Information published in this Newsletter is for educational purposes only and should not be considered as medical advice, diagnosis or treatment of Guillain-Barré Syndrome, CIDP, related neuropathies or any other medical condition.

NEWSLETTER DECEMBER 2011

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New Zealand

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<td><a href="http://www.gbsnz.org.nz">www.gbsnz.org.nz</a></td>
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Editors Note

I attended the Trustee meeting early November and was amazed at the amount of work done by Bob, Tony and Don behind the scenes resulting in a set of guidelines and training procedures for volunteers and an excellent power point presentation that will be available to members who find themselves in a position to speak to others on GBS. I took the prototype to our last coffee group and everyone was very impressed.

We have had two successful coffee mornings here in the Bay and those that attended the last one were pleased (at least I think they were) that I had secured the AGM. More details on that elsewhere in the magazine.

The All Blacks scraped home by the narrowest of margins, much to everyone’s relief I am sure. However GBS didn’t take time off and several new cases were reported. I wish all those who have been struck the very best with their recovery, and remember you are not alone, there will be someone near you who can visit it and give moral support during this tough time. Contact Jenny and she will send someone your way.

Well I did crash and burn doing the 10,000 step challenge. Two weeks of doing over 110,000 steps took its toll and the last week was a rather pathetic effort. Our team finished third, but we blame the “virtual” stops we had in the West Coast pubs. It was fun and a good way to keep a track on how much exercise we really DON’T do during the day. My pedometer is still ticking over but it could be better ……..

Subs are due so please get them into Peter as soon as possible. They can be mailed in (cheques only please) or done online this time.

A big thank you to all who have sent in articles for the newsletter. It is very much appreciated and makes the task so much easier.

I would like to wish you all a very merry Christmas and a Happy New Year

Chris

Letters to the Editor

Many thanks for my newsletter. I really look forward to it. I love to read about other people’s personal stories and professor Gareth Parry articles, they are always very good.

I got GBS in 1993. I still have some residuals. I had the Miller-Fisher Variant of GBS. I still have numbness in my face and I get over tired.
Anyway I really love getting your newsletter. I am sending you my memnbership which I hope will cover me for another while.
Keep up the good work.
Many Thanks

Deirdre Hussey
Ireland
When you have GBS or CIDP it is a very emotional time which impacts on family and those close to you. On the plus side, the experience of these rare and strange conditions often predisposes one, upon recovery, to want to help others. And this willingness to help is a universal human condition evident around the world. All of this is to say how much we appreciate the help we have received, as an organisation, from kindred organisations overseas. When we got started, Jenny Murray received enormous help from the GBS/CIDP Foundation International in America and from the national organisation in Britain. My visits to the conferences of the Foundation reinforce many times over, the readiness to reach out and help. We are part of an international fraternity of shared experiences.

So it is that we have recently received great assistance in the preparation of ‘hand out’ material, from Britain. Another form of willingness to help is manifest in the Medical Advisory Board which Professor Gareth Parry has gathered together for our on-going benefit. The members of the MAB are featured elsewhere in the Newsletter but I thank them all, in advance, for offering their services. I hope that we will get a chance to meet them at our national conference in Wellington in 2013.

Your elected trustees met in Wellington a couple of weeks ago to process a large chunk of business. Topics ranged from the aforementioned information from Britain to an ID card system for Hospital Visitors, to the Medical Advisory Board, to expenditure and budget approval, to web site improvement to national publicity and public relations, to ACC to an ‘awareness’ power point presentation, to the terms of appointment for trustees. As you can see, it was a lengthy agenda dealt with by people who through their personal encounters with GBS/CIDP, want to give their time to helping others.

We are planning to crank up our Hospital visiting and to offer training to volunteers hence our seeking advice from other providers. The recognition of support groups (by Hospitals across a variety of support groups) varies from district to district so we are also planning to crank up our profile as a useful, discreet and valuable support organisation. The Medical Advisory Board is part of this strategy as is the training for Hospital visitors. We will improve our website and our communication with hospitals. From small beginnings great things can grow.

