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NEWSLETTER JUNE 2014

If Undelivered Please Return To:

*Chris Hewlett
51 Killen Road
RD 2
KATIKATI, 3178*

Patron	Hon. Steve Chadwick		
President	Ken Daniels	12 Mallam Street, Karori, Wellington,	Ph: (04) 476 4323 Email: espin.karori@xtra.co.nz
National Coordinator	Jenny Murray, QSM	27 Grenville Street, New Plymouth, 4310	Ph/Fax: (06) 751 1014 Email: jenny.gbs.nz@clear.net.nz
Secretary	Tony Pearson	113 Weka Road, Mariri, RD 2, Upper Moutere, Nelson, 7175	Ph/fax: (03) 526 6076 Email: tonypearson@xtra.co.nz
Treasurer	Peter Scott	P.O. Box 4162, Palmerston North, 4442	Ph: (06) 357 8436 Email: peterscott@clear.net.nz
Newsletter Editor	Chris Hewlett	51 Killen Road, RD 2, Katikati, 3178	Ph: (07) 549 0931 Email: chrispy57@gmail.com
Publicity Officer			
Medical Advisor	Gareth Parry ONZM.MD.FRACP.ChB		
Web Site	Support	Education	Research www.gbsnz.org.nz

Guillain – Barré Syndrome Support Group New Zealand Trust

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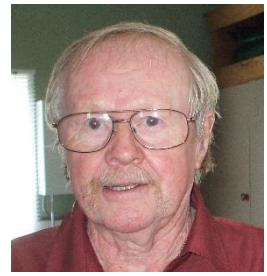
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ONZM, MB, ChB, FRACP
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Dr. Chris Lynch
Neurologist and Neurophysiologist at Waikato Hospital
Honorary Senior Clinical Lecturer at the Auckland
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Dr. Pralene Maharaj
Pathology Registrar ADHB
And Trainee in Pathology with the Royal College of
Pathologists Australasia
Member of GBS Support Group since contracting GBS
in 2006

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Auckland District Health Board

Kathryn Quick
Senior Physiotherapist Neuro – Services at Auckland
District Health Board
BSc(Hons) MCSP NZRP

Penny Sender
Clinical Psychologist
Dip Clin. Psych

Editor's Note



The year is flying by and just how close Christmas is was brought to my attention by a friend on Facebook. He has something really special planned so of course he is counting down the days. I on the other hand don't wish to even think about that event just yet.

Very few new cases of GBS have been brought to our attention which I hope means that it is not rearing its ugly head and knocking down another unsuspecting victim, but it could also be because hospital staff are still reluctant to contact us. This is an on-going problem with no real solution in sight. Until we can convince the hospital hierarchy that all we want to do is offer **support** and show patients that they will recover in time we will continue to be shut out. The patients who are lucky enough to get a hospital visitor always say how much it lifted their spirits and gave them hope in what seemed a hopeless situation. We will keep trying to break through this barrier. In support of this we require someone to be a hospital visitor coordinator. The job entails contacting hospital visitors when they are needed, following up on the visit and keeping records of visits etc. Not an onerous job but one that does require confidentiality being a high priority.

The AGM was held in New Plymouth and we were lucky enough to have Jenny and Ian Murray attend. Jenny is the unsung hero of our group. Not only did she start the group but she continues to donate a huge amount of her time and energy despite health issues of her own.

Rotorua will be the place to be in May next year as that is the area chosen for our Bi Annual Conference. Dates and details will be posted in the magazine, on our web site and Face Book in the coming months as details are finalized. The draft itinerary looks every bit as good as the 2013 Conference so start thinking about attending now. You won't be disappointed.

We welcome two new Trustees to the board. Dr. Pralene Maharaj and Doug Young. Doug is a keen duck shooter and never misses opening day so it was pretty hard on him when this year's AGM fell on the that weekend but he managed to get an early morning shoot in before jumping on a plane and heading north for the AGM. He wasn't saying if he reached his bag limit.

