Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

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NEWSLETTER JUNE 2010

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Editors Note

The formalities at the AGM saw all incumbrants re-elected so here I am again trying to put together some interesting reading for you all. My thanks to all who have sent in contributions for the magazine this make the job so much easier for me.

There have been several new cases of GBS since our last newsletter. The Auckland area being the worst affected. I hope the individuals struck down are making good progress on the long road to recovery. To those newly diagnosed, if you would like to be visited by a GBS/CIDP person please contact Jenny Murray and she will put you in touch with someone in your area.

Lil, our web minder has set up a Facebook account for GBS/CIDP so join up and let's try and get some meaningful discussion going. It will also give you the chance to get to know fellow members who you could then meet face to face at the Conference next May. Don't forget you also have the Support Group Web site to visit as well.

With winter on the way and the threats of this flu and that flu, vaccinate or not vaccinate I have reprinted an article from the NZ Neurological magazine on the "GBS – the unlikely consequence of Swine Flu Vaccination".

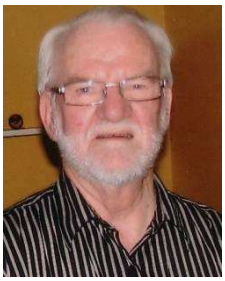
And from Dr. Gareth Parry:

As always, the advice is that the risks must be weighed against the benefits. It is always hard to predict what each seasons 'flu will be like, but I would definitely recommend that a patient who has had GBS should go ahead and get vaccinated. It is a little more difficult with CIDP but even there I am recommending that they get the vaccine unless there is a clear history of worsening with vaccines in the past.

So there you have it, your winter worries solved it's time to sit back, feet up, cuppa in hand and enjoy this edition of your magazine.

Chris

Presidents Paragraph:



The Annual General Meeting was held recently in the Psychology Department of Massey University of Manawatu. I mention that fact to remind everyone that our national support group has a core of people who contribute their time and energy for the benefit of others. We are well served in this regard and John Podd, who works in the Psychology Department, made his time, and work spaces available for our meeting and he looked after the catering. Others contributed in various ways and the meeting was successful.

In particular, we had a chance to view two DVD's (one on GBS and one on CIDP) which have been made and should be available soon, to members. We were fortunate to be able to use excellent material from the International GBS/CIDP Foundation and add our own introduction and ending to make it relevant to New Zealand. We'll let you know as soon as they become available for distribution.

I want also to acknowledge (I have done this in my annual report) the contributions during the past year of Professor Gareth Parry for wise and informed advice, Jenny Murray for tact, discretion and endless assistance, Tony Pearson for immaculate secretarial services, Peter Scott for minding the money, Julie Rivett for looking after the South Island, Don Martin for his enthusiasm, John Davies for his Auckland presence, Chris Hewlett for editing the Newsletter, Lil Morgan for minding the web site and everyone who helps without being asked.

The next big event is the national conference (the only one in New Zealand to focus on GBS/CIDP) being held in Wellington, 30 April to 2 May, 2011. Don't miss it.

And a reminder that Margaret and I will be attending the GBS/CIDP Foundation International Conference in Philadelphia this November and we'd love to have a strong New Zealand presence there. Get in touch if you intend to attend.

