

Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

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NEWSLETTER MARCH 2010

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Editors Note



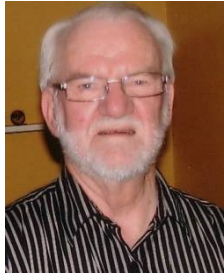
This magazine is a little late in reaching your letter boxes but we have been away showing a friend from America the beautiful West Coast of the South Island.

The AGM is creeping up fast; details appear on the back page of the magazine. Please try and attend if you can. While not as full on as our Bi- Annual conference it is still a vital part of keeping the Group up and running. New ideas and volunteers are always welcome.

The GBS/CIDP Foundation International's magazine is now available online. If you receive this in the post and want to continue doing so you need to return the form they sent out. I have put a copy of it in the magazine in case you have misplaced yours. Anybody who wants access to this magazine can get it online at: www.gbs-cidp.org

Chris

Presidents Paragraph:



Jenny Murray contacted me recently about a sad case of patient neglect for a sufferer of Guillain-Barré Syndrome. It was distressing to read about how an immobile, frightened patient was ignored, bullied and maltreated in what amounted to patient abuse. It reflected a total lack of understanding on the part of the nursing staff in the institution about the specifics of GBS. I would not have liked to have been incarcerated in that un-caring place. There was little we could do to alleviate the suffering of this person but it does raise several points. Jenny was

moved to write to the nurse's magazine to raise several points and she will be sending material to training institutions.

These days, patients have rights and these rights are advertised in hospitals and nursing homes and caregivers and families are entitled to ask for a copy and to take action if deemed necessary. If you consider that there is insufficient understanding of GBS as a rare illness and the resulting inability of patients to grip, to move easily, feed themselves, perhaps to swallow, quite apart from the possibility of intense pain, do something about it exercising your rights.

Unfortunately this is not an isolated case as an article in the March 2010 North and South magazine indicates how wide spread (in hospitals and nursing homes) a lack of care can be. It is well worth reading the North South piece. I do not wish to leave the impression that it is all bad. I was treated wonderfully well and through my occasional hospital visiting I am aware of nurses and specialists providing compassionate and professional care. When the care drops below an acceptable norm however, we need to take action on behalf of distressed patients.

I hasten to add that the role of our support group is to provide sensitive, informed support for GBS/CIDP sufferers and their families. It is not our role to charge into an institution and throw our weight about. Our hospital visitors are expected to be discreet, to act in a professional manner and to maintain the strictest confidentiality.

And another magazine always worth reading is Headlines, the newsletter of the Neurological Foundation of New Zealand. Much food for thought in the latest issue.

As we are now well into the new year of a new decade, allow me to wish you well for healthy and enjoyable experiences in the months to come.

Bob Stothart

Secretary's Jottings



So with our third grandchild (Chloe) safely arrived with all necessary bits and pieces and a somewhat disjointed Christmas (more later) behind us Vivienne and I girded our loins for a busy summer of visitors and trips – so far, so good with a 3500km drive showing our UK neighbours (who were VERY pleased to escape the British weather!) around South island over the past 12 days now successfully complete – and a 3 day breather before we are off again. But it's better than being bored!!

A very big THANK YOU to the 90 of you that completed the survey. With that quantity of replies it should be possible to get some meaningful results – to be announced at the AGM and publish in a subsequent Newsletter. If my planning over the next short while holds good I also hope to get the majority of membership renewals away and another thank you to those of you who have responded so promptly to the renewal request – it helps keep our Treasurer happy even if you have to wait a

little while for your new membership cards.

There have been a number of interesting articles appearing in various publications over the past few months. The last issue of the GBS/CIDP Foundation International carried an interesting paper on the development of “measuring standards” for CIDP'ers like me. It involved a lot of detailed medical and statistical work by a panel of medical experts but resulted in a simple scale that laypeople can more easily understand, which in summary was:-

1. Cured (more than 5 years off Treatment)
2. Remission (less than 5 years off Treatment)
3. Stable (more than 1 year on Treatment)
4. Improvement (more than 3 months on Treatment)
5. Active Disease (Abnormal examination with progressive or relapsing course)

Whilst I am sure that (as with all things GBS) there will be individual cases that don't fit the pattern it would be interesting to see how our membership fits in with this research. I will see if it possible to deduce that from the survey results and perhaps at the next conference we might circulate a little survey to CIDP'ers present for a “self assessment”.