Please let me know if you would like to receive your newsletter by email. It looks so much better in colour and helps make our limited funds go further.

As always I'd love to receive your story.

Chris

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

Editorial
Presidents Annual Report
Secretary's Report
2014 AGM Report
Correspondence from Sweden
Letters to MAB
Personal Encounter
Brain Day 2014
Codicil
BOP/Waikato Coffee Group

Chris Hewlett
Ken Daniels
Tony Pearson
Tony Pearson
Claus Zimmermann Pedersen
Answered by Dr. G Parry
Sue
Maurice and Kath Vickers
GBS Support Group Trust
Photos by Meike Schmidt-Meiberg

Presidents Annual Report 2014:



Last year our long time president Bob Stothart handed over the role of president. It became quickly evident that the energy and dedication that Bob gave to the group was very hard to match. I am deeply grateful to Bob for all his past efforts and it has not been possible for me to rise to his level of commitment. Consequently it has been a fairly quiet year for the support group. The main effort has been carried on by our tireless secretary Tony Pearson, the treasurer Peter Scott and other members of the board. To them the GBS support group owes a great debt of gratitude.

I also would like to thank the Medical Advisory Board. It is only with access to expert knowledge that our members can have confidence in decisions they make following the challenges of GBS. The backing of the medical experts also gives confidence to the family members whose parallel suffering is often under appreciated. Special mention needs to be given to Dr. Gareth Parry whose guidance and quiet wisdom has helped so many members of the group.

Thanks for the past years work needs also to be given to those like Chris Hewlett whose efforts have been reflected in the production of the magazine, and all those who have organised community coffee meetings, visited people in hospitals and generally made life just that little bit easier for our members.

I would like to acknowledge the special and long-time help and support of our National Coordinator Jenny Murray QSM whose energy and assistance have been an inspiration and joy to all who have worked with her.

As with many charitable groups in New Zealand heavy reliance on sponsorship and donations is a reality of life for our society. We couldn't continue our work in the field of GBS support without the kind and generous support from the ARA Lodge 348 IC Charitable trust and the NZ Lotteries Commission. We will always be grateful for their kind assistance. Membership fees and donations have also contributed to the help the group provides. Thanks to all of you.

It is hoped that during the year ahead we can do more to support those who face the interesting and at times painful experience of Guillain Barré Syndrome. It often helps to remember what it was like for you in order to appreciate the gratitude that sufferers feel when you visit or even given them a phone call. I know that the support of the society has been of immense help to me even over the last few months.

Thanks to you all

Ken Daniels



The Board of Trustees hard at work prior to the AGM

Secretary's Jottings



Taranaki is a beautiful region so when it was decided to hold the 2014 Board meeting and AGM in New Plymouth Vivienne and I resolved to renew our acquaintance with the area and have a few days holiday following the completion of “official business”. However Taranaki also gets a lot of rain! Checks with the Met service in the days running up to our departure to New Plymouth indicated a somewhat soggy sojourn lay ahead– not to mention gale force winds for our crossing of Cook Strait! New Zealand

weather is however notoriously difficult to predict and for once we were glad the Met service got it wrong and we enjoyed a goodly share of sunshine and almost perfect weather for our Straits crossings. I have reported on the proceeding of the AGM elsewhere in this newsletter but let me just add that it was followed by a 2 hour walk in glorious sunshine along that superb coastal walkway that New Plymouth offers.

The weekend started with a dinner on Saturday evening attended by a number of Board members and their better halves together with Phyllis and Royce Wood and Kath and Maurice Vickers - long standing and solid supporters of the Group. Our guests of honour were Jenny and Ian Murray and it was a real treat to be able to catch up with them again in person particularly as ill health has prevented both of them from attending the Conferences for the past few years.