I wish you all a joyous festive season and a rewarding New Year.

Bob Stothart
Well the European holiday is over and we are both very glad to be home. Spain (on the Plain) was very hot although the Pyrenees were a much more acceptable temperature. Vivienne celebrated her 65th birthday in a REAL castle – with dinner in the torture chamber (somewhat upgraded of course!). Greece was very windy with life jackets more in evidence than bikinis on the boat and as for England – boy are we glad to be away from the traffic!! – but catching up with old friends and seeing the relatives was good. Once back home there followed a busy couple of weeks “catching up” with family and the inevitable pile of paperwork and then before you knew it I was off to Wellington to meet with the rest of the GBS Board for the first of our half yearly meetings.

A constructive day’s work ensued with the focus very much on planning the development a Hospital Visitor network, backed up with suitable training and guidelines for those who volunteer for this very important aspect of the Group’s activities. Alongside this high priority initiative we also reviewed the Work Place GBS/CIDP Powerpoint presentation that Don Martin has adapted from the UK Group’s library. This is now available within the Group for those members who are minded to further the Group’s message within the professional sphere of Hospitals and Medical Clinics. With Dr Parry coming” home” to New Zealand in January the formation of the Medical Advisory Board to support the Group will become a reality providing not only an essential source of expert knowledge to help members of the Group but also giving us credibility to a sometimes “wary” medical profession.

After some “firm” lobbying from Chris Hewlett it was agreed to hold the next AGM on the 28th April 2012 in Tauranga – put the date in your new diaries. Further information on venue and timing in due course.

A few bits of “admin”:-

We are still in need of a Website Co-ordinator. You do not need to be a “techi” or “geek” just willing to act as liaison between the Group and our Website Manager, be organized and be comfortable working with your computer. Let me know if you feel the urge to help the Group with this important role.

I have been persuaded by Chris and Maria to open a Facebook Account – something I have been quite nervous about as you hear some scary stories about intrusion but they assure me I can avoid all the nuisance issues and most importantly can access and take part in the Group’s Facebook forum. I am waiting for my computer savvy daughter to find time in her busy life to sit beside me ( probably over her Christmas break) whilst I venture into this new aspect of my computer experience. I will let you know how I get on!

This issue of the Newsletter contains an Invoice for the 2011/2012 membership subscriptions. Please use this form to renew your membership and , if you have not previously been a financial member, PLEASE give serious consideration to formally “joining up” Whilst the subscription is not substantial a strong membership base provides the Group with not only a solid financial structure but also carries weight with the charitable funding sources when we apply for grants to further our aims and activities. You will notice on the Form there is the opportunity to pay subscriptions by direct bank credit. Details of the necessary procedure are explained elsewhere in the Newsletter.

Like us the UK GBS Support Group publish a quarterly Newsletter. I was particularly struck by a “letter to the Editor” in a recent issue which whilst applauding the reports of major achievements of recovering GBS’ers ( usually linked to fund raising efforts) made the very valid point that for her major milestones in her recovery were “to walk to the corner shop on crutches and carry home half a dozen eggs and to take a cup of tea upstairs to her husband in bed”. I think we can all relate to the sense of achievement we got when little by little we recovered the ability to do those simple essentials of day to day living that we took for granted before GBS knocked on our door.