A couple of articles/letters in the pre Christmas editions of the Listener recorded the fact that NZ is no longer top of the list for “the worst in the world” for Campylobacter problems although things are still pretty bad. Much of the improvement (particularly in the contamination of our chicken) seems to stem from good hygiene improvements in the food processing and preparation side of the industry but I was staggered to learn that contamination happens “on the ground” largely from pastures contaminated with the campylobacter microbe arising either from cattle and sheep management practices or transferred to the poultry farms on people's boots! Apparently in Iceland and Sweden the poultry stock is virtually campylobacter free because of the care taken to ensure flocks are not in contact (or close to) contaminated ground. There's a lesson here for us surely!

AND .. we are not the only ones with a rare neuropathy. The Nelson Mail recently carried a story about a girl in the USA developing GBS like symptoms – after months and months of test and seeing dozens of doctors the cause was eventually placed at the door of her denture cream!!! – apparently denture cream contains high levels of zinc which if absorbed in significant quantities interferes with the absorption of copper into the blood stream leading to a neuropathy – we live and learn!!

This will be the last Newsletter before the AGM. I shall be sending out the appropriate papers by the end of this month to financial members and a formal note is included elsewhere in this Newsletter. If you can't make the meeting in person please do take the trouble to complete the Proxy Form. AGM's I know tend to be lots of formal “admin stuff” but we have had some interesting presentations at past AGM's and this one should be no exception with the airing of our own informative DVD and the presentation of the Survey results. I look forward to seeing you there.

And so back to our disrupted Christmas celebrations. Grandchildren are a true joy as those of you lucky enough to have them already know BUT ... they also bring complications! We were all set up to have a family Christmas at eldest daughter's new house in the Waihopai (Spy) Valley near Blenheim. A few days before we were due to go over we received a phone call saying grandson has been in contact with little friends who have developed Chicken Pox. Well apart from the desire not to pass on the “pox” to the other grandchildren – one of whom was, of course, just weeks old I have always understood that Chicken Pox (or Shingles in adults) is a probably re-trigger for GBS/CIDP – so planned celebrations were called off for the advised 14 day incubation period and with no spots appearing we all then had Christmas dinner in January! A similar event happen just last week when a meeting I was due to attend had to get along without me as I learned that the minors of the household were also sporting the pox spots – although they were probably no longer contagious –and again I cried off. This got me wondering – am I reacting to “an old wives tale” or is there some truth in the Chicken Pox/GBS risk. If you have any personal experience of this do please phone or e mail me – I suspect our other grandchildren will encounter the sickness in due course and it would be good to know if I am worrying unnecessarily.

As always take care
Tony



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

Pulsed steroids in CIDP – an update

- We have now treated more than 40 CIDP patients with pulsed steroids (methylprednisolone 500 mg once weekly).
- The “permanent” remission rate is about 60%.
- Patients who remain on steroids are generally on lower doses (100-300 mg once weekly).
- Adverse effects remain annoying but manageable:
 - Insomnia (70%).
 - Irritability (60%).
 - Heartburn and indigestion (30%).
- Older patients showed a reduction in bone density during treatment, despite co-administration of calcium and vitamin D, and treatment with bisphosphonates should be considered.
- Only one patient has stopped treatment because of AE's.
- Treatment is most effective if started early:
 - All but one of the patients started within 2 years of the onset of weakness is in remission.
- Treatment can be used to reduce dependence on IVIG in patients who have been started on that treatment first.
- We are currently preparing a study comparing different doses to see if a lower (250 mg) and therefore better tolerated dose would be equally effective.

A new treatment for CIDP.

