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Guillain – Barré Syndrome Support Group New Zealand Trust

Registered N.Z. Charity No. CC20639 Charities Act 2005

NEWSLETTER March 2017



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In this Issue

Editorø Note	Chris Hewlett
Presidents Report	Doug Young
Secretaryø Jottings	Tony Pearson
Obituary ó Jenny Murray	Tony Pearson
Aids for Sufferers	Grant McKay and Russell Brokenshire
Update on GBS Survivor Val Simpson	Tony Pearson
Fatigue in GBS ó Conference 2015 Presentation	Dr Gareth Parry
Letters to the Editor	Linda Bannister and Maurice Vickers
Waikato/BOP Coffee Group Meeting	Meike Schmidt-Meiburg
Notice Board	Chris Hewlett
Subs Renewal and Conference Registration Forms	Treasurer Peter Scott

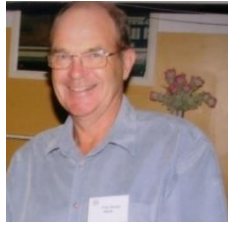
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Meike Schmidt-Meiburg

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.

WANTED RIDE TO CONFERENCE

We have a member who lives in Wanganui who would like a ride to the conference in Rotorua. If anybody in that area is able to help please contact our Secretary, Tony Pearson.

Room Sharing

If you are going to the conference on your own and would like to share a room please contact the Secretary, Tony Pearson.

Editor's Note



Hi everyone

Just after the last magazine went to print we heard the news that our Founder and most ardent supporter Jenny Murray had passed away. I'm sure many of you would have had contact with Jenny and know what a truly amazing lady she was. Our heartfelt sympathy to her family.

The big event for the year is our Conference which is being held in Rotorua on the weekend of the Friday 5th to Sunday 7th May. Registration form and all relevant information is included in this newsletter. If you intend to go but have yet to register please do so now as our Treasurer is getting a little twitchy over the low number of registrations he has received so far. I might add that I fall into the ōtuitō category, but I have now got my entry form ready to post.

The Waikato/BOP coffee group seems to be going from strength to strength with another well attended meeting held in Tirau last month. The cycling group is also gaining momentum. The shared lunches are something not to be missed. We welcomed a couple of Nordic walkers to our Lake Karapiro Ride and I believe we will have a scooter rider on the next outing in the Karangahake Gorge. So if you feel like a bit of low key exercise come along.

The Auckland Group had to cancel their meeting as despite having interested members the day didn't suit so they are planning another get together in July. Details will be in the June magazine.

Brain Day is on again at Auckland University on Saturday 25th March and we will be having a stand lead by John Davies. If you can lend a hand at all during the day I'm sure John would be pleased to see you. For those that receive the magazine by email I have attached the flyer sent out by the organisers.

I have also attached the annual subscription form again as our treasurer has said they have been slow to roll in. Your subs go towards the production of the magazine, brochures for new patients and the general running of the Support Group. We appreciate your continued support.

It has been 9 years since I took over the magazine and I have enjoyed the job immensely but having said that if someone else would like to pick up the reigns going forward I am quite happy to step aside. New blood is always good. I'm expecting lots of interest for the job at the AGM.

Chris



The late Bob Stothart and his wife Margaret with Albert Handermann and others at the US Symposium.

Photo sent in by Albert Handermann

Presidents Report

Welcome to all our readers.

The welcome is tinged with sadness as we have lost our organisations founding member, Jenny Murray, on the 13th December at New Plymouth.



A brief obituary further through the magazine tells her story. She provided the essential service of acting as a clearing house for information and advice, of where to go for help, with so many GBS sufferers and their caregivers.

We (myself included) owe her a large debt in gratitude for the time and effort she put into this organisation.

Thank you to Peter Scott who was able to represent the GBS support group at Jenny's funeral.

Our intention is to have a detailed obituary of Jenny along with Bob Stothart during the conference in Rotorua in May.

The last three months has been focused on the up-coming conference in Rotorua on May 5th 6th & 7th, and has been the main activity for our committee members.

Tony Pearson along with Gareth Parry have put together an impressive program for the Saturday which will provide a busy but very informative day, covering all aspects of GBS and CIDP.