Bob Stothart

Secretary's Jottings

G'day – as they say in this part of the world!
I'm writing this whilst on holiday in South Western Australia so I am sure you will forgive me if any local "flavour" creeps in. We have had a great tour starting with a few days in Perth and then south to the Margaret River area and now a few days in Albany on the south coast before heading back north for the flight home. A "near miss" with a kangaroo that decided to cross the highway in broad daylight and walking through the giant Tingle trees – at treetop level – have added to our Aussie experience…. But back to the office!!
The A.G.M. at the beginning of May went smoothly (from a Secretary's perspective) with some 20 members making the effort to attend in person and nearly 50 lodging their proxy votes with the President. The Board was re-elected, with the exception of Dr Forbes Bennett who has resigned due to the pressure of his professional commitments. I understand, via e mail, that Bob has approached a suitable replacement who has enthusiastically accepted the request to join the Board of Trustees.
Bob's Annual Report gave details of another successful year for the Group with a continuing strong membership base and increasing "awareness" activities – although a volunteer for the post of Publicity Officer would be a wonderful asset for the Group in this arena. Under Gareth's guidance the formation of the Medical Advisory Panel is in hand and plans for the 2011 Conference in Wellington were outlined.
Our Treasurer Peter Scott once again produced a solid set of Accounts, supported by an unqualified Auditor's Report. The Group remains financial secure in spite of considerable "self funding" of the 2009 Conference. If you would like a copy of the Accounts please contact me and I will arrange to send you a set.
Membership subs will remain at present levels with a new "Medical Group" membership category being introduced at $50 per annum to accommodate requests from Hospital Nurses and other medical professional groups in hospitals around the country to learn about our organization's activities and information dissemination.
The AGM concluded with the Premier of the Group's new DVDs on GBS and CIDP – published with the generous consent of our USA counterparts but "Kiwi-ised" by John Podd and his team at Massey University. Thank you John for a job well done – and also thanks for your efforts in organising the venue and refreshments for the AGM. Multiple copies of the DVD's will now be produced and become part of our freely available literature for distribution to GBS patients and their supporters.
I have asked our Editor to publish (if she has room in this issue) the brief summary of the membership survey that I presented at the AGM. I will make a more detailed analysis of the results in due course but this report will highlight some of the more significant issues that came out of the survey. Very many thanks to all of you that took the time to complete the survey form.
At the suggestion of a couple of Life members I will no longer send out annual renewal membership cards to such members. Should you lose your membership card let me know and I will send a replacement.
One of the pleasures of a holiday for me is the ability to catch up on my backlog of reading. I particularly enjoy reading the Listener but am usually several issues in arrears so I was interested to read an article published earlier this year which bemoaned the cost inefficiency of New Zealand's plethora of 21 District Health Boards. Rationalisation would, of course, be nigh impossible given the parochial diversity of the regions concerned! But I had to smile when the author – one Bill Ralston –concluded his article by noting that in another arena – namely Super 14 Rugby – with differences every bit as passionate – it had been possible to rationalise New Zealand into 5 area teams very successfully! Food for thought for our Health Minister Tony Ryall perhaps!!
As most of you know Vivienne and I enjoy our walking and whilst in Aussie we made a number of excursions up their local "mountains" – at least that's what they call them – but as most are well under a 1000 metres they would probably only rate as "hills" in N.Z. That got me thinking (over a glass of excellent Margaret River wine) about our own GBS hills and mountains. When I read some of the stories published in the Newsletter and on the Website I am humbled to realize just how my own CIDP hill – scary though it was at the time – pales into insignificance at the GBS mountains that some of you have climbed, and indeed, in some cases, are still climbing!
I think it is important that as a Group we keep focused on these mountain climbs so keep your stories (and relevant updates) coming in to Chris and Lil. You MAY think that no one else is interested in hearing about your trials/tribulations/progress and conquests as you coped with this rare condition but you would be wrong. It may just be that someone recently struck down by GBS will gain hope, inspiration and valuable experienced based advice by reading your story
Well I suppose I'd better HOP off this computer and go and put the BILLIE on for TEA and DAMPER for "she who will obeyed" ! – we shall look forward to being back in NZ soon.

As always take care
Tony

A Personnel Encounter ..... by Fay

My GBS is directly attributable to the flu injection. This is how mine started: bad bout of flu -recovered -flu injection - bad 2nd bout of flu - THEN CAME THE MONSTER G.B.S.

Late May, 2006. My eldest son and I always walked over 4 kilometers 5 days a week - along the metal road - no effort - loved it. Suddenly my right knee gave way and I nearly fell over. I get arthritis, so I blamed it on that. This happened again and again, - and I cannot remember which happened first, my feet started to go a little numb. I kept the walking going. Did my garden Sunday, mid June, agonising back pain Monday - blamed it on the gardening of course! Chronic, agonising back pain -- I could actually feel my right shoulder blade melting and I could feel the hot liquid going down my back. It was ghastly, no sleep - the slightest movement in bed was agony, and if my husband even took a deep breath I squawked in agony. My son took me to the Dr. - had my back x-rayed - my back is in very good condition for my age - nothing wrong -I KNEW something was wrong, I also had no reflexes. 2 days later back to the Dr. with my husband, absolutely no reflexes - in utter agony, - off to hospital. She thought I may have ME. Unfortunately I struck the week-long doctors strike, so I lay there, getting more and more agony, my feet felt like concrete blocks [big ones] the pain was truly unbearable, I had dark thoughts, whilst at the same time hoping I would survive what-ever I had. I had to go to the loo of course, I used to struggle out of bed [I was fast losing the ability to walk] lurch from bed end to bed end, out the door, down the wall holding on to anything I could find, couldn't lock the door, was walked in on [too sick to care anymore] by a young man, then back to bed. A nurse actually yelled nastily at me **WE TRY HERE!!!!** I kept going but said to her - I'm trying, don't worry about that - I got an apology for that from the Charge nurse, who actually heard it. She was a nurse that came in when they were short staffed, not actual Hospital staff.
By this time, I had NO CONTROL over any of my body, i.e. hands arms, legs, feet, fell over several times - hurt like mad sitting on the loo - my whole body felt as though I had been badly beaten up. I found out later they were about to send me home!! Then it happened, I collapsed trying to get to the loo. I had had many falls - but this was only my second SPLAT - like I was a wooden puppet on a string and someone let the string go, landed like a starfish. Had to get winched back to bed - too sick to care!! Finally some attention - a wonderful Neurologist came. I couldn't lift either foot even 1 millimeter off the sheet, almost paralyzed. He tested me thoroughly, this is weird, I could feel nothing except hideous pain and numbness [not good numbness - agonising numbness] he pushed a metal rod up my feet - I felt nothing, BUT it tickled and I did a tiny laugh - I haven't figured that out yet - I am terribly ticklish!! Sheets and blankets on my feet were pure torture - so of course the heating was broken down in the acute ward!! I also got pins and needles - all over - real hard pins about 3 inches long, everything I tried to touch hurt badly. I was in almost unbearable agony - all over. My face was so terribly painful - still is when I am tired at night - my eyes couldn't look sideways for nearly 3 years, I would attempt to look sideways, yelp [very quietly] with pain and my eyes would bounce back to looking ahead - I had no control over it, so [of course] I wasn't pleased at all about that - so I made sure I fully faced whoever I was talking too!!

