Registered for the Conference yet?
So what are you waiting for?
It’s not too late. Entry form is in this magazine.
Post yours today you won’t be sorry.
Editors Note

The year is flying by. Luckily we haven’t heard of too many new cases of GBS but then a lot go undetected for one reason or another. I would like to see a survey done to see when most cases happen in the various regions around the country. It seems November to January are the most likely months in the Bay of Plenty. Makes you wonder why this would be.

Next month is the Conference. I hope a good number have registered as the Board go to quite a bit of effort to arrange guest speakers, both professional and lay people to educate and entertain us with their connections to GBS. I have included the registration form in the magazine for those who make a last minute decision to attend.

Congratulations must go to Kathy Eggers for her outstanding effort in the Taupo Ironman event. If ever we want a pinup girl for our organisation she should be it. She is an inspiration to us all and a reminder that with a lot of grit and determination anyone of us can achieve our goals.

Our coffee group meetings continue to be a success, so much so that we have progressed from going for a mid morning coffee to having lunch meetings instead. We have all become good friends and it has been great seeing the progress everybody has made over time. Our next meeting will be in May and details are further on in the magazine. Linda Bannister is keen to start a similar event in the Te Awamutu area so if anyone is interested contact Linda at bannister@ihug.co.nz.

Gareth was unable to complete the last article in his series in time for this newsletter so instead he provided an updated article on Miller Fisher. This was very fortuitous as our personal story this edition is from a young lady who has recently had Miller Fisher.

Could some of you please put pen to paper and write a wee piece on your encounter with GBS/ CIDP or any of the variants as I desperately need them for upcoming magazines. Pictures are always appreciated but please don’t resize them if you email them to me.

Thank you everyone who has paid their subs for this year. If you have yet to do so the renewal form is on the last page of the newsletter.

Keep smiling, stay positive and you will beat this syndrome.

Chris

Kathy can still manage a smile
during the grueling Ironman challenge.

An Inspiration to us all.
I became your President in 2006 and as I look back across those years I have to note considerable growth and strength in our organisation. I mention this not to emphasise my role in any of these developments but indicate that change is inevitable and we have changed. Many people have contributed, none more so that Jenny Murray, the absolute stalwart of our organisation. She had the original vision to establish a support organisation and gathered around her people who could help to realise that vision. Others have helped with money management, secretarial duties, local activities, legal things, newsletter production and in contributing to the conferences.

To note some of those items which make our organisation function, is interesting:

- we have a biennial conference which brings us the most up-to-date research and information:
- we have a regular, informative Newsletter:
- we have had a conference in Auckland:
- we have had an AGM in Christchurch (remember the rain?)
- we have a strong system of hospital visiting:
- we have an esteemed Medical Advisory Board:
- we have an energetic Board to provide leadership and direction:
- we have many people throughout the organisation who give their time selflessly for the benefit of others and that is the real strength of the support group.

I have adopted this reflective tone as I intend to step aside from the President’s role at the AGM in April. I will remain on the Board but I do want to thank all the people who engage in hospital visiting, and the members of the Board (over my time) who given me support and who have given time, expertise and energy to the ongoing success of the organisation.

Bob Stothart

A very big thank you to Mavis Gillies who left $5000 to the Support Group in her will. Mavis was a widow with no family. She contracted GBS when she was 75 years old and had supported the group ever since. We truly appreciate this very generous gesture.

Special thanks are extended to Hookers Transport who came to the rescue when Jenny had two large heavy boxes of paperwork to send to Tony in Nelson. On hearing that we were a charity organisation they picked up and delivered the items free of charge.

