contact:

Doug Young: [deyoungs@xtra.co.nz](mailto:deyoungs@xtra.co.nz)

Or

Tony Pearson: [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz)

## What's Your Story?

Urgently needed are your stories to publish in your magazine.

Please take the time to write about your GBS/CIDP (and or other Variants) and post or email to me – your editor. Details on the front of the newsletter.

## Your Ideas Wanted

What topics would you like the MAB to cover at the next Conference?

Send your wish list to the Editor

Email: [chrispy57@gmail.com](mailto:chrispy57@gmail.com)

## WAIKATO/BAY OF PLENTY COFFEE GROUP

Thursday 23<sup>rd</sup> February

Where: **The Loose Goose**

7 Main Road Tirau  
<http://loosegoose.co.nz/>

Time: 11am onwards



Please let Meike know if you are attending so she can confirm numbers with the Café.

Email: [schmidtfarm@xtra.co.nz](mailto:schmidtfarm@xtra.co.nz)  
Cell Ph: 027 3250369

**Everybody  
welcome.**



Our next bike ride is on

**Wednesday 1st February at Lake Karapiro.**

Please bring a shared lunch (or your own)

**Directions:** Coming from Cambridge end, drive into Leamington. The main street is called Shakespeare Road. Turn left into Browning St. We will meet at the corner of Browning and Scott Streets. If you get lost phone Grant for directions; 021 865 620

## Conference and AGM 5-7 May 2017

Attached to this newsletter is the registration form for the 2017 Conference and Annual General Meeting to be held in the Novotel Complex in Rotorua.

Accommodation is available in either the Novotel Hotel \$185 per room per night or the adjacent Ibis Hotel \$135 per room per night. The Novotel is a little more upmarket than the Ibis. The Novotel is accessed from the Ibis by a covered walkway (except for the first 20/30 metres)

An interesting program is being organised, so please make an effort to attend. Prompt registration will assist the organisers and the hotels.

# Guillain Barré Syndrome Support Group Trust N.Z.

Registered Charity No CC20639 [www.gbsnz.org.nz](http://www.gbsnz.org.nz)

## INVOICE

### 2016-2017 MEMBERSHIP ANNUAL SUBSCRIPTION

Subscriptions for membership of the Group for the financial year commencing on 1<sup>st</sup> December 2016 are now due and your ongoing support would be appreciated to help further the important roles the Group plays in supporting new and existing sufferers of this devastating syndrome.

**Please detach the bottom section of this page, complete the information requested and send with your remittance to the address detailed below.**

#### Subscription Rates

Single Annual \$15.00

Single Life \$150.00

*Subscriptions can be paid Direct Credit the Group's Bank Account  
Taranaki Savings Bank (TSB) Moturoa Branch New Plymouth  
Bank Account No:- 15 3949 0339362 00*

***Be sure to reference your name on the transfer***

You can also now receive the Group's Newsletter by e-mail (thus helping us with the cost of stationery and postage) if you would like to take up this option and have not already notified our Editor Chris Hewlett please e-mail her at ([chrispy57@gmail.com](mailto:chrispy57@gmail.com)) or add your e-mail details below and we will arrange for this to happen.

**Thank you on behalf of the Board of Trustees.**

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**Please detach and post this remittance advice with your subscription to:-  
Peter Scott PO Box 4162 Palmerston North 4442**

NAME(s).....

MEMBERSHIP NUMBER(s) (if known).....

SUBSCRIPTION(s) PAID .....

DONATION .....

TOTAL =====



If your address or contact details (Email/Phone) have changed recently please make a note of the new details here.....

.....  
.....

## GUILLIAN BARRE SYNDROME SUPPORT GROUP NEW ZEALAND TRUST

### 2017 CONFERENCE AND ANNUAL GENERAL MEETING ROTORUA 5-7 MAY 2017

I/We will be attending the Conference as follows

|          |         |                               |               | No<br>Attending |
|----------|---------|-------------------------------|---------------|-----------------|
| FRIDAY   | 5th May | Hospital Visitors Meeting     | 3pm           | _____           |
|          |         | Registration                  | from 4pm      | _____           |
|          |         | Wine,Cheese and Chat          | 5.30pm-7pmish | _____           |
|          |         | Dinner (optional) at own cost | 7.30pm        | _____           |
| SATURDAY | 6th May | Conference welcome            | 8.45am        | _____           |
|          |         | Conference starts             | 9.00am        | _____           |
|          |         | Conference Dinner             | 7pm           | _____           |
|          |         | (Own Expense)                 |               | _____           |
| SUNDAY   | 7th May | Annual General Meeting        | 9am           | _____           |

### REGISTRATION COSTS

|                    | <u>If paid by</u><br><u>28-Feb-17</u> |          |
|--------------------|---------------------------------------|----------|
| Full Registration  | \$100                                 | _____    |
| Saturday Only      | \$80                                  | _____    |
| For 2nd person     | \$50                                  | _____    |
| in family          |                                       | _____    |
| Full Time Students | \$30                                  | _____    |
| Dinner (Optional)  | \$45 ph                               | _____    |
| TOTAL              |                                       | \$ _____ |

Special Dietary Requirements (ie GF etc)Please advise \_\_\_\_\_

All those who register pay before 28 Feb 2017 will go in a draw to win a nights accommodation to the value of \$135 or for those not staying in the Hotels a refund of their registration fee up to the value of \$100.

### ARRIVAL METHOD & ESTIMATED TIME

Friday/Saturday/Sunday (Please circle which day)  
 Estimated time of arrival \_\_\_\_\_am/pm  
 Method Car/Plane/Other (Please circle one)

### PLEASE NOTE THAT YOU WILL NEED TO MAKE YOUR OWN HOTEL BOOKINGS DIRECT TO EITHER HOTEL

Novotel Lake End Tutanekai St Rotorua Ph (07) 349 8110

Ibis Lake End Rangiuru St Ph (07) 346 3999

OR email both hotels on h1874-re1@accor.com quoting GBS Conference and the hotel you want to book into

If you need a disabled room please advise hotel at time of booking.

Are you interested in sharing a room? Please advise if you are

Is this your first Conference Yes/No (please indicate)

Who is the sufferer? \_\_\_\_\_

Who is(was) the carer/spouse \_\_\_\_\_

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

E-Mail Address \_\_\_\_\_

Given Name (Nick) name (s) for name tags \_\_\_\_\_

\_\_\_\_\_

**PLEASE RETURN TO GBS PO BOX 4162 PALMERSTON NORTH 4442 WITH YOUR PAYMENT. IF PAYING BY DIRECT CREDIT INSURE THAT YOU SEND THIS FORM TO THE ABOVE BOX NUMBER. PAYMENTS/REGISTRATION FORMS RECEIVED AFTER THE 28th FEBRUARY 2017 WILL NOT GO IN THE DRAW.**

