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## Guillain – Barré Syndrome Support Group New Zealand Trust

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### NEWSLETTER December 2017



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# Medical Advisory Board



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<b>Dr. Pralene Maharaj</b> <b>Pathology Registrar ADHB</b> <b>And Trainee in Pathology with the Royal College of</b> <b>Pathologists Australasia</b> <b>Member of GBS Support Group since contracting</b> <b>GBS in 2006</b>	<b>Dr. Suzie Mudge</b> Director & Physiotherapist Neuro Rehab Results Senior Lecturer/Senior Research Officer Health and Rehabilitation Research Institute, AUT University
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## ***In this Issue***

Editor's Note	Chris Hewlett
Presidents Report	Doug Young
Secretary's Jottings	Tony Pearson
A new way to receive an established treatment	Dr David Gow
Obituary of Celia Stephenson	Tony Pearson
A Personnel Encounter (Part One)	Frances and Ross Bidmead
New Website Development	Tony Pearson
Christchurch Coffee Group	Tony Pearson
A Personnel Encounter	Steve Cincotta
Report on the Onga Onga Research Project	Tony Pearson
Report on the West Auckland Coffee Group Meeting	Eileen Jacobsen
Notice Board	Chris Hewlett

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## Publicity Officer

The Group **desperately** needs a Publicity Officer ó someone with the experience to help us get our message ó indeed our very existence ó out into the public domain via the media.

Do you have the skills to help us?

The Board has approved the payment of an **Honorarium of up to \$1000pa** (depending on the level of skill and experience demonstrated) to encourage someone to step forward ó could it be you!

Contact the President or Secretary if you are interested.

## Editor's Note



Another year has ended and we have gained a few more members to our group. I hope you are all making good progress on your GBS journey and have found the Support Group helpful and enlightening.

We are very lucky to have the support of a very knowledgeable Medical Advisory Board and they have agreed to each produce an article for the newsletter on a roster system. Dr. David Gow has started the ball rolling with an article on new ways to receive an established treatment. Next issue will be from a physio point of view so if anyone has anything they would like to hear about in that field please let me know so I can pass it on. I would need your input no later than 22<sup>nd</sup> January.

Thanks to everyone who has contributed to the magazine over the past year. Without this it would be very difficult to produce this magazine. I am always wanting personal stories so please don't be shy. I have one and a half stories in hand for the March newsletter so things aren't grim yet.

Also a big thank you to those members who have been supporting the coffee group get togethers, happening around the country. It can be a struggle for the organiser to get things off the ground but I believe it is well worth the effort.

Last month I had planned to put the 'Chair Exercises' given to us at the Conference by the staff at QE Health but I managed to forget to include them but I guess no one was feeling particularly active as I didn't receive a single request or query about their lack of inclusion. Due to ample content for this magazine I am going to hold them off till the March magazine. By then you will all be back from the beach and ready to take on some pre winter activity.

Wishing you all a fun filled festive season.

Chris

### Obituary - Celia Stephenson

We were saddened to learn last month that Celia had passed away so soon after her devoted husband Gordon had died.

Celia and Gordon were staunch supporters of our Group for many years and whilst they were rarely seen apart. They always had time to listen and give support to others who had come face to face with GBS and were regular attendees and active contributors at our Conferences enjoying the friendship and camaraderie that these events engender.

Their contribution to the wellbeing of this country was not just limited to the GBS Support Group for they were active in many ecological and social fields and were the instigators of the Q.E. 2 Trust to protect large areas of New Zealand from development and adverse change.

We shall miss them both at future events but are grateful to have known them as friends and to have had them as members of our special community.



# Presidents Report



Welcome to all our readers.

Summer on its way?

So starting the message with an interesting thought. It's the 4<sup>th</sup> December and I am sitting in Invercargill, 10.00pm in the evening and its 21.5 degrees outside ó scary stuff!

Thinking of fellow board member Beverly Whitaker of Havelock North / Hastings area, can she spare a glass of water for her friends from Napier city who may run out of water in some parts of their city tonight? Television showing dirty water out of some taps, which should get any GBS sufferers alarm bells ringing.

Especially after the Havelock North water contamination issue.

We never know what Mother Nature is going to throw at us just around the corner. A lack of suitable drinking water may force some people to drink water from an alternative source. That source may contain contaminants that their immune system is not 'primed' for?

This leads to a stomach illness, next thing the person has GBS.

Napier was facing an extreme weather event, which its existing infrastructure couldn't cope with and summer has only just arrived. I am left wondering how many of our cities could end up facing a similar situation this year.

Moral of the story: Water is our second most precious resource on earth, don't take it for granted, and be aware of how it gets into your glass, fit for human consumption, without it making you sick!

Our board members have been active in the background over the last 3 months.

Matt Peacey working on the new website which has now completed the development phase for the trust. We are now looking for volunteers to 'populate' the content into each section. So any of you, computer literate members who love messing around on your computers contact Matt Peacey or Tony Pearson to find out what's required.

Tony Pearson has been attempting to set up contact with the Christchurch District Health Board to promote ourselves in the Canterbury area without much success. We need someone to run the hospital visitors program in the area. Even though there has been a number of high profile cases in the area, we don't seem to have picked up any membership from it. Great effort by Tony thanks.

Meike Schmidt-Meiburg has been promoting her coffee group throughout the Coromandel area via the local GP's & medical centres.

