



Guillain – Barré Syndrome Support Group New Zealand Trust

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NEWSLETTER DECEMBER 2013

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What's in your Magazine this month.....

Editorial

Awesome Fund Raising Achievement

Presidents Report

Secretary's Report

Acute Physiotherapy in GBS

Glossary of Terms Often Used in Connection with GBS or its Variants

Events and Other Things

Chris Hewlett

Submitted by Tony Pearson

Ken Daniels

Tony Pearson

Kathryn Quick

Chris Hewlett (reprint)



Editor's Note



Articles from members were very thin on the ground this time round, in fact to be more precise a big fat zero so what to put in for you to read has been a challenge. Thanks go to Kathryn Quick a new member of the MOB for her article, "Acute Physiotherapy in GBS". I shouldn't complain as it is the first time in my 4.5 years as Editor that this has happened.

Reported cases of GBS have been few in the last few months which is a good thing but sadly a number of these cases have been young children. We wish these kids and their parents all the very best on the road to recovery. Our resources are stretched in this department as few of us have had to deal with children with GBS. If you have been in this situation and could offer support please get in contact with Ken Daniels and have a chat with him about becoming part of the GBS Support System.

I had the chance to visit the Mahia Peninsula in October and spent a great couple days with Lil Morgan, our Web Guru and her husband Bill. Actually a whole gang of us motorcyclists converged on them and we were treated to awesome hospitality. A silver lining to GBS is the wonderful new friendships that are formed.

Marty and I flew to Wellington to get a bit of culture by viewing the Impressionist and Aztec Exhibitions at Te Papa. The first people we saw when we exited the Farmers car park was Bob and Margaret Stothart. It would have been much better to have seen them at the end of the day as we became horribly lost trying to find our way back to the car, discovering in the process that there are two Farmers car parks and we of course went to the wrong one. A ten minute walk from Te Papa turned into a 40 minute workout with us arriving at the car with 5 mins to spare before the car park shut.

Our last coffee group meeting was held in November. Another good turnout. Thank you everyone for your attendance over the year. Before summer ends I intend to try and organize a small cycling event finishing at a café for refreshments. Just got to find a suitable location so Grant and Barry can race their 3 wheelers. I will put the details on the web site and Facebook and email locals when it is sorted.

Overwhelming support for the conference to be held in Rotorua has been taken on board and a decision on this will be made early in the New Year.

Thank you to everyone who has contributed to the magazine this year. Your input has been very much appreciated.

I wish you and your families all the very best for the festive season.

Chris

An Awesome Effort.....

Maurice and Kath Vickers, long standing Auckland members have just posted a cheque off to our Treasurer Peter for \$600, being funds raised from their annual fund raising theatre evening at the Dolphin Theatre. This year's play "Calendar Girls" was obviously a great success.

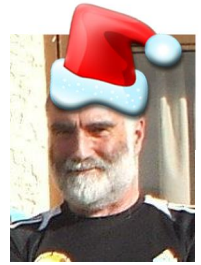
Thank you both for your wonderful support. It is truly appreciated by us all.

(Just wondering, "Did you have a part Kath?" Ed)



Presidents Paragraph:

I thought that as the years roll on and I become more familiar with the way things work in the world that I would no longer be surprised at how fast time flies. But as I get slower the time goes faster! At this rate Christmas will come every 6 months or so. It seems a bit like that already!



It is interesting to note, by the way, that the Chinese government must read our newsletter. I remarked in the last edition that there were some interesting anomalies with the Chinese one child policy. No sooner had the article appeared than the Chinese government announced that there would be some changes to policy to enable more families to have more than one child! The power of our magazine!

During 2014 we are going to be contacting members to update our memberships detail and to generally find out how things are for you. Don't get a surprise then to get a call from a board member early in the New Year. We will probably be able to give you some more details then about a rather special 2015 conference at a rather special location! Details to follow!

I am aware that there are often increased stresses at this time of year. Many of us are faced with extra family gatherings, meals to cook, presents to buy, children and grandchildren to entertain, sunburn to soothe and disruptions in family routines generally. On behalf of the GBS/CIDP board I wish you a stress free summer, without pain, without family tensions and plenty of Christmas cheer. I have it on good advice that a little Christmas cheer helps with the alleviation of pain and steadies the limbs!!

