

Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

Registered N.Z Charity No. CC20639 Charities Act 2005



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NEWSLETTER JUNE 2009

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A Note from the Editor:



Hello everyone, I have taken over the job as Editor from Jenny Murray. She expressed a desire to hand this task on at the conference/AGM so I decided to put my hand up. Jenny has done a sterling job over the years and I'm sure you will join me in thanking her for all the time and effort she has put into producing our newsletter. I hope she now has a little more free time to pamper herself.

A little about me and my GBS connection. I live in Katikati on a kiwifruit orchard with my husband. Our children (2 boys), have flown the coup so we are free to travel, fish and ride our motorbikes.

I contracted GBS in November 2000 after returning home from an overseas trip. I thought I was coming home to pay off the VISA but instead spent the next three months in Tauranga Hospital. Not the ideal holiday destination but I did get waited on hand and foot and had all my meals cooked for me. I was released once I proved I could use a set of crutches and I couldn't get home fast enough. My husband had come into visit me that afternoon on his motorbike so I sent him straight home (30 odd kms) to get the car. It was then that the hard work started. Recovery was slow, painful and exceeding frustrating at times but thanks to my family, friends I am now enjoying doing the things I love again albeit with a few nanny naps thrown in when fatigue rears its ugly head.

Any contributions any of you may have for the magazine will be great fully received. My email and address are on the front page so please don't be shy.

Presidents Report:



We know that times are tough, nevertheless, over eighty members turned up for the biennial conference in Auckland in May and they were well rewarded. Not with Lotto-like wealth but in new knowledge about the weirdness that is GBS and CIDP, in the renewal of old friendships and the making of new ones. For me, there were four stand out aspects of the conference:

1. We were able to pay tribute in person to Professor Gareth Parry in recognition of him receiving a high award in the New Year honours list as well as listen to his presentations about up to the minute information about our neurological malady;
2. We heard courageous and informative addresses from Pralene Maharaj and Joanne Ho and we listened while Harry Randall's Dad told us about how the family coped with Harry's illness;
3. Dr Donald Campbell from the Food Safety Authority reminded us about the dangers inherent in food handling and of campylobacter in particular;
4. The notable involvement of many members (too numerous to mention in person) who contributed to the overall success by welcoming people in the foyer, (especially new attendees) and those who assisted in various un-asked ways with the smooth running of the event.

I'm already getting ideas together for next conference in Wellington in 2011.

Warmly
Bob Stothart
President

Secretary's Jottings:



Where has the last month gone! It hardly seems like yesterday that we were in Auckland at the Conference. Changing from a proven venue is always a concern for conference organizers but the Auckland team did a great job and whilst the hotel may not have been 21st century the willingness of its staff to meet our every requirement more than made up for that.

We had a GREAT gathering! – I am always amazed that what might seem “the same old same old” always turns out to be not just a good learning experience but also a most enjoyable couple of days meeting old friends and making new acquaintances.

The presentations were engaging. Hats off to Vicki and Ian Randall for dealing with their epic medical struggles – of which son Harry’s GBS was only a part- with such a positive attitude - a lesson for us all. Harry had us all entranced – although his meanderings thro the connections of the loudspeaker systems did cause our “Master of Electronics” Don Martin a headache or two!

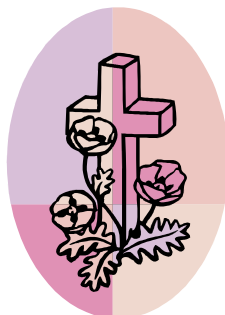
Gareth’s presentation, as always, is an essential part of the conference and brings us “down under” GBS’ers up to date with the cutting edge of research and clinical practice. The success of his work with “Pulsed steroids” for persistent CIDP sufferers and the potential of the “new” drug Rituximab to offer a solution to GBS’ers who do not respond to IVIG or Plasma Exchange is not only exciting from a patient’s viewpoint but offers the potential to save the Health Authorities huge amounts of money compared to conventional treatment options. Gareth’s recounting of his investigations into the GBS outbreak amongst workers in pig processing plants in the USA last year, whilst somewhat gory in places was hugely interesting and something we were all looking forward to hearing about. If you would like a copy of Gareth’s full Power Point presentation slides e mail me.

Often when we hear things at lectures or presentations it is difficult to see those relating to our own practical experience – well it has happened in Nelson! By chance Gareth was visiting our area and called into Nelson Hospital to see an old friend who had gone down with CIDP a couple of months previously and was not responding as well as he had hoped to standard treatment and was becoming something of a fixture in the Rehab ward. Gareth consulted with the local (very experienced) neurologist treating the patient and they agreed to give the new “Pulsed Steroid” treatment a go – the effect has been remarkable – I called into Nelson Hospital yesterday to have another chat to the patient – only to be told – Oh he gone home!!