And our Auckland team has seen John & Margaret Davies absent for the last two months on a little adventure to Ireland and Norway, I am sure they missed you both, welcome back.

That's it from me, merry Christmas and a happy and safe festive season.

Regards to you all.

Doug Young  
President.





## Secretary's Jottings



A couple of evenings ago Vivienne and I (and about 500 others- mainly young Mums!) went to a lecture on the developing young brain from birth to adolescence. With grandchildren fast approaching the 'difficult' age we thought it might be good to get some 'expert advice'. After a couple of hours, rapid fire, delivery of both highly relevant and often hilarious information I came away with a couple of thoughts:-

1. **Information is empowerment** - not in the 'I am in charge' sense but rather that armed with the relevant information you are in a position to make informed judgements and be in control of situations you find yourself in. That is one of the Group's PRIME tasks - to get that information to people in need - either by pamphlet hard copy - website - Facebook or just simple conversation.
2. **Support provides encouragement and hope for a better future.** As GBS Survivors I think we can all relate to that whether it was family support or Group support in the form of a Hospital visitor or a friend over a cup of coffee - it sure as hell helped!

The evening was organised by a local organisation that provides help and encouragement to young people to give them confidence in their own ability and to learn to mix with and be better members of the Community and the General Manager encouraged us - as we left - to apply the 'positive thinking' approach enthused by the Presenter to our everyday lives - so here I go !!

A wee while ago I was put in contact with a family whose father - a working man of 66 (no age in my book!!) had gone down with CIDP and at the time of the contact had been 2 months in ICU in the Taranaki Base Hospital in New Plymouth. Now some of you (hopefully all of you) will recall that some 20 years ago a very special lady called Jenny Murray started our Support Group IN NEW PLYMOUTH!!

Not one single person - Consultant, Doctor, Nurse or support staff ever mentioned our existence to the family and subsequently a doctor attending the case said he had never heard of us! The family were put in contact with us by a relative living in Western Australia for goodness sake!

Now - I WAS going to have a jolly good moan about this but - with positive thinking in mind - I concluded what the hell - they DID make contact. OK it would have been better two months earlier but with the help of a lot of telephone conversations, pamphlets, links to the website and a visit by a couple of dedicated local members we have provided that INFORMATION and SUPPORT they so desperately wanted and have given them - as one of the sons said - *'hope and strength to deal with our father's present condition'*.

Well it is the time of year for **Good Will to All Men** - so perhaps we can forgive the inevitably overworked medics at the Base Hospital but we had better get some Group advertising up on their Notice Boards pretty damn quick.

The 2016/17 Annual Report of the USA Support Group has a cover page that states

*'It's only Rare - Until it's you'*

How true is that - and it's worth us 'old stagers' who have been around the Syndrome for too many years reminding ourselves of just how scary it was when it first arrived unannounced and unexplained and to perhaps deal more sympathetically with new sufferers who we might initially think are overreacting to their misfortune. A very fit and healthy good friend of mine in our Walking Group was set back recently when he was diagnosed with SCLERODERMA - no I had never heard of it either - but there IS a support Group! At least with GBS our odds of making a pretty good recovery are somewhat better than the Lotto - with some of the strains of that (not so rare disease as I now know) I am not so sure!!

Well the end of the Group's Financial year has arrived and Peter and I must 'gird our loins' to meet the requirements of the law and the Charities Commission - not to mention ensuring our members know their subs and donations have been judiciously used and looked after. From here on in membership of the Group is free - but the costs don't go away so please, if you can, be generous with any donation you feel able to give to support the ongoing work of the Group. I will sign off with Season's Greetings to you all and wish you, not WEALTH, but HEALTH - there is no doubt about which is the most important!

Take Care  
Tony

# ***A new way to receive an established treatment.***

**By Dr. David Gow**

Intravenous immunoglobulin (IVIG) is a well - established treatment for immune mediated neuropathy. In the case of GBS, one course is usually all that is required and most patients probably forget about receiving it, as it is just a small part of a long inpatient journey. This is in contrast to CIDP and multi focal motor neuropathy (MMN) where patients need to receive regular infusions. The impact of coming backwards and forwards to hospital on a regular basis, anywhere between 3 and 6 weeks in most cases cannot be underestimated.

Around 5 years ago in Manchester UK, we started to explore using sub cutaneous immunoglobulin preparations. They had been used in immunodeficiency patients for some time in our hospitals. This is another group of patients who require regular infusions. Because of the burden of these repeated hospital visits attempts were made to treat these patients at home. Initially with home IVIG but as this required intravenous access it was still problematic and required significant community nursing resources. Subcutaneous immunoglobulin (SCIG) can be totally patient delivered with the right training and upper limb function and as such this quickly replaced home IVIG in our area as the alternative to hospital based IVIG for the immunodeficiency patients. We were keen to try this in our MMN and CIDP patients and built up a cohort of patients that we studied carefully including assessing quality of life as well as monitoring neuromuscular function. The patients used a clockwork pump and infused on a weekly basis. They would hook up the pump and then get on with their daily life. A delivery and community support network was required and the patients were trained by a specialist neuromuscular nurse.

The SCIG was effective and quality of life measures improved in our small cohort.