A nice gesture in these tough economic times.
First and foremost a BIG thank you to everyone who has renewed their membership for the 12/13 year – followed quickly by another BIG – this time an apology for the delay in getting your membership cards to you. Rest assured our trusty Treasurer Peter has banked your funds in the Group’s account but your Secretary can only plead a nonstop 6 weeks of in house overseas guests as his excuse for not dealing with his end of the issue. It’s great having friends from overseas visit but the 24/7 entertainment requirement sure cuts into “office” time! – not quite clear yet but I hope to get everything cleared in the next month – as my Dad (an Engineer by trade) used to say “We are up against the bosses deadline son but with the aid of God and a good Compressor we will get there “ (it was the age when the Hovercraft and Helicopters he was responsible for building were held together with pop rivets which were fitted by tools needing compressed air!!). As an aside we – like most of the country- have been blessed over the last six weeks with fantastic weather – great if you are a tourist - not necessarily if you are a horticulturist or farmer – but our visitors have gone back to a very cold, wet (and often snowing) UK thinking we truly do live in “Godszone”.

To business! – The formal Notice of AGM is printed elsewhere in this Newsletter – if you have paid your sub for this year I will be sending the papers for the meeting to you early next month. If you, or a friend, think you can give something back to the Group don’t be shy in your nominations to the Board – new blood is always welcome! And – you will find – it’s not an onerous role, in fact one that is full of satisfaction and reward knowing you are helping those less fortunate in their current circumstances than yourself.

Conference is just round the corner, we have a goodly number of delegates signed up already but, if you are hesitating, bear in mind this is the ONLY opportunity you have in NZ to get up close and personal to some of the top experts in the country – if not the world - on our “little problem”. If these people can’t help you – or increase your knowledge of GBS – then perhaps no one can. I hope to see you there! I am sure Chris our Editor will ensure Registration Forms and venue details are accessible through the Newsletter information. Us Nelsonian GBS’ers are about to “hang out the flags” as we are shortly to get our own dedicated (lady) Neurologist – after a year’s gap – a gap filled in as he was able by our own Dr Parry. Personally all I wish is that she is more amiable to getting the Group involved in her GBS patient’s post crisis recovery than her predecessor – we are helpful friends – not interfering busybodies!!

Some of you will know about the Ironman NZ (or should it be Iron women) challenge that GBS’er Kathy Eggers has undertaken – gosh that takes guts and a hell of a lot of training – but helps to publicize our cause and increase general knowledge of this “rare thing” we all are so devoted (or locked in) to. For my own part I am in training for the Tongariro Crossing – a much more modest effort – at the end of March. If I make it I look forward to seeing you all again at the Conference and AGM!

As always
Take care

Tony
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. However, there is a risk of aspiration of food or fluids into the lungs when eating and this needs to be closely monitored. 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.

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Sam: My Miller Fisher Experience

We are lucky to receive a personal story from a Miller Fisher Syndrome patient for our newsletter. Her name is Sam, she is 27, and her story comes to us from England. She is currently on no medication but has the common clumsy walk, prickly feelings in her skin, tires easily and has occasional back pain. Onset just a couple of months ago.

Thanks Sam for your story and we wish you well.

Guillain-Barré Miller-Fisher variant - this is difficult to describe but I hope someone else with mild Guillain-Barré/mild Miller-Fisher finds this useful in some way.

25th December - 5th January 2013
Heavy cold, possibly flu, spots on tonsils caused me to go to the doctor 3rd January, was given Amoxycillin.

4th January
Tonsils etc. already clearing but in the evening I noticed I had pins and needles in my feet, and later my hands. I worried this could be an adverse reaction to antibiotics so stopped taking them.

5th January
Pins and needles not gone, so go to walk-in centre as it's a Saturday. They check me over and tell me it doesn't seem to be a reaction to the drugs but to go to the doctor on Monday if it persists.

5th-7th January
Pins and needles spreading up legs and arms and in mouth, tongue and lips.
Sam - My Miller Fisher Experience continued....

7th January
Visit doctor who sends me for blood tests.

8th January
Over the course of the day I start to lose my balance, legs seem wobbly and fingers not doing what they should.

9th January
Blood test results normal so book appointment with doctor for following day.

10th January
Doctor sees me try to walk and after hearing other symptoms sends me straight to A&E. Am examined by neurologist who explains I have suspected Guillain-Barré and admits me in to hospital. Tell me I will need lumbar puncture. By now I can walk but coordination is terrible and I have absolutely no reflexes. Neurology exam shows I haven't actually lost any strength in muscles, only coordination.