A goodly percentage of you have already renewed your memberships but I shall shortly be chasing those who have yet to continue their support. I know times are tough financially for a lot of people but if the Group is to continue to provide essential support to new and ongoing sufferers then we need your continuing membership support – please help us if you can.

Otherwise nothing too exciting on the admin front. I have completed our first annual return under the new Charities Act – not as daunting as it first appeared. Now that the winter is upon us I will get stuck into the list of “tasks” that came my way from the Conference and AGM and am looking forward to celebrating that strange NZ event of Mid Winter Christmas in a week or so.

As always Take Care
Tony



Obituary

It was with deep sadness that we learned at the conference that a dear old lady, Mrs. McMahon had passed away. She was in a rest home in Cambridge, and a new member to our group. We extend our sincere sympathy to her family and friends.



Annual General Meeting 2009 Report

After a very full Conference day on Saturday it was gratifying to welcome some 30 members to the AGM early on Sunday morning. Lots of familiar faces, of course, but also some new friends made over the last 48 hours – the Friday evening Wine and Cheese get together is a great “barrier remover”!

With the new Trust Deed now operational elections to the Board took a new procedural route but ended up with the same Board continuing for another year; - very helpful for the Secretary as there is no one new to be “broken in” so to speak!

We learnt that the Group is beginning to spread its wings and took its message to other gatherings of medical professionals in Auckland and Wellington during the year. We are planning to “man our stand” at the Nurses 100th Conference celebrations in Wellington in September – all part of the plan to increase the awareness of the GBS and the support group to the medical world and general public.

Our President Bob Stothart’s annual report is reproduced elsewhere in this newsletter.

Peter Scott our Treasurer presented a reassuring set of accounts with adequate cash in the bank – but coupled with a warning of tough times ahead as the economic recession inevitably impacts on membership numbers and donation levels.

There is no change in the cost of Annual (\$10) or Life (\$100) membership – value for money at its utmost in my opinion when compared to my annual sub of \$45 to the UK group (which I maintain out of loyalty to the group that first supported me through my CIDP experience) and \$40 to the USA group.

The President and Secretary gave a short presentation of the Board’s policy plans for the Group in the coming months and years including plans to appoint a publicity officer, develop a hospital visitor’s network across the country and streamline our internal operation.

We met our new website controller Lil Morgan. Under her guidance the site just gets better and better – if you haven’t accessed it yet please do – you will not be disappointed! Go to www.gbsnz.org.nz Lil is keen to receive your personal stories. We all have different experiences to relate and broadcasting them may help more people than you realise!

Our conference key note speaker Gareth Parry urged us to improve the quality and depth of our Medical Advisory Board and this is now actively underway. Before too long we will have access to some of the best specialist advice in the country on GBS and its related conditions.

The 2010 AGM will be held in Palmerston North and the 2011 Conference in Wellington.

A good and lively meeting, lasting barely an hour, but nonetheless very important for the Board to get a sense and understanding of where the membership want the Group to go.

Tony Pearson - Secretary

Helping to Spread the Word...

Hi,

My name is Beth and I volunteer to help spread the word about a new free Schizophrenia online support group.

As I know this falls within your interest I thought that you might want to help us in the quest to reach as many people as possible (the more people know about the group the better help they will get). You can support us in many ways (not financially): telling people you know, linking to it, writing a blog or forum post and participating in the group discussions.

Your help is much needed and any support will be most appreciated.

You can check out the group at: www.mdjunction.com/schizophrenia

Beth Green,

POB 200067, Pittsburgh, PA

ANNUAL REPORT OF THE GUILLAIN-BARRE SYNDROME SUPPORT GROUP NEW ZEALAND TRUST MAY 2009

Introduction

I am proud to present this report on the activities of the New Zealand Guillain-Barré Support Group. I am proud because the organization has visited people in hospital suffering from Guillain-Barré Syndrome and CIDP (and other neuropathies), held a very successful Annual General Meeting in Christchurch and have provided information, stories and research findings for the benefit of interested people. The integrity and excellence of these activities are provided by volunteers who want to help others and the quality of the services offered is noteworthy.

Recognition

In the New Year Honours list, Professor Gareth Parry was recognized with the award of Order of New Zealand Merit (ONZM) in recognition for his services to neurology in New Zealand. Members join me in extending sincere and heartfelt congratulations to Professor Parry. His generous and memorable contributions to our bi-annual conferences and his support (through workshops) for New Zealand neurologists, has been outstanding. We are informed that it is very unusual for New Zealanders resident out of New Zealand to receive such recognition so we are particularly proud on Professor Parry's behalf. Professor Parry is held in high regard in the international world of neurology and is in constant demand as a keynote speaker.

Thanks

We thank without reservation Taranaki Savings Bank (TSB) and ARA Lodge No 384, for their on-going support. Without their contributions our task would be much more difficult.