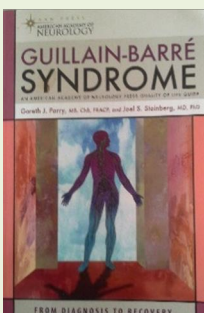
To make significant changes in health care we need large well designed studies to provide evidence that treatments are equivalent or better to current practice. This means that despite experience from centres like Manchester clinical trials were required to prove that SCIG was effective.

The PATH study, a trial of high and low dose SCIG versus placebo (1) has recently reported in Lancet Neurology. This trial confirmed that when SCIG was used in a group of CIDP patients who had previously responded to IVIG that it was effective at reducing relapses in comparison to placebo.

Although the study showed that SCIG was effective at controlling CIDP 30% of the high dose SCIG group and 39% of the low dose group either had a relapse or stopped the treatment for other reasons. This suggests that it is not going to suit every patient but may be the answer for some. Over all this is an encouraging piece of work and it will provide some much needed evidence when we look to expand treatment options for patients with chronic immune neuropathy. Clearly there will be a need to develop a community infrastructure to facilitate after care also.

## **Reference**

1. Subcutaneous immunoglobulin for maintenance treatment in chronic inflammatory demyelinating polyneuropathy (PATH): a randomised, double-blind, placebo-controlled, phase 3 trial. van Schaik et al. PATH study group. Lancet Neurol. 2017 Nov 6. pii: S1474-4422(17)30378-2. doi: 10.1016/S1474-4422(17)30378-2. [Epub ahead of print]



New Stocks of this easy to read and enlightening book written by Dr Gareth Parry and Dr. Joel S. Steinberg are now available.

\$30 including P & P.

If you would like to purchase one contact:

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

# Our experience with GBS

*Frances and Ross Bidmead*

Our experience with GBS began with Frances feeling her legs were a bit tingly and 'not right'. Within a week she was completely paralysed, able only to blink and on a ventilator. Nine months later she is walking, cycling and working full time. This is something of our experience as patient and partner.

## Guillain Barré Onset in Samoa – Frances's Story

I waved the cyclists off on their tour, pleased to have everyone fitted and on their way to catch the noon ferry to Savaii. It was another warm day in Samoa, the sea sparkled and the coconut palms gently swayed. I thought of all the things that we had to finish before our departure to New Zealand in just two days, little knowing that my life was about to change dramatically and that I would be travelling home by private jet. With the shed closed and our Samoan staff heading home I walked back to our cottage. I always enjoy the wander up our long driveway past the pink Teuila flowers, star fruit, lime and apu trees but am also conscious of the towering coconut trees with their coconut bombs ready to drop on unsuspecting heads. Tofi, our semi wild Samoan cat, greeted me on the driveway and strutted purposefully ahead of me with her tail high in the air hoping to guide me to her plate.

Later I collected some esi (papaya) from our trees which was tricky by myself. Poking to dislodge the Esi with a long stick whilst simultaneously catching it is always a challenge. It's normally a two-person task but Ross was away on Savaii on a mission to climb Mt Silisili, Samoa's highest mountain. It's a three-day walking trip using Samoan guides to show the route and I was keen to know how it had gone and looking forward to his return the next day.

My legs felt strangely sore and tired for no reason. Increasingly during the evening my feet felt like pins and needles and my knees felt wobbly. I googled these symptoms including Zika in the search. The results weren't promising and feeling some unease I headed to bed hoping that they would feel better in the morning. During the night, I woke a couple of times with increasing numbness and with growing concern I unlocked the door and put my cell phone next to the bed.

On the next morning, Monday 20 November 2016, I managed breakfast and cautiously wobbled my way down to the shed. Julie helped me start the stocktake by counting the bike bags, pacsafes, bike pumps and panniers whilst I sat and recorded the numbers. I had a cup of lemon grass tea and was sure that it was made with off water as it tasted like dirty metallic socks. Feeling tired after a couple of hours I stood up to head back to the cottage. I couldn't walk! It was strange and disconcerting. With Julie's assistance, I made it to the cane couch and rang Ross to let him know what was happening. They were on the ferry and about an hour away.

It felt a very long hour waiting for the Ross to return. Julie gave me a flick massage of my legs which was comforting and finally Ross arrived back and I was bundled into the car to start the hour-long drive to Apia where the new hospital is located. We talked about this and that in the car skirting around the possibility of Zika and in the back of my mind Guillain Barre Syndrome (GBS). Earlier in the year I had spent some time looking up the Zika virus and the possible side effects including GBS, so I knew the symptoms. Zika was a topic of concern to us as it could be caught in Samoa and an issue for our cyclists. The Brazilian Rio Olympics had profiled Zika alongside microcephaly in babies and we were having a spin off effect with lower tourism numbers.

We pulled up at A & E and were promptly asked to move the car from the entrance. Ross managed to assist me into the waiting room. As with most A& E situations nothing seemed to happen for a long time. There were several excursions to the toilet with decreasing leg function each time and finally a wheelchair was found for me. This would be the last time that I stood for 6 weeks.

A fifth-year Samoan medical student examined me and gave the tentative diagnosis of GBS. We weren't surprised. Later the neurologist saw me and confirmed the diagnosis with blood tests. We asked what could be done. He said that IVIG transfusion was important but sorry they didn't have any in Samoa. He then suggested a plasma transfusion was the next best thing but then noted that my O- blood type was extremely rare in Samoa. Perhaps we could rally enough palangis to donate blood to create the plasma.