10th-16th January
Lumbar puncture reveals slightly elevated protein and white blood cell count. As a side note the lumbar puncture did not hurt in the slightest. Due to the somewhat vague results of the lumbar puncture I am sent for an MRI of the brain and nerve conduction study. MRI is normal and nerve conduction confirms Miller Fisher variant, which is strange as although my mouth is affected, I have no double vision. Reflexes have returned surprisingly. Doctors decide I can go home to recover without treatment. By now my coordination is terrible, I can't hold a knife and fork very easily and drinks tip if I try to hold them. Typing is virtually impossible. Still no actual strength lost but pins and needles moving in to chest which is uncomfortable. No paralysis ever experienced but now walk with a cane.

17th January
Pins and needles in hands and feet has changed to a burning feeling, almost like they are covered in something too hot. I can clench my fists but it feels very strange, like my muscles are resisting. I'm a musician, and it's distressing to find although I can play slowly and badly on the piano, playing the guitar is almost impossible. At this time severe upper back pain has started at night, on the spine between my shoulder blades. I find this eases with strong painkillers and sitting up in bed rather than lying down.

18th - 21st January
Legs feel a little better, strangely although muscles seem in full working order, they all feel intensely stiff, I assume this is just that the nerves aren't telling them what to do properly. Hands especially stiff. Sunday 20th back pain pretty bad.

21st January
Arms starting to hurt, but hands changing from burning feeling to just somewhat numb and stiff.

23rd January
Arms really starting to hurt, especially on the left. Over the course of this my left side is always worse.

24th - 25th January
Arms still painful at night, chest and neck starting to feel much worse with burning feeling similar to hands and feet had been previously. Breathing not restricted, but sensations in ribcage and chest area mean it is worrying and very conscious of all sensations. Legs however seem to be improving; can stand on one leg for a short while, so I believe some places on the body can be getting worse while others are recovering.

26th January
Arm and back pain gone but still sleep very badly, always waking up and body feels like lead weight which makes it hard to get back to sleep.
Sam: My Miller Fisher Experience continued…….

27th January

Burning sensations more or less gone everywhere, legs better still, but arms, chest and neck have intense feeling of stiffness and heaviness, although there is no pain.

28th January

Can play a little more guitar, which is encouraging. Chest and neck badly affected and constantly worrying about heart and lungs although they seem to be working fine. Not sure if this is my mind playing tricks or just because muscles in chest are actually affected.

28th - 12th February

Symptoms seem to be leveling out now, legs getting much better; hands getting more supple while chest and neck stiff and tight. Overall feeling of intense heaviness, especially in limbs and at night. Precautionary MRI of back, doctors tell me I shouldn't exercise too much in case there is a complication in my spine. Walking for about 5 mins gets me incredibly tired and chest feels like it could explode!

12th - 28th February

Mostly same symptoms staying but getting a little better each day, co-ordination coming back, heaviness slowly going, but sometimes intense prickling and what feels like tiny electric shocks especially in hands and feet. I believe this is probably nerve regeneration but hard to tell. Piano and guitar playing getting easier, and finally got MRI of spine back clear yesterday. Of course I am not recovered yet, I get tired easily, my skin all over is still numb/prickly, my muscles are incredibly tight, and I walk stiffly, but can see I will get better.

Overall points

These symptoms are hard to describe, and can be terrifying. If you are going through this, try to keep a positive mindset, we are lucky that we have a possibility of recovery and I felt better when I thought positively. I tried to eat and drink for nerve repair; I took vitamins and cod liver oil alternative days. I ate lots of mackerel and other fish; avocados; nuts and plenty of fruit and vegetables. Although I didn't exercise until my spine MRI came back clear, I kept stretching to keep my muscles as supple as possible, but rested as much as possible. It seems strange to me that I was diagnosed with Miller-Fisher as my weakness was ascending and I had no double-vision, but I realised somewhere in all this that I had far more 'floaters' in my eyes than normal and a slight fuzz to my vision, guess I just got lucky. On the whole, it seems symptoms vary hugely between sufferers, so try not to panic at each different thing, although I did and googled everything almost to obsession. Don't be too concerned with the recommended time to nadir/plateau/recovery timelines as I think progression and recovery could overlap.

