

# Guillain-Barré Syndrome

## SUPPORT GROUP NEW ZEALAND TRUST

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## NEWSLETTER SEPTEMBER 2009

***If undelivered please return to:***

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## Editors Note



It has been a busy time in the Bay of Plenty with several outbreaks of GBS coming to our attention. Unfortunately it hasn't been via the hospital network, but by chance visits of people who are aware of the support group and/or relatives finding out about us via our web site. Getting hospitals to acknowledge our Group is an on- going battle throughout New Zealand and one we need to continue. Having been a GBS patient and now a hospital visitor seeing it from the other side, I firmly believe that patients do benefit from seeing a recovered GBS patient. I always get positive feedback from those we visit. I hope that the presence of our President and Treasurer and their wives at the Wellington Nurses conference will have a beneficial result.

Nobody has put up their hand to take on the role as Publicity Officer, or become part of the Card System so both are being advertised again. The board will have to rethink both these roles if we get no response.

**To those of you that have sent in your stories and haven't seen them in print yet.** Don't despair, they are much appreciated and will be in future editions of the newsletter. Anyone who hasn't yet written their story and would like to, please do so and email to me. Any caregiver who would like to write about their role would be equally well received as the caregiver is sometimes quite overlooked and maybe under - valued in the recovery process.

In fact any contributions towards the newsletter are very, very welcome.

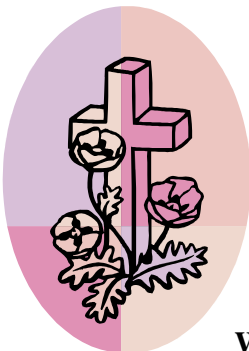
We extend a warm welcome to all those newly diagnosed with GBS, CIDP or variants to the group and wish them a speedy recovery. Remember if you want to talk to someone or have someone visit you to offer support or just to chat they are only an email or phone call away. Contact Jenny Murray and she can put you and your family in touch with someone in your area. This applies to caregivers as they too need support during these very difficult and trying times.

I hope you all keep **Getting Better Slowly**

Chris

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## Obituary



**I received a letter shortly after the last newsletter was sent out from Barbara Mildenhall telling me her husband Ray passed away in May.**

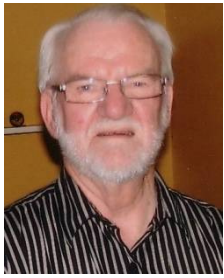
**She wrote: "He did enjoy your mail (the newsletter) over the years. He would spend all day reading the sometimes many pages of other stories and advice. Thank you very much your efforts are appreciated by others I am sure."**



**We extend our sincere sympathy to Barbara her family and friends.**

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## Presidents Paragraph:



This is a story of congratulations and profound thanks. Members will know that Gareth Parry received a significant award in the 2009 New Year Honours for his services to neurology and embedded within that award is recognition for his services to New Zealand sufferers of Guillain-Barré Syndrome and CIDP and all the variants. I was privileged, along with my wife Margaret and Dr Lindsay Haas (a Wellington neurologist) to accompany Gareth and his wife Cathy to the investiture ceremony held at Premier House in Wellington in early September.

It is unusual for expatriate New Zealanders to receive honours so Gareth's recognition is particularly noteworthy. His official award is Officer of the Order of New Zealand Merit (ONZM) and is up there just below a knighthood. So sincere congratulations are in order for Gareth and this was conveyed to him on behalf of all Support Group members when a small cluster of well-wishers met at the James Cook Hotel in Wellington to celebrate lunch with Gareth and Cathy.

The New Zealand award goes along with a recent prestigious prize from Gareth's university: The University of Minnesota Prize for Clinical Innovation. The point of all this is to indicate quite clearly that when we get advice from Gareth it is as up to date and as professional as anywhere in the world. From the very beginning of the New Zealand Support Group Gareth has offered his services for the benefit of afflicted New Zealanders without hesitation and without thought of monetary reward.