As always
Take Care
Tony
Publicity Officer’s Plug

Maria has been busy shifting south in order to start a new job and was unable to send in a report this edition. However below is a summary of what she has achieved in her short time in the role. Maria presented this report at the Trustee Meeting. We all owe Maria a great deal of thanks for her endeavours in raising the profile of GBS. Ed

Year to date activity:

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<th>Month</th>
<th>Activity</th>
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<tr>
<td>January</td>
<td>Introductory e-mail out to health reporters from mainstream media and specialist health media (introducing myself and the group)</td>
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<td></td>
<td><em>Kai Tiaki Nursing New Zealand</em> listed the conference in its conference listings &amp; <em>Physio Matters</em> into its calendar of events. The Royal New Zealand College of General Practitioners put the conference on its website and in its e-newsletter in February.</td>
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<td>March</td>
<td>Article in <em>Physio Matters</em> Physiotherapy New Zealand magazine on The Consumer Perspective pages &quot;Pain and Fatigue Main Features of Guillain-Barre Syndrome&quot; (two-page spread)</td>
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<td>Mid March</td>
<td>Issued &amp; scooped conference media release &quot;International expert to give medical insights into rare disorder at NZ conference&quot;</td>
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<td>17 April</td>
<td>Radio NZ, One in Five, Professor Gareth Parry and Bob Stothart interviewed by Mike Gourley</td>
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<td>Mid April</td>
<td>Issued &amp; Scooped second pre-conference release &quot;Health law expert to discuss patients' rights at GBS Conference&quot;</td>
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<td>28 May</td>
<td><em>Nelson Mail</em>, &quot;Taming of the dread&quot; by Naomi Arnold, profile piece on Gareth/GBS, with input from Tony Pearson also</td>
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<td>August</td>
<td><em>Kai Tiaki Nursing New Zealand</em>, &quot;Nursing a Patient with Guillain-Barre Syndrome&quot; (two-page spread)</td>
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<td>Same article reproduced on the Health &amp; Disability Commission website</td>
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<td>Recently</td>
<td>UK GBS group reproduced article on &quot;Helping Children Cope&quot; in their newsletter and new families pack</td>
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Currently working on:

- Wheels rolling on story looking at relationship between campylobacter and NZ’s higher incidence of GBS cases – hoping to piggyback off food safety campaigns over summer.
  - Have sewn the seed for a story idea with Gill Higgins, *Close Up*, based around Renee Ball as an inspirational and educational personal profile piece and Professor Parry as a world expert on the condition returning home. Just nurturing that relationship and interest and hopefully it will bear fruit in the new year. If not, Renee is continuing to “truck on” with writing her story and working on choreography for a dance production based on her experience so there are opportunities for a women’s magazine story such as NEXT.

Looking Ahead:

- As Gareth is originally from Kaiapoi and went to Christchurch Boys High School I hope to push with the Christchurch *Press*’ Health reporter to consider him for a feature story in the new year sometime (depending on his placement for interviews) and also *Dominion Post* health reporter worth a shot if he is going to be doing some work/research based there too. I also plan to target his NZ alma mater - the University of Otago medical school - to do a feature in their alumni magazine. One of their communications team (Kim Thomas) is a former Health reporter and a good contact.
  - Publicising G H Jones Legacy
  - Release around workplace information session/awareness presentation
  - Publicity around group’s participation in Brain Awareness Week events
  - Linking up with publicity officers for other related support groups in NZ to look at opportunities for joint campaigns
My Late Mum’s GBS Experience - by Wendy Larsen

This is my Mum’s story of her experience with GBS. I hope it will inspire others how you can overcome and live life following this illness.

Mum contracted GBS when she was 68 years old, and was thought to be the first woman in NZ to be diagnosed with this distressing illness. Mum spent 3 months on a respirator and 12 months in Hastings/Napier hospitals.

Mum was completely paralyzed from her eyes down. Mum was unable to speak. Our only way to communicate with her was by holding up alphabet letters and spelling out words to Mum. She would blink once for yes and 2 blinks for no. It must have been terrifying for her.

Once leaving hospital she spent many years of extensive physiotherapy, learning to walk, talk and write again which she achieved with incredible strength and determination. Family and friends were so wonderfully supportive which gave Mum that encouragement. It has had an incredible impact on our parents’ life and ours as children. It was very scary to see Mum so sick.

Mum learnt to walk again but with the aid of her RED WALK. (We nicknamed it her Ferrari).