I was in hospital one month.

I once asked if someone could PLEASE cut my toenails and fingernails - they're not allowed to. From the very beginning until a couple of months ago I felt as though someone was trying to pull my nails out - keeping them very short helped. My big toes still hurt like mad; they felt like metal torpedoes sticking straight out in front of my feet, but improving at long last.

Things I couldn't do: Walk, no muscles - no balance. Get my meal up to my mouth without my hand turning the spoon sideways and losing my food back onto my plate. I did manage - but I was always watched - offered help - but I am a determined person!!
Look sideways - or back.
Look sideways, up or down whilst walking.
Turn around
Go around corners without my arms way out - I still have to do that.
Sleep on either side for well over a year, my face was too sore and my ribs felt as though they were poking into something very raw and very sore.

10 mins. to get knickers and nightgown off for shower, 10 mins. to get them on again - IT WAS TERRIBLE.

The Neurologist ordered me to have 3 bottles of gamma globulin a night for 3 nights. $1,000 a bottle. - WOW - WONDERFUL - the first night my back pain disappeared - that was fantastic. Nothing else, but I was thrilled. I was put on hourly watch, as I was very close to getting a lot worse apparently. Luckily there was no intensive care for me.
Also the drip didn't hurt as much as in the old days.
I had a lumbar puncture, not as bad as they sound -- 3 or 4 or 5 young students tried for at least half an hour and got nothing [fluid from my spine] - so a doctor came the next day and did it - without pain - in about 2 minutes -- where was he the day before???? I had the electric shock treatment, unpleasant - and much to my surprise I survived it!!

I was visited by 6 or 7 students who, asked questions and generally looked me over for clues as to what I had. Only one tentatively suggested it could be Guillain-Barré Syndrome - but one of the students was the doctor who was on my ward, he must have looked it all up and I am sure he gave up his lunch hour the next day and sat and kindly told me EVERYTHING about GBS. I will forever be grateful for that. I had never heard of it - neither had anyone else it seems!! Nothing got better - other than my back pain - BUT nothing got worse. It stopped attacking me. After 2 weeks in acute I was taken to Rehabilitation - for another 2 weeks. When they told me they were going to teach me how to walk etc. I said 'okay' and smiled, but I was thinking I KNOW HOW TO WALK -then I tried!! Even standing up for the first time was almost impossible and terrifying. When they put me on a bed in Rehab I put my face into the side of my brown bag with my pathetic belongings in it and I cried, long and quietly, I have very long hair so my face was nicely hidden. Everyone was marvelous, they left me alone, when I was finished the lady in the next bed introduced herself and we spoke for about a minute. From then on we were all firm friends. I only cried once, though I have wanted to lately. I had a walker, lots of walking lessons, then a walking stick for months. I could only wear slippers for months. I now use a shepherds crook if I'm going to walk down the back of our 2½ acres and back. I made it to the far side border fence about 3 months ago - felt like a proper person again - marvelous.

My pins and needles just vanished overnight after about 8 months - that was wonderful - my chronic fatigue suddenly disappeared about 3 weeks ago, overnight again - that is a terrible thing to get. Though I am still very tired - it is nothing like the chronic fatigue malady.
I can now - for about 10 or 12 months - balance nicely around the house - inside only - but I can't do the looking up, down, back, around, or hurry around corners yet. Outside I look slightly drunk!! I have had unwanted and unappreciated remarks, but I know I look as though I've been drinking. I never drink, [weddings etc. yes - a little] otherwise no. I'm alive and getting better VERY VERY SLOWLY - our house is untidy - I'm too tired - used to be very very tidy I forgot to mention, Cicada insects have been singing in my ears for almost 3½ years, and I itch something terrible, and when I scratch the itch it hurts like mad. Luckily I have a very-much-alive sense of humour. It left me once though when a man in town asked me if I have invented a new way of walking!! I have to keep my arms out on both sides, about 8 inches to a foot, and right out when I go up and down the kerb. But I try very hard not to attract attention.
One more thing, my right leg suddenly [now and again] swings across in front of my left leg, always of course in town!! Now that is embarrassing!! I couldn't drive for well over a year, and still hardly ever do. I've been driving since I was 19, and I intend to get back to it.