The good news is that Gareth and Cathy are planning to spend more time in New Zealand so he will be even more available to members of the Support Group. It is a great comfort to know that the skills Gareth has accumulated will be shared with New Zealanders both patients and professionals on an ongoing basis.

We look forward to Gareth and Cathy residing in New Zealand in the near future.

Warmly  
Bob Stothart  
President



*Following Gareth's appointment as an Officer of the New Zealand Order of Merit for services to Neurology by the Governor General in Wellington on September 2<sup>nd</sup> a small group of family and GBS Support Group friends met for lunch to celebrate this important occasion. Pictured are Gareth and Cathy with Group President Bob Stothart (and the medal)*

## Secretary's Jottings:

Well Spring is on its way but - judging by the very variable wet/windy and cold snaps we are having in Nelson - only reluctantly so. Nevertheless the daffodils are out, the lambs are bouncing around and the surrounding orchards are in bud – so a special time of renewal and anticipation and a chance to forget the poorer days of winter (although, in truth- and compared to the UK – winter ain't so bad in N.Z.!!) For many of us I think that's how we dealt with our brush with GBS – a passing “nasty” but something to get through and get over and an urgency to “get on with life” after GBS. However we perhaps need to spare a thought for those members of our select group who haven't been so lucky and continue to bear the burden of muscles or nerves damaged during the passage of GBS thro' their system BUT – almost invariably - although GBS might have impaired them physically their spirits and moral never cease to amaze me and one of the enduring features of being a member of this group is the growing number of so very positive people that I am now able to call friend!

So what has your Secretary been up to in the last three months? – well heaps actually but not a lot of it to do with GBS – a number of other Groups that I am fortunate to be involved with (Walking/Sailing/Community and Restoration Projects) seem to have had a lot of AGM's Membership Renewals, Submissions to Council, Pot Luck Lunches and so on – all of which usefully occupy my and Vivienne's spare time – and that precious commodity is getting more and more restricted as the grandchildren grow and need more active entertaining – as many of you will have experienced!

But we haven't been idle. In a couple of weeks under the supervision of our President Bob and his lady wife Margaret – ably assisted by our Treasurer Peter we shall have a stand at the Nurses Centennial Conference in Wellington to increase the “awareness” of GBS amongst that august body (300 delegates expected so plenty of our brochures should get into circulation).

Some of you will have seen the report in the Dominion Post (and also picked up by a number of local papers) about our member in Christchurch who contracted GBS after a vaccination and – as I have reported before- has been able to successfully pursue a claim on ACC for assistance (essentially because of the proximity of the vaccination on Friday to the onset of GBS on Sunday). I received a number of contacts from both TV and Radio for a follow up article but not only did our member wish to remain anonymous (sensibly in my view!) but the media seemed to be pushing the Agenda of “Don't have a swine flu jab or you will contract GBS” – which I firmly advised was NOT our message! They were not interested in the far more serious issue of ACC usually denying claims for financial assistance to help with the hardship caused by GBS (and other illnesses such as Cancer) because they are not ACCIDENTS!! However all reasonable publicity is welcome and the success of this first claim may be the forerunner of more.

***Just for the record those members at the Auckland Conference will recall Gareth's advice on Flu vaccinations that – for the majority of us - the risk of getting flu was probably more serious than potentially re-contracting GBS but GBS'er who did so react in the past and those having contracted the Syndrome recently should probably avoid it. Best to consult your GP if in doubt!!***

I think we are all aware of the potential for campylobacter to initiate a GBS attack so I was hearten to read about the NZ Food Safety Campaign that is encouraging eating establishments to display a sticker on their windows confirming they operate an approved Food Control Plan.

Finally I have asked Chris, our new Editor, to include a membership application form in this Newsletter. This is primarily aimed at current non members who, whilst enjoying the Newsletter, perhaps doesn't feel the need to become a “paid up” member – the truth is we need your help to continue the Group's work of supporting new GBS'ers and their Carers. The annual membership fee of \$10 is not excessive but the income and numbers from a strong membership enable the Group to constructively pursue its objectives!