- CIDP is an auto-immune disease in which antibodies and activated lymphocytes (white blood cells) attack the nerves.
- Rituximab is a monoclonal antibody that specifically targets a protein on the surface of the class of lymphocytes that produces antibodies and kills these cells.
- If the antibody-producing cells are eliminated the CIDP should improve.

Rituximab in CIDP

- We have treated 4 CIDP patients with rituximab:
 - All patients had been treated with IVIg, PLEX and pulsed steroids, alone and in various combinations.
 - 2 patients had been treated with cyclophosphamide.
 - All patients were continuing to respond to treatment but only if very high doses and frequent treatments were used.
 - All patients tolerated the rituximab treatment without adverse effects.
 - All patients have been able to reduce other treatments following treatment with rituximab.
- IVIg was increased to once every 2 weeks, then once a week and then twice a week, always with improvement but the increasing doses were of major concern.
- Despite twice weekly IVIg and twice weekly steroids she continued to lose function.
- PLEX was substituted for IVIG but did not result in further improvement.
- In 2006 she had a one year course of chemotherapy (cyclophosphamide) and during that time both steroids and IVIg were able to be reduced for 2007 and early 2008.
- By mid-2008 she requiring twice weekly steroids and PLEX to maintain function.
- In November 2008 she received 2 doses of rituximab 2 weeks apart.
- April 2009 she is receiving MP 250 mg once weekly and PLEX once every 2 weeks.
- She is working fulltime, has normal strength and her energy is good.
- Rituximab may prove to be an effective treatment for CIDP and warrants further study.
- It is an expensive treatment but much cheaper than IVIg and only needs to be administered every 6-12 months.
- Long term safety is a concern but it has been used in rheumatoid arthritis for many years with few problems.



We are what we Eat.....

You are what you eat, so eat well. A stupendous insight of civilizations past has now been confirmed by today's investigative, nutritional sciences. They have shown that what was once called 'The Doctrine of Signatures' was astoundingly correct. It now contends that every whole food has a pattern that resembles a body organ or physiological function and that this pattern acts as a signal or sign as to the benefit the food provides the eater. Here is just a short list of examples of Whole Food Signatures.



A sliced Carrot looks like the human eye. The pupil, iris and radiating lines look just like the human eye...and science shows that carrots greatly enhance blood flow to and aid function of the eyes



A Tomato has four chambers and is red. The heart is red and has four chambers. All of the research shows tomatoes are indeed pure heart and blood food.



Grapes hang in a cluster that has the shape of the heart. Each grape looks like a blood cell and all of the research today shows that grapes are also profound heart and blood vitalizing food.



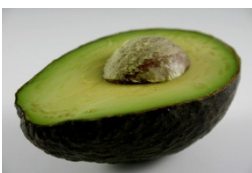
A Walnut looks like a little brain, a left and right hemisphere, upper cerebrums and lower cerebellums. Even the wrinkles or folds are on the nut just like the neo-cortex. We now know that walnuts help develop over 3 dozen neuron-transmitters for brain function.



Kidney Beans actually heal and help maintain kidney function and yes, they look exactly like the human kidneys.



Celery, Bok Choy, Rhubarb and more look just like bones. These foods specifically target bone strength. Bones are 23% sodium and these foods are 23% sodium. If you don't have enough sodium in your diet the body pulls it from the bones, making them weak. These foods replenish the skeletal needs of the body.



Eggplant, Avocados and Pears target the health and function of the womb and cervix of the female - they look just like these organs. Today's research shows that when a woman eats 1 avocado a week, it balances hormones, sheds unwanted birth weight and prevents cervical cancers. And how profound is this? It takes exactly 9 months to grow an avocado from blossom to ripened fruit. There are over 14,000 photolytic chemical constituents of nutrition in each one of these foods (modern science has only studied and named about 141 of them).

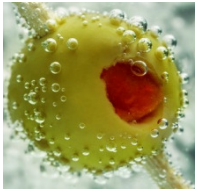


Figs are full of seeds and hang in twos when they grow. Figs increase the motility of male sperm and increase the numbers of sperm as well to overcome male sterility.