Special thanks are due to all those who have visited people in hospitals or elsewhere providing messages of hope and encouragement. The work you do is important, generous and highly valued.

Thanks are due to people who sustain the organization: Jenny Murray who coordinates our activities with great attention to detail and confidentiality; Tony Pearson who provides outstanding secretarial services; Peter Scott who looks after our financial affairs with tact and skill; Gareth Parry who provides a constant flow of wise advice on medical matters and other members of the committee who are always on hand for advice and ideas: Don Martin, Forbes Bennett, John Podd, Julie Rivett, John Davies and Chris Hewlett.

Particular thanks are due to our patron Steve Chadwick MP for her on-going support and encouragement.

Members

Our membership fluctuates from year to year. Some people welcome our support when they are initially afflicted and as they recover then no longer wish to remain connected; others renew their commitment annually and contribute in various ways.

Currently we have 230 financial members

Our regular Newsletter is distributed to 500 plus recipients.

Activities

The law regarding the role and status of charities changed in 2005 and thanks to the meticulous work of Tony Pearson with legal assistance from John Chadwick we are a properly registered charity under the new legislation: No CC20639.

I have already mentioned hospital visiting which is a core activity. The publication of a regular Newsletter is also a core function. The Newsletter contains articles which focus on recent research, stories of personal encounters with GBS/CIDP and other neuropathies. It is the main vehicle for keeping people informed and in touch. Jenny Murray carries out the multiple tasks of gathering copy, typing and distribution.

International

I was fortunate (along with my wife Margaret) to be able to attend the GBS/CIDP Foundation's symposium in Chicago in November (where Professor Gareth Parry was a keynote speaker). This is the biggest GBS/CIDP conference in the world and the best researchers and speakers are assembled for this event. Information gained at the conference has been communicated through the Newsletter.

Conference 2009

By the time this report has been read, the fourth national conference will have been held, in Auckland. The bi-annual conference is our shop-window and we try to present a programme which is of interest and value to all members. The sharing of experiences with GBS/CIDP, the availability of up to date research and the forming and renewal of friendships, make the conference a very significant component of what we offer to members.

In Conclusion

I repeat my thanks to all who help to make the organization useful in providing, education, research and continued support.

Bob Stothart
President

PLANNING AHEAD.....Philadelphia here we come

Bob and Margaret Stothart intend to be present at the GBS/CIDP Foundation's Symposium in Philadelphia in early November, 2010. If you're planning to see Auntie Mary in Canada around then, or you need to visit your married daughter in Maine, stop over for the symposium and you will not regret it. Bob and Margaret are prepared to lead a group (or an individual or couple) and your NZ support group will assist with Registration Fees. The full details of the symposium will appear in the magazine The Communicator which you receive as part of your NZ membership. It is a great conference with contributors from around the world (including Gareth Parry) and you come away with a wealth of research and information. This time will be especially noteworthy as Estelle Benson, who founded the organization a few decades ago when her husband went down with GBS, is likely to retire. Your attendance guarantees that you become part of the international fraternity of GBS/CIDP people. If you're thinking of attending contact Bob.



A Personal Encounter...

by Jon Anda

CIDP - My Story

On Friday April 17th 2009 I was diagnosed with CIDP.

This came three days after being admitted to Nelson hospital as an emergency patient by my doctor, after repeated efforts to see a neurologist had drawn less than the urgent attention I felt I needed.

It has now been two weeks since my diagnosis and hospital discharge. With time to reflect I now realise my road to CIDP actually started over a year ago all with a new pair of shoes. I'm 49 years old and this is my story.

March 2008 I purchased a new pair of good quality sports shoes and after wearing them for a few days I noticed they felt uncomfortable in the front section as if the toe space was made from hard rubber. I took them back to the shop and was shown a new way to lace them that would help keep my heel back and thus relieve the pressure off my toes. This new lacing technique did offer me some relief and I further accepted that I just needed to 'break the shoes in'.

Little did I know...

July 2008 I noticed that, for a fit guy who lifts weights at the gym regularly four nights a week, my leg muscles appeared to have lost a little size and condition. I decided to work on my legs a little more to get them back to their former proportional specifications. ☺

August 2008 On a cold rainy winter's night I was driving to Nelson for dinner when I felt a cold clammy and numbing sensation in both of my legs from my waist down to my feet. It felt like cold water was being pumped through my legs, and even with the floor heater on full they still felt very cold. I was sweating up top and freezing down below. Thinking I must be fatigued I stopped and bought two muesli bars and a can of apple juice to boost myself up. This episode lasted about 6 minutes.

September 2008 I was standing on the tail-gate of my Hilux pick-up truck and jumped off onto the asphalt. Bang! I hit the ground with a bone-jarring thud that felt like I had jumped off grandma's garden shed hugging a sack of bricks. "Bloody hell, what happened here!"