As always Take Care  
Tony





# Vaccinations in GBS/CIDP

**Should patients who have had GBS in the past or who have CIDP be vaccinated?**

- If GBS was clearly associated with a vaccination there is no evidence that revaccination is contraindicated but it seems prudent to avoid the vaccine that triggered the initial event.
  - The GBS should have appeared 1-3 weeks after the vaccination.
  - There was no other antecedent event.
- If such an individual had a disease that would put him/her at high risk of serious complications of the 'flu (COPD, HIV, cancer, etc), the risk of triggering GBS should be weighed against the risk of being getting the 'flu.
- If GBS was not associated with a vaccination it is suggested that all vaccines be avoided during the first year following onset of disease.
- Vaccines are probably not contraindicated in CIDP:
  - The risk of triggering a relapse is small
  - CIDP does not usually cause such severe weakness as GBS.
  - Even if a relapse occurs it will respond to treatment.
- Patients with severe CIDP, especially if it has run a relapsing course, might be wise to avoid vaccinations.
- *In all cases the risk of vaccination should be weighed against the risk of the disease for which the vaccine is being administered.*

**Gareth's bottom line in 2007 was and still is:**

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.



# Twelve Ideas to Ease Leg Pains

*This was taken from the Fall 1994 Issue of 'The Communicator'*

*Reprinted with the kind permission of Robert Gregory and GBS/CIDP Foundation International*

*I believe it is still very relevant for today's sufferers of residual pain.*

Those of us who have encountered Guillain – Barré Syndrome and recovered may well be left with residual pains, either constant or occasional, and especially pains located in our legs. Although each case is different, some actions can be taken to ease pains. The list below includes those tactics that I have tried since I was diagnosed with Guillain – Barré around five years ago. *(That would now be 20 years ago. Ed)*

Not being a physician, I cannot prescribe or claim any medical expertise, but as a person with leg pains resulting from GBS, I feel reporting my experiences may be useful to others.

**Robert J. Gregory Ph.D.**

1. **Hot Baths** – the relaxation, heat and water combine to remove muscle tension and pain. Hot water bottles and heating pads may also offer a similar resource.
2. **Massage and Self-Massage** – both surface and deep tissue can be of definite benefit. While easier when another person provides the massage, a self-directed massage can also be useful and can be carried out simply and virtually anywhere.
3. **Vibration** – either a hand held, pad, bed or full chair vibrator can offer relaxation and reduce pains. The sensations of pain are often described as similar to vibration, and yet, vibration can help.
4. **Counseling** – long talks with sympathetic listeners can do a world of good. Having at least one empathetic friend is essential.
5. **Elevation when sitting** – a proper chair designed to elevate feet is very helpful and can be used briefly during a day, or for an extended period of time in the evening.
6. **Charts or graphs** – keeping a record of times and places and associations with pain and without pain can offer clues to activities and links with pain which may be helpful in tracking down anything that increases or decreases pain sensations.
7. **Moderate Exercise** – a walk once or twice a day, swimming, or other types of exercise may result in less pain.
8. **Alter Sleep Patterns** – if pain interferes with sleep, it may be useful to take afternoon naps or otherwise change sleeping patterns to fit times when pains are less.
9. **Yoga** – meditation, breathing exercises and postures may offer benefits.
10. **Pharmaceuticals** – such products as Bengay, aspirin, paracetamol and others may be helpful.
11. **Acupuncture** – may relieve pain dramatically for some people.
12. **Making Love** – the physical release as well as intimacy may offer help which alleviates leg pains.

These ideas may be worth a try. It would be interesting to learn of additional tactics that others have tried.



# **A Personal Encounter...**

## **Grant McKay**

My story starts in October 2003 just after my 53<sup>rd</sup> birthday.