At the Board meeting on Sunday morning a full Agenda kept us busy – matters of significance (not mentioned in my AGM report) included a decision to update our range of explanatory brochures and pamphlets and once cleared by the MAB to put them on our website where they can be read online – or downloaded at will. Our Medical Advisory Board has been expanded by the addition of a Physiotherapist and a Psychologist and Dr. Parry expressed himself satisfied that we now have a broad range of medical expertise backing up Group operations. Our new Board member Doug Young has taken on the fairly monumental task of preparing a Medical Contacts List that will aim to enable us to regularly contact the relevant senior medical personnel in all the main hospitals to remind them about the Group and how we may be able to assist in supporting their GBS patients. If you have information/contact details of a medical professional in your local hospital who has been particularly helpful in putting patients in touch with the Group do let Doug know. He can be contacted on deyoungs.doug@xtra.co.nz or 03 230 4060.

Perhaps the most exciting news tabled at the Board meeting was the plan to hold the 2015 Conference in Rotorua in May – this has yet to be “firmed up” but I am keeping my fingers crossed.

Finally, thanks to Vivienne’s acquisition of an iPad and the assistance of a “techno” daughter, the Pearson’s now have a Facebook account and we have enjoyed reading the input on the Group’s site. I still can’t come to terms with this urge on the part of half the world to put the minutia of their lives on their Facebook site for the rest of the world to read but I do see the value of OUR site in providing a forum for members to benefit from the trading of ideas and experiences and as a source of information to be gleaned from our MAB.

As Always – take Care

Tony



Support Group members enjoy a meal out in New Plymouth prior to the AGM

Report on the proceedings of the 2014 Annual General Meeting in New Plymouth

22 members attended the AGM on Sunday 4th May on a lovely sunny day in New Plymouth. Although not large in number members came from as far afield as Auckland and Invercargill! Thank you to those who made the effort and those of you who took the trouble to complete your proxy forms. We were delighted that Jenny and Ian Murray were able to attend and were looking so well.

The President's Report and a summary of the Accounts for the past year will, if room permits, be found elsewhere in the Newsletter. As usual our Auditor delivered an unqualified Report on the Accounts – a tribute to our Treasurer's good bookkeeping. Thanks to some generous donations and assistance from the ARA Lodge and Lotteries we kept our head above water financially for the year enabling the Treasurer to recommend that subs for the coming year remain unchanged and that we should be able to run the 2015 Conference without dependence on outside grants and still maintain a reasonable Delegates fee. Members were updated on the progress of the Hospital Visitors program and were encouraged to visit the "new look" website, now up and running.

The "main event", so to speak, at the AGM were the changes to the Board of Trustees. Don Martin's resignation was accepted with regret. Don has done sterling work for the Group over many years and we wish him well for the future. With now two vacancies on the Board we were delighted to elect Doug Young and Dr. Pralene Marharaj to the Board. Doug (a CIDPer) comes from Invercargill and brings a wealth of experience to the Board from his business background and the many committees and Trust Boards he has served on in the South. Pralene is already known to many of us as a member of the Medical Advisory Board and a speaker at the last Conference when she recounted her unpleasant encounter with GBS.

Under the annual rotational rules of the Trust 3 serving members are required to resign and submit themselves for re-election to the AGM. This year it was the turn of the Executive, Ken, Peter and Tony, to resign and they were grateful to be re-elected to the Board which has subsequently asked them to continue in their Executive roles. It is particularly pleasing that Ken felt able to continue – at least for the time being – as President having got on top of the medical issues that have laid him low over the past year.

At the Board meeting earlier in the day the head of our MAB Gareth had announced that the Parry family wished to establish an annual donation of some \$2500 per year to the Group to be utilised at the Board's discretion for providing financial assistance to sufferers and their carers to attend future Conferences or other Group events or to further the research aims of the Memorial Fund. This is a most generous gesture and will be highly valued by the Group. The operational mechanics of how the funds might be distributed will be worked out in the coming months with Dr. Parry and will be announced in future Newsletters and on the website.

The meeting also learnt that the Group will shortly be calling for applications for funding assistance from the Memorial Fund for projects that advance our knowledge of the causes, treatment and effect of GBS. The Group will, in the first instance look to our Medical Advisory Board for project nominations.