The height from the tail-gate to the road is just a measly 89cm, or 35 inches! At 6' 2" I could have almost walked off!

I clearly remember thinking "Is this what it's like to grow old?"

October 2008 I was walking down a ramp off my Hilux when I experienced a very unusual and unstable transition at the point where my leading foot met up with the level ground. This feeling of instability repeated itself several times over the coming months when walking down the same ramp. It didn't hurt. It just didn't feel normal either.

November 2008 I spent the day walking the Abel Tasman National Park track. After about 13km of walking in my still 'very uncomfortable shoes' I decided to walk the last 4km barefoot. This wasn't much fun either, as I struggled to walk barefoot on the gravel track and "ouch, ouch, ouch" was muttered often. I clearly remember putting this barefoot pain down to the fact that I had soft 'townie feet' and I decided I would go barefoot more to get my 'country feet' back.

It was only as I got towards the end of the walk that I realised the track was almost entirely formed of sand. There is no gravel on the Abel Tasman coastal track...

December 2008 By now I had noticed my feet were feeling numb, tingly, and swollen. My fingertips were also feeling slightly numb.

I thought my balance might also be mildly affected - but I wasn't sure.

I had just passed my commercial pilot licence medical renewal with no problems. Surely this can't be anything serious? I'm good to go!

Then a friend of mine suggests I may have mercury poisoning due the amount of tuna I eat! Yeah right. I was beginning to wonder and worry...

December 17th 2008 Was my first doctor's visit with my concerns about the growing numbness and tingling feelings in my feet and fingers. He reassured me it was probably nothing to worry about and scheduled blood tests and checked out my heart. He also did some reflex tests and I recall thinking at the time that my responses didn't look particularly award winning. My blood tests concluded nothing out of the norm and my heart was good to go! He then referred me to a physiotherapist to investigate the possibility that I may have pinched a nerve in my back as a result of a snow boarding accident last winter.

So with 2008 coming to a close my feet hurt in my shoes. I thought I dribbled more in my sleep. I went to the toilet too many times at night and with more urgency in the mornings. My legs appeared to tire from walking up one flight of steps and my thigh muscles looked like they were getting smaller. I also remember waking up the day after any serious physical exercise feeling like I had been punched around the ring; On the other hand I still managed to go to the gym four days a week, I could hang off the end of my chainsaw in steep bush country for 4 hours straight, I could snowboard all day virtually without more than a toilet stop and I could ride my motor-cross bike non stop in the 5 hour Honda Iron Man motorcycle race. Nothing wrong with that!

I simply concluded that 2008 was the year I was physically ageing faster than I would have liked. I definitely noticed it, I definitely noted it, but I didn't think I had enough wrong with me for anyone to take me too seriously. After all, some would say that at 48 I am not a spring chicken anymore.

January 7th 2009 I now felt the intensity of the numbness and tingling in my feet and hands increasing at a predictable rate. I had my first physiotherapy session and I was shown some back and leg stretches to improve my somewhat poor flexibility. By now I had also noticed the soles of my feet had appeared to become very 'slippery' when walking barefoot on carpet or dry grass. My feet just seemed to have lost some of their natural grip and traction.

January 12th 2009 My second physiotherapy session and nothing new here just the same painful leg and back stretches.

January 19th 2009 My third physiotherapy session and with no improvement in my health the physiotherapist wisely referred me back to my doctor saying he couldn't help me.

February 23rd 2009 Was the week before my 49th birthday. It was back to the doctor for another round of blood tests and this time he also recommended I see a neurologist. I agreed.

February 2009 I felt the numbness and tingling increasing and extending up my legs and forearms in waves. I felt also the odd 'twinge' across my body - mostly in my arms, abdomen or chest. I sometimes woke up at night with cramps in both my legs at the same time, which was something I had never experienced before. I made a note to get more magnesium in my diet to counteract the cramps. I also noticed that the all-over buzzing sensation I was experiencing was possibly being aggravated by heat such as taking a hot shower or a spa, and even warming up on the cycle at the gym.

March 27th 2009 I was driving home from Hanmer Springs and I accidentally stood on the gas pedal instead of the brake pedal. I then noticed that the brake pedal felt unusually distant under my foot. Pressing the brake pedal felt as if I was driving with a towel wrapped around my shoe, thus reducing the expected pedal feel.

Monday 6th April 2009 Was the first day I had difficulty walking. When I walked from my car to the changing rooms at the gym I noticed my gait was somewhat staggered. I also noticed one of my knees would sporadically 'let go'. This caused me to lurch and sometimes flail my arms momentarily. To some it looked like I was a dancing drunk. That night at the gym a friend asked me jokingly "are you pissed?" I also didn't manage to finish my gym session for the first time ever.