I have had 12 hours at night in bed for 3½ years, I sit up with 4 pillows and read; I can now stay up until 8.15 or so, get up about 7 am. I only go to town for a meeting and the supermarket once a week. About 10 other outings - my life almost stopped.

My body is repairing/replacing all my myelin sheath; I got it severely, so it is a long job. GBS mainly attacks a healthy person, and that is a good thought if you are down.
I hope for a full recovery!! I am trying!! I will do it!!

p.s. My back has never been the same; it hurts a little, quite often. I put on 12 kilos, [this really makes me annoyed] - but I will lose it. I tried not to, but the lack of movement has obviously caused that. I've been on painkillers for 3½years. YIKES!!

Painful feet, multiple stabbing pains in my feet and heels and toes -- EVERY NIGHT. No warning pain, I nearly jump out of bed with fright and pain. They are ghastly. It's like getting shot or a multiple injection episode, and it goes on and on. Always waits until I'm almost asleep - or actually asleepand that frightens me terribly. I have this caterpillar [like the back melting] that is huge and fury and has injection needles for feet, he walks along my toes every now and again, it hurts terribly - and it is CREEPY. I want to cry with exhaustion and hopelessness - but I don't, and after about 20 minutes it goes away and lets me sleep. I hope it goes away. Our youngest son came up one day about a month ago and took me to town for the day, I got terrifically tired BUT I had a wonderful time, felt real again, felt wonderful. My 2 sons and husband have really tried to help me.

Good luck to everyone who read this and is suffering. After about 2 years ago I found 2 kiwi fruit a day has noticeably helped so I suggest you look for foods that may give you a little energy

Cognitive Testing

Anne Molloy an Occupational Therapist in Private Practice for over 20 yrs advises that there is a new cognitive test available to assist members, and their GPs' in deciding whether or not the person is safe to drive.

The test is an objective science based touch screen test and takes between 30- 60 mins.
No previous computer experience is required.

This test is being adopted in British Columbia as their measure of driving competency. It is also being used in USA Canada (where it was developed by Dr Al Dobbs) Australia and now I am providing it in NZ.

Many medical conditions and the medications can alter cognition, so it may be necessary to test this aspect prior to driving a vehicle.

You may have members who would like to go for a driving licence but have no objective measure to help decide whether this is possible or advisable.

For more information they can visit my website www.aucklanddrivingassessments.com

Anne Molloy NZROT
Occupational Therapy Consultancy
DriveABLE NZAuckland

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GBS SUPPORT GROUP OF NEW ZEALAND
SUMMARY OF THE RESULTS OF THE INFORMAL SURVEY OF THE GBS EXPERIENCES OF THE NEWSLETTER READERSHIP

GENERAL

Over one third of the personal readership responded – 92 surveys in all – an excellent response.
The responses were almost exactly 50/50 male/female and there was no real variation in the ages when each sex was "hit" by GBS with 40% contracting it between the ages of 46 and 60 and another 30% between 61 and 75
GBS accounted for 80% of the diagnosis, CIDP for 13% and Miller Fisher 7% - I will check but I think this pretty much reflects the "world" average!!
22 of the respondents believed GBS was triggered by an infection of one sort or another – another 18 were sure Campylobacter was the culprit whilst a further 8 put the blame on a vaccination. Only 3 or 4 thought, like me, that Stress was the cause.
55% of respondents were diagnosed within a week of becoming "concerned" with their condition – the other 45% with a delayed diagnosis, not surprisingly, included all those like myself subsequently diagnosed with CIDP.
73% of us were satisfied with the explanation provided by our medical professional once our condition had been diagnosed.
And where did we go to find out more about this thing called GBS ? – Well 40% went to Jenny, or other personal contacts. 35% accessed the internet – either our site or other international sites - with books or the Library accounting for a further15%.

TREATMENT

95% of respondents ended up in Hospital with 40% of these in ICU and 30% being ventilated as well so a fair percentage of "serious" cases.
Plasma Exchange or IVig (usually with or followed by Steroids) accounted for 82% of the treatment regimes. Special or experimental drugs dealt to another 6% whilst a surprising (at least to me) 12% got no treatment at all being told to "let nature take its course". But no treatment DID NOT mean a slower recovery and this group recovered in the same 6 to 24 months like the bulk of the rest of the respondents.
Pain was the predominate experience whilst incapacitated, with 80% of respondents suffering from it and obviously severe levels in some cases. 40% of respondents reported suffering from hallucinations and 50% from constipation of urinary issues whilst bedridden.
Sadly only 20% were visited by a representative of the Group whilst in Hospital and whilst some cases clearly occurred before the Group became active in this respect we can and must "Try Harder".
And what did we think of the performance of our medical professionals during our "encounter"???
60% of us were happy with our GP's performance – although another 30% clearly were not!
75% of us thought we had good service from our Consultant although again 15% were particularly unhappy.
But.. 80% of us felt the nursing staff had done a good job. Of the 20% that registered an "unhappy" vote there was a common thread that, in most cases, this was because the nurses did not have an understanding of the particular issues that a GBS patient has which need attending to in a particular way. This is clearly something we ought to be able to improve by the provision of further information and education to nursing staff at the "coal face".