# Guillain Barré Onset in Samoa – Frances's Story

Ross suggested a medi vac to NZ at which he positively beamed and gave us the thumbs up that this was the best possible option available.

I spent the night in intensive care in Apia Hospital. The nurses were lovely but during the night each time a patient required any attention the main and only light was unceremoniously turned on so that all four patients in the room were wide awake. There were no pillows and it proved an uncomfortable time sleeping with my bundle of clothes as a pillow. The night was long, lonely and scary, not knowing what was going to happen.

In the morning, Ross was back and after a great deal of coordination we were given the OK that our Visa Card insurance would cover a medical evacuation to NZ. We breathed a sigh of relief that we wouldn't be footing the \$120,000 medical evacuation by air ambulance. Our Samoan employees visited me and quickly headed off to buy a pillow to make me more comfortable. This soft Samoan pillow was to be my constant companion for the next 8 weeks in hospital.

It felt like a long wait but finally the New Zealand air ambulance crew strode confidently into the ward with the stretcher. It felt good and very comforting that they were there and we were about to embark on our journey home. They checked me out, ensured that the catheter was in place and confirmed that I wouldn't need to be intubated for the flight as my breathing was fine. The time was early evening. I was strapped to the stretcher, attached to various monitors and soon heading to the airport by ambulance. Our Samoan staff met us as we were about to drive onto the runway and passed us the one 5kg bag that we were allowed.

I don't recall much about the flight but know that the flight stretcher was narrow and very uncomfortable - I couldn't move at all as I was so snugly tied in. We stopped in Tonga to refuel. Ross kept up a conversation with the flight nurse and doctor and I was apparently annoyed that the conversation revolved around Trump and the American election.

Suddenly we were in Auckland. Customs and Immigration completed the formalities quickly and then I was transferred between the two air ambulances on a high platform vehicle. It was bitterly cold. It was a quick flight to Wellington where the airport allowed an emergency early morning landing. The waiting ambulance took me directly to Wellington Hospital. It was 4 am on Tuesday morning 22 November 2016. Our one lady welcoming committee, good friend Moira, was already waiting there. Time and again we would be overwhelmed by the generosity of time, thoughtfulness, support, messages and gifts from family and friends during the coming weeks.

At Wellington Hospital the diagnosis of GBS was reconfirmed. I remember clearly the doctor saying to me that this would be one of the hardest things that I would ever have to do and that I must have hope. This message was probably one of the defining moments in my illness and I think stayed with me throughout my decline and subsequent recovery. Hope.

Our daughters Hazel and Keri visited and were looking very concerned but said that I looked much better than they expected. Keri asked me how I could possibly be so calm. I answered that there wasn't much else that I could do. Over the next few days I watched with interest as slowly my legs became completely numb and my hands receded. It was an almost out of body experience as I observed this steady decline. Blowing into the spirometer was a challenge and I argued vehemently that the nurses were doing the readings wrong ó how else could I get the exact same reading over three separate tests. My lung function decreased and decreased till it became critical that I be intubated. My request that I get to talk to my family before the procedure was honoured but it was a close-run thing. Keri was nearby working at Southern Cross Hospital but Ross and Hazel were running up Mt Kau Kau and didn't hear the phone. When they finally got the voicemail they headed straight in, sweaty & smelly but with minutes to spare we said our brief goodbyes and òI love youö knowing that I would not be able to communicate in the coming weeks.



# Guillain Barré Onset in Samoa – Frances's Story

## The Decline – Ross's perspective

Fortunately, the client I was guiding worked at the hospital and she helped by phoning ahead to ED. Apia hospital is far from the ideal place to be seriously ill, but the 5th year Med student who admitted Frances had received a good heads up and immediately set about eliminating the other possibilities. That evening the hospital's only neurologist turned up and formally confirmed the intern's view that it was GBS. Recently the neurologist was fired for not being a formally qualified doctor. There is some debate around his qualifications and both his English and manner were a bit frustrating, but he was spot on in the diagnosis.

I had already been in touch with our medical/travel insurance providers and after a bit of a run around to prove that Frances was covered they leapt into action ordering an air ambulance jet from NZ. This seemed a bit of overkill but it was deemed essential that Frances at least travel with a specialist who could intubate her in flight and start her on a ventilator. The Air Ambo arrived late Tuesday afternoon and we enjoyed what will probably be our only private jet charter, arriving in Wellington Hospital at 4 am. There was an interesting conversation with the (Australian based) insurance company on which hospital with a starting point that it should be in Australia. I expressed a preference for Wellington to be near family and friends and it was absolutely the right place. We had a strong support network and home there and the medical care we received was excellent.

While waiting for the Air Ambo I had time to devour quite a bit on GBS, particularly from the NZ and British GBS societies, who had good material. This was fortunate as the registrar on duty at Wellington ICU suggested starting Frances on steroids which the society's notes said were 'contra indicated'. This was a delicate discussion as I didn't want to come across as Dr Google, but I did convince him to check before proceeding and steroids were never mentioned again. Later in the day Frances was given intravenous Immunoglobulin and transferred to a general ward.

By Friday and after a second immunoglobulin transfusion the paralysis had spread to the point where Frances was having trouble breathing and elected to be intubated. My email to friends that day records: 'Talking to her before the intubation she was amazingly brave. Knowing that communication for the next month or so is likely to be difficult and that she faces a long slow recovery once the autoimmune system stops attacking her nerves she was calm and concerned about my ability to focus on [our business]'. Over the next few days the GBS claimed the last of her movement, except for a slow and erratic blink. Her blood pressure soared, her heart rate was high and erratic and her temperature regulation uneven; it was stressful.