All of this is just my experience and I've put it as scientifically as possible, but of course it's completely subjective.

GBS Website news.

Over recent months Ben Chapman (webmaster) has been updating and modernising the website. Currently you are only able to view it in the original format.

Set up is improved, font increased for easy reading, colours have been brightened, and basically all bought up to date and modernised.

More photos will be added once it has all been finalised. Has anyone a got a super photo of a group of people having a very happy time? This is required for the opening page. More info at the Conference!

Lil Morgan
Something from the Kitchen

I wonder how many of you remember having these as kids. My Grandmother used to make these for my brother and I and they were always a favourite. I continued the tradition by making them for my own boys.

They never lasted long.

Golden Honey Bars

Ingredients

- 125 g butter
- 2 tablespoons honey
- 1 cup Sugar
- 2 cups rice bubbles

Method

Spray a sponge roll tin, approximately 20 x 30 cm, with non stick baking spray.

Place butter, honey and sugar in a medium sized saucepan. Stir over medium-high heat until it boils. Turn heat down but maintain the boiling for 5 minutes. Remove from heat and stir in the rice bubbles. Press into the prepared sponge roll tin and leave to set. Mark into squares. When completely cold remove from the tin and cut along the marks. Store in an airtight container.

Preparation time: 4 minutes
Cooking time: 8 minutes

Deaths:

Since the last newsletter we have received word on the passing of some of our members.

Harry Lines passed away in October last year

Mavis Gillies passed away in September last year.

Our deepest sympathy to the families of these members.
We are looking for a name for our magazine.

Have you any novel, exciting ideas?

If so send them in to the Secretary Tony Pearson.

His contact details are on the front page of the magazine.

Bay of Plenty / Waikato Coffee Group.

Venue: Villa Ridge Café – 528 Cambridge Road, Tauriko Tauranga

Date & Time: Friday 24th May 12.30pm
The 11th AGM: 09.30pm Sunday 28th April 2013.
Brentwood Hotel, Kilbirnie, Wellington

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all financial members of the Trust in early April. Everyone is welcome to attend the meeting but only financial members are eligible to speak and vote at the meeting.

Members who are unable to attend the meeting may nominate a Proxy to vote for them, either our President Bob Stothart or another member of their choice.

Nominations for membership of the Trust Board are always welcome and should be lodged with the Secretary as soon as possible but no later than Thursday 25th April. Nominations should be signed by the candidate who will need to be, or become, a member of the Trust and supported by a Proposer and Seconder who must also be members, together with a brief C.V. of the candidate. If no nominations are received prior to the meeting the Board may accept oral nominations at the meeting.

If you have any questions about the forthcoming AGM please direct them to:
The Secretary: Tony Pearson on 03 526 6076 or tonypearson@xtra.co.nz

Hospital Visitors

"Are you interested in providing support as hospital visitor? We will be running a training session at the GBS Conference in April in Wellington and will be accepting applications.

For more information please
Email: Don on don_martin@xtra.co.nz
or Phone: Don on 021 060 5892
or Ken Daniels on 021 621 411

Conference Guest: - Shannon Tisbury

The generosity of Nelson GBS’er Murray has facilitated sponsorship of a member of the Nelson Marlborough DHB to attend the Conference. Shannon will join us for the Wine and Cheese on Friday evening and attend the conference sessions on Saturday. I asked Shannon to do a brief summary of her medical experience and she writes:

I am a NZ trained physiotherapist who has worked in Neuro rehabilitation both here and overseas over the past 18 years. I returned to NZ after 13 years abroad and initially based myself in Christchurch working at the Burwood Spinal Unit. After the earthquakes I decided to follow the sun and moved to Nelson to be closer to family. I have a split job with hospital outpatients and community based work with ACC. I have worked with persons with Guillain Barré in the acute setting through into their rehabilitation into the community. I recognise the importance of the whole team in working with these clients to help them achieve their goals and maximise their recovery. I am incredibly grateful for the generosity of the Guillain-Barré Support Group in giving me this opportunity to attend this year’s conference. I am looking forward to meeting other clinicians and those persons who have experienced first hand the effects of Guillain-Barré.