April 8th 2009 Back to the doctor I now felt I needed specialist help sooner rather than later. My doctor ordered a final round of blood tests and sent a letter to Nelson hospital requesting an appointment with the neurologist. He warned me that the hospital appointment could be a few months away due to the long waiting list and suggested I consider the option to go



private, and I agreed; but with no private neurologist available in Nelson he referred me to a rheumatologist instead. When I received the rheumatologist's appointment I was told my initial 30 minute consultation would cost me \$250. Two hundred and fifty dollars for just 30 minutes! That's \$500 an hour for a guy who might not even be the right guy to help me! "And I am pretty sure I do not have rheumatism!" So, rightly or wrongly, I promptly cancelled that appointment and immediately returned to my doctor requesting I see a neurologist, and preferably a free one! About this time I also began emailing the neurologist's secretary with my updated symptoms, asking that I be seen at the earliest available opportunity. I even requested that in the neurologist's absence (at that time) that anyone there with some neurological expertise just read my communicated symptoms. To be honest, communication with them was pretty much one way traffic and right up to the day I was admitted to hospital I never actually received an appointment date ☹.

Monday 13th April 2009 I started experiencing singular and multiple electric shocks today, mostly in my legs and feet but occasionally in my fingers and arms. The shocks were lightning fast and felt like a fish biting hard and fast at a hook. At first they were quite scary because they would strike without warning. Some multiple attacks lasted up to 10 seconds.

Wednesday 15th April 2009 I woke up with my body being wracked by continuous waves of uncomfortable tingling, cramping, numbing and electric shocks. I felt a warm burning sensation in my legs and walking was difficult, painful and unstable. My hips ached and my balance was somewhat disappointing. As I prepared for work I soon realised I now had more important things to sort out: My health. I had endured enough. I felt like I had been sliding along a wire cable for the past few months collecting new symptoms and losing none. I could now clearly see the wall coming and felt something not nice was possibly about to happen. I emailed both my doctor and the neurologist's secretary again with my latest feelings and symptoms and once more headed to the doctor's. He again rang the hospital and was told the earliest the neurologist could see me now was possibly still over a week away. My doctor then told me he was going to admit me as an emergency. It sounded extreme, but for the first time in months I felt relieved and happy that someone was finally going to see me. It's important to remember that at this time I still didn't know if I had a tumour growing in my brain or just a gorse prickle in my foot.

When I arrived at the emergency department they were expecting me. I spent the next few hours undergoing general, blood and reflex tests. I was then told I was being admitted to hospital.

I'm 49 years old, single, being admitted to hospital for the first time in my life, and nobody is telling me much. I was scared but very relieved to be there.

Thursday 16th April 2009 Today I met Dr Clark the neurologist for the first time and after he examined me he told me I was to have conductivity tests done the following day. A nurse later came into my room and told me Dr Clark is the "the man", and that if anyone can get to the bottom of this he can. I was happy and confident she was right.

Friday 17th April 2009 Dr Clark came and took me for my conductivity tests. Conductivity tests sound much better than they really are. You get electric fence strength electricity pulsed into your nerves and joints right where you really wouldn't want it. They fire it into your wrist, elbow, ankle and even the side of your knee. My results indicated poor nerve conductivity and Dr Clark then advised me that he suspected I had something called - CIDP. He said this theory would be supported by having a lumbar puncture and looking for elevated levels of protein in my spinal fluid. To be honest at that time I felt nauseous and I didn't hear much about CIDP, blah, blah, blah... because I had locked onto the bit about the lumbar puncture. That just plain didn't sound very nice. The lumbar puncture was scheduled for that afternoon and actually wasn't as bad as I expected. They took three vials of a clear spinal fluid from my lower back and the results indeed indicated an elevated protein level of .86

I was finally given the official diagnosis of CIDP – Chronic Inflammatory Demyelinating Polyneuropathy. Dr Clark informed me that I'm one of about 20 people with this type of disease in Nelson.

Dr Clark almost immediately offered me a couple of treatment options:

I could spend a further 4 days in hospital having IVIG treatment (a drip) or I could try a home-based treatment using a daily dose of 50mg Prednisone (a corticosteroid) and 50mg Azathioprine (an immunosuppressive). I was also told it would take up to three weeks for the medication to have any significant effect. I opted to go home and was discharged on Saturday morning with pills in hand.

April 26th 2009 I have now been home and on my medication for 11 days. Some days are good and some days are not so good. Overall I have seen no overall improvement in my health and I can still feel the fish nibbling at my right foot as I write this.

April 28th 2009 Today was my first post-hospital follow-up with my doctor, which went well. We discussed my medication and booked the scheduled monthly blood tests. I also think he now has a better appreciation of CIDP and what it is, how I feel, and what I have endured. After the doctor's I hobbled into my local pharmacy to seek some 'doctor-approved' Nurofen Plus. Obviously due to my somewhat unsteady gait, I was promptly refused access to purchase Nurofen Plus, which is a non-prescription codeine based pain reliever. Phooey! The pharmacist told me she only supplies Nurofen Plus to people she knows. Upon her refusal of my immediate and genuine offer to develop a sincere and lasting friendship I had to hobble back to the doctor to get written verification of my condition. Back to the pharmacy. I received a sincere apology from the pharmacist for her "bad error in judgement" and I finally got hold of the only pain relief for CIDP that I possess.