## Staying Mentally on Top

The hospital support systems swung into action around this point and at their suggestion we had two long meetings with staff. The first with the Head Nurse and the second with the head of the medical team. They were blunt in stating that Frances's reaction was at the severe end of the scale. She would suffer a series of medical challenges including pneumonia, but they could deal with all those. Their big worry was her mental health. Trapped in a frightening situation with none of the usual stress relief options available (exercise, talking, diversion etc), their focus and mine needed to be on keeping her calm and with a sense of control. There were quite a few strategies involved. We were encouraged to keep a bedside diary so she could fill in the missing days as she recovered, to avoid bringing problems to her and to keep talking to her and touching her. Methods of communication were explained and they would get her out of ICU for short visits whenever possible. I think we were lucky to have such good medical and nursing leadership which translated into excellent care. Frances also had an amazing attitude, always believing she would fully recover.

They were also concerned that I looked after myself, recommending a variety of support agencies and in practical terms covering some of the more usual challenges. We were however in a more fortunate position than many as we didn't have to work and had a very strong network of friends and family.

I had given Frances the odd health concern (including a nasty bike accident in Ecuador) and as Frances recovered she commented that 'it was your turn to see just how hard it is as caregiver, being the patient is easy'.

# Guillain Barré Onset in Samoa – Frances's Story

About that time, I listened to a radio broadcaster asking people for their scariest moments. I had quite a long list of serious boating, climbing and cycling incidents, but the most terrifying and gut churning events are those where immediate family are seriously sick and it's beyond my control to fix.

With many friends enquiring about Frances's health and offering to help I started a daily email update. Part of the update always included a 'Highlights of the day' section. I had seen this idea in 'Redz NZ Journey', Lynn Patterson's blog of circumnavigating New Zealand in a kayak. It sometimes took a few moments to find these positive points but the effort was very rewarding. My entry for Day 7 is included below and for those who are interested the full diary of emails is at <http://gbsrecovery.blogspot.com>

## 27/11/16 (Day 7)

All

Frances was more deeply sedated today and her head movements were weaker. She is still initiating her breaths but the ventilator appears to be working harder.

We had a long chat with the Doctor and it appears we can expect a long slow haul with at least a month in ICU and quite possibly much longer. Her autoimmune system is still eating her nerves. Apparently the short gap when the decline slowed on Wednesday and Thursday is a hopeful sign that she may take a slightly faster recovery track.

### Highlights

- Great gf food from Mark and Nic and Trish
- Cooking breakfast for Keri and Hazel
- Another run (a few more and I will risk a game of squash)
- lots of support from family and friends

I see my title below - It was a harder day to meet the standards of Chief Enthusiasm Officer.

Ross Bidmead

**Chief Enthusiasm Officer**

Outdoor.co.nz Limited

Our eldest daughter, Hazel was just back from 2 years OE and planning to move into our house while she found a job etc. This was great for me as it meant someone to share the load and talk things through with. She also ensured I got out for a run and a mental break every day. Later I would add a weekly walk over Mt Kaukau with friends followed by coffees in the local café.

## To be Continued.....



## New Website Development

The framework for the new website has been constructed by the Indian Website designers that our Board member Matt Peacey is working with and whilst there are a few tweaks needed it appears to address all the areas that we would wish to promulgate to our members and new patients/supporters looking for advice and assistance.

The next stage is to populate the framework with words, pictures, videos and web links.

This task will be spread amongst other Board members and Dr Parry has agreed to take on the lion's share of writing all the medical descriptions and treatments for each of the GBS types – a big job - so many thanks Gareth – but I guess he does know quite a bit about these things!!

**BUT – we also need input from you the members** – in the jargon of web building it's called "Testimonials". What we need is short statements or essays (no more than 150 words please) and maybe a picture or two saying why being a member of the Group is important to you – or how helpful you found the website and support available from the Group as a whole – or your experience of either being a HOSPITAL VISITOR – or a PATIENT/SUPPORTER having received a visit from one. All ages and genders welcome – if you have had the terrible experience of your child getting GBS perhaps record some of their own words? Please Email them to me at [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz) or write to me at 30 Higgs Road Mapua 7005 – **This IS IMPORTANT** and I shall be seeking similar help from those members who are Facebook followers

Thank you – Tony



## New Christchurch Coffee and Chat Group

Just when I was on the edge of despair of ever being able to encourage a GBS community in the Christchurch region to get together along come a few Mum's who are Facebook users and take matters into their own hands – and very full hands they seem to be coping with GBS in themselves or members of their families- and the very first **COFFEE and CHAT** get together is currently planned to be held on Saturday January 20<sup>th</sup> at a time and venue yet to be decided but one that will definitely be "kid friendly".

If you would like to join them please get in contact with Kirsty Bell at [domashbenpop@gmail.com](mailto:domashbenpop@gmail.com) – or via our Facebook site if that is your preferred communication medium. As a Group we are VERY keen to encourage GBSers in the Christchurch area to support one another. At this time we do not have a Board member or Medical Advisor in the Christchurch region but we are working on that AND if there was enough local interest we would love to hold an official Group gathering in May next year in the region – let us know!