Two weeks prior to this I had had a bout of diarrhoea which was over in a few days. The Doctors think it probably was *Campylobacter* due to the severity of the GBS, but this could not be proven as my bowels did not move again for three weeks.

On the Monday evening I mowed the lawns so was not too bad at that point. Tuesday, I had developed abdominal pains so decided to go to my GP to check this out. He gave me pills to start my bowel working again and sent me home. Back to GP on Wednesday with the same problem. This time was given an injection as well and sent home. By the evening my arm strength was going and I had developed pains in my lower legs and lower arms. I spent a very disturbed night as pains got worse and weakness increased. Thursday morning back to GP, by this stage I could barely walk and required a wheelchair to get from car to Doctors rooms. GP shook his head and sent me off to Waikato Hospital where after various tests and a lumbar puncture was diagnosed with GBS. By this stage could not walk at all and paralysis had set in.



From here went to HDU and as my breathing failed to ICU where I was put onto a ventilator for ten days which was a very frightening experience. By now I was paralysed from my shoulders down. The pain I was having in my arms and legs went after about a month and have not returned. My sensory nerves have not been affected at all so sensation has always been good. I have not had pins and needles, numbness or tingling. My motor nerves have been affected limiting my mobility significantly. This is when the long haul started.

I was in Waikato Hospital for 8 ½ months then to a private hospital for 2 ½ months. I won't go into the details in hospital (I could write a book) except to say the Health Professionals that I have worked with have been great, the Physiotherapists, Occupational Therapists, Nurses and most Doctors do a wonderful job despite the lack of resources.

I lay there for nearly three months before any movement started to return. After 8 ½ months I was on my feet with the aid of a walking machine to hold me up and my arms were beginning to move. At this point I was discharged with a head operated electric wheelchair to a private hospital to continue with rehab. The wheelchair was soon converted to hand operation as my arm and hand movement improved.



At 11 months I finally came home still being hoisted in and out of bed and into my electric wheelchair, shower chair etc.

Intense Physiotherapy has continued until the end of 2007 when the funding was cut. Progress has been slow but steady, plateauing often. In October it will be 5 years; I still have an ongoing balance problem and have very little ankle movement. Steps are a problem and my hands are quite deformed despite lots of work by Occupational Therapists and Hand Therapists.



I walk outside with 2 sticks and inside unaided. My walking is quite bouncy but is getting better as my balance improves. I still have a Caregiver to help with showering and she continues to work with my hands each day.

On a brighter note, earlier this year I passed my driving test so this has given me back some much needed independence.

I cannot stress enough the toll an illness such as this takes on our Family Caregivers. They are expected to care for us and in our case work to sustain a reasonable lifestyle with very little help available.

I may not be able to work again but with a positive attitude, lots of determination, a good sense of humour and a loving wife and supportive family we are beating this life shattering syndrome and are now looking forward to the rest of our lives.