I am sure you will all make her welcome and take the opportunity to quiz her about any aspects of physio care that you may wish to know more about.
Guillain-Barre Syndrome Support Group of New Zealand

CONFERENCE PROGRAMME
April 26 – 28, 2013
Brentwood Hotel, Kilbirnie, Wellington

FRIDAY 26 April
2-00pm  Training for Hospital Visitors and Local Coordinators
4-00pm  Registration
5-30pm  Wine, Cheese and Chat with conference members
(Own arrangements for dinner)

SATURDAY 27 April
7.30am  Meeting of the Medical Advisory Board
8-30am  Official Welcome and Conference Opening by Steve Chadwick, Patron,
8.45am  Presidential welcome to the Members of the Medical Advisory Board.
9-00am  Keynote Address:  Gareth Parry: GBS Overview
9-45am  Morning Tea
10-15am  A personal encounter: Lil Morgan
10-30am  Comment by Gareth and discussion amongst the group.
10-45am  Keynote Address: Dr Suzie Mudge, Auckland: Rehabilitation
11.15am  A personal encounter with CIDP: Kathy Eggers
11.30am  Comment by Gareth and discussion amongst the group.
11.45am  Small group discussions
12-45pm  LUNCH
1-45pm  Keynote Address Michael Baker, Otago University, Wellington Campus:
Campylobactor jejuni and its relationship to GBS in New Zealand
2-30pm  A Personal Encounter on GBS outcome after C.jejuni: Peter Scott
2-45pm  A personal encounter with pain and fatigue: Dr Pralene Maharaj, Auckland
3-00pm  Afternoon Tea
3-15pm  Keynote: Pain: Dr Dean Kilfoyle, Auckland
3-45pm  Keynote: Fatigue: Dr Chris Lynch, Waikato
4-15pm  Ask The Experts: Medical Advisory Board
7-00pm  Conference Dinner (optional)

SUNDAY 28 April
8-30am  Meeting of the Trust
9-30am  AGM of the New Zealand Support Group

Organised by the Guillain-Barré Syndrome Support Group of New Zealand Trust
Enquiries to Bob Stothart  stothart@ihug.co.nz
Registered Charity No CC20639
www.gbsnz.org.nz
REGISTRATION FORM

Guillain-Barré CIDP Conference
Friday 26th April – Sunday 28 April 2013

Name…………………………………………
Address…………………………………………
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Phone……………..
Email………………………….

Please enclose registration fee with this form and post to: Tony Pearson, Skylark Ridge,
113 Weka Road, Mairiri, RD2, Upper Moutere, Nelson, 7175

$100.00 full registration……………………………………
$80.00 for Saturday only……………………………………
$50.00 for second person in a family………………………
$30.00 for full-time students………………………………
$40.00 for conference dinner, this is optional…………..

TOTAL $……………………………………………………

A $20.00 late fee will be required for registration after 12 April 2013

Make cheques payable to Guillain-Barré Syndrome Support Group and cross, Not Transferable

Reserve your own accommodation, quote reference73929 and mention GBS Conference to get special rates at the Brentwood Hotel.
(Phone: 04 920 0400). Please specify any disability requirements.
Subscriptions for membership of the Group for the financial year commencing on 1st December 2012 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
Be sure to reference your name on the transfer

You can also now receive the Group’s Newsletter by e mail (thus helping us with the cost of stationery and postage) if you would like to take up this option and have not already notified our Editor Chris Hewlett please e mail her at (chrispy57@gmail.com) or add your e mail details below and we will arrange for this to happen.

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

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Thank you on behalf of the Board of Trustees.