

Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

Registered N.Z Charity No. CC20639 Charities Act 2005



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 SEPTEMBER 2010

If undelivered please return to:

Chris Hewlett
51 Killen Road, RD 2
Katikati, 3178
New Zealand

Patron	Hon. Steve Chadwick MP		
President	Bob Stothart	4/326 The Terrace, Wellington, 6011	Ph: (04) 385 0240 Email: stothart@ihug.co.nz
National Coordinator	Jenny Murray	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
Medical Advisor	Gareth Parry ONZM.MDO.FRACP.ChB		
Web Site	Support	Education	Research www.gbsnz.org.nz

Editors Note



We have had seven new members join our group since the last newsletter. Almost an epidemic!! I would like to wish these new sufferers of both GBS and CIDP a good recovery and hope that through contact with other members of the group they can find the strength and inspiration to win the battle and enjoy life to the full once again.

Now is the time to start thinking about attending the Bi Annual Conference which will be held in Wellington at the end of April next year. These conferences are well worth attending not only for the wealth of information that can be gained but more importantly the opportunity to meet and talk to fellow sufferers/survivors who can offer support and encouragement on the long journey to recovery.

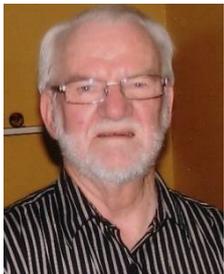
I made a small mistake when entering the dates of the Conference in the last magazine, I inadvertently used my 2010 calendar instead of a 2011. Luckily both Bob and Tony were onto it and I now have the correct date inserted.

It is good to see people are looking at the Web Site, but as yet everyone is too shy to post anything. Come on folks the success of this rests on the click of your mouse button. The Facebook page is slow to take off as well, with only 9 members signing up. Both these sites offer a chance to offer or gain support from others if they are used.

GBS International are updating their mailing address and have asked that any NZ members who receive the magazine by post and who don't have a suburb or postcode on their current address to advise them of these details to ensure the magazine reaches them. To simplify the process for them could anyone in this situation please let me know and I will forward one list to them to action with the correct details. Likewise if you no longer want to receive that magazine I will advise them of that also.

Chris

Presidents Paragraph:



I'm writing this on the first day of spring looking out on our blossoming kowhai tree and watching a noisy tui work its way around the fresh yellow flowers. Spring, the time of renewal, refreshment and new hope. My wish is for all readers to flourish as this new season develops into summer.

New cases of GBS and CIDP keep turning up every month and our hospital visitors continue their hugely reassuring work with patients, caregivers and families. Here in Wellington I've been giving some thought to our next conference to be held here in Wellington April 29/30 and 1 May, 2011, at the Brentwood Hotel. More specific details in another Newsletter, in the meantime, take note of the dates and start saving because the conference is like spring in giving hope and refreshment to sufferers and recoverers of GBS and CIDP. The programme is taking shape and we will have up to date, state of the art presenters who will give us the benefits of the experience and expertise. We will also include, as we always do, presenters who will share their personal experiences of their battle with this rare, frightening and disabling medical condition. It is a conference for everyone as those who keep coming back each time will attest.

The good news is that Professor Gareth Parry, who has given us immeasurable help over the years and who has led keynote presentations at our conferences, is preparing to re-locate in New Zealand in the not too distant future. We look forward to his ongoing help and his unstinting contribution. We are fortunate indeed to have the services of Professor Parry.

In the meantime, soak up the fresh weather, look forward to the better weather and plan to be at the conference.

Bob Stothart

Secretary's Jottings



So the recession (which as most ordinary folk know is NOT over yet) has claimed another victim and Alan Hubbard's South Canterbury Finance has gone to the wall. Clearly it's investment strategy went off course over the last few years but strangely enough the place Vivienne and I are currently staying for a weeks' walking holiday in the Mount Hutt area of Canterbury is one of the many solid enterprises that Alan Hubbard supported in earlier times and the owners – like many Cantabrians I suspect – cannot speak too highly of the way he has dealt with them. And so a man who has been described as the Edmund Hilary

of Finance for Canterbury has suddenly had the wind knocked out of his sails and whilst I am sure it will not affect his moral integrity it will most surely impact on his confidence and quality of life. Fortunately for those investors who put, in many cases, their life savings and hence plans for their future into South Canterbury the Government has stepped in to bail them out – albeit at taxpayers' expense. No such luck for GBS sufferers though I'm afraid. The same devastating knock down in most cases does not have the Government come charging to the rescue. Sure in the majority of cases the treatment we have had from the Health system has been praiseworthy but financial and emotional assistance is almost none existent. And those sufferers who have been lucky enough to get help tell of the huge bureaucratic mountain that has to be climbed to extract assistance.