## **A Personnel Encounter - by Steve Cincotta**

Greetings folks, my name is Steve - a 49 year old naval officer who had served in the nation's submarine force for nearly three decades; or at least that's who I was at the beginning of 2017 as I was finishing my military career at the Pentagon, awaiting retirement in May of that year. The Winter of 2017 started rough in the DC area, with a larger than normal percentage of the Capital area's workforce coming down with what was best described as "the crud" - a nasty upper respiratory infection that just seemed to linger on and on and on. Regrettably I was no exception.

I had contracted "the crud" in early January and was quickly seen by urgent care at the DiLorenzo Medical Clinic in the Pentagon. I was prescribed a "Z-pack" (later told by ENT at Walter Reed National Military Medical Center - where my story is heading - that the Z-Pack is pretty much worthless) and did my best to continue working despite the annoyance of the URI (upper respiratory infection - no offense to the University of Rhode Island). I was managing reasonably well, despite the lingering illness; that is until Wednesday, 1 February, 2017, the morning I woke up to find my left arm and leg feeling rather like "pins and needles" when your arm or leg goes to sleep (I later learned the word "paresthesia" - I believe I still pronounce it wrong, but eventually this would take on my entire body. . . but I'm getting ahead of myself).

Well, when a man of my age wakes up in the morning feeling numbness on one side of his body, it is rather natural to think of the worst reason for having such a condition - am I having a stroke? I'm concerned enough to have my wife drive me from our condo in Arlington, VA, around the beltway north to the hospital of the President - Walter Reed National Military Medical Center. After all, this made sense as I was an Active Duty naval officer at the time. Upon arriving at the ER that Wednesday morning, I got the rather strange sense that the crack-medical staff suited for emergencies didn't quite know what to think of my complaints of numbness, once they performed an EKG of course and ruled out any cardiovascular concerns. I was told by the attending that perhaps the over-the-counter medicine I was taking for "the crud" was somehow affecting me (basically blaming NyQuil I guess - the ineffective Z-pack had been given 3 weeks ago), and for the first time out of many it was suggested I may be having a physical manifestation of anxiety due to my pending retirement (more on this in a bit).

I return home and stay there for the day rather than going to work feeling, well, a bit numb on my left side; perhaps I'd feel better tomorrow. The next morning (Thursday, February 2nd) I woke up unable to sustain the weight of my body on my left side. Determined, I dragged myself to the bathroom for my morning shower, only to call my wife in distress - I can't feel the water on my left side and I certainly cannot get out of the tub! For most, this should have been a 911 moment - if ever in this predicament that's exactly what I suggest you do - however, being rather indisposed and fully aware that a local ambulance would take me to a local hospital, while all of my medical records reside at Walter Reed, I convince my wife to get help (the facilities manager finds a wheel chair for me and helps pour me into my vehicle) and I have her drive me back to the ER that dismissed me just the day before. Something was seriously wrong and we needed answers.

Wheeled into the ER at Walter Reed, we again seem to be baffling the medical staff as they cannot find a reason for the weakness I was feeling. By this time, my speech was beginning to labored and slowed, again giving me the impression of a stroke victim or someone with palsy. As it seems the ER was about to once again dismiss me and send me home, my devoted wife, Gina, adamantly tells the doctors "you are not sending my husband home like this, this is not normal!" It was also at that time that, though a devout follower of Jesus not prone to profanity, I explained to the Resident "this is not (explicative) anxiety!" By early afternoon the numbness had circled around me right side and now my fully body is in paresthesia, my speech is slurred, and my eyes are beginning to see double. I'm admitted into the hospital and scheduled for an MRI at 2 am the next morning (chest, neck, head). Never leaving my side, Gina and I begin to urgently search the web for possible causes for unknown numbness as Walter Reed begins to parade a stream of professionals in to see me, starting with the head of psychiatry. Ironically, it would be next morning when I would be wheeled in front of a panel of a dozen psychiatrists and in my best stroke-like voice I would be interviewed by the Rod-Dangerfield-esk Behavioral Health Department head, speeding 45 minutes with me as I explained why this was not anxiety as I gave my testimony as a born again Christian. Very surreal, but to be fair I should mention that there was an earlier period of my life when I was diagnosed with depression,



## **A Personnel Encounter – by Steve Cincotta**

so the strong press on the mental health side of the issue was worth investigating. We closed our session with the fact that if I wasn't anxious before having this ailment, I certainly was a bit anxious now (I was prescribed Zoloft for a short period of time).

Friday was also the day they conducted a spinal tap to determine if I had elevated level in my fluid that would give them a better perspective on what was going on - along with a battery of blood test. The MRI had come back normal with the exception of a very nasty sinus infection (not uncommon for me as I've had sinusitis several times in my life), so a treatment of antibiotics was prescribed as I lay in bed, for all intents and purposes paralyzed with blurred double vision. This day was also the first time I had ever heard of the term GBS. As disciples, Gina and I began to pray in earnest for some understanding and wisdom in our situation. I can honestly tell you, though it would never be my desire to depart from my wife, I was not panic stricken or distressed over the thought of dying - there is a certain peace and calmness I believe when you find yourself in relationship with your Maker in my perspective - what DID concern me terribly (and rather cowardly you might think) what I didn't want this to be my "new normal," and in fact that's what I feared the most. In the midst of our prayers, one of the couples from our marriage ministry group called and asked us if we were looking into Guillain-Barré Syndrome - never heard of it, what's that? There was a nurse in our group that heard of our plight and conveyed this to the couple that called. The symptoms seemed to match, so began (Gina often had to speak for me) to start pressing the Walter Reed staff to tell us if this is what they were thinking.