*Jenny and Ian Murray were guest of
honour at the AGM*

Correspondence from Sweden:

Dear GBS/CIDP co-workers,

I had my GBS attack in 1998 and have recently discovered a unique and quite unexpected source of relief. I am so pleased and excited with my results that the Swedish GBS/CIDP Support Group has created a way for other GBS groups to test the BAUD device the same way I did - at no cost. The BAUD is very safe, and it uses only sound to stimulate brain plasticity, so results appear very quickly.

My improvement happened after 10 years of no changes or improvements in my condition (actually my walking ability and pain level got worse the latest years). I have seen not just relief - but actual improvement!

Knowing that one of the main reasons for the establishment of GBS/CIDP Support Groups "is to provide support to those affected by these disorders so that every patient obtains an early diagnosis, proper treatment and the opportunity for a full recovery" I am very pleased to be inform you of the following:

After the GBS-attack I was left with heavy and widespread nerve damage in the legs, feet, arms and hands. This included 2 drop feet which made my walking look and sound almost as a modern "Frankenstein." And I suffered nerve pains 24 hours a day ranging between 2 – 8 in the intensity scale.

Here is what I have experienced so far:

From the 13th of March when I first used this device I have experienced:

- NO need of any pain killers. (after using oxycodone daily and morphine several times per week for 15 years)
- my pain has reduced to level 0-2 on a daily basis
- a new and improving ability to walk more naturally
- ability to feel different substances beneath my feet
- feeling that my legs beneath the knees and my feet are parts of my body
- ability to walk side-to-side and backwards
- ability to move my toes and ankles a little

All of this for the first time in 15 years! Of course much is left to overcome – however the progress and the journey to my current status has been – and is – just astonishing – with no negative side effects so far.

I know that my problems are shared by many other GBS sufferers, and there are very few options for us. The BAUD system can easily be used by the average person, and has been featured on television shows like The Doctors as well as Dr. Phil, and it is approved by the FDA in US. This system is not meant to replace already existing and approved medication and treatment, but just a supplement; in my case a fantastic and effective one in reality:

OUR OFFER TO YOU!

Because of these promising results and a strong wish to look deeper into this kind of treatment the Swedish GBS/CIDP Support Group has decided to buy 3 copies of the BAUD System and will now give all GBS/CIDP Support Groups the chance to test this in the same way I did.

We will make a system available to groups on a first-come, first-served basis. You will have the BAUD system on loan for 60 days, and can make it available to your members to try.

Please inform me if you are interested in participating. I then will notify my contact in Kansas, US, Mr. L. Richard Bruusema (Mr. Bruursema has been so kind to be willing to evaluate the equipment after each return to ensure it is in proper working order). He will also offer coaching if needed via phone or Skype. Your only cost will be shipping charges to and from your location.

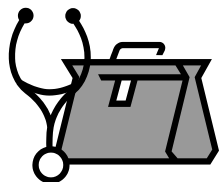
For further information about the BAUD system please check www.BAUDtherapy.com or www.mybaud.com. You will see that it is a very easy system for the average person to use.

Best

Claus Zimmermann Pedersen

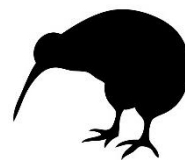
President and founder of the Swedish GBS/CIDP Patient Support Group

If anyone is interested in trialing this device please contact Ken Daniels or Tony Pearson. The Group is not endorsing the product but if there is sufficient interest the Board would consider obtaining a unit to trial.



Letters to the Medical Advisory Board

Answered by Dr. Gareth Parry



Question:

My wife and I are heading to East Africa later this year and was wondering if you could ask Gareth if he would have any concerns about me having the Yellow fever vaccine, Cholera vaccine and malaria tablets. I had GBS 8 years ago. Just being a little cautious. Just want to make sure.

Answer

1. Definitely no problem with malaria tablets.
2. As always, there is a small risk with vaccines but most all the data is from influenza vaccination. However, in this case the benefit of the vaccine far outweighs the tiny risk.