As a Group we need to try and find a way through this maze of paperwork and draw up a blueprint to assist GBS "newcomers" to acquire all the help they are entitled to from the "system". Clearly not everyone will succeed but if by pointing out the directional essentials we can get help for even a small number of our members it will be worth the effort. An important task for us in the coming months! If you have personal experience of success (or rejection) with ACC/WINZ and the other "assistance" agencies PLEASE contact me with the details – copies of paperwork received etc – it will help establish a database of experience that we can draw on in attempting to write a 101 guide to assistance success for GBS'ers.

With spring now officially here I suspect many of you will be focusing on planning garden or DIY house projects or holiday plans for the coming months, if so don't forget to "pencil in" the Conference in Wellington at the end of April. Organisational arrangements are underway, speakers are being lined up and entertainments planned. My focus is, of course, on the more mundane (but essential) aspects of the business of the Annual General Meeting as well as ensuring our delegates registration process is sound and properly organised. I look forward to meeting both regulars and newcomers to our biennial get together and know I shall come away encouraged and invigorated by the courage and determination of the less fortunate members of our Group.

There are still a few members who have not renewed their 2009/2010 members and I shall be sending them a gentle reminder in the next week or so. If renewal has just slipped your mind then do please continue to support the Group – the membership fee \$10 is not excessive but a strong membership base is important for the credibility of the Group both in the eyes of the medical profession and donors.

Our "Top of the South" GBS/CIDP group had our annual get together for a coffee and chat back in June – enjoyable as always. One of the topics of conversation was the incidence of more than one case of GBS within families – either current or past generation with a couple of members confirming sibling or predecessor cases within their or acquaintances families. It would be interesting to know just how widespread this is amongst our NZ group – it's SUPPOSED to be very rare on a worldwide basis – if you have other members of your families who have also met up with GBS do let me know.

Well the sun is out, the mountains look spectacular with their snow covered tops and it's time to start up the car (one of the few around here that doesn't have those strange stick things called ski's strapped to its roof) and set off for another jaunt in this super part of NZ

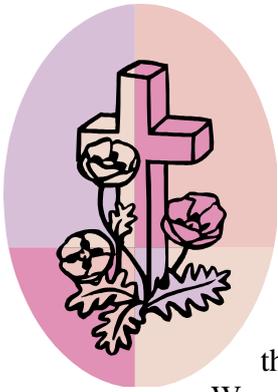
As always take care
Tony

Give a person a fish and you feed them for a day.
Teach a person to use the internet and they won't
bother you for weeks.



Obituary

William James Fraser [Bill]



Sadly Bill died in July from cancer. Bill also had CIDP and it was thanks to Jenny Murray that we were put in contact and became good friends. Bill was a very straight and honest man with a good sense of humour and a positive outlook who was willing to help anyone in any way he could.

Bill was part of our informal coffee evenings that we hold here in Christchurch as well as with Pat [his wife] hosting a few.

Many people will remember Bill and Pat as they attended the conferences and it was through Bill and his many contacts that we organised the AGM held here in Christchurch.

We will miss him dearly and we pass on our sincere sympathy to Pat and his family.

Julie Rivett (Christchurch)

Footnote: GBS NZ would like to say a special thank you to Bill's family for the receipt of a cheque for almost \$500 being donations made at his funeral.