RECOVERY AND REHABILITATION

Whilst 30% of respondents felt that the rehabilitation help they received was only average or worse the remaining 70% rated it "Good or Excellent"
60% of respondents felt that they had "recovered" within 6 to 24 months of their encounter with GBS with the remaining 40% feeling recovery was still "in progress". BUT, most importantly, only 15% felt that they had achieved 95% or above of their pre GBS physical fitness levels. Some respondents were clearly well below pre GBS levels and some never expected to improve any further. Clearly advancing age in some cases is a factor but the large percentage of cases that fail to get back to near normal is a concern – I will do more research into the levels of response.

RESIDUALS

The questionnaire asked respondents to report if they "have or had" any of the listed residuals so the results DO NOT imply all respondents CONTINUALLY have any of the conditions reported – merely that post "recovery" they experienced some of them for varying degrees of time.

80% of us reported experiencing Pins and Needles / Tingling and/or numbness in hands, feet and limbs with 60% reporting footdrop or unsteady walking (I trip a lot when tired!!)

Muscle weakness in arms, legs and hands affects or has affected 70% of GBS'ers and a staggering 90% reported loss of Stamina or Fatigue. This is clearly a BIG ongoing issue for lots of us and one that has already been identified by Gareth Parry in his research although resolution remains elusive.

On-going or sporadic pain is still an issue for 40% of respondents and a similar number reported difficulty in getting to (or staying) asleep – often citing cramps or restless legs as the cause.

CONCLUSION

Although the majority of us were diagnosed promptly, treated efficiently and were back on our feet again within a year or so it is pretty clear from the results of this informal membership survey that whilst GBS may not kill us it sure as hell sets us back physically and emotionally, reduces our quality of life and, more often than not, leaves us with a legacy of reduced physical capacity compared to our pre GBS days.

Thank you everyone that took the trouble of completing the survey. I will report the findings more fully in a future Newsletter – together with some thoughts that have arisen as a result of processing the numbers and which could make an interesting specific future survey – perhaps to be held as part of the next Conference.

Tony Pearson
28th April 2010.

ADVANCE NOTICE OF THE NZ GBS SUPPORT GROUP BI ANNUAL CONFERENCE

Where: Brentwood Hotel, Kilbirnie, Wellington

When: Friday April 30th 2011 to Sunday2 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

Guillain – Barré Syndrome an unlikely consequence of swine flu

Taken from the Headlines the National Newsletter of the Neurological Foundation of NZ with special thanks to the American Academy of Neurology.

The Centers for Disease Control and Prevention (CDC) and the American Academy of Neurology (AAN) are requesting neurologists to report any possible new cases of Guillain-Barré syndrome (GBS) following 2009 H1N1 flu vaccination. It is not anticipated that the 2009 H1N1 vaccine will have an increased risk of GBS. However, out of an abundance of caution and given that GBS may be of greater concern with any pandemic vaccine because of the association of GBS with the 1976 swine flu vaccine, the CDC and AAN are asking neurologists to report any potential new cases of GBS after-vaccination as part of the CDC's national vaccine safety monitoring campaign.

GBS is a disorder in which the body's immune system attacks part of the peripheral nervous system. Some detail of its identification by French doctors was published in Volume 84 of *Headlines*. Georges Charles Guillain was a prominent French neurologist. With his war-time colleague and friend Jean Barré, he published a large work on clinical experiences during the war in 1920.
The first symptoms of this disorder include varying degrees of weakness or tingling sensations in the legs. In many instances the weakness and abnormal sensations spread to the arms and upper body. These symptoms can increase in intensity until certain muscles cannot be used at all and, when severe, the patient is almost totally paralysed. In these cases the disorder is life threatening - potentially interfering with breathing and, at times, with blood pressure or heart rate - and is considered a medical emergency. Such a patient is often put on a respirator to assist with breathing and is watched closely for problems such as an abnormal heart beat, infections, blood clots and high or low blood pressure. Most patients, however, recover from even the most severe cases of Guillain-Barré syndrome, although some continue to have a certain degree of weakness. Guillain-Barré syndrome can affect anybody. It can strike at any age and both sexes are almost equally prone to the disorder (men slightly more than women). The syndrome is rare, however, afflicting a little more than one person in 100,000; about 40 people each year. Usually GBS occurs a few days or weeks after the patient has had symptoms of a respiratory or gastrointestinal viral infection. Occasionally surgery or vaccinations will trigger the syndrome.

After the first clinical manifestations of the disease, the symptoms can progress over the course of hours, days, or weeks. Most people reach the stage of greatest weakness within the first two weeks after symptoms appear and by the third week of the illness 90% of all patients are at their weakest.