We are what we Eat continued....



Sweet Potatoes look like the pancreas and actually balance the glycemic index of diabetics.



Olives assist the health and function of the ovaries.



Grapefruits, Oranges, and other citrus fruits look just like the mammary glands of the female and actually assist the health of the breasts and the movement of lymph in and out of the breasts.



Onions look like body cells. Today's research shows that onions help clear waste materials from all of the body cells. They even produce tears which wash the epithelial layers of the eyes.

'The news isn't that fruits and vegetables are good for you, it's that they are so good for you, they can save your life.'

Garlic 'Cures'

Reproduced courtesy of Headlines, the National Newsletter of the neurological Foundation of New Zealand.

For those who believe in the power of garlic, the Garlic Research Bureau (GRB) has produced some recommendations. The GRB is an industry organisation and therefore a degree of scepticism maybe advisable.

Colds, sore throats and upper respiratory infections

To ease coughs and colds, pound five or six cloves of garlic to a paste, add six teaspoons of wine vinegar and stir. Leave in the fridge to mature for 24 hours. Warm, add 2 tablespoons of honey and stir in four teaspoons of lemon juice. Leave to cool and allow two teaspoons to trickle down your throat, giving a little gargle, three times a day. A crushed clove of garlic in a small cup of warm milk also soothes a sore throat.

Catarrh

Raw garlic within a few hours according to the GRB. Add a clove or two to a salad.

Bites and Stings

Rub a slice of fresh garlic on the sting. Make sure any sting is removed first.

General Tonic

Mash six to eight cloves of garlic with four teaspoons of finely chopped parsley and the same amount of lemon juice. Keep in the fridge for 24 hours, stirring from time to time. Add 250ml (8fl oz) of white wine, and take two teaspoons morning and night. "Your breath will smell but after a week, you will feel a million dollars", says the GRB.

The "Do not experiment with high doses of garlic on young children and consult your doctor if symptoms persist" with which the GRB's recommendations conclude is sound advice.



A Personnel Encounter

by Derek Bowden.....

When I had my GBS I could not understand what was happening to me. “Auto- immune disease” did not mean a thing to me. Not only was I mystified but my family was also. My two children, both at university at the time, visited the university libraries and even the medical school libraries and brought to me in hospital all the information t they could find on the subject including a few odd papers which could only be described as speculation. Nevertheless I seemed to have an explanation which was more satisfactory to me than any of the replies which I obtained from the medical staff around me. What I discovered was much more comforting to me than “It is your body destroying your nervous tissues” from the medical fraternity.

But the comforting “You will get worse before you start to get better” and “don’t worry if it gets to your chest we can keep you alive on a ventilator and if it affects your heart we can keep you alive on the heart lung machine until you plateau and start your recovery” In the meantime I had to keep blowing into a machine to test my lung function.

I avidly read the literature provided by my children. Protein material which does not have a blood supply can be destroyed and replaced as the body thinks is necessary. If it is damaged, this may be a slow process. This did not satisfy me as I still said why?

It was stated that most cases of GBS were preceded by a virus infection of some kind. A flu attack or gastric infection or diarrhea, although it was mostly pointed out that GBS was not a virus infection. All this did not satisfy my enquiry - “Why?”

Then I read a paper on the mechanics of a virus infection. A virus will invade a cell without damaging the outside walls and proceed to use the cell materials to reproduce itself, rapidly multiplying and filling the available envelope. During this time virus waste material is being discharge into the blood stream so the immune system will be alerted.

But because the cell envelope is unchanged and still similar to all the normal cells the white blood cells cannot find it to destroy. Then the pressure of the new viruses within the cell causes it to rupture and to discharge millions of new viruses into the blood and the surrounding cells.

The white blood cells rush to the damaged protein cell to destroy it as an enemy producing the virus waste product and starts attacking the adjoining cells coated in the same virus waste and with viruses in them.

But there are now many more cells with viruses in them so the immune system has to step up its activity and destroy these protein cells at a great rate. The protein cell damage is dependent on how good or bad is your immune system.