THE BENEFITS OF HAVING FRUITS AND VEGETABLES

Fruit	Benefit	Benefit	Benefit	Benefit	Benefit
apples	Protects your heart	prevents constipation	Blocks diarrhoea	Improves lung capacity	Cushions joints
apricots	Combats cancer	Controls blood pressure	Saves your eyesight	Shields against Alzheimer's	Slows aging process
artichokes	Aids digestion	Lowers cholesterol	Protects your heart	Stabilizes blood sugar	Guard s against liver disease
avocados	Battles diabetes	Lowers cholesterol	Helps stops strokes	Controls blood pressure	Smoothes skin
bananas	Protects your heart	Quiets a cough	Strengthens bones	Controls blood pressure	Blocks diarrhoea
beans	Prevents constipation	Helps haemorrhoids	Lowers cholesterol	Combats cancer	Stabilizes blood sugar
beets	Controls blood pressure	Combats cancer	Strengthens bones	Protects your heart	Aids weight loss
blueberries	Combats cancer	Protects your heart	Stabilizes blood sugar	Boosts memory	Prevents constipation
broccoli	Strengthens bones	Saves eyesight	Combats cancer	Protects your heart	Controls blood pressure
cabbage	Combats cancer	Prevents constipation	Promotes weight loss	Protects your heart	Helps haemorrhoids
cantaloupe	Saves eyesight	Controls blood pressure	Lowers cholesterol	Combats cancer	Supports immune system

A Personnel Encounter from Jacqui

I was afflicted with Guillain-Barré Syndrome in 1975. The treatment back in the '70's was very different from the plasma exchange and high dose immunoglobulin therapy used today. I read in an article recently which stated, "The use of steroid hormones has also been tried as a way to reduce the severity of Guillain-Barré, but controlled clinical trials have demonstrated that the previously used steroid treatment not only is not effective but may have deleterious effect on the disease." What can I say! In 1975 steroid treatment was all there was – it worked for me.

I had recently returned to England and in Feb. 1975 was nursing at the Cheltenham General. The first sign all was not well came in the dull ache in my lower back, eased only by bending forward from the waist. This struck me suddenly one evening, followed by a sleepless night of which my main recollection is lying in bed and groaning with severe pain and tingling sensations down my body. In the morning a friend took me to the staff sick bay where I was examined by our staff medical doctor, who apart from telling me my symptoms were extremely similar to alcoholic neuritis and querying my recent alcohol intake, had no idea what was wrong with me. Reassured by my protestations that I had just finished a 4 night – 48 hour stint on night duty (and therefore had not been drinking) he admitted me for observation.

Confined to bed I lay there, the tingling in my upper and lower limbs worsened, my back ached constantly and the muscles and major nerve trunks in my body were acutely tender. The date was February 6th – Waitangi Day.

Over the following week I was x-rayed and seen by Mr. Lennox, the hospital's Orthopedic Consultant, several times but he could find no orthopedic reason for my symptoms. Still the limb tingling and pain in my back continued and by now my entire body felt incredibly tender to touch.

Thanks to a conspiracy amongst my nursing friends and other staff, I had been denied access to a mirror, so was oblivious to the facial paralysis which was becoming apparent to others. Lulled into a false sense of security because I could see and therefore knew to move my limbs when required, I was unaware of the extent of the paralysis. In my mind I must have damaged my back in some way, perhaps lifting a heavy patient! The fact I might be seriously ill didn't enter my mind. On the 6th day, fed up with instructions to ring for assistance and ignoring the fact I had been told not to get out of bed by myself, I attempted to do so to get to the loo. I ended up in a useless heap on the floor by the bed. I couldn't feel the floor. I couldn't stand up. The weakness had spread to involve my trunk, all limbs, muscles, tendon reflexes and peripheral sensory system. Unbeknown to me, maximal paralysis was on its way.

On the 13th February I was examined by David Stephens, Consultant Neurologist, who performed a lumbar puncture. I remember commenting to my nursing friends, "Don't know why patients complain about lumbar punctures, they don't hurt a bit"!! Following the lumbar puncture a definite diagnosis was agreed upon. I was suffering from Guillain-Barré Syndrome. I had never heard of this, nor had many of the staff, so I remained oblivious to the seriousness of my situation. I seriously thought the reason for my weakness was because I had been in bed for a week and not eaten much. Ignorance can be bliss!

Alarm bells rang a short time later when I casually mentioned to David Stephens that I felt a tightness across my chest and breathing becoming just a wee bit difficult. Suddenly the room came alive and I was rushed, bed and all, out of the staff sick bay into the nearby Coronary ward and placed in a single room, next to the office. David Stephens and Dr Cranna spoke to me at length about the graveness of my condition and suddenly my world turned upside down. I was 26yrs old, 12000 miles away from my home and family in New Zealand, and for the first time in over a week, I realised I was now in serious trouble.