Why me?

To be honest with you I have never actually asked myself that question and it's not even important to me. What is important is that I accept I have CIDP and that I get on and do the very best I can to manage it so I can get back to my normal healthy, active life.

So how did I get CIDP?

I'm told that CIDP can possibly manifest itself from an infection of some sort. Me get sick? I don't smoke, eat junk food, or even drink alcohol! I did go to the gym 4 days a week and I will deliberately get physically active any chance I can. So if I didn't get sick very often then there is nothing much I can tell you here. Or is there... Well, I do clearly recall this happening on more than one occasion: My gym is 45 km from home. I would drive there at 5pm for training and head home again about 7.00pm. On my way home I would often stop at the supermarket and buy groceries. Fighting off hunger pangs on the 45km homeward trip I would often snack or graze on my groceries. Maybe an apple, a slice of ham or some dried figs... nothing wrong with that, except for the small bout of tummy pain I sometimes got the next morning. You see, as far as I'm concerned the knurled handles on gym equipment has got to carry a lot of germs on them and sucking your fingers after handling dirty weights can't be too good for you! By the middle of 2008 I actually decided to carry an antiseptic pump spray in my car so I could disinfect my hands before I ate on the fly. Who really knows? By then my shoes were already uncomfortable.

So, that's my lot and what an interesting ride it's been so far. My shoes never got broken in, my leg muscles never got bigger, magnesium in my diet never stopped my night time cramps, and I never got 'country feet' last summer and, oh, that cold clammy feeling flowing through my legs last winter? Well that returned last week, twice. To make matters worse the global swine flu pandemic has just possibly touched down in Nelson at a time when I have been told to be very careful with my health due to my medically reduced immune system...

All I know is that I want to be able to fly an aeroplane again, go snow boarding, ride my dirt bikes, work up on my land and get back to the gym. I've still got too much I want to do and I am going to get there. Watch me. I'm Jon Anda and I'm from Nelson, New Zealand, jon@pinksalt.co.nz

Jon's hot tip for CIDP feet relief

The only tip I have for CIDP sufferers is: Protect your sensitive feet! Buy yourself some Muck Boots. Muck Boots are a super-comfortable insulated gumboot made from thick neoprene, which is basically wetsuit material. They are spacious, comfortable and offer far more foot protection than slippers, which are the only other footwear I have been able to wear for the past two weeks. Muck Boots are distributed in NZ by Swannndri and you can get them from most farm stores like Fruit fed and CRT. www.swannndri.co.nz



Exercises to Help with Balance

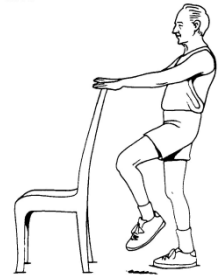
Exercise 1: *One legged Stands Eyes Closed*

Hold onto the back of a chair and close eyes.

Balance on one leg and hold as long as possible.

Repeat on other leg.

Repeat 10 times.

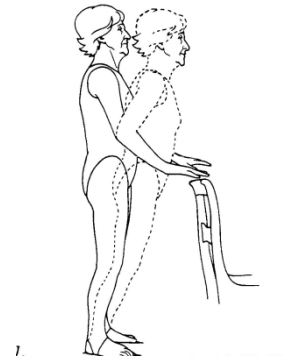


Exercise 2: *Front Leans*

Bring body weight forward and back as far as possible.

Try to maintain balance without holding onto chair.

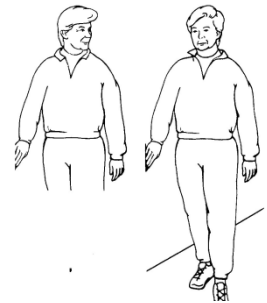
Repeat 10 times.



Exercise 3: *Walking Head Turns*

Standing close to wall, walk turning head right and then left.

Touch wall if necessary to keep balance.