Happy Christmas

Ken Daniels



BOP/WAIKATO Coffee Group Meeting

Left: Front to Back:

Jan and Ken Arden, Rex Soppett, Meike Schmidt - Meiburg, Rod Bellerby, Judy and Barry Deed

Head of the Table:

Rosemary McBride

Right: Back to Front:

Grant and Fran McKay, Lauren McBride, Chris Hewlett, Linda and Rex Bannister



Secretary's Jottings

We all know that GBS is no respecter of gender, ethnic background, social standing or age and this has been graphically illustrated over the last few months with a spate of babies and very young children being diagnosed with GBS ó those of you at the Conference may recall the young couple who were in a similar situation with their child.

It is bad enough coping with the impact of GBS as an adult, I cannot begin to imagine what it must be like for a baby ó especially the pain - and the anguish suffered by the parents who can do little to ameliorate the situation must be unbearable. We have offered what support we can but, in truth, most of us have no experience of infant GBS and I hope the most constructive thing that we have done is to put parents with GBS impacted children in touch with one another so they may mutually assist each other with their own experience. I guess all we can take hope from is the knowledge that babies are hugely resilient and with the right medical assistance and lots of TLC will grow up none the worse from their untimely meeting with GBS.

For some years now the Group has received a complimentary copy of *Kai Tiaki* Nursing the official journal of the New Zealand Nurses Organisation ó and there have been some very interesting articles however, as an immigrant (12 years ago now!!) I have often been confused by references to various other nursing Groups. The recent magazine listed 14 (yes 14) recognised nursing organisations ó the NZ Nurses Organisation is by far the largest and has its own Maori arm but other groups cover specialist areas such as midwifery, palliative care and mental health. But when it comes down to it and you are lying in intensive care with tubes coming from every orifice it matters not which organisation your nurse belongs to ó just that he or she is knowledgeable and caring.

Our family has recently come face to face with the impact of cancer with my son in law's Mum, who lives in the North island, being diagnosed with a terminal condition (óyou should see this Christmas ó but don't count on next! was her Consultants advice) and yet after her stay with us last month to catch up with her South Island family I am left with nothing but admiration for her determination to cope and enjoy life to the full as much as her weakening body will allow ó she looks very elegant in her new wig, necessitated by a prolonged course of chemo! I felt just the same after reading John Moynihan's story in the last Newsletter ó talk about carrying on regardless! Human willpower is a force to be reckoned with.

I suspect the leader of our Medical Advisory Group Dr Parry is sick and fed up with answering questions on the pros and cons of having the annual flu vaccination -HOWEVER a report in the Autumn issue of the UK Group's magazine óIn the Know! highlighted the findings of a study sponsored by the Canadian Institute of Health Research that found (if I have interpreted it correctly) that whilst there was a small increase in GBS incidences after vaccination the risk of getting GBS after a bout of Influenza was some 16 times greater. The Doctor who led the research is quoted as saying: - "What to tell patients? I would tell them that if they are worried about getting GBS from Influenza vaccines they should know that there is actually a much greater risk of getting GBS from Influenza illness and since Influenza vaccines can help reduce the risk of Influenza infection, not to mention the serious complications associated with Influenza infection, the benefit of vaccines probably outweigh the risk" As always we are talking very small numbers ó something like one extra person per million contracting GBS after a vaccination compared to 17 per million from Influenza infection but, if I recall Dr Parry's advice, it ain't so clear cut for CIDP'ers like me.

And finally ó my tussle with technology continues ó the good news is that in spite of the best attempts of the technical geeks who seem to delight in writing all the instructions on websites in double-dutch we have managed to acquire new admin and membership data handling programs for the Group from Microsoft at VERY reduced rates which Peter Scott will utilise as he takes over the membership records from me during 2014. ALSO... the Pearsons have bought an iPad and are attending lessons at Senior Net to learn how to work it. I asked for an instruction book from the guy who sold it to us at the Apple Store and he just laughed and said I wouldn't need one as it was all intuitive ó well it may be to a 7 year old but not me! So don't hold your breath Chris but my Facebook account is one step nearer.

As always - take care and enjoy summer

Tony

Acute physiotherapy in GBS, it's not all about getting physical!

By Kathryn Quick

For all patients, being diagnosed with Guillain Barré Syndrome (GBS) is a life changing experience, often happening to fit and healthy people who may have little previous experience of being in a hospital. So how do we focus on hope and making positive changes for the future? This is not an easy task that has a quick solution, but in my clinical practice, early rehabilitation, education and goal setting are fundamental components in managing the initial weeks of the syndrome.