This will also determine how long it will be to plateau, which will be why the cases of GBS vary so much in .different individuals

The white blood cells will keep destroying the protein cells until the virus waste no longer shows in the blood at which stage the action stops and the condition has reached a plateau. Unfortunately many of the healthy protein cells have been destroyed in the process either because the white cells could not tell the difference between infected and uninfected or because they were adjacent when a cell envelope ruptured and spilled virus material all over them.

If this happens to the protein covering the nerve cords called myelin it will be GBS,

If it happens to the protein cells of the joints it is called arthritis.

If it happens to the protein cells which produce insulin it causes one form of diabetes.

A similar process may be happening with other syndromes but I have not a sufficient knowledge of anatomy to even speculate but it would be well worth investigating.

This thesis is based on logic and not clinical research but I hope that any clinical researchers who may read this will be encouraged to do some practical research, like checking the blood of a GBS sufferer at the active stage to see if there are any signs of ruptured cells not yet engulfed by white blood cells. This of course may be an impossible task.

Derek's Tips:

1. After several years of suffering from cramp in my calf muscles an athletic friend suggested that I should take homeopathic magnesium,

This did not have much effect for me and on perusing the various other homeopathic remedies, the salesperson said try the real product and offered me Blackmore's BIO Magnesium. This worked well so now no morning cramps. Better than this previously, my ankles and feet felt as if they had concrete blocks cast on them. Heavy and no ankle flexibility and after taking the bio magnesium the concrete blocks disappeared so that now I can wriggle my toes inside my shoes and I can actually feel the inside of my shoes.

The most recent improvement happened last week when my toes were aching so much that I had to get out of bed and take two panadol tablets before I could go to sleep, The next morning I was amazed at how much more movement I had in my foot and toes. Each time this has happened I believe that some myelin has grown back. That is eighteen years after the original attack. It looks as if the younger you are at the time of the attack the better your chances are of recovering. Provided that you do not get any ghost attacks following an attack of flu. I have had three, which have caused neuropathy in my hands and arms which did not occur after the original attack. The nearest that I can get to explaining the feeling is that it is like when you wake up having lain awkwardly on your arm. Needles and pins or even hot or cold and then aching before the feeling returns. I hope that this may help other sufferers to have a positive attitude to this ghastly disease. I am pleased when some part of my anatomy feels peculiar because it usually means it is getting better. Somewhere I was told that if I could manage to live long enough I could expect to fully recover. True or not it is my mantra.

2. My balance is still very bad and I have developed a method of standing between the bed and a chest of drawers to put on my trousers, so that when I lost balance I could quickly gain support on either side. But a couple of weeks ago I was listening to a radio program on balance, in spinal injuries, when they suggested rocking from side to side to reset your balance before lifting a foot. With me it works although I still take my position between bed and furniture, just in case.

I did enjoy the conference and I wish to thank you and all those who worked so hard to enable it to be such a success.

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.

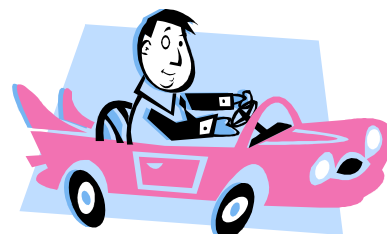
Many medical conditions and the medications can alter cognition, so it may be necessary to test this aspect prior to driving a vehicle.