My daily treatment then began. Twice daily ACTH (Steroid) injections 80 units IM; testing of my reflexes with a little hammer – all tendon reflexes were absent; electromyography sessions (i.e. nerve conduction studies) and twice daily peak flow readings. The latter, the simple act of drawing in air then blowing out as hard as I could into the peak flow machine became the bane of my life as I rarely made an impression with my blowing. This and the fact I could not even wriggle my nose became two things by which I would rate my condition.

A Personnel Encounter from Jacqui continued...

A large frame was placed under the covers at the end of my bed to keep the weight off my legs. For the next seven days I remained in bed, relying on nurses for my every need. I learned patients do not intentionally upend their bedpans in the bed and that there is quite an art to performing on a bedpan while being held upright on either side by nurses. The situation was strange. As long as I could see what I was doing I could hold things. Close my eyes and I could hold nothing. I could feel nothing. I could do nothing.

This daily regime continued into a 2nd week, I appeared to be improving and optimism was high. Then without warning I began to tire easily, my peak flow levels dropped considerably and my condition worsened. A ban on visitors was put in place and I was constantly monitored. Concerns were raised that I might need a tracheotomy and staff in ITU were advised to be ready at short notice. I had suffered a relapse, which is not uncommon with GBS patients, and even though I was unaware of where it might be leading I sensed the deep concern of those around me. It was a frightening time but my nursing friends and doctors did a great job of keeping my spirits up. My symptoms stabilised, peak flow levels settled back to an acceptable level – and although I was now weaker I entered the plateau phase and I was spared a tracheotomy.

The following week I began physio. Progress was initially slow, just being lifted out of bed and placed in a chair was exhausting. Gradually the time I spent in the chair increased although not able to feel my body, the chair or the floor, I flopped like a rag doll. As physio progressed we learned that if a mirror was placed in front of me I could attempt the simplest of movements. I couldn't feel my body or anything I came in contact with but if I could see myself in a mirror, and what I should be doing or touching, I could at least attempt to follow instructions. A simple movement like moving or slightly lifting a limb was hopeless unless I could watch myself in the mirror.

Learning to walk again was a biggie and something one of my closest nursing friends found too difficult to watch. I thought I was doing so well, but she found it distressing to watch me shuffle along, legs rigid, body swaying from side to side, arms out to the side for balance, trying to walk a little further each day. She said I looked awful and it upset her so much she refused to visit me unless I was in bed or sitting in a chair. I stayed in hospital for a further four weeks then moved to convalesce in the home of a radiographer friend, who promised the doctors she would keep a strict eye on my progress.

Looking back I think the most painful time for me was the convalescing and recovery. The horrendous jarring feeling in my body whenever I bumped against something or someone touched me. It was as if all my nerve endings had come together at one time, in one place and decided to activate themselves. It was agony and lasted for several more weeks. Despite this I gradually regained enough strength and mobility to return to light nursing duties. I had been away from my job for over four months.

How, where or why I contracted GBS is still a mystery. I had no flu symptoms or gastro problems. I was working on a surgical ward – nothing was obvious. I do recall a tingling in my hands and fingers during the previous night shift but I have bad blood circulation and my fingers have always tingled and felt numb during cold weather. Certainly there was nothing out of the ordinary to warn me of what was to come.

The twice daily ACTH injections, while helping to reduce the inflammation and problems with my breathing, did have side effects. Apart from acquiring a 'moon' shaped face, my face and chests became covered in spots. The spots did disappear and I was left with facial hair and no eye brows! I complained once to David Stephens about the spots and facial hair, his reply was to remind me that it was a small price to pay for my recovery. That certainly put things back into perspective.

I currently work for Breast Screen Aotearoa, based at the Breast Care Centre, Waikato Hospital and it was while out on one of our mobile units in Morrinsville that I came across a lady who had also been a GBS sufferer. Apart from patients in hospitals I had never come across a fellow GBS/sufferer/survivor before. She put me in touch with the Support Group and through the newsletter I have begun to realise that some of what I call my 'physical nuisances' may well result from my having had GBS.



A Personnel Encounter from Jacqui continued...