One patient I was working with recently referred to her early rehabilitation as this:

‘It gave me encouragement and hope to go that little bit further than I thought I could. Slowly becoming more and more independent, there is no doubt that I would not be where I am now if it wasn't for those sessions’

Acute physiotherapy treatment in the management of GBS often targets optimising respiratory function, preventing tightness of weak muscles and improving a person's independence through strengthening and endurance exercises. What are the challenges faced by patients when rehabilitating in the acute stages of GBS? Two of the most common difficulties patients experience in early rehabilitation are pain and fatigue.

Pain associated with GBS is one of the most debilitating symptoms of the syndrome affecting up to 89% patients. Pain in the early stages is known to be most severe and have the highest prevalence. Pain can come from different sources including; neuropathic - the nervous system, musculoskeletal - muscles, joint, ligaments etc and also the visceral system of your internal organs (Liu et al 2013). Physiotherapists work closely with the medical team and ward team to ensure that pain medication is optimised for the patient to be able to participate in their rehabilitation. Early rehabilitation can indirectly or directly help reduce all of these pain sources through the following ways:

- Neuropathic pain of sensory stimulation to the person's limbs (for example with touch and taking weight through the hands and feet) can stimulate nerve pathways, this can help to lower hypersensitive responses making symptoms more tolerable over time.
- Musculoskeletal pain of muscles and joints can become tight and stiff as a result of staying in bed during the early stage of GBS. Regular stretching, changing positions, sitting and standing exercises can reduce the discomfort experienced from muscles and joints.
- Visceral pain of Diffuse muscle weakness, reduced sensation and immobility can result in complications on the body's many systems and automatic functions. For example; constipation, pressure sores, urinary retention and changes in blood pressure. Mobilisation and exercises can help reduce these side effects. This was reinforced to me recently by another patient in the acute stages of GBS.

‘My physio sessions helped with my whole well-being, it helped all my bodily functions, I felt much better after my exercise even though I had some pain and felt tired’

Fatigue is the silent symptom of GBS. In people with GBS the fatigue that they experience is different from that experienced by healthy adults, it can be independent of muscle power and functional status. In addition to the fatigue associated with the response of the peripheral nervous system, people with GBS often become very deconditioned, this is related to periods of bed rest and their lowered mobility status. Research exists to support that exercise can help lower fatigue rates, improve quality of life and reduce depression scores in people with GBS (Garssen et al 2004).

The role of the acute physiotherapist is being able to measure the fatigue levels of the patient and balance this with providing therapy to improve stamina and exercise tolerance. We know that no activity is likely to make stamina levels worse, but too much activity can cause weakness in the muscle groups you are trying to strengthen (Khan & Amatya 2012).

Despite understanding GBS, knowing the benefits of exercise, and appreciating the value of physiotherapy it can be still hard to apply practically. Acute physiotherapy management needs to be underpinned by communication and education, but it is also about giving control back to the individual living with GBS. Regaining an element of control can help re-establish hope and hope is what drives us forward.

Acute physiotherapy in GBS, it's not all about getting physical!

By Kathryn Quick

The end point is the focus, *'I want to walk again'* or *'I want to be a healthy, normal father for my children'* and goal setting is an excellent starting point. Goal setting is the intended result of a treatment intervention; goals motivate, focus the therapy teams interventions and can monitor the effectiveness of treatment (Wade 2009).

These are just a few concepts that can help drive rehabilitation in the early stages, with the intended aim to help a person to regain independence and reduce some of the secondary complications associated with GBS.

'Although it was hard, during my sessions I put everything I had into it, the sense of achievement afterwards was what gave me hope, getting a little bit better every day' A quote from a person with GBS during her stay in the high dependency unit.

References

Garssen et al. Physical training and fatigue, fitness and quality of life in Guillain Barré Syndrome and CIDP *Neurology* 2004; **63**: 2393-2395

Khan, F and Amatya, B. Rehabilitation in patients with acute demyelinating inflammatory poly neuropathy; a systematic review *European Journal of Physical Medicine* 2012; 48(3) 507-22

Liu J, Want LN and McNicol ED. Pharmacological treatment for pain in Guillain Barré Syndrome (Review) *the Cochrane Library* 2013; 10: 1-33

Wade DT. Goal setting in rehabilitation: an overview of what, why and how *Clinical Rehabilitation* 2009; **23**: 291-295



Glossary of Terms Often Used in Connection with GBS or its Variants

Here are just a few of the terms you might come across in dealing with Guillain-Barré Syndrome or its variant illnesses.