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 NZ Auckland



NOTES FROM MY DIARIES

Nola

- 1991** May 17 and August 28 – Saw specialist regarding episodes of blurred/crossed vision.
Sept.26-Oct.1 – attended physiotherapy for cervical spine pain and tingling hands/feet.
Oct. 7 - Consulted GP regarding numb feet and tingling sensations. Eyes OK now.
Oct.9, - Seen by Neurological Specialist. After tests had been completed, a biopsy was done with subsequent diagnosis of Chronic Inflammatory Demyelinating Polyneuropathy. A 6month course of Prednisone was prescribed to treat the illness.
- 1992** Jan. First noticed spasm-like sensations in right leg. Prednisone by now being gradually reduced.
April 21, Prednisone programme completed. Leg spasms still present and numbness in toes noticeable.
May 28, Discharged by Neurological Specialist. Pronounced completely recovered from CIDP. He was not unduly concerned about spasms in right leg and in addition groin pain and numbness in both feet. I was assured there wasn't anything I couldn't do.
June 29. Seen at Hospital Neurology Clinic. Numbness worsening. Received script for 3 x 25gm Amitriptyline to be taken daily for pain. Just made me stupid.
Oct.6, Attended Physiotherapist for help dealing with development of back pain in addition to muscle spasms, numbness in feet etc. Treatment was unsuccessful and acupuncture was suggested.
Oct.21 commenced Acupuncture treatment but after two months this was deemed unsuccessful.
- 1993** Seen again at Hospital Neurology Clinic. Further tests were arranged. I was advised to ask less, physically, of right foot and leg.
- July 19, Follow-up visit to Hospital Neurology Clinic. Told neuropathy had not returned and that the problems were of a mechanical nature – not Neurology's province. More Amitriptyline prescribed. Told "Just the nerves."
- July/August – tried surface and deep tissue massage therapy which was discontinued after only two sessions as the massaging stirred up the nerves in right hip and leg.
- Aug.1993-May 1994**, Sought help from Osteopath. Not successful after 10 months' treatment.
- 1994** May 4, attended Podiatrist for advice regarding possible connection between affected right leg and both feet being numb.
June 2, began process of finding help through Orthopedic Specialist, leading to central decompression operation on bi-lateral Vertebrae L4 and L5 on Nov.30. Some relief from back pain. All other symptoms reassert themselves.
- 1995** Consulted the Neurological Specialist after referral by the Orthopedic Specialist. Groin pain now severe. Balance and mobility restricted. Bowel problems on attempting walking for exercise, or during normal course of housework/gardening/shopping. Numbness in both feet now very dense. Right leg constantly painful. Specialist advised no walking – physically do only what I have to do.
June 16, MRI scan undertaken as arranged by Neurological Specialist.
July 12, Enquired of GP regarding results of MRI Scan. The Neurological report indicated the need for further investigation which was being undertaken. More amitriptyline prescribed for leg discomfort and arrangements were made for blood samples to be supplied to Neurological Specialist.
July 31, Phone call from Neurological Specialist conveyed the information that blood tests had all been normal. There is no further line of investigation. He advised me that he accepted the existence of a problem relating to numb right leg and both feet, but was unable to account for it neurologically other than that it might be residual spinal column nerve damage after the CIDP. He was unable to prove this in any way. The only treatment would be for pain relief by medication which unfortunately had serious side effects.

NOTES FROM MY DIARIES *continued...*

- Sept. 11 Kept an appointment made in advance of scheduled one in Nov. with Orthopedic Specialist who did the back operation. Said I was at the end of my tether etc. As a last shot he suggested a bone scan (scintigraphy) which was subsequently arranged.
- Sept.12 After isotope injection, scan was undertaken.
- Sept.25 Orthopedic Specialist phoned me to say the Scintigraphy was negative. He was referring me on to the Hospital Pain Clinic.

1996 March 11, Attended Pain Management Clinic, Auckland Hospital. Interviewed by a psychiatrist then a Physiotherapist who lent me a TENS machine for a week's trial and prescribed Fleconides. The Pain Management classes were not deemed to be useful as I was seen to be managing the pain very well. Advised to join a Gym and take Fleconides at night.

2001 Feb, Colonoscopy undertaken at North Shore Hospital – some diverticuli, polyps and Bowel Cancer found.
April 30, Right hemi colectomy performed. Lymph nodes unaffected.
May, Residual nerve damage from CIDP kicks in. Both feet, right leg and groin affected. GP keeping watching brief.
June 15, GP prescribes 1 Nortryptiline (10mg) and 1 Fleconides (100mg) nightly.
June 17, Medication increased to 2xNortryptiline/1Fleconides nightly.
June 22, After a week, discontinued the above medications. No noticeable pain relief in groin during daytime. Leg and feet still densely affected. However, a side effect of the medication is serious constipation for which GP prescribed a daily enema. That's not acceptable so I discontinued the medication.