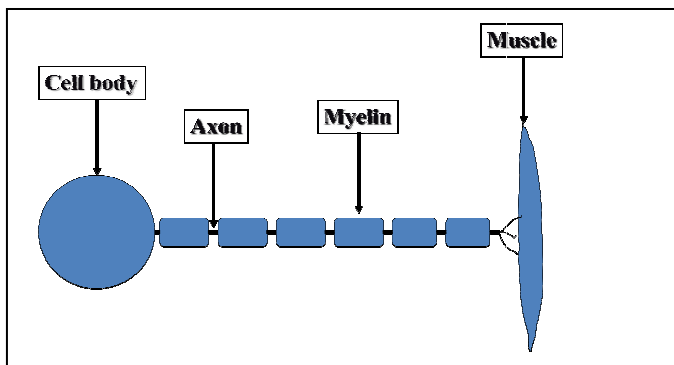


# Points of Interest from Dr Gareth Parry's Conference Presentation (Part One)

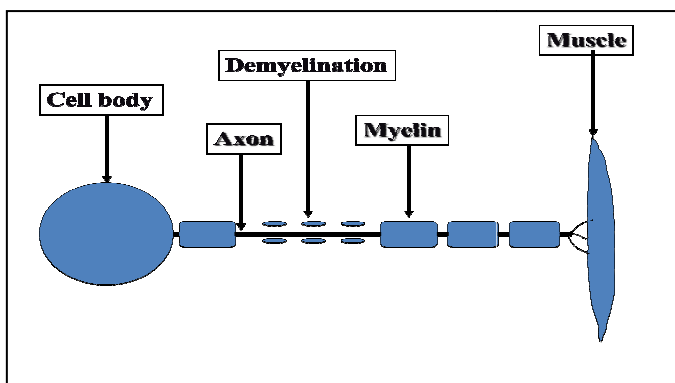
## Acute motor axonal neuropathy (AMAN)

There are several different kinds of GBS:

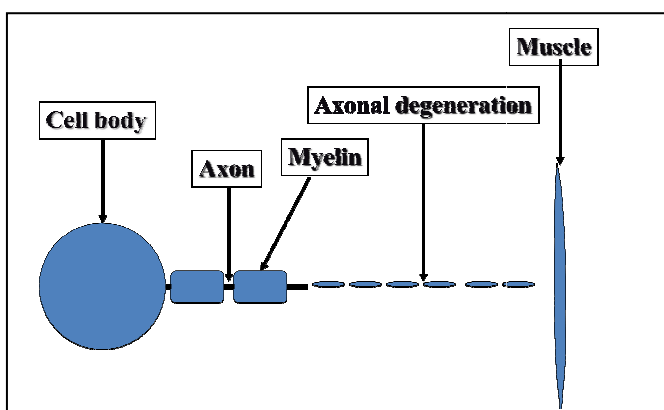
- Acute inflammatory demyelinating polyneuropathy (AIDP)
- Acute motor axonal neuropathy (AMAN).
- Acute motor and sensory axonal neuropathy (AMSAN).
- Acute autonomic neuropathy.
- Miller Fisher syndrome (MFS).
- Acute sensory neuronopathy



A healthy nerve working as it should delivering messages to the muscle.



- The commonest form of GBS in developed countries is AIDP.
- In AIDP the **myelin sheath** is the primary target.



- In under-developed countries (China, India, Central America) AMAN is a common form.
- In AMAN the **axon** is the primary target.



## Acute Motor Axonal Neuropathy (AMAN)

- Some axonal damage is invariable in AIDP and may be severe even though the primary target is the myelin sheath.
- Axons are injured in an “innocent bystander” reaction.
- If axonal damage is minimal the prognosis is excellent because the myelin sheath can be reconstituted rapidly and completely.
- If axonal degeneration is severe the prognosis is poor because the “scaffolding” of the myelin sheath is destroyed and there is no guide for the regenerating axons.
- Although the primary target in AMAN is the axon, the myelin sheath degenerates because it needs the axon to survive.
- Prognosis is good in AMAN because the “scaffolding” remains intact and provides a guide for the axons to regenerate.
- AMAN more likely to follow diarrhea (C.jejuni).
- AMAN more likely to have specific anti-nerve antibodies (GM1 ganglioside).
- More severe cases have sensory nerve involvement (AMSAN).
- Clinically indistinguishable from AIDP but the electrophysiological features are different.
- No difference in the treatment.
- No difference in prognosis.

## A New Treatment for GBS.

- In auto-immune diseases, antibodies bind to the target tissue and then recruit a variety of chemicals that damage that tissue.
- One of the chemicals that is activated during this process is complement and there is abundant evidence that activation of complement damages nerves in GBS.
- Eculizumab is a monoclonal antibody that inhibits activation of complement and should reduce tissue injury in GBS (and other auto-immune neuropathies).
- Human studies of eculizumab in a non-neurological auto-immune blood disease have shown a major protective effect and this drug is now approved for treatment of this disease.
- Human studies of eculizumab in myasthenia gravis (an auto-immune disease of muscle) have started in the US.
- In a laboratory model of GBS in mice, eculizumab had a major protective effect.
- Human studies of eculizumab in GBS are being planned.
- How do you study a new drug in humans with a disease for which effective, but imperfect, treatments already exist?
  - *Combined treatment (IVIg + eculizumab) versus IVIg alone.*
  - *Eculizumab versus placebo as initial treatment followed by IVIg experiments*