Life was difficult and often suffering much nerve pain, to which she found great relief using Rawleighs Anti pain oil. It was the only thing that worked for her.

Mum has just passed away at aged 90. What a courageous brave lady she was.

AIDS TO HELP GBS SUFFERERS

We have all used the basic aids offered by hospitals and rehab units during our recovery period so now we would like you to send in pictures and information on any “Gadget” you found/made to help you with everyday tasks. This month we have an adaption to make it easier to use the phone.

*The hands free device is good for answering your phone using your elbow and hitting the speaker button when someone calls*
Something from the Kitchen

Glenda Ryan sent in her Great Grandmother’s recipe which still remains a family favourite

Fruit Cake

3/4 Lb Flour
1 Lb fruit Mixed
1/2 Lb Butter
1 teaspoon Baking Powder
½ Lb Sugar
1 Cup Water
3 eggs
1 Dessertspoon Custard powder

Make sauce of Custard Powder and water let cool and add Butter to mixture while cooling.
Beat eggs and sugar until creamed and add cooled custard powder and butter mixture mix together.
Add fruit mix well and then add Flour and baking Powder.
Pour into a 20cmx20cm cake pan and bake 350 degree for 1 ½ hours.

Enjoy…

BOP Coffee Morning

Our next get together will be on:

Wednesday 22 Feb 2012
At
10.30am
At the
Villa Ridge Garden Café
528 Cambridge Road
Tauriko, Tauranga

November gathering of the Clan: BOP members enjoy a pre Christmas get together. Left to right: Maurice Williams, Meike Scmidt, Robin Campbell, Glenda Ryan, Jan Morrow, Zelda Menzies, Chris Hewlett and Christine Wilton.
The commonest form of Guillain–Barre Syndrome (GBS) is acute inflammatory demyelinating polyneuropathy (AIDP). In this form of the disease inflammatory cells and antibodies attack the myelin sheath causing demyelination. There is always some accompanying injury to the underlying nerve fiber, the axon, but it is usually relatively mild. Repair of the myelin sheath (remyelination) is a quite rapid and effective process and results in near normal restoration of the ability of peripheral nerves to transmit electrical impulses. This is why AIDP usually makes an excellent recovery; 70%-85% of AIDP patients fully recover strength within a year or two of the initial attack. It is generally accepted that those patients who incompletely recover are those with more severe damage to the axon since axonal repair is a slower and less effective process. However, in some patients there is residual slowing of the speed of conduction of electrical impulses, the hallmark of incomplete repair of the myelin sheath, even years after the initial event. The degree to which this reduces efficiency of nerve and muscle function is not completely known. It is certainly possible that the residual fatigue that has been reported in up to about 80% of GBS patients could be related to incomplete remyelination reducing the efficiency of electrical impulse transmission. It is also possible that some component of any residual weakness and sensory loss could also be due to incomplete remyelination.

The chemical 4-aminopyridine (4-AP) has been shown to improve nerve conduction in the central nervous system (CNS) in experimental studies. It does so by blocking the potassium channel in the wall of the axon. In incompletely remyelinated axons the potassium channels are exposed and potassium leaks out of the axon, leading to loss of the ability of the axon to conduct the electrical impulses. 4-AP partially prevents leakage of potassium and improves nerve conduction. Recently, a sustained release form of 4-AP (known as dalfampridine or Ampyra), has been shown to improve walking in MS patients, presumably by blocking potassium channels and improving nerve conduction. Since MS is characterized by demyelination and incomplete remyelination in the CNS it is plausible that dalfampridine may also help AIDP patients with residual weakness, sensory loss or fatigue due to incomplete remyelination and also patients with CIDP.