From time to time I suffer from sharp pains down both shins; trip for no apparent reason, get cramp in my calf muscles and toes, pins and needles in my fingers, my balance isn't always 100% - at such times I can feel a little spaced out – and I bruise markedly from the slightest touch, especially on my arms and hands. I should be interested to hear from others who might have similar 'nuisances' which they attribute to GBS.

It has been suggested I bruise easily because of the heavy steroid dose I was on, but in reality it's just as likely to be because of thin blood, thin skin and reaching 60 years!

Thirty five years on I acknowledge the wonderful support I received from the hospital team and my friends. Especially since from day one they were literally 'flying by the seat of their pants' in their treatment of my illness. My own GP in New Zealand, when contacted by my parents, was unable to offer them advice regarding GBS, as in 1975 little was known about the condition. A few years ago a colleague and her husband were travelling overseas and not able to access early treatment when he was struck down with GBS. He remained paralysed and dependent on others for the rest of his life. He died last year.

I consider myself very lucky to have been in the right place at the right time.

ADVANCE NOTICE OF THE NZ GBS SUPPORT GROUP BI ANNUAL CONFERENCE

Where: Brentwood Hotel, Kilbirnie, Wellington

When: Friday April 29th 2011 to Sunday 1st May 2011

What's on:

Friday night: Wine and cheese, meet and greet

Saturday: Full day of interesting key note speakers including the opportunity to ask questions.

Saturday Night: Dinner and further chance to chat to fellow members

Sunday Morning: The AGM



Notes from My Diaries further continued....

By Nola

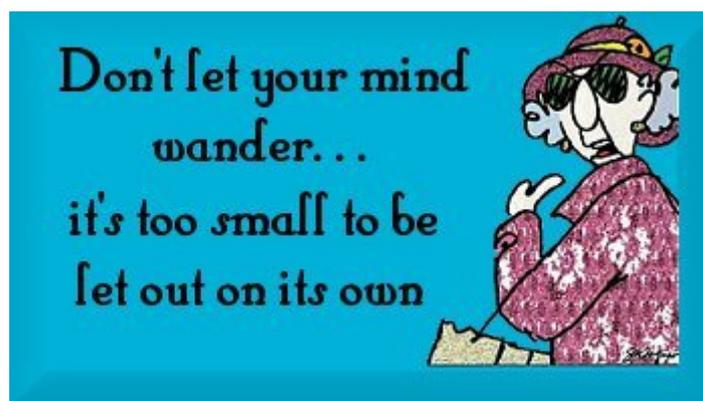
I concluded the above article in the March Newsletter with 6 questions. To the 6th question - *Is it worth watching this space!?* Chris answered with a big YES. So here goes with the more of the Saga.

My GP sent me to a Neurological Specialist in order to go back to the beginning of the CIDP assault in 1991. She gave me a thorough onceover to no avail and asked for my GP to arrange hip and groin x-rays. Meantime, I was forwarded on to have Nerve Conduction Studies done, to no avail. My wonderful GP spotted a note in the Radiologists Report on the x-rays mentioning noticeable heavy calcification in the groin. To a Vascular Surgeon she dispatched me (more specialist dollars) and he ordered an MRI scan (private - more dollars) which identified a blockage in the right femoral artery and another in the iliac artery. A Right Femoral Endarterectomy was suggested first, to be followed by an Iliac Angioplasty with Stent and would I like to wait for 6 months for attention in the public hospital, or 4-6 weeks to have the operation done in private? No choice really! So without any health insurance to my name other than a small, 5-figure dedicated personal medical-needs bank account, enough was scabbled together to hopefully cover the Surgeon's, the Private Hospital's, the Anesthetist's, and the Radiologist's estimates for the operation.

In due course the pesky occlusion (*blockage* to the uneducated) was surgically removed. The dear surgeon thought I might like to keep it, so it was bottled and screw topped and passed into my tender care. The thing was at least 4cm long and a good 1cm in diameter and my youngest grandson is going to be thrilled to see it! And the surgeon said: "No wonder you've had difficulties walking, housework, bending, crouching etc..." and I had an almost instantaneous relief from pain in the groin. And with the Iliac Angioplasty with Stent to follow in about 6 weeks, I look forward to being able to do some abseiling later in my 74th year (no, I'm joking, really.....).