I can only add to the committee's desire for as many GBS sufferers and their care givers to attend as possible.

The conference is a core activity of the support group and is a once in two year opportunity for everyone to get together and share their experiences and knowledge of this debilitating syndrome.

Regards to you all.

Doug Young
President.



Cyclists and Nordic Walkers at Lake Karapiro:

Left to Right: Meike Schmidt-Meiburg, Rex Bannister, Fran McKay, Chris Hewlett, Judy and Barry Deed
Front: Linda Bannister and Grant McKay



Secretary's Jottings

After a number of months of almost no new GBS cases the last couple have seen a rash of contacts made to the Group for support and information and the main trigger that patients can recall is a "tummy bug and sickness". Now - given the proximity of the Christmas holidays and the kiwi love of BBQs - the "Pearson Conclusion" is that our old friend *Campylobacter* is to blame for the majority of new cases. Interestingly the January edition of the Consumer magazine reported "of the 40 fresh chicken products we purchased from supermarkets 65% tested positive for campylobacter" and Michael Baker ó Professor of Public Health at Otago University (who presented on this topic at a previous Conference) is reported as saying that whilst there are other sources of *Campylobacter* contamination (swimming in or drinking polluted water) fresh chicken is implicated in at least 50% of cases and annually is the equivalent of SIX Havelock North outbreaks ! Talking of which the likely source/cause of that outbreak looks to have been tracked down to a faulty water bore which allowed surface water contaminated by sheep poo to leak into the bore pipe. The Local and Regional Authorities are pointing the finger of responsibility at each other, of course, but there seems to be little doubt that delayed communication to the area's population about the pollution was a significant cause of the high incidence of people succumbing to the bug.

There are estimated to be some 9000 New Zealanders suffering the effects of contracting Polio earlier in their lives. Known as Post Polio Syndrome these effects include Fatigue, Muscle weakness, joint and muscle pain, shortened tendons and difficulty with sleeping and breathing ó not to mention psychological stress ó sounds familiar ?? To try and help and support these patients a network of specialised clinics, based in our major cities, is being set up to provide expert assessment and rehabilitation plans. I wonder if there might be a case for joining such an initiative and extending its remit to include GBSers who are experiencing similar ongoing issues that don't seem to get resolved by normal medical resources. I will ask the Board to give the matter consideration at its meeting at the Conference in May.

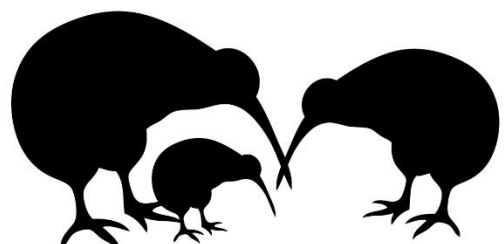
And so to the Conference! ó The Saturday programme has been pretty much finalised with presentations focusing on CIDP and other less common variants, a couple of very interesting "personal stories" and a "Rotorua surprise session" as well as our usual Break Out Groups and Ask the Experts panel time at the end of the day. Most of our Medical Advisory Board have indicated they will be attending and, of course, several will be giving Presentations.

If you feel that you would like to "give something back" by assisting new patients then come along to the Hospital Visitors Workshop on Friday afternoon ó none of the 20 or so already Authorised Visitors would call ourselves "experts" but we are leaning as we go and the Workshop is a chance to share our ideas and experiences and review, and if necessary, amend our protocols and advice for running our Visitors programme. A couple of points relating to conference attendance. If you would like to come but your finances are a bit stretched then the Group has a fund to assist just this situation. Contact the President Doug Young deyoungs.doug@xtra.co.nz or 027 227 2501 in TOTAL confidence and we will help if we can. ALSO ó happy to share a room at the Hotel to save costs? ó if so let me know and I will put you in contact with other like - minded members to see what can be sorted out.

The Neurological Foundation's Brain Day will be held in Auckland on Saturday 25th March and the Group will be manning a stall to hand out information on GBS and its variants to the public and the many medical professionals who attend. If you are able to provide a few hours assistance to man the stall please contact John Davies cymro6391@gmail.com or 022 629 9517 ó he will be very grateful for your help. We are hoping to have our new Brochures available for this event.