There are important differences between CNS and peripheral nervous system (PNS) myelinated axons. Firstly, the CNS remyelinates much less effectively than the PNS; it is possible that there is not significant potassium leakage in the PNS because the axons have more effectively remyelinated so that 4-AP might not, therefore, be helpful. Secondly, CNS axons need to transmit extremely rapid trains of impulses at rates of 100-300 impulses each second whereas PNS axons transmit at a much slower rate of 40-50. Thus, electrical impulse transmission in CNS axons is much more likely to fail and is more likely to benefit from 4-AP. Despite these caveats, there is a possibility that 4-AP in the form of dalfampridine could produce meaningful improvement in GBS patients who have incompletely recovered, particularly those in whom fatigue is the most disabling symptom. A clinical trial will be necessary to determine whether there is any benefit; the drug cannot be prescribed except for MS patients.
In 1956 Dr C Miller Fisher described a syndrome of ataxia, areflexia and ophthalmoplegia and suggested that it was a variant of Guillain-Barré Syndrome (GBS). Ophthalmoplegia, or weakness of the muscles around the eyes, causes double vision (diplopia) and droopy eyelids (ptosis); the reaction of the pupil to light stimulation may also be affected. Loss of coordination and balance (ataxia) mainly affects walking but there may also be clumsiness of the arms. The combination of diplopia and ataxia makes walking particularly hazardous and falls are a substantial risk.

When the patient is examined there is loss of the reflexes (areflexia) when the tendons at the ankles and knees and in the arms are tapped. Other cranial nerves may also be involved causing facial weakness, difficulty swallowing and slurred speech but these effects are usually mild. There may also be mild weakness of limb muscles. Some patients may progress from an initial pure MFS to a more generalized GBS, even including respiratory failure, but this is very uncommon. Nonetheless, patients with MFS should be admitted to the hospital for observation to ensure that the effects remain restricted to the cranial area. As in typical GBS, the symptoms often come a week or two after some kind of infectious illness. The disease progresses usually for 1-2 weeks but occasionally for as long as 4 weeks, then stabilises and steadily improves. Prognosis for full recovery is excellent with most patients being back to normal within 2-3 months although a few have mild residual ataxia for longer; diplopia and ptosis almost always completely resolve.

There is no consensus concerning the treatment for MFS, mainly because there have been no carefully controlled therapeutic trials. The most important treatment is supportive. Patients should ambulate with care to avoid falls. An eye patch will eliminate diplopia which can be very distressing. Regular testing of bulbar functions (speech and swallowing) should be made to detect and appropriately manage any swallowing difficulty. Most of the immunological treatments that have been shown to benefit standard GBS have also been tried in MFS and many anecdotes in the literature attest to their benefit. Because most cases have only mild disability, improve rapidly without immunological treatment and fully recover, I generally do not recommend treatment unless there is ataxia of sufficient severity to interfere with safe ambulation. If treatment is used I recommend intravenous gammaglobulin (Intragam) rather than Plasmapheresis as it is better tolerated and easier to administer.

Most cases of GBS result from antibodies attacking the myelin sheath of peripheral nerves; occasionally the axon is the primary target. Recent research has shown that MFS is very strongly associated with antibodies to a component of myelin called GQ1b. Over 90% of patients with MFS have these antibodies. In most countries MFS makes up about 5% of cases but in Japan it is about 25%. The figure for New Zealand is unknown but it has been my impression over the last two years that MFS is more common here than in North America but certainly is not as common as in Japan. The unusually high incidence of MFS in Japan and perhaps New Zealand suggests that some populations are genetically more likely to develop GQ1b antibodies in response to a bacterial or viral infection.