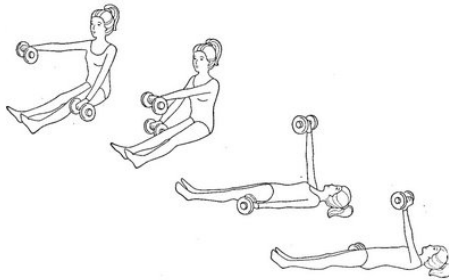




# Exercises to Help Strength & Flexibility

## Dumbbell Activities and Weights Routine for Arms

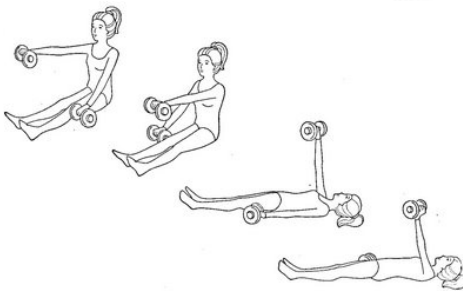
Use a 1kg set of dumbbells; do exercises in sitting and lying positions on the floor



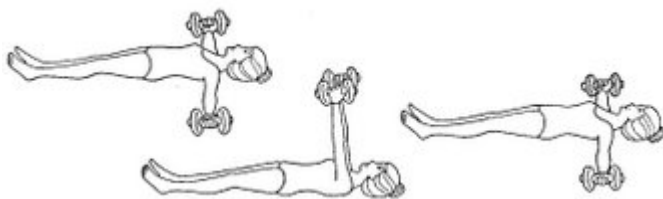
**Exercise 1:** Starting with arms at sides, raise dumbbells to shoulder level, alternating hands so that they pass each other.



**Exercise 2:** Raise dumbbells forward and upward to a vertical position keeping arms straight and close to your ears as you raise them over your head. Lower dumbbells to forward position, then to starting position.



**Exercise 3:** Vigorously push dumbbells forwards and backwards from chest to arm outstretched position, alternating hands so they pass each other.



**Exercise 4:** Lie on your back with arms extended at shoulder height. Keep arms straight. Raise vertically over chest. With palms facing each other lower both arms sideways to the floor to return to starting position.



**Exercise 5:** Rowing. Bend over from the waist with legs straight and both arms hanging straight down. Bring the weights up to the chest and return to starting position.

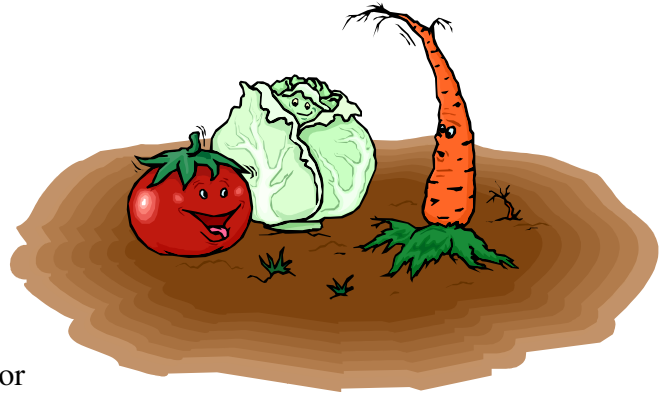


**Exercise 6:** Lie on your back, with arms extended and palms down so that dumbbells rest against the thighs. Keep arms straight and parallel. Bring arms upward and backward, stretching hard, until the backs of hands touch the floor. Return to starting position.