Question from our FB Page:

Just wondering if any of you have had an epidural or spinal anesthetic for a Caesarian section after a history of GBS. I'm going into National Women's next week for pregnancy complications & recall reading somewhere that epidurals might be an issue for us...

Answer

There are reports of GBS after spinal epidural anesthesia but they are, in my opinion, totally implausible. GBS is going to occur in association with any event but unless there is a recognizable pattern you cannot implicate that event as the trigger. If you got GBS after your daughter's wedding would you blame the wedding? No, it is just a chance association and that is the case with epidural anesthesia. I should add that there is no risk in terms of other complications of epidural anesthesia or surgery in patients who have had GBS unless they have severe residual weakness.

Question:

I read in a recent issue of "The Communicator" (GBS/CIDP Foundation International) about MMN (Multifocal Motor Neuropathy) which has similar symptoms to CIDP. My specialist, Dr. David Abernethy, (Wellington Hospital) has expressed doubts that my condition is not true CIDP but possibly more related to my Type 2 Diabetes condition and I am wondering if in fact I have MMN. My condition was diagnosed about 8 years ago with the presence of protein in the spinal tap sample.

Apart from the initial loss of sensation and strength, I have never suffered from complete paralysis or extreme pain, just a considerable loss of strength and muscular tiredness with restricted walking and cold, numb feet. Regular infusions of Intragram have provided a very slow improvement, compounded by my age – now 74.

I guess my question really is - Is this condition is recognised in New Zealand?

Answer

MMN is often referred to as Parry's syndrome because I was the first person to discover this disease and reported on it in 1985 so it is most certainly recognized in NZ. It is generally easy to distinguish from CIDP because it is highly focal; that is, just a few individual nerves are affected. It also has no sensory symptoms (numbness, tingling and the like) which are very common in CIDP. Diabetics can get neuropathy due to their diabetes but are also at a higher risk than the general population of getting CIDP. The fact that slow improvement is occurring argues for a diagnosis of CIDP in a diabetic.

Letters to the Medical Advisory Board *continued...*

Question from our FB Page:

I first got GBS in July last year it got to my waist and was unable to walk for a few weeks. I got better to a certain extent but keep having relapses and now they have found out it's turned into a very rare form of GBS called CIAP and not CIDP.

Answer

There are really 2 issues within the Facebook post. Firstly, if the disease is relapsing it is certainly not GBS. A single minor relapse within a month of GBS onset may occur but not recurrent relapses. I therefore agree that this patient does not have GBS. The 2nd issue is about CIAP. This is chronic inflammatory **AXONAL** neuropathy which is a controversial entity but one that probably does exist, just as there is an axonal form of GBS called acute motor axonal neuropathy (AMAN). However, chronic inflammatory **DEMYELINATING** neuropathy (CIDP) is much more common. Patients with CIDP often have a lot of axonal injury and can look like CIAP. The treatment of CIDP and CIAP is the same and consists of high dose weekly steroids (preferred) or gammaglobulin (IVIg).



Andy Griffiths Encounter with GBS

Go to this website and read his story.

http://www.guideposts.org/inspiration/inspirational-stories/guideposts-classics-andy-griffith-on-accepting-gods-grace?utm_source=Facebook&utm_medium=GP&utm_campaign=AndyGriffith
06.19.14



GBS – A Personal Encounter

From Sue

On approximately 6 September 2013, I started to feel unwell with almost 'flu like symptoms i.e. runny nose, sore throat and extreme lethargy. After two weeks spending most of my days and nights in bed (which I never do when I have 'flu), I started to develop numbness in my extremities i.e.: fingers, hands, toes, feet etc. My fingertips were also extremely cold. On 23 September I visited the doctor as, as well as my 'flu like symptoms, I was losing my sense of balance and having to hold on to something when standing or walking. By this stage, I was becoming quite frightened not knowing what was wrong with me. The doctor prescribed Amoxycillin which, I believe, is an anti-biotic, and was told that if these did not help improve my situation in three days, I was to revisit the doctor. On 25 September I returned to the doctor as the anti-biotics had caused thrush so I was advised to stop taking these. I was given Nilstat for the thrush and Ibuprofen for the pain (headaches and a pain in the lower chest which radiated to my right shoulder). At this stage, as well as feeling very unwell, I was getting very worried as to what was wrong with me. I have kept fairly fit all my life and blessed with reasonably good health so this condition was completely alien to me.