2002 Pushed on minus any medication with the exception of Brufen taken on the days I play outdoor bowls.

2007 Some 6 months of BowenTherapy failed to improve the situation.

2008 4 months of 'gentle manipulation' by a Chiropractic Physio came to nothing.

2009 Sept. Have asked my GP for help with groin, leg and feet pain for which Neuronton (now known as Nupentin) has been prescribed. I've also asked for an appointment to be arranged with a Neurological Specialist as I'm aware of a worsening in all the symptoms and have the sensation that the numbness is progressing up both legs towards the knee. I'm finding my ability to walk has lessened and about 200m is my limit before the pain worsens.

Do I have a recurrence of CIDP?

Is the recently diagnosed Raynauds Phenomenon an influence in all the above?

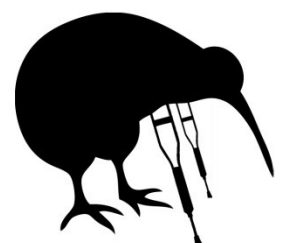
Was the back operation anything to do with the CIDP?

Was the bowel cancer a red herring?

Is it worth watching this space!?

YES

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



Something from the Kitchen

Courgettes are very plentiful at this time of year so here is a recipe that is quick and easy and a lovely way to use up the surplus.

Bread and Butter Pickles

Ingredients

8 cups sliced courgettes	3 medium onions
2 – 3 tablespoons common salt	2 cups sugar
3 cups white vinegar	2 teaspoons mustard seed
2 teaspoons tumeric	

Method:

Slice vegetables into bowl – sprinkle with salt and leave overnight
Drain liquid off, rinse lightly with cold water

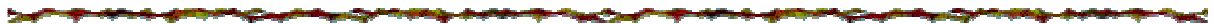
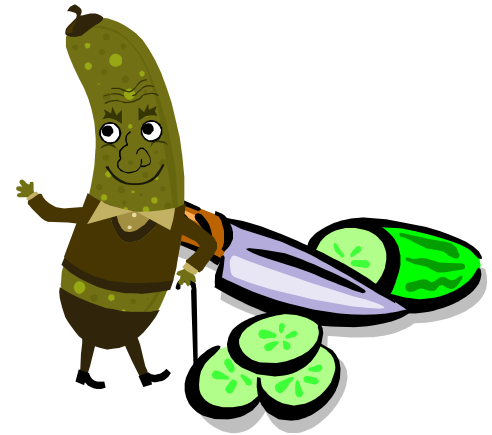
Put vinegar, sugar and spices into a pot, bring to boil and simmer for 2 minutes.

Add vegetables, bring back to boil and simmer for 5 minutes.

Put into jars.

Note: Any other veges could be added to this – cauli, carrots etc.

It is not necessary to have the exact amount of courgettes/onions (I prefer more onions), and the quantity does not matter as long as there is enough liquid! Any left over liquid can be re-boiled and used for the next batch.

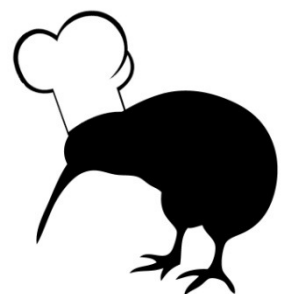


Correction:

Last months quiche recipe had a couple of errors for which I apologise. My proof reading obviously was not as good as it should have been.

Should have read:

2 eggs lightly beaten
150ml ($\frac{2}{3}$ cup) of cream



Glossary of Terms Often Used in Connection with GBS or its Variants

Here are just a few of the terms you might come across in dealing with Guillain-Barré Syndrome or its variant illnesses.

Syndrome: A collection of symptoms that make up an illness. There maybe only a few of these symptoms present in each patient, but enough to make a GBS diagnosis.

Acute: Happening fairly quickly.

Chronic: Lasting a long time.

Ventilator: Mechanical apparatus used to aid ones breathing.