If you are reading this story, then you most likely already know how difficult it can be to diagnose GBS. The spinal tap had come back negative, and though there was a blood test that could be sent away to a specialty lab and take up to three weeks to verify the antibodies for GBS (which is exactly how long it took, and yes my blood tested positive), the medical team was determined to investigate and rule out any other possible cause. That's how rare this syndrome is, as I was only the 3rd GBS patient the neurology head at Walter Reed (the President's hospital, mind you) had ever seen in 20 years of practice, and the first with Miller-Fisher variant.

Anyway, back to my story. It's now Super Bowl weekend and I'm being tended to by the polite, young weekend staff as we wait for Monday and the return of the specialist (ENT, Ophthalmology, and Neurophysiologist). My eyesight is completely jacked up at this point and I'm wearing an eyepatch, alternating between eyes, to try and have some sort of vision. It got so bad, that as I was watching my beloved Patriots play the Falcons (hey, I'm from Maine - don't be a hater!) I literally give up on trying to watch as they go down 21-0 to Atlanta, turning off the TV, and to this day I've still not seen the greatest comeback in football history play-out in real time (it would be my mother-in-law who would inform me of the conclusion as she flew out from San Diego that night to assist my wife in caring for me). On Monday, ENT scopes my nose and gives an update on the sinuses. Optho confers my claims of loss of eye control and Neuro recognizes I've lost all my reflexes. Not until Tuesday, and my new good buddy Dr. Mark Landau (a good humored Woody Allen-like Jewish neurophysiologist from Brooklyn, same accent, same mannerism) sees me and in thirty seconds says, "Oh, I know what this is; it's GBS of course." After 7 days of being in patient at Walter Reed I am clinically diagnosed with GBS and scheduled to receive treatment in the form of a 10 hour IVIG that I'm told cost \$35K per treatment (thank you Tricare!).

I spend the next 5 days receiving the IVIG treatment which, along with prayer, begins to turn the tide of my paralysis. By day 14 in the hospital I am able to at least get myself to the bathroom under my own power and I am released for thirty days convalescing at home with a physical therapist visiting me twice a week during that time frame. My recovery at this point is nothing short of miraculous, relearning to walk and the return of my speech happening rather rapidly. My beautiful wife and caring mother-in-law tending to me throughout, we come across this website and read the various other stories of men and women experiencing GBS and sharing their stories -thus I wanted to share mine. After 30 days at home I was back to work, the longest recovery for me being my sight returning to semi-normal. It would not be until late April that I was able to see well enough to drive again (my peripheral vision to this day is still lacking, but we're talking

## **A Personnel Encounter - by Steve Cincotta**

merely a couple months before some resemblance of normality). I am able to retire on time from the Navy and re-locate to SOCAL under the caring watch of both TRICARE and the VA as I find myself with only intermittent lingering effects from Miller-Fisher. I give all the glory to God and my Savior for this season in my life, working through the folks who treated me and many many prayers of loved ones and fellow believers who petitioned for me daily.

If you are experiencing GBS, my prayers are with you and my encouragement to tell you there is absolutely hope! I never experienced the respiratory failure so common to traditional GBS, for which I am thankful, but so long as you have the medical attention to sustain you even in the worst of symptoms there is still an extremely good chance you will come through this as an incredible story to tell and a testimony to give - at least that's been my experience. God Bless you all, if you made it this far in reading I hope you found comfort in my story and realize, as rare as GBS may be, you're not alone.



### **Waikato/BOP Christmas Luncheon**



Jan Gribble, Linda and Rex Bannister, Judy and Barry Deed, Marty and Chris Hewlett, Fran McKay, Julia and Ken Ardern, Michael and Roberta Cameron, Fiona Green, Grant McKay, Rex and Karen Soppett, Yvonne and David Powell, Emma and Phil Wolfe enjoying themselves at the BOP/Waikato Christmas luncheon.

This was a most successful gathering with everyone enjoying themselves so much that we occupied our space in the café for 4 hours. It was great to see everyone mingling and making the most of the opportunity to talk to like- minded people about their GBS experience. Also good to have such a large number of care givers/spouses attending.

Santa arrived and as everyone had been so well behaved over the year everyone received a small gift.

# Report on the Onga Onga Project Progress

Vivienne and I had the pleasure of Meeting Dr Eric Buenz a Research Professor at NMIT to discuss the Projects progress. The following is a short summary of the hour and half conversation with him and is in Layman's terms -as some of the work was too technical for us and we may not have got it all correct but have done our best!

**The Process:** The first step is to collect the leaves of often from remote places of DOC and IWI approvals acquired for this- then the needles (called Active Spurs) are removed from the (Inactive) leaves one by one using the equivalent of cuticle scissors. Through a several stage crushing and filtering process the plant juice is separately extracted from the Spurs and Leaves and then dried to a pure powder. A sack full of the plant will render only 10mg of powder! The next stage is to compare the chemical makeup of the Spurs powder to that of the Leaf powder and see what is in



the distinguishing active powder that is NOT in the inactive leaf powder. This is a highly technical process and the equipment to do this is not available in NZ. Originally it was analysed as a favour by the Mayo Clinic in the States and the team then once our funding became available - planned to use a Laboratory in the Netherlands which was not cheap. However, during an invitation visit to a Chinese University and its centre of Botanical excellence, Eric was offered a collaboration that effectively provides the analytical process for free under the terms of a formal Memorandum of Understanding. A trial batch of the powders sent some months back has been approved as suitable for processing and the first olive test results are expected back at NMIT in a matter of weeks.