On 26 September, the numbness in my hands and feet had spread to my lips and I couldn't close my mouth properly. I struggled to form words with my lips and tongue and I was lisping. I was also feeling extremely nauseous and had an episode of vomiting. I was eating very little and if I managed breakfast, I usually couldn't manage anything else for the rest of the day. On 27 September I returned to the doctor with my partner and my mother both of whom were determined to obtain some sort of definite answer as to what was wrong with me. The doctor agreed with both of them that I should be in hospital and he diagnosed that I had had a stroke.

I was admitted to Nelson Hospital's Emergency Department and after a CT Head Scan, they decided it was unlikely that I had had a stroke but I was admitted to the Medical Department for observation. The Emergency Dept. had established that I was unable to close my eyes properly, unable to wrinkle my forehead or nose and a generally poor sensation over my facial area. All tests indicated poor results on my left side and my mobilisation was very, very poor. On 8 October I underwent a Nerve Conduction Study which confirmed what the doctors and nursing staff had begun to suspect – Guillain Barré Syndrome. On admission to the Medical Dept. I was unable to walk and had to be hoisted to the toilet, showered by a nurse, fed by a tube and extreme reaction to heat (e.g. a warm shower) resulting in extreme fatigue.

My condition gradually improved and I started to use crutches and a stroller to assist movement. Throughout my recovery, I learnt very quickly, not to overdo things. If I tried to do too much, I would have an almost Migraine-like headache the next day and had to spend a day in bed, curtains drawn and feeling thoroughly miserable. I was sleeping normally at night but needed an afternoon sleep too.

I was very lucky to have a visitor after I had moved down to the Rehabilitation Unit in the hospital (Tony Pearson, the secretary of the Guillain Barré Syndrome Support Group). Tony gave me a heap of information about GBS – the most relevant of which was a book "Guillain Barré Syndrome – from diagnosis to recovery" by Gareth J Parry and Joel S Steinberg. I would strongly advise any GBS sufferer to read this. It gave me a heap of information and understanding particularly about my almost Migraine-like headaches.

Doctors had passed this off as "I was just a headachy type of person". Tony's book had one sentence that really set my mind at rest. The book was discussing symptoms that GBS sufferers might experience and one of the symptoms was - devastating headaches caused by high blood pressure!! Now, months down the track, I no longer suffer from these headaches although I am still on blood pressure pills.



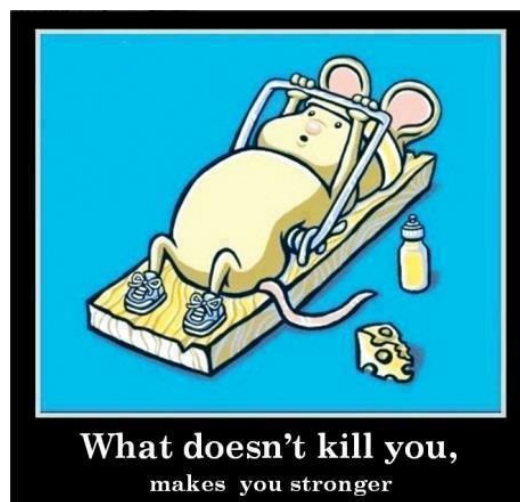
GBS – A Personal Encounter

From Suecontinued

GBS is a syndrome (a collection of symptoms and signs. It is not a single disease but consists of several; related diseases). It affects 1 – 2 people in every 100,000. The form of GBS that affected me was Miller Fisher Syndrome which affects 5% of those attacked by GBS. How rare is that?