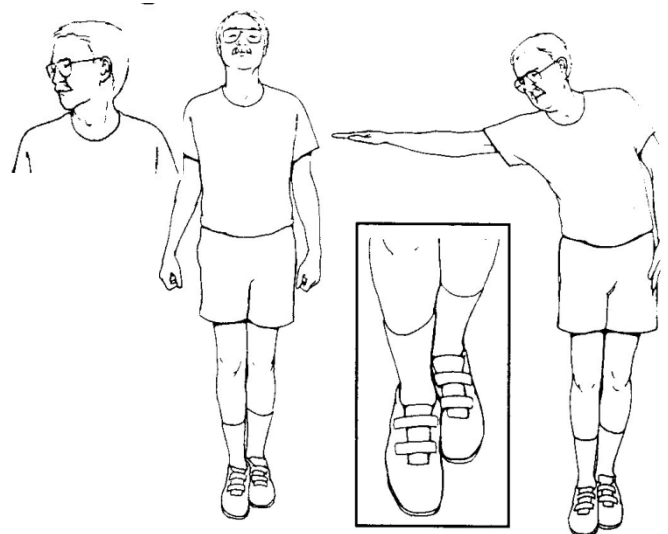


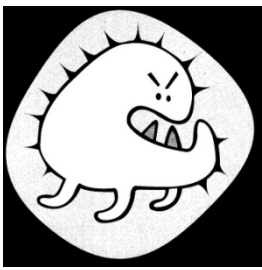
Exercise 4: *Semi Tandem Standing*

Stand with heel of one foot against arch of other foot.

- A. Look up 5 times
- B. Look right 5 times
- C. Look left 5 times
- D. With RIGHT/LEFT arm, reach right, left, forward and back.

Repeat 10 times.





Campylobacter

Donald Campbell from the NZ Food Safety Authority spoke at the conference on campylobacter. Here are a few facts and figures from that speech which you may find quite interesting. If you would like a copy of the article presented by Donald Campbell contact Jenny Murray.

1. It is caused by bacteria found in the gut of birds, especially poultry and animals such as cattle, sheep, cats and dogs
2. It is passed on in the faeces (poo) of infected birds, animals and humans.
3. It survives refrigeration (food needs to be frozen for up to 6 weeks to kill the bacteria)
4. Small infectious dose can have an incubation period 2-5 days, (range 1-10 days)
5. Symptoms of Illness: diarrhoea, abdominal cramps, fever, nausea;
6. First isolated 1909. Disease not recognised until mid 1970s
7. NZ has one of world's highest rates
8. Campylobacteriosis risk strongly associated with raw or undercooked chicken & chicken eaten in restaurants.

Risk also associated with overseas travel, use of roof water collection, raw dairy products, contact with puppies and calves, minced & diced meat & poultry from supermarkets & butchers.

89% (203/250) chicken meat samples collected positive for *Campylobacter*

<10% contamination of other meats sampled

9. Guillain-Barré syndrome

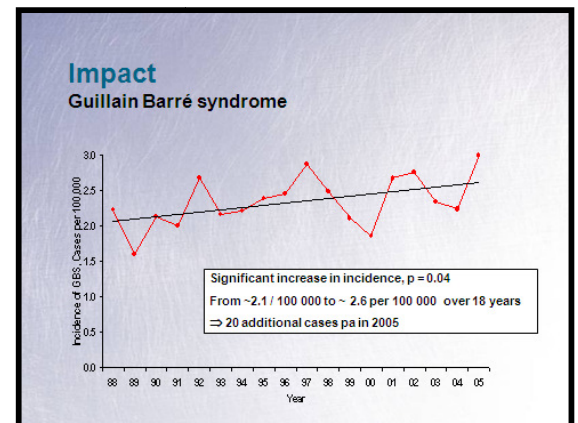
Peripheral neuropathy, spectrum from muscular weakness → complete paralysis → death. 10% fatal, 20% disabled, major driver of costs from *Campylobacter* infection

Significant increase in incidence 1988-2005

Significant correlation between increase & rise in campylobacteriosis

10. NZ has a serious campylobacteriosis problem with large public health impact

11. Fresh poultry has been dominant source (50-75%)



Ways to Lower Risks:

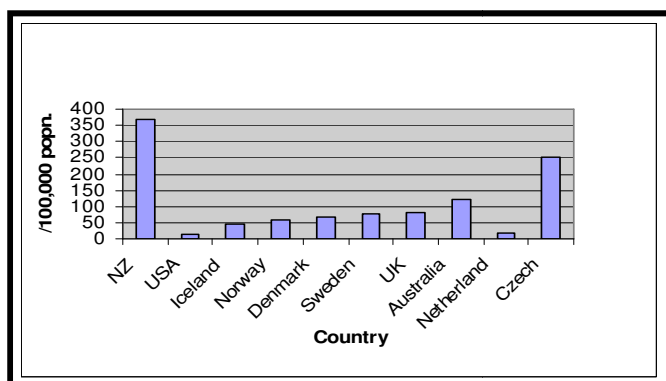
If possible use separate chopping boards when preparing raw foods, (especially meat and poultry) and cooked foods.