If a chemical is identified as specific to the active Spur material it will be compared to the National Plant Library records to determine if it has already been recognised (and its properties defined) or not and if not then Bingo the possibility of a new discovery exists.

**Testing:** Using samples of the refined active product testing of its neurological properties has commenced in NZ using firstly Brine Shrimps (known in NZ as Sea Monkeys we understand?) by introducing varying strength microscopic quantities into test tanks of shrimps and watching how it affects their development from the cyst. The Shrimps apparently have very specific neuro triggers in the course of their growth.

Originally this test was planned to be carried out in the Mayo clinic using prepared rodent cells at US\$500 a time and taking a month to produce results. The shrimps cost NZ\$50 a bucket and produce results in 24hours of a No8 wire solution if ever there was one! The equipment to record what happens to the shrimps has been manufactured in Motueka!

A second test is being carried out for the team by the University of Otago touches the feet of Rats with a tiny filament which makes them move and when the filament is coated with the active fluid the numbing effect results in no movement by the rat. Both tests are ongoing.



*Active spore under the microscope*

**What Next:** Our Seeding Funds have been used to acquire all the regulatory permits needed to collect and export the product and its extracts and to carry out these initial process and testing activities and will carry them forward to a stage that the team can confidently report they have a viable Project and then they need big money and that will be sourced from appropriate National and International bodies using the results they have gathered as evidence of a solid Research base on which to build.. Issues of Commercial viability, synthetic replication, Patents etc are a long way into the future but will be addressed by the team at NMIT as they arise.



# GBS Coffee Group Report

19.11.17 Hobsonville, West Auckland

Sunday afternoon we enjoyed a lovely time getting to know some new folk who shared their stories and on-going progress in their encounters with GBS.

We came across this article, internet address below, posted by Alisdair Baxter in Facebook GBS Support Group that helps explain residual symptoms in GBS. It arrived just in time for our meeting and proved helpful in several ways, not the least of which was gaining understanding of how experiencing residuals, however difficult they may be, doesn't mean that you are getting a *second* bout of GBS.



<https://www.thefreelibrary.com/amp/Understanding+residuals+in+Guillain-Barre+Syndrome%3A+peripheral+nerve...-a0121416904>

GBS Support Group was contacted by Auckland DHB earlier in the month regarding consultation about the proposed relocation of Reablement Inpatient services (part of which is currently housed in Rehab Plus in Point Chevalier) to Auckland City Hospital by March 2018. The Support Group will be responding in due course.



## Guillain Barré Syndrome Support Group New Zealand Trust Membership Renewal Form 2017 /2018

NAMEí .

PRESENT ADDRESS (not required for renewals unless details have changed)

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**YES PLEASE** Renew my membership

**NO THANKYOU** Please cancel my membership and stop Newsletter deliveries

(Delete as appropriate)

**Ongoing Membership of the Group is free but Donations to the Group are gratefully received to enable the Group to continue to provide support to new and existing patients and their carers.**

**You are encouraged to make a suggested donation of \$20/\$50/\$100 – or whatever you can afford.**

**Donations above \$5 are eligible for the donation rebate of 33% from the IRD.**

Please complete the form as appropriate and return with your donation cheque (payable to the

**Guillain Barre Syndrome Support Group New Zealand Trust**) to the Treasurer

**Peter Scott, PO Box 4162 Palmerston North 4442**

Alternatively you can pay your donation by direct bank transfer to our bank:-

Taranaki Savings Bank (TSB) óMoturoa Branch, New Plymouth

Bank Account No. 15 3949 0339362 00

Please be sure to put your NAME in the reference area of the form so that it appears on our bank statement so the Treasurer can issue you with a receipt.

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OFFICE USE ONLY:      Date Recdí í í í í í í .. Ref Noí í í í í í í í .



## NOTICEBOARD

### 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.

### WAIKATO/BAY OF PLENTY COFFEE GROUP

**Where:** Café 19, Fairview Golf and Country Club  
34 Sharp Road, KATIKATI

**When:** Thursday 22<sup>nd</sup> February 2018

**Time:** 11.30am onwards



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

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

Cell Ph: 027 6113246

Ph: 07 5490931

**Everybody  
welcome.**



### GBS Cycle Group

**When:** Tuesday 23<sup>rd</sup> January

**Where:** Lake Karipro

É **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

**Time:** 10.30am for cyclists  
12.00am for non - cyclists who wish to join the pack for a shared picnic lunch by the lake.

### HOBSONVILLE WEST AUCKLAND COFFEE GROUP

**WHERE:** 35 DeHavilland Rd, Hobsonville

**WHEN:** 18<sup>th</sup> February 2018 @ 2pm.

**CONTACT:** Sharon

**Phone:** 09 473 1128

**Email:** [sharon@dixonnz.nz](mailto:sharon@dixonnz.nz)

Eileen

**Phone** 021 1133607

**Email:** [eileenmagnajacobsen@hotmail.com](mailto:eileenmagnajacobsen@hotmail.com)

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