In summary, MFS is a relatively benign variant of GBS that has a highly characteristic clinical appearance that is easily recognised. Like typical GBS, the disorder is self-limited and almost never returns. Prognosis is excellent and specific immune-therapy is seldom necessary.
I contracted GBS in 1995 and without going into detail after a missed diagnosis I ended up in Intensive Care in Auckland hospital. I was very lucky. After a lumbar puncture and all the various tests, and at this point paralysed arms, legs, and very limited lung function, the hospital discharged me after one week saying, "We need your bed, and oh yes it is a 3 year recovery". They gave me a hospital admittance number with the advice to come straight back to hospital if I got worse. "Hmmm 3 year recovery", I said to myself, "I’ll do it in one"!! In actual fact it was more like a 5 year recovery, with a couple of relapses along the way, and finding out for myself how to manage the fatigue, aching muscles, pin pricks in my legs as they slowly came back to life. I was single, in my 40’s, and in a new city and struggling financially. With the help of good friends, a good GP (new, after the miss diagnosis), and dedication to rehab I slowly but surely recovered. (Cranial osteopathy treatments were very helpful in the healing process, but I did deep water walking, paid attention to my diet and got plenty of rest as well).

I met, my now, husband during this time and he quickly got to know the fatigue signs as on our 3rd date I fell asleep at the table!

16 years on what I am left with?

The tips of my fingers still have no feeling in them so I am a bit prone to dropping things
My muscles, especially thighs, fatigue easily. Two flights of stairs are OK, then they burn!

My proprioception/coordination is poor (I am never quite sure what my feet are doing unless I am looking at them). Therefore going down stairs, walking over uneven ground etc is challenging. There have been more than a few sprained ankles along the way! Below average lung function. And general fatigue if I do not "pace" myself and get enough sleep.

What do I do about it?

I walk briskly at least 5 times a week, including a hill, for 40-60 minutes. (I needed to get good supportive shoes to stop my knees from tipping inwards initially, and to date only wear shoes with arch support)
I do Pilates exercises for strength and stretching
I get a regular monthly massage and a "tune up" from the osteopath if I need it.
I have a flu shot before each winter (always a double edged sword that one, but to date I have never had a bad reaction)

I am so lucky, at 60 I have my health, a supportive husband, beautiful grandchildren to spend time with. I work 16-20 hours a week in a job I can manage around my fatigue levels. Life is good!
If I could say anything to people who get GBS it would be "Don't give up that you will get better than you are now"

Jo Latter

Jon Anda – Update by Tony Pearson

Most of us recover to a greater or lesser extent from our encounter with GBS/CIDP but regrettably not all. You will no doubt recall Jon’s battle with his extremely rare form of progressive GBS – Anti mag. When all conventional treatments failed to stop or even slow down his deteriorating condition Jon decided to take the huge “leap of faith” and try a stem cell transplant in America - high risk, VERY expensive but with the potential to give Jon back something of his former active and quality lifestyle. Regrettably, nearly a year on, the miracle cure has not occurred and Jon’s body is once again wracked by the involuntary muscle spasm, electric shocks and needle stabs that are a feature of GBS – but at an intensity and frequency that most of us could not contemplate bearing. Jon has had huge support, both financially and emotionally from family and friends but most of all has had the strength of character to persevere when many a lesser person would give up. As he says after 3 years of flooding his body with toxic drugs, swallowing some 15,000 pills and having a “loyalty card” relationship with the local Hospital he and his medical advisors are no closer to realizing a cure – a pretty depressing scenario by anyone’s standards. Additionally, like a number of other members of the Group, Jon has found that although the NZ welfare support system might be good for accident victims it provides only the barest minimum of support for those laid low by illness. In the face of such adversity one can only admire Jon’s courage and hope that some medical break though will relieve his suffering, let him regain a life and shake off this nasty form of GBS. Our thoughts and prayers are with you Jon.
Jenny now has a new stock of Gareth and Joel’s book.

**Cost $35 plus p&p**

Written in an “easy to read and understand” format for the layman, it covers a wide range of topics including symptoms and diagnosis, caregiver guidelines, rehabilitation and much more.

If you or any of your family members want a greater understanding of GBS then I strongly recommend this book.

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**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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Occupation………………………………………..

Date…./…./……
AGM 2012

When:  Saturday 28th April 2012

Where:  To be held at the Tauranga Classic Motorcycle Clubrooms, Cherokee Place Reserve Mount Maunganui. 5 mins drive from airport.