I do consider myself very lucky though. When I was first admitted to Nelson Hospital, I was under Dr. King who said to me "You will be here for 6 months – prove me wrong!" I was out of hospital in one month. My second piece of luck is that I was afflicted with the Miller Fisher Syndrome which, I believe, sufferers fully recover from.

My biggest achievement happened in March 2014 – I completed the Otago Rail Trail in 3 days. It was hard work but it was a goal I'd set myself and I managed it! So never give up GBS sufferers...you can do it. You may have to change direction slightly but it is possible.



**What doesn't kill you,
makes you stronger**

2014 Auckland Brain Day

Maurice and Kath Vickers

The Neurological Foundation in conjunction with Auckland University hosted the Brain Day where support groups could show to the public their aims and objectives. 29 groups set up displays in the Owen Glen Business School Auditorium in two rows of back to back tables.

As well as these displays two lecture theatres were in continuous use giving lectures on various subjects. Guillain-Barré Syndrome support Group was represented ourselves and Pat Douglas who, during the course of the day spoke to 60 members of the general public as well as 12 medical professionals. Also we met 4 ex patients or friends of ex patients who did not know of the GBS Support Group.

Most people were handed a slip showing our website. Those who showed greater interest were given more information and literature.

The GBS table was at the end of a row close to the doorway to the lecture theatre. This meant the frontage was virtually doubled and we were not chair bound behind a table. Also the position made it possible to catch people as they left a lecture.

The day was considered a worthwhile exercise.



Young and old found something of interest at our stand at Brain Day

Bi- Annual Conference 2015

This will be held in **ROTORUA** May 2015

Watch this Space for More Details

Codicil to an existing Will

If you have already made a Will you can still help the Guillain Barré Syndrome Support Group by adding a codicil to your Will.

If you would like further information or would like to talk to a Trustee of the Group about making a bequest to the Charity please contact us on 03 526 6076.

We do advise consulting with your legal advisor before completing this codicil form

Please take this form to your legal advisor

I(name)

of

.....(address)

Declare this to be a(first/second) codicil to my Will dated/...../.....

In addition to any legacies given in my said Will I give to the Guillain Barré Syndrome Support Group New Zealand Trust, of 113 Weka Road, Mariri, RD2, Upper Moutere, Nelson 7175 (or any other premises which the Support Group may hereafter occupy) a charity registered in New Zealand No. CC20639,

A share of of my estate or the sum of NZ\$ and/or

..... (a specific sum)

to be used for general purposes and I declare that the receipt of the Treasurer or duly authorized officer shall be full and sufficient discharge. *

In all other aspects I confirm my said Will and all other codicils thereto.

**please complete as required and cross out those options not required.*

Signed

Signed by the above named in our presence and witnessed by us in the presence of him/her and each other

Witnessed by:

Signature.....

Name

Address.....

.....

.....

Occupation.....

Date...../...../.....

Witnessed by:

Signature.....

Name.....

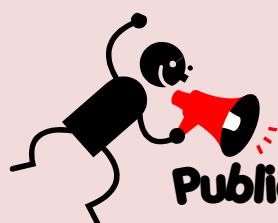
Address.....

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Wanted

Publicity Officer and Hospital Visitor Coordinator

If you think you have what it takes to promote our Support Group or be the liaison person for our hospital visitor program 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.

Bay of Plenty / Waikato Coffee Group.

Venue: L & P Café Paeroa

Date and Time: Friday 22nd August 2014 11.30am



We had a cracker meeting in May with 18 attending including 3 generations of one family.



Left: Sue Dixon, Jan and Ray Morrow



Right: Grant and Fran Mackay



Left: Meike Schmidt-Meiburg and Chris Hewlett



Right: Ken Arden, John Dixon and Rex Soppett



Above: Shanti Singh with her daughter and granddaughter Marnie and Tara Deobhakta



Left: Judy and Barry Deed

Right: Marilyn and Warren Turnwald

Rod Bellerby present but camera shy