Cause of Guillain-Barré Syndrome

Why GBS strikes some people and not others is not known. A common trigger, campylobacter jejuni, affects about 15 people per 100,000 each year yet GBS results in only a small proportion of those affected.

What scientists do know is that the body's immune system begins to attack the body itself, causing what is known as an autoimmune disease. Usually the cells of the immune system attack only foreign material and invading organisms. In the most common form of GBS affecting New Zealanders, Acute Inflammatory Demyelinating Polyradiculoneuropathy, the immune system starts to destroy the myelin sheath that surrounds the axons of many peripheral nerves, or even the axons themselves (axons are long, thin extensions of the nerve cells; they carry nerve signals). The myelin sheath surrounding the axon speeds up the transmission of nerve signals and allows the transmission of signals over long distances.
In diseases in which the peripheral nerves' myelin sheaths are injured or degraded, the nerves cannot transmit signals efficiently. That is why the muscles begin to lose their ability to respond to the brain's commands, commands that must be carried through the nerve network. The brain also receives fewer sensory signals from the rest of the body, resulting in an inability to feel textures, heat, pain, and other sensations. Alternately, the brain may receive inappropriate signals that result in tingling, "crawling-skin" or painful sensations. Because the signals to and from the arms and legs must travel the longest distances they are most vulnerable to interruption. Therefore, muscle weakness and tingling sensations usually first appear in the hands and feet and progress upwards.

When GBS is preceded by a viral or bacterial infection, it is possible that the virus has changed the nature of cells in the nervous system so that the immune system treats them as foreign cells. It is also possible that the virus makes the immune system itself less discriminating about what cells it recognises as its own, allowing some of the immune cells, such as certain kinds of lymphocytes and macrophages, to attack the myelin.

Sensitised T lymphocytes cooperate with B lymphocytes to produce antibodies against components of the myelin sheath and may contribute to destruction of the myelin. Scientists are investigating these and other possibilities to find why the immune system goes awry in GBS and other autoimmune diseases. The cause and course of this disorder is an active area of neurological investigation, incorporating the cooperative efforts of neurological scientists, immunologists and virologists.

Diagnosis

GBS is called a syndrome rather than a disease because it is not clear that a specific disease-causing agent is involved. A syndrome is a medical condition characterised by a collection of symptoms (what the patient feels) and signs **(**what a doctor can observe or measure). The signs and symptoms of the syndrome can be quite varied, so doctors may, on rare occasions, find it difficult to diagnose GBS in its earliest stages.

Several disorders have symptoms similar to those found in GBS, so doctors examine and question patients carefully before making a diagnosis. Collectively, the signs and symptoms form a certain pattern that helps doctors differentiate Guillain-Barré from other disorders. For example, physicians will note whether the symptoms appear on both sides of the body (most common in GBS) and the quickness with which the symptoms appear (in other disorders, muscle weakness may progress over months rather than days or weeks). In GBS, reflexes such as knee jerks are usually lost. Because the signals travelling along the nerve are slower, a nerve conduction velocity (NCV) test can give a doctor clues to aid the diagnosis. In GBS patients, the cerebrospinal fluid that bathes the spinal cord and brain contains more protein than usual. Therefore a physician may decide to perform a spinal tap, a procedure in which the doctor inserts a needle into the patient's lower back to draw cerebrospinal fluid from the spinal column.

Treatment

There is no known cure for GBS. However, there are therapies that lessen the severity of the illness and accelerate the recovery in most patients. There are also several ways to treat the complications of the disease.

Currently, plasma exchange (sometimes called plasmapheresis) and high-dose immunoglobulin therapy are used. Both of them are equally effective, but immunoglobulin is easier to administer. Plasma exchange is a method by which whole blood is removed from the body and processed so that the red and white blood cells are separated from the plasma, or liquid portion of the blood. The blood cells are then returned to the patient without the plasma, which the body quickly replaces. Scientists still don't know exactly why plasma exchange works but the technique seems to reduce the severity and duration of the GBS episode. This may be because the plasma portion of the blood contains elements of the immune system that may be toxic to the myelin.

In high-dose immunoglobulin therapy doctors give intravenous injections of the proteins that, in small quantities, the immune system uses naturally to attack invading organisms. Investigators have found that giving high doses of these immunoglobulins, derived from a pool of thousands of normal donors, to GBS patients can lessen the immune attack on the nervous system. Investigators don't know why or how this works, although several hypotheses have been proposed.

The use of steroid hormones has also been tried as a way to reduce the severity of GBS but controlled clinical trials have demonstrated that this treatment not only is not effective but may even have a deleterious effect on the disease.

The most critical part of the treatment for this syndrome consists of keeping the patient's body functioning during recovery of the nervous system. This can sometimes require placing the patient on a respirator, a heart monitor, or other machines that assist body function. The need for this sophisticated machinery is one reason why GBS patients are usually treated in hospitals, often in an intensive care ward. In the hospital, doctors can also look for and treat the many problems that can afflict any paralysed patient - complications such as pneumonia or bed sores.