So you see, all the Hospital Neurology Clinic attendances, the physiotherapists, acupuncture treatment (\$), drugs, massage therapy (\$), Osteopathic treatment (\$) Podiatrist (\$), central decompression back operation, negative Scintigraphy (\$), Pain Clinic, Gym membership (\$) using Brufen pain relief to be able to play outdoor bowl (\$), Bowen Therapy (\$), Chiropractic Physio (\$)..... was all just throwing good money after bad. Don't you agree I could've easily funded my recent private appointments and operations with it all?

However, we have not yet finished with this episode. The Right Femoral Endarterectomy site became infected in the private hospital and I landed up in the city public hospital as an emergency admission with a nasty condition called Cellulitis. For 6 days I enjoyed regular 6-8 hourly injections of an antibiotic via an Intravenous Drip. I have recovered to the point where daily legs-up rest at home has been encouraging a recovery from the nasty Cellulitis and my dear GP organised for blood to be taken and last night phoned to say no infection was present in the sample. YEE HA! The husband and I are off to Invercargill next Monday and will then go to Christchurch in order to join a 2-week coach tour going down and up the West Coast of the South Island from Milford Sound to Blenheim. That should well prepare me for all the rigours which may yet be experienced with the much anticipated Iliac Angioplasty with Stent still to come and from which I desire at the very least a little more feeling in the right leg and foot. Oh Please!



An Opportunity to Assist with Research Programs

A new website has been started with the object of recruiting participants for medical research programmes. Excerpts from their press release:

AUCKLAND, (JULY 2010): Six months since it was launched an award-winning New Zealand start-up is already showing it is making a key difference to new health research projects by helping them much more efficiently recruit volunteers, health researchers say. .

“I am really excited by the way the site is already delivering results,” Jamie Mannion, a researcher and co-founder of Getparticipants said. “Having seen for myself just how hard it can be to get volunteers I decided there had to be a better way. Lots of people want to be in studies, but still lots of studies can’t find enough participants. Getparticipants brings the two together online for the first time.”

Current trials range from cholesterol-lowering trials, effects of antidepressants and a dairy and nutrition study

If you are interested in participating contact:

Jamie Mannion

Founder – General Manager

Getparticipants.com

0210629007

Jamie.mannion@getparticipants.com

Something from the Kitchen

CREAMY BROCCOLI MACARONI

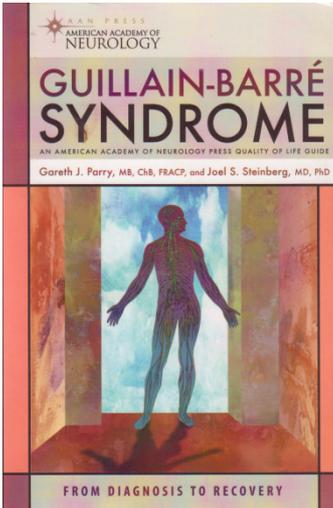
120 gms Blue Vein Cheese Crumbled
120 gms Uncooked Macaroni
200 mls Low Fat Milk
3 tsp Cornflour
1 Chicken Stock Cube
1 Head Broccoli Florets (Blanched 2 Minutes)
1 Onion Diced Finely
1 Red Pepper Seeded & Sliced
1 cup sliced Mushrooms
1/2 tsp Minced Garlic
4 tsp Margarine



Cook macaroni in boiling salted water, drain and set aside. In a large saucepan heat margarine, sauté onion, garlic and red pepper gently. In a small bowl, mix cornflour and milk together, add to onion mixture, crumble stock cube into saucepan, stir until thickened, add cheese, stir until cheese has melted, add broccoli and macaroni and stir to combine. Pour mixture into a sprayed shallow casserole dish and heat in oven for 20 minutes at 180C.



NEW STOCK NOW AVAILABLE



Jenny now has a new stock of Gareth and Joel's book.

Cost \$35

Contact Jenny to get your copy.

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.

Fundraising

Kath and Maurice Vickers sent in a novel way of fundraising. They have done it with some success and our group (GBS NZ) have been the lucky beneficiaries of their endeavours. On behalf of the group I'd like to thank them for their efforts. In these tough times we are very grateful for donations received as they enable the group to continue offering support to new and old sufferers.