**Points to Remember:** Have a partner work with you for assistance and safety. Start with light weights and make any increase in weights very gradual. Weights or dumbbells can be purchased at a store or you can make your own by filling bags with sand, dirt or rocks. Try to do 3 repetitions of 10 for each exercise.

# Gardening Tips for Spring

More and more people are planting edibles this year so I hope you have got your vege plot ready and are keen to grow some awesome fruits and veges for summer BBQ and salads.



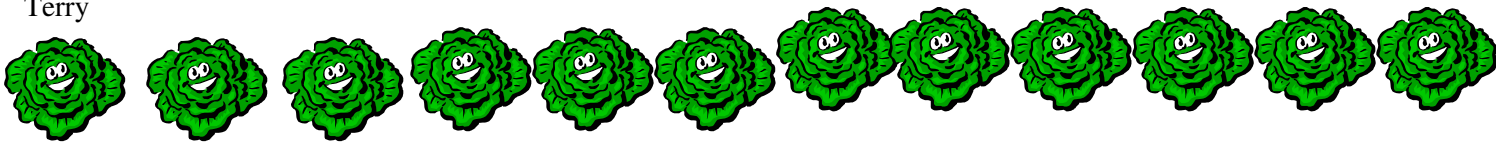
We recommend sheep pellets as a good all round fertiliser for your gardens. There are your straight sheep pellets which are very good and there are also some mixed with Nitrophoska Blue which is better. These cost a little more but you don't have to use as much.

Time to plant seed potato's for Christmas, and lettuces, beetroot, celery etc but in the colder climates I would etc.

Don't forget the slug bait! An excellent bait for gardens where you have pets is Quash. This has animal repellents in it and a different make up so it will not harm your pets even if they do eat it. For you big coffee drinkers, sprinkle you coffee grounds into the garden to help repel slugs and snails.

Hope you all enjoy the fruits of your labour from the garden this spring and summer.

Terry



## Something from the Kitchen

### PEAR AND GINGER CRUMBLE

#### Ingredients:

425gm pear halves

¼ cup pear juice

#### Topping:

½ cup rolled oats

¼ cup flour

¼ cup coconut

¼ cup brown sugar

½ tsp ground ginger

50 gm butter



#### Method:

Place pears and juice in a lightly greased ovenproof dish

Mix together rolled oats, flour, coconut, brown sugar and ginger

Melt butter and mix into dry ingredients. Sprinkle mixture evenly over the pears

Bake 1t 180°C for 25 minutes. Serve warm with cream or ice cream.

# Notice board

## Website

We have a web site that is being much underutilized. It is a good way to swap ideas, thoughts and information so how about giving it a go.

## AGM 2010

Next years AGM is to be held on **Saturday 1<sup>st</sup> May** at Massey University Psychology Dept, Palmerston North. Organiser is John Podd. More details will be published closer to the time.

## Professional Day to promote the Support Group

Peter and Robin Scott and Bob and Margaret Stothart are staffing a stall at the Duxton Hotel during a nurse's professional development day. They will be making the Support Group very visible with our fold out poster, the lovely table cloth and lots of hand out material.

## Situation Vacant:

**Publicity Officer:** responsibilities include keeping the support network in the public eye; communicating regularly with departments of neurology in hospital, liaising with media and generally putting our good news stories out in public etc.

If you have the experience, the time, the passion and the skills for this role please contact Bob Stothart at [stothart@ihug.co.nz](mailto:stothart@ihug.co.nz)

## Volunteers Wanted:

At the recent Board of trustees meeting it was decided to form a **Greeting Card System for new GBS/CIDP Sufferers**. This is based on a system started overseas where said volunteers will be notified of a new patient and they will then (at their own expense) send a greeting /get well card to that person. As GBS/CIDP is not a common occurrence we wouldn't expect the volunteers to incur huge costs. A supply of \$1 cards and a few stamps might set you back \$10 a year.

Please contact me (Chris) if you would like to become involved in this project.

Email me at: [chrispy57@gmail.com](mailto:chrispy57@gmail.com)