Often, even before recovery begins, caregivers may be instructed to manually move the patient's limbs to help keep the muscles flexible and strong. Later, as the patient begins to recover limb control, physical therapy begins. Carefully planned clinical trials of new and experimental therapies are the key to improving the treatment of patients with GBS. Such clinical trials begin with the research of basic and clinical scientists who, working with clinicians, identify new approaches to treating patients with the disease.

The long-term outlook

GBS can be a devastating disorder because of its sudden and unexpected onset. In addition, recovery is not necessarily quick. As noted above, patients usually reach the point of greatest weakness or paralysis days or weeks after the first symptoms occur. Symptoms then stabilise at this level for a period of days, weeks, or, sometimes, months. The recovery period may be as little as a few weeks or as long as a few years. About 30% of those with GBS still have a residual weakness after three years. About 3% may suffer a relapse of muscle weakness and tingling sensations many years after the initial attack.

GBS patients face not only physical difficulties, but emotionally painful periods as well. It is often extremely difficult for patients to adjust to sudden paralysis and dependence on others for help with routine daily activities. Patients sometimes need psychological counseling to help them adapt.

Research

Scientists are concentrating on finding new treatments and refining existing ones. Scientists are also looking at the workings of the immune system to find which cells are responsible for beginning and carrying out the attack on the nervous system. The fact that so many cases of GBS begin after a viral or bacterial infection suggests that certain characteristics of some viruses and bacteria may activate the immune system inappropriately. Investigators are searching for those characteristics. Neurological scientists, immunologists, virologists and pharmacologists are all working collaboratively to learn how to prevent this disorder and to make better therapies available when it strikes.

Three Years On and Our Web Minder Lil hits back……..

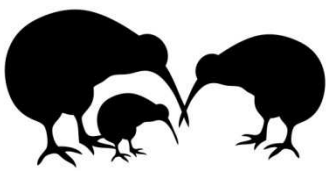
Notice with golf results in Gisborne Herald.

"There was a tear in the eye of popular Mahia player Lil Morgan when accepting the overall net prize at the Fletcher Meat Treat women's tournament last Thursday. The former Northern Zone Rep carded her best round in years -88-23-65- and it was fitting to do it among players from most of the Poverty Bay region's courses. Morgan was out of golf for a considerable period of time with illness a few years ago and her presence on and off the course was missed by all, especially her clubmates."

A note from Lil:

Yep, Chris, I did the big howly bags...was a very emotional day, and shows we can all fight back.

N.B. the golf hasn't been that hot since that day!



"Brain Day 2010."

Saturday dawned fine and warm. The ideal day for "The Centre for Brain Research," in conjunction with the "Neurological Foundation," to hold an Open Day in order to draw the attention to, and create public awareness of, the multiplicity of neurological disorders and brain malfunctions.

In former years the Open Day was held at the Auckland Medical School – being a very successful and well attended event. The premise was that visitor numbers were increasing year by year, and that a larger venue was needed. So this year the Open Day was held at the Owen G. Glenn Building at the University of Auckland Business Dept., and was every bit as successful and well attended as in the previous two years. The day consisted of Lectures, Seminars, a Science Lab., and Hands-on Activities throughout the. There was something of interest for everyone, from Brain Research; Depression; Stem Cells; Deafness; Parkinson's; Memory Loss; just to name a few.

The GBS Support Group exhibit was part of the "Community Group" display, of which there were twenty-seven different organisations taking part. We were informed that we could start to set up our exhibit at 0800hrs, in readiness for the general public to be admitted at 0900hrs. I arrived with my wife Margaret at the designated time, closely followed by Maurice and Cath Vickers. We quickly found our allocated "spot," but found that the table, on which we were expected to place our information booklets and associated paraphernalia, was far too small. So we "purloined"- a word I prefer to use rather than "steal," an adjacent table, setting up very quickly before anyone could notice or complain, and there we stayed for the duration of the Open Day. Here I have to give credit to the people on the adjacent exhibit – The Acoustic Neuroma Assoc., for donating a number of clear laminated vertical display stands to us, enabling us to display our booklets to their best advantage rather than just laying them out flat on the table. And again I must mention the unceasing assistance given to us all by Jenny Murray, our National Co-ordinator, for providing booklets and other materials, and for whom nothing is too much trouble.

Long before the opening time, the public came in, and then continued to stream in all day. The four of us were kept busy answering queries and questions almost non-stop. We had decided from the outset that we would 'ration' the number of booklets on the tables, so that only those with a genuine interest in GBS would be given them. We had learned from past experience that there were many 'collectors' at these events, so discretion was needed. It worked well. To give an idea of the kind s of people we encountered during the day, here are a few examples: - Community Nurses; Psychiatric Trainees; a doctor from Afghanistan and another from India; Post Graduate Students; a Public Entertainer; Speech Therapist; a Russian Nurse working in Canada; Rehab Nurses; Diagnostic Blood Technicians; and Pre-School Trainers; past sufferers of GBS, and relatives of the same.
However, one of our most illustrious visitors was Prof. Richard Faull, the most eminent brain researcher in New Zealand, a world authority in brain research, and the discoverer of The Pathway of the Brain. An absolute unassuming gentleman who took the time to visit every Community Group during some part of the day.