Splints: Aids used to prevent the curling of fingers, and also used to prevent footdrop. While uncomfortable, they provide valuable long term results.

Lumbar Puncture: A process of withdrawing fluid from the spinal column in order to test for a positive diagnosis of GBS.

Nerve Conduction Tests: Not a most pleasant experience, but one used to calculate the degree of nerve damage by testing what information is getting through from the brain to the nerves.

Plasmapheresis: Is a process in which some of the patients blood is removed, the liquid part separated, and the blood cells returned to the body.

Paresthesias: Tingling, twitching, crawling sensations felt by the GBS patient. These weird sensations are very disturbing and annoying.

Prognosis: The likely outcome of the illness.

Corticosteriods: Hormones, normally made by the adrenal gland above the kidneys.

C.I.D.P. Chronic Inflammatory demyelinating Polyneuropathy. While C.I.D.P shares many features with GBS, it is often recurrent and may require ongoing treatment.

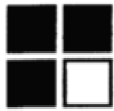
Demyelinating: Damage of or removal of nerve insulation.

Polyneuropathy: Disease of many nerves.

Fisher Syndrome: Also known as Miller Fisher Syndrome. This varies from GBS in that it involves eye problems, (weakness or double or blurred vision) in conjunction with facial weakness, abnormal sensations, and speech problems.

Axons: The best way to describe this is to regard the similarity with the electric jug cord. If you imagine the plastic coating on the outside of the jug cord is the myelin, and the inside of the cord (the wires) are the axons. The messages from the brain are passed through the nerve axons to the muscles. Once the message is interrupted by a damaged or stripped axon, then the message is interrupted and the muscles do not receive that message.

Myelin: The coating around the axons which protects and insulates the axon.



GBS/CIDP Foundation International

Serving patients of GBS, CIDP and Variants with support, education and research

Guillain-Barré Syndrome • Chronic Inflammatory Demyelinating Polyneuropathy

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February 5, 2010

Dear GBS/CIDP Foundation International member:

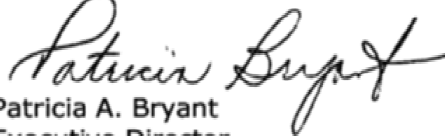
We are pleased to announce that you can now access the Foundation's quarterly newsletter, *The Communicator* on our website at www.gbs-cidp.org.

If you wish to continue to receive a hard copy in the mail, please email your request to info@gbs-cidp.org and include your complete mailing address or simply fill out the form below and return it to our office at:

The GBS/CIDP Foundation International
The Holly Building
104 1/2 Forrest Ave.
Narberth, PA 19072
USA

We are here to be of service to you.

Sincerely,



Patricia A. Bryant
Executive Director

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The official registration and financial information of GBSFI may be obtained from the PA Dept. of State by calling toll free, within PA, 1-800-732-0999. Registration does not imply endorsement

This website has a very interesting article on Flu Vaccinations and GBS. I could not get permission to reproduce the full article in our newsletter, only 200 words which could not do justice to the article so check it out it is worth reading.

<http://www.newscientist.com/article/dn18014-swine-flu-myth>

Notice Board

The 8th AGM: Saturday 1st May 2010 Palmerston North

Venue: - Psychology Department - Massey University. **Organiser:** John Podd

Time: 1300hrs or 1pm for those non-military people.

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all financial members of the Trust by the end of March. 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 welcome and should be lodged with the Secretary as soon as possible but no later than Friday 30th 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 CV of the of the candidate. If no nominations are received prior to the meeting the board may accept oral nominations at the meeting.

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

John has organised a room that will hold 40 people, and has coffee & tea making available - and toilets. Lift access is available close to the room. He is working on reserved parking at the moment.
A map (via email) is available from Jenny or the editor with the Psychology Dept on it.

Trustee Meeting:

This will be held prior to the AGM at 12 o'clock.

Subs are now Overdue

If you have forgotten to renew it's not too late.
Just send a cheque for \$10 to the Treasurer with
your details and he will do the rest.
See front page for address details.