They would like to share their idea with us, in the hope that others may pick up on it and raise more funds for the Group.

Here is what they did:

Approached local theatre groups and ask if they would consider accepting an offer of a block booking (a third or half of their capacity) at a discount price on the understanding there would be no returns or refunds and that the tickets would be on sold at a premium with the difference going to a charity organisation.

Maurice says "Probus clubs, gardening clubs, retirement villages etc are good places to on sell tickets. If this exercise is done once or twice a year a substantial base of regular patrons is built up and selling is very much easier."



Ecounselling

Lynda Hannah, MNZAC is offering a counselling service available that caters to the needs of people who for some reason may not be able to access suitable quality counselling in their community. It's called Ecounselling and it works via email.

She has been counselling for 16 years and has considerable experience of working with grief and loss, anxiety and depression, with adults with special needs, and with carers of people with health challenges. There is a list of the benefits of ecounselling here: www.ecounselling.co.nz

Please feel free to email her if you have any questions.

Website: www.ecounselling.co.nz

Email: lynda@ecounselling.co.nz

**Are you a Professional Person who would like to advertise in our Quarterly Magazine for a small donation?
If the answer is YES then contact the Editor or Secretary for further information**

NZORD - the New Zealand Organisation for Rare Disorders

Pass this information on to anyone you know who might meet the criteria for this international study into undiagnosed conditions. The study has undergone IRB (ethics committee) review and approval and is listed at clinicaltrials.gov:

<http://clinicaltrials.gov/ct2/show/NCT00955370?term=undiagnosed&rank=2>

The National Human Genome Research Institute at the National Institutes of Health in the United States is sponsoring a study that seeks to learn more about how parents of children with an undiagnosed medical condition think and feel about their child's condition. We hope that this knowledge will improve the health care and counseling for these parents. Men and women who are 18 years or older and have at least one child with a medical condition that has remained undiagnosed for more than 2 years are needed to take part in this study. Participation involves one survey that takes about 45 minutes to finish. The survey can be taken online or a paper copy can be mailed to you. For additional information about this study, you may review the Notice to Participants <<http://www.surveymonkey.com/StudyNoticeUncertainty>> disclosure.

If you have questions, please contact:

Anne C. Madeo, MS, Principal Investigator Genetic Counselor National Human Research Institute National Institutes of Health Bldg. 31, Room B1B36

31 Center Drive, MSC 2073
Bethesda, MD 20892-2073
Phone: 301-443-2635

Email: anne.madeo@nih.gov

NZORD encourages wide distribution of this information to eligible people.

Notice Board

NZ Facebook Support Group

Lil has set up a support Group on Facebook under the section 'common interest and health and well being'. If you are on Facebook join up and start some discussion going.
Guillain-Barré/CIDP Support Group

The GBS/CIDP Foundation International's magazine is now available online. Anybody who wants access to this magazine can get it online at:
www.gbs-cidp.org

International Conference Philadelphia November 2010

Bob and Margaret are going via San Francisco, Yosemite National Park and Monterey Marine Centre on their way to Philadelphia. They'd love to be in Philadelphia with fellow New Zealanders. It's a great symposium.
Contact them direct if you wish to go. It is a great opportunity to meet fellow sufferers and learn more about GBS from the many renowned medical personnel who will be speaking there (including our own Dr G. Parry).



NEW Membership Category

For "Hospital Groups" - \$50 per annum – formal receipt can be issued if required by "sponsoring" DHB or Association
Contact Tony Pearson for more information

Situation Vacant

We are still looking for a Publicity Officer.
Responsibilities include keeping the support network in the public eye; communicating regularly with departments of neurology in hospitals, liaising with media and generally putting our good news stories out in the public etc.
If you have the experience, the time, the passion and skills for this role, please contact: Bob Stothart
stothart@ihug.co.nz

Coffee Morning for BOP members Or any others wishing to attend

When: Tuesday 21st September
Where: The Manor Café
514 Cambridge Road, Tauriko, Tauranga
Time: 10.30am
Please let Chris know if you can make it (07 5490931)
We have a table booked and the café is looking forward to hosting us. Hope to see you there.

More Personal Stories Wanted For Publication Please. Email or Post to the Editor