Well that's all for now
As always Take Care

Tony



Jenny Murray: Obituary

Jenny Murray 23rd March 1950 to 13th December 2016.

Jenny was 66 when she left us but I wonder if at the age of 46 she had any idea of the legacy she would be leaving. There are members of the Group who were involved with Jenny in the days of the formation of the NZ GBS Support Group some 20 years ago like Terry Watton and Bob Gregory who are better qualified to speak of those early times and I hope they will do so at the Conference in Rotorua in early May but none of us can have any doubt that it was Jenny's determination and energy that got us started and her boundless caring and loving nature that brought hope and strength to so many of us who became victims of GBS in all its forms.



Jenny came from a large family and leaves an even larger one and her children, grandchildren nieces and nephews will all be missing that very special lady that was so much a part of their lives and was the central focus of Jenny's BUT close behind came her GBS family. Over the last year or so Jenny had sent me all her records and files ó I still marvel at the quantity of them. Response, advice and encouragement to everyone who contacted her ó all hand written and õproperlyõ filed away ó a truly remarkable testament to an even more remarkable woman.

Jenny's efforts were acknowledged by the nation with the award in 2003 of the Queen's Service Medal ó a fitting tribute to her and well deserved. What posthumous award can we make to Jenny? ó I believe it is to ensure that the Support Group she founded all those years ago continues to provide the support to the GBS community. Methods of support have changed considerably with Email and the Internet but nothing changes personal contact being the best help to those people newly diagnosed, something Jenny understood completely

It has been a privilege to have known and worked with you Jenny - We won't let you down!

Tributes to Jenny and Bob

So sad to hear of the passing of Jenny Murray. She always made me feel so connected to the New Zealand Support Group, even from thousands of miles away here on the east coast of the US. Please extend my heartfelt condolences to her loved ones.

Joel Steinberg MD, PhD

Founding member, GBS/CIDP Fndn. Int'l.

Member, Fndn. Medical Advisory Board

That is very sad Chris. What a tireless worker for sufferers of GBS. She has departed with the humility she always wore.

Moe mai Jenny

Arohanui

Steve Chadwick

Very very sad to learn that both Bob Stothart and Jenny Murray have passed away.

For sure, this time, my visit to New Zealand is going to be different than all previous visits (5)

Bob was so special and nice. The same applies to Jenny.

Jos Roebroek

Thank you for letting me know about Jenny Murray's passing. Jenny was a dear friend. Sadly missed. Jenny and Ian together again. RIP

Melva & Joe Behr

Sad to read of Bob Stotart's death, and to know of Jenny's passing. Both will be greatly missed and have contributed so much

Glennys Sanders

GBS UK

From Tony I learned about Jenny's passing and also about Bob's death. I knew Bob quite well, having met him and Margaret several times at the symposium. So sad to lose two such wonderful people who contributed greatly to the group. My condolences.

Patricia Blonkwist-Markens

GBS Liason Holland

AIDS TO HELP GBS SUFFERERS



This nifty little device enables GBS sufferer Grant to eat his meals without relying on others to assist with the basics like cutting his food.

The fork holder was originally given to Grant by the Occupational Therapists in Waikato Hospital. Presumably all Community OTs would have access to them. Grant has recently had more made by a local upholsterer.

Russell Brokenshire uses and models the Dictus Band

The place where you can buy the ankle brace is on the web site: www.alliedmedical.co.nz and it is a Dictus Band Outdoor. They make an indoor one too which is a slightly different design for when you are not wearing shoes ie bare feet. I have not used that one.

The ankle band is in my view superior to the previously used plastic foot brace because it allows me to walk more naturally. The web site has some videos showing the difference which are good to watch. I have found the brace invaluable for avoiding trips and falls which is a constant threat with the 45 degree angle foot drop I have as a result of GBS. The rubber band keeps my foot level and the flex gives me a greater range of foot movement as I walk. You do need to be able to insert the hooks into your shoe so shoes with laces are necessary. I now regret my love of slip on shoes pre GBS but the testament to how well it works is I could still wear slip on shoes with the plastic foot support but I much prefer the Dictus Band so I have bought shoes with laces. The rubber band on the Dictus Band does over 2 -3 months split (not break) losing some of its flex at which point you need to replace it. I think you get 3 -4 bands and spare hooks with your first order but make sure you have spares when ordering and you can order on line the replacement bands.