Scrub your chopping boards in clean hot soapy water

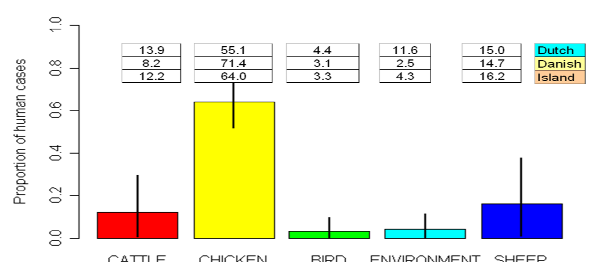
Cook poultry until the juices are clear

Keep raw meat covered and separate from other foods and store at the bottom of the fridge.

Wash your hands in hot soapy water.



Where is it coming from?

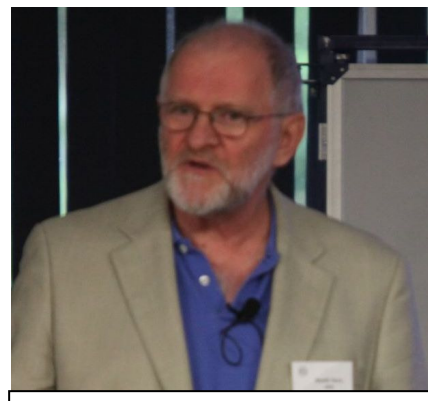




Ian Randall



Jenny murray



Professor Gareth Parry

Conference Organisers And Guest Speakers



Donald Campbell



Dr Pralene Maharaj



Steve Chadwick - Patron



Joanne Ho



Vivienne Pearson and Margaret Stothart

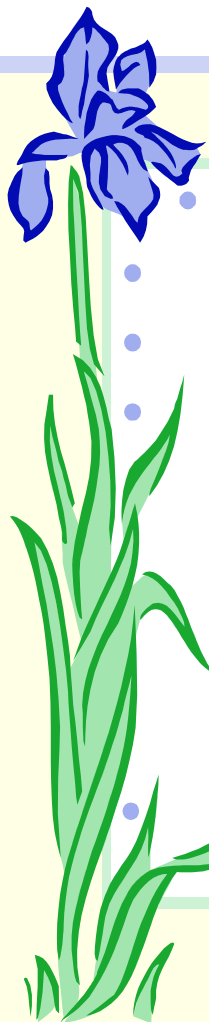


Peter Scott, Bob Stothart and Tony Pearson

Members Enjoying the Conference



Gardening Tips

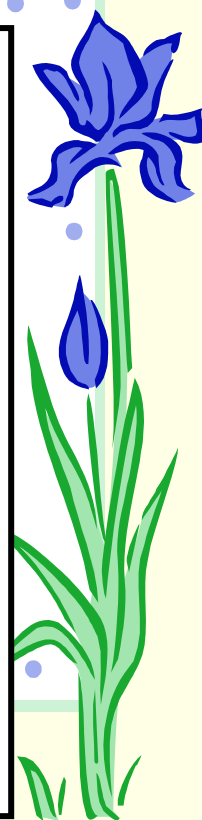


Time to start thinking about and preparing a space in the garden for Garlic, Shallots and Strawberry plants. These should all be available in your local garden centre from the beginning of June. The general rule for Garlic and Shallots is to plant on the shortest day, June 20th and harvest longest day, December 20th.

June is also the time to start looking at any rose care and maintenance that is needed as well as any fruit tree pruning that may be required. If you are not able to do these yourselves, enquire at your local garden centre, they may either have a pruning service or know of someone who provides such a service.

Keep planting the vegies so you can continue to enjoy the fruits of your labour. It is also a great time to replant your flower gardens with winter flowering annuals like Pansies, Primulas, Violas, Poppies, Polyanthus, Stocks. While doing this throw in a few spring flowering bulbs like Tulips or daffodils to come up among the annuals.

Have a safe, warm winter
Terry Watton



Something from the Kitchen

CORN & PUMPKIN SOUP

(Made in the Microwave)

INGREDIENTS

*1 Butternut or Pumpkin
2 onions
60gms butter
3.5 cups chicken stock
440gm cream corn
3tsp Worcester sauce
1.5 cups cream
1tsp chopped chives*

METHOD

*Combine pumpkin, onion, and butter in a large bowl.
Cover and cook on high for 3 minutes.
Add chicken stock, cover and cook on high for 30 mins.
Stir three times while cooking.
Puree in blender.
Stir in corn, Worcester sauce and cream.
Add chives and serve.*



Notice board



We have a web site that is being much underutilized. Lots of members appear to be looking but are too scared to write anything. It is a good way to swap ideas, thoughts and information so how about giving it a go.

Go to the website and get active. If you aren't a member already you simply follow the screen prompts and you are away.

Go to: www.nzordforums.org.nz NOW and have your say.

For Sale:

GBS NZ BADGE: Our own unique badge. It's a silver outlined kiwi

With paua shell centre and the words GBS NZ written below.

\$5.00 ea plus p&p \$2

GBS Teddy Bear with lettering GBS NZ on its shirt

\$7.00ea plus p&p \$2



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

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