Time:  1.30pm followed by afternoon tea.

Pickup from airport will be available for anyone requiring it.

Trustee Meeting will be held prior to the AGM starting time 11am

Hospital Visitor Training

If you would like to become a hospital visitor and receive training please register your interest with either:-
Bob Stothart: E Mail - stothart@ihug.co.nz

Don Martin: E Mail: don_martin@xtra.co.nz

Moving or Changing your Email Server??

Don’t forget to let the Secretary and/or Editor know your new details.

Wanted

Have you made or found a device that helps with day to day tasks? If so we’d to share it with other members.
Please send to the Editor.
E Mail: chrispy57@gmail.com or Mail to Chris Hewlett 51 Killen Road, RD 2 KATIKATI, 3178

Wanted

Your personnel story whether you be a sufferer or a caregiver we would love to hear from you.
Please send to the Editor.
E Mail: chrispy57@gmail.com or Mail to Chris Hewlett 51 Killen Road, RD 2 KATIKATI, 3178

In the early nineteenth century, physicians treating pneumonia did not recognize its cause (germs) and so did not know how to provide appropriate treatment. Two hundred years later, physicians treating chronic pain are in pretty much the same boat. Often, they are unable to identify the cause of pain and so are limited in their understanding of how to treat it. Although there are many treatments available for chronic pain, they do not always offer complete relief and, for some, relief appears to be unavailable.

Until recently, a major stumbling block was the unavailability of a “test” for pain. There is, however, a new research tool that seems to be shedding some light on the origins of pain. It is called functional brain imaging.

Functional brain imaging makes use of two recently-discovered technologies: positron emission tomography (PET) and functional magnetic resonance imaging (fMRI). Both methods work by measuring blood flow through the brain. The fMRI resembles the regular magnetic resonance imaging picture of the brain’s anatomy, except that areas of the brain that are active during the experience of pain are seen as small red islands on an otherwise gray, detailed picture of the brain. While the fMRI looks at brain anatomy, PET looks at metabolic activity within the brain. Using these technologies in combination, researchers are now able to identify the exact parts of the brain involved in the experience of pain.

Through functional brain imaging, researchers have discovered that the brain reacts differently in people with chronic pain, when compared with “pain-free” individuals. Moreover, in different kinds of chronic pain, the fMRI and PET brain pictures can vary. This is particularly important, since different kinds of pain tend to respond to different medical treatments.

These findings can help medical researchers to use functional brain imaging to tailor drug treatments to specific kinds of chronic pain.

Although still in its infancy, in the near future brain imaging may become the “test for pain.” Its use can greatly benefit the many people who suffer from chronic pain and, by providing hope for treatment, the depression that often accompanies it.
INVOICE

2011-2012 MEMBERSHIP ANNUAL SUBSCRIPTION

Subscriptions for membership of the Group for the financial year commencing on 1st December 2011 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 this page, complete the information requested and send with your remittance to the address below.

Subscription Rates
Single Annual  $10.00
Single Life    $100.00
Medical Group  $50.00

NAME(s).................................................................

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

SUBSCRIPTION(s) PAID  ....................

DONATION  ......................

TOTAL  =========

If your address or contact details have changed recently please make a note of the new details here............................................................

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

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.

Please post this Invoice with your remittance to:-
Peter Scott PO Box 4162 Palmerston North 4442

Thank you on behalf of the Board of Trustees.

A Note from the Treasurer

Subscriptions can be paid either by cheque, cash or as a trial this year by direct crediting to our bank account.

PLEASE NO NZ Post money orders as our bank won’t accept them and it’s a hassle converting them to cash especially when they are made out to GBS.

If you are paying direct into our bank account it is imperative that you put your NAME(s) in the reference area of the form so that it appears on our bank statement.

Any payment over and above the subscription will be treated as a donation. Receipts/membership cards will be issued in due course.