GBS Survivor Val Simpson continues the Fight



Those members who attended the 2007 Conference will doubtless remember the moving presentation given by our Patron Steve Chadwick's sister Val Simpson and her husband Peter. Val was hit very hard by GBS and over the ensuing years has had to cope with complications and setbacks (as indeed has her husband Pete who himself is very unwell)

At the time our late President Bob Stothart wrote:

"I will never forget the emotional power of Val and Peter Simpson's presentation. They spoke from the heart and gave us such a thoughtful message of loss, hope and recovery tinged with compassion and strength. Their determination to cope with GBS and to get well, while telling the doctors exactly how they felt was a model of patient feedback and tenacity"

Unfortunately their wish to get well has yet to come true but being the indefatigable person she is Val has continued to inspire others and the picture above shows Val talking to the new nursing intake at Melbourne Hospital earlier this year. Val was also on the planning team for the re-design of the Melbourne Hospital ICU – no doubt bringing a very focussed 'consumer' viewpoint to the discussions!



BRAIN DAY 2017 **SATURDAY 25TH MARCH 9.30AM – 3PM**

WHERE: University of Auckland, Owen G Glenn Building
12 Grafton Road
Grafton, AUCKLAND

We will be having a stand so drop by and lend a hand if you can.

Fatigue in Guillain-Barré Syndrome (GBS)

Dr. Gareth Parry

University of Minnesota

(conference presentation 2015)

Fatigue in GBS

- Fatigue is common following GBS
 - 50% - 80% of patients who have GBS subsequently suffer fatigue
 - Fatigue is not necessarily related to the residual effects such as pain and weakness but it is certainly more common in those more severely affected.
 - Fatigue can persist for several years, even when recovery seems otherwise complete.

Fatigue in GBS

- Fatigue is not necessarily a direct consequence of having had GBS.
 - Concomitant physical illness such as anemia, low thyroid function, diabetes, heart disease and chronic lung diseases may contribute to fatigue.
 - Sleep disorders are common and contribute to fatigue.
 - Medications used to treat many conditions may exacerbate fatigue, especially pain medications.
 - Untreated pain can contribute to fatigue.
 - Depression is common following GBS and can manifest primarily as fatigue.
 - Deconditioning is an important contributor to fatigue.

Management of Fatigue in GBS

- Remember to make sure that there is not some other cause of fatigue.
- Cornerstone for the management of fatigue is exercise.
 - Establish the habit of exercise, even if it seems trivial at first.
 - Light aerobic exercise.
 - Goal is to exercise 4-5 days a week.
 - Increase pulse by about 1/3 and maintain it at that level for 15-20 minutes
- Weight loss
- Judicious use of stimulants
 - Amantadine which is used in MS-related fatigue does not seem to benefit GBS patients.
 - SSRI/SNRI medications are mildly stimulant and have the added benefit of elevating mood.
 - Methylphenidate (Ritalin), dextro-amphetamine (Adderal) and modafinil (Provigil or Nuvigil) have not been formally studied in GBS but clinical experience suggests that they can be beneficial.
 - Important to use on an *as needed* basis to avoid tolerance.



Letters to the Editor

Just a note to say that both Rex and I really enjoyed the book, *The Student Body* by Simon Wyatt.

Congratulations on your book it really holds your attention. We are looking forward to your next one.

This year we were holidaying in the West Auckland region & Piha so were very interested in visiting the areas we only remembered from our youth and also from your book.

I worked in Glendene as a school Dental Nurse in the mid 70s.

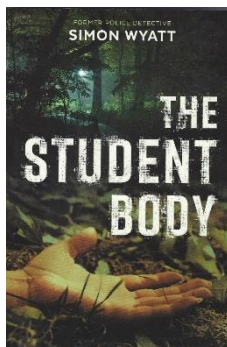
It's refreshing to think you were able to look above your fight with GBS and write this book.