Syndrome: A collection of symptoms that make up an illness. There may be only a few of these symptoms present in each patient, but enough to make a GBS diagnosis.

Acute: Happening fairly quickly.

Chronic: Lasting a long time.

Ventilator: Mechanical apparatus used to aid ones breathing.

Splints: Aids used to prevent the curling of fingers, and also used to prevent foot drop. While uncomfortable, they provide valuable long term results.

Lumbar Puncture: A process of withdrawing fluid from the spinal column in order to test for a positive diagnosis of GBS.

Nerve Conduction Tests: Not a most pleasant experience, but one used to calculate the degree of nerve damage by testing what information is getting through from the brain to the nerves.

Plasmapheresis: Is a process in which some of the patient's blood is removed, the liquid part separated, and the blood cells returned to the body.

Paresthesias: Tingling, twitching, crawling sensations felt by the GBS patient. These weird sensations are very disturbing and annoying.

Prognosis: The likely outcome of the illness.

Corticosteroids: Hormones, normally made by the adrenal gland above the kidneys.

C.I.D.P. Chronic Inflammatory demyelinating Polyneuropathy. While C.I.D.P shares many features with GBS, it is often recurrent and may require ongoing treatment.

Demyelinating: Damage of or removal of nerve insulation.

Polyneuropathy: Disease of many nerves.

Fisher Syndrome: Also known as Miller Fisher Syndrome. This varies from GBS in that it involves eye problems, (weakness or double or blurred vision) in conjunction with facial weakness, abnormal sensations, and speech problems.

Axons: The best way to describe this is to regard the similarity with the electric jug cord. If you imagine the plastic coating on the outside of the jug cord is the myelin, and the inside of the cord (the wires) are the axons. The messages from the brain are passed through the nerve axons to the muscles. Once the message is interrupted by a damaged or stripped axon, then the message is interrupted and the muscles do not receive that message.

Myelin: The coating around the axons which protects and insulates the axon.





A very special thank you to Don Martin, who recently resigned as a Trustee. Don has been involved in the processing of many of our recent policies and procedure literature. He played a major role in creating the model for our Visitor Screening and Training program. He also collated and produced a booklet which also comes with a power point presentation. An awesome resource tool.

He also made sure we had the necessary computer equipment at our conferences and kept that part of the proceedings running smoothly.

We wish Don and his family all the best in their new life on the Kapiti Coast and thank him for his enormous contribution to the group over the years. His input will be missed.

**THANK
YOU**



Congratulations!



To our Patron the Hon. Steve Chadwick who won the mayoralty race in the recent local body elections.

We wish her well in her term as Mayor.

Bay of Plenty / Waikato Coffee Group.

Venue: Waharoa Cheese Company, 2 Hawes Street, Waharoa
(just off St Highway 27)

Date and Time: Friday 21st February 2014 11.30am



2014 AGM

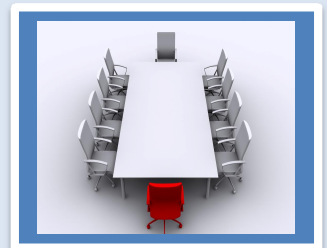
The 2014 AGM is to be held in NEW PLYMOUTH

On: Sunday May 4th

Time: 12.30pm, but preceded by a finger food buffet from 12 noon

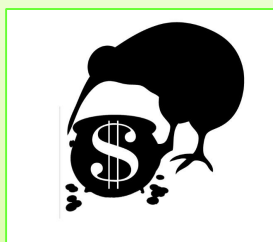
Venue: Auto Lodge Motor Inn, Devon Street East

The Board will meet at 10am ahead of the AGM



SUBS ARE DUE

PLEASE POST YOURS TODAY.



Wanted

Publicity Officer

If you think you have what it takes to promote our Support Group please contact Ken Daniels or Tony Pearson.

Their contact details are on the front page of the magazine and they'd love to hear from you.

Guillain Barré Syndrome Support Group Trust N.Z.

Registered Charity No CC20639 www.gbsnz.org.nz

INVOICE

2013-2014 MEMBERSHIP ANNUAL SUBSCRIPTION

Subscriptions for membership of the Group for the financial year commencing on 1st December 2013 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

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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) or add your e-mail details below and we will arrange for this to happen.

Thank you on behalf of the Board of Trustees.

**Please detach and post this remittance advice with your subscription to:-
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