I think that I can honestly say that being part of the Open Day, helps to bring to the awareness of the general public, the problems associated with our syndrome, and our efforts in some small way as a GBS Support Group, to help all those who are afflicted. I am sure that the four of us concerned with this years Open Day went away tired but happy at the end, and I'm quite sure, willing to do our stint at the next one, all being well.

John Davies, and on behalf of Margaret, Maurice & Cath Vickers.

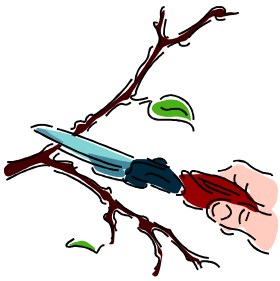
Results of the "Grow a bigger brain in seven days" challenge

Held in March in conjunction with Brain Awareness Week

Reprinted with the kind permission on the Neurological Foundation of New Zealand

The Brain Week website (www.brainweek.co.nz) and the campaign to "*Grow a bigger brain in seven days*" was a huge success. During the campaign period, the site received over 40,000 visitors and the Manawatu region took out the award for growing the most brain cells, the women easily beat the men, and the 60 year olds trounced all other age groups.

So there you have it. If you are a 60 plus female living in the Manawatu I suggest you get yourself onto Millionaire Hot seat pronto.

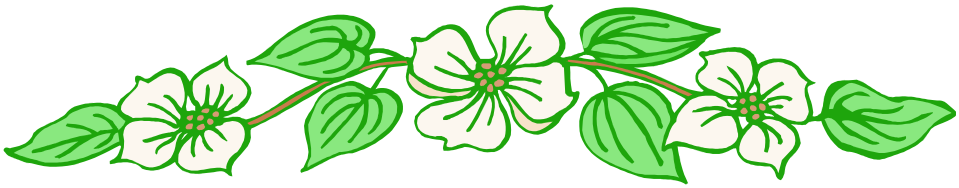


Garden Tips for winter clean-up

It is getting near that time of the year where you will have to do a little pruning to keep your treasured plants in check and make them perform and produce better next year. First up are the fruit trees. As soon as the deciduous ones, the apples, nectarines, peaches etc have lost their leaves you can get in and give them a good prune. A good guide to remember is that pip fruit (apples, pears etc) fruit develops on two year old wood; you can often see the spurs where the fruit is going to form. This is where you need to prune them back to. However, stone fruit (peach, nectarine, etc) which fruit on the one year old wood. This means that you need to thin out the older growth from the past years but trim back/thin out some of the new laterals that have grown for fruit to form on this coming season.

If the trees are older you may have lichen and/or moss growing on the branches. If this is not cleaned up it will gradually suck the goodness out of the tree. To control lichen and moss, spray with Lime Sulphur in May/early June, just after you have pruned. You could also give your roses a blast as well, especially if you have had a Blackspot problem. Prepare to prune your roses in June/July. Don't prune the roses too soon as they will produce new growth which will get damaged by frost and set the plant back.

In regards to shrubs, perennials and trees that do receive frost damage during the winter months, leave the damaged foliage on the plant no matter how ugly it looks as this will protect the rest of the plant. Only prune this off once frosts have gone.



Something from the Kitchen

With winter just around the corner there is nothing better than a good old fashioned steamed pud. This recipe was given to me by my Grandmother and it is still a family favourite.

Golden Syrup Steamed Pudding

Ingredients:

1½ cups flour
55gm butter
½ cup sugar
2 tbsp golden syrup
¾ cup hot water

1

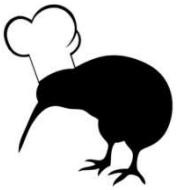
Sauce
1 level tbsp baking powder
⅛ tsp salt
55gm butter
20 to 150ml milk

Method:

Sift the flour, baking powder and salt. Rub in the butter to make a fine crumb. Mix with the milk to give a rather moist dough. Place the dough in a greased basin suitable for steaming.

Place all the sauce ingredients in a small saucepan and bring to the boil. Pour the sauce over the dough. Do not cover the basin, but place in a large saucepan containing about 25mm depth of boiling water. Place the lid on the saucepan and steam the pudding for an hour.

When cooked, invert the pudding onto a serving plate. The syrupy sauce will then be on top and down sides of the pudding. Excellent with cream or ice-cream. Serves 4.



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

Lil and I (*the Ed*) are the only members so far……

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 have offered to lead a group (or an individual, or couple) to this conference. Contact them direct if you wish to go. It is a great opportunity to meet fellow suffers 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

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