In my case too, although unable to work I was thinking ahead to my husband's retirement and our future running a Bed and Breakfast. I have moved on to enjoy life as a 'Landscape Artist' so it just shows life can take you on a whole new journey.

Life just gets better.

Linda has a copy of the book and is happy to pass it on to anybody in the group whom would like to read it.

Contact her on: bannister_r@hotmail.com



About Victoria (a doll)

In 1993 Georgina Campbell of Kaitiaia, aged 81, a survivor of Guillain-Barré Syndrome created a 45cm tall doll dressed in Victorian clothes. She gifted the doll to the GBS Support Group to be used to raise operating funds.

The raffle was won by Maurice Vickers of Blockhouse Bay in Auckland who is also a GBS survivor.

After a number of years of patiently standing in her Perspex case Victoria passed through a number of hands, then was handed to the St Dominic's Catholic Primary School in Blockhouse Bay to be the centre of a fund raising project in support of Mae Sot Orphanage in Thailand. This orphanage is managed by a group of Dominican Nuns to care for and educate up to 60 children without any aid from Thai administrations. Victoria is now being lovingly cared for as the treasure of Laura living in Greenbay Auckland.

For Mae Sot Orphanage

www.holyinfantorphanage.org



Members Enjoying a Shared Lunch after a not so strenuous morning of cycling and Nordic walking.



Top Left: Rex and Linda Bannister

Top Right: Judy and Barry Deed

Bottom Left: Marty and Chris Hewlett and Grant and Fran McKay.

Photographer: Meike Schmidt-Meiburg

You can be forgiven for thinking it's all about the food. Our shared lunch was a positive feast.

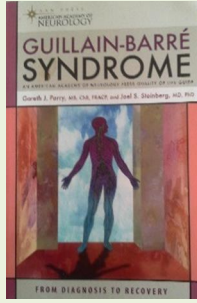
Coffee Group Meeting at the Loose Goose Tirau



Back left to Right: John Dixon, Grant McKay, Rex and Karen Soppet, Jan Gribble, Chris Hewlett, Emma Wolfe, Russell Brokenshire, Ken Ardern, Meike Schmidt-Meiburg

Front left to right: Julia Ardern, Fiona Green, Fran McKay, Sue Dixon, Jan Morrow

NOTICEBOARD



New Stocks of this easy to read and enlightening book are now available. \$30 including P & P. If you would like to purchase one contact:
Chris Hewlett:
chrispy57@gmail.com
Or
Tony Pearson:
tonvpearson@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: devoungs@xtra.co.nz

Or

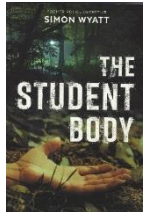
Tony Pearson: tonvpearson@xtra.co.nz

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.

If you would like a copy of this book please contact Tony Pearson who has a few complimentary copies available.



WAIKATO/BAY OF PLENTY COFFEE GROUP

Thursday 8th June



Where: Fairview Country Estate

34 Sharp Road, RD 2, Katikati
<http://www.fairviewestate.co.nz/cafe/>

Time: 11am onwards

Please let Meike know by Monday 5th if you are attending so she can confirm numbers with the Café.

Email: schmidtfarm@xtra.co.nz

Cell Ph: 027 3250369

Ph: 07 867 3163

Everybody welcome.



Waikato/BOP Cycle Group

Our next bike ride is on

Wednesday 5th April in the Karangahake Gorge

Please bring a shared lunch (or your own)

Directions: Meet at Victoria Battery at 10am.

This is about 1.5km from the Waikino Hotel on the Paeroa side. A single lane bridge crosses the river, go over the bridge and immediately turn left, drive along about 1.5km to the end of the road. It is very pot holey.

Contact Judy for further info.

Judy Deed 021 10335471

(walkers welcome too)

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

INVOICE

2016-2017 MEMBERSHIP ANNUAL SUBSCRIPTION

Subscriptions for membership of the Group for the financial year commencing on 1st 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) 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:-
Peter Scott PO Box 4162 Palmerston North 4442**

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

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

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