

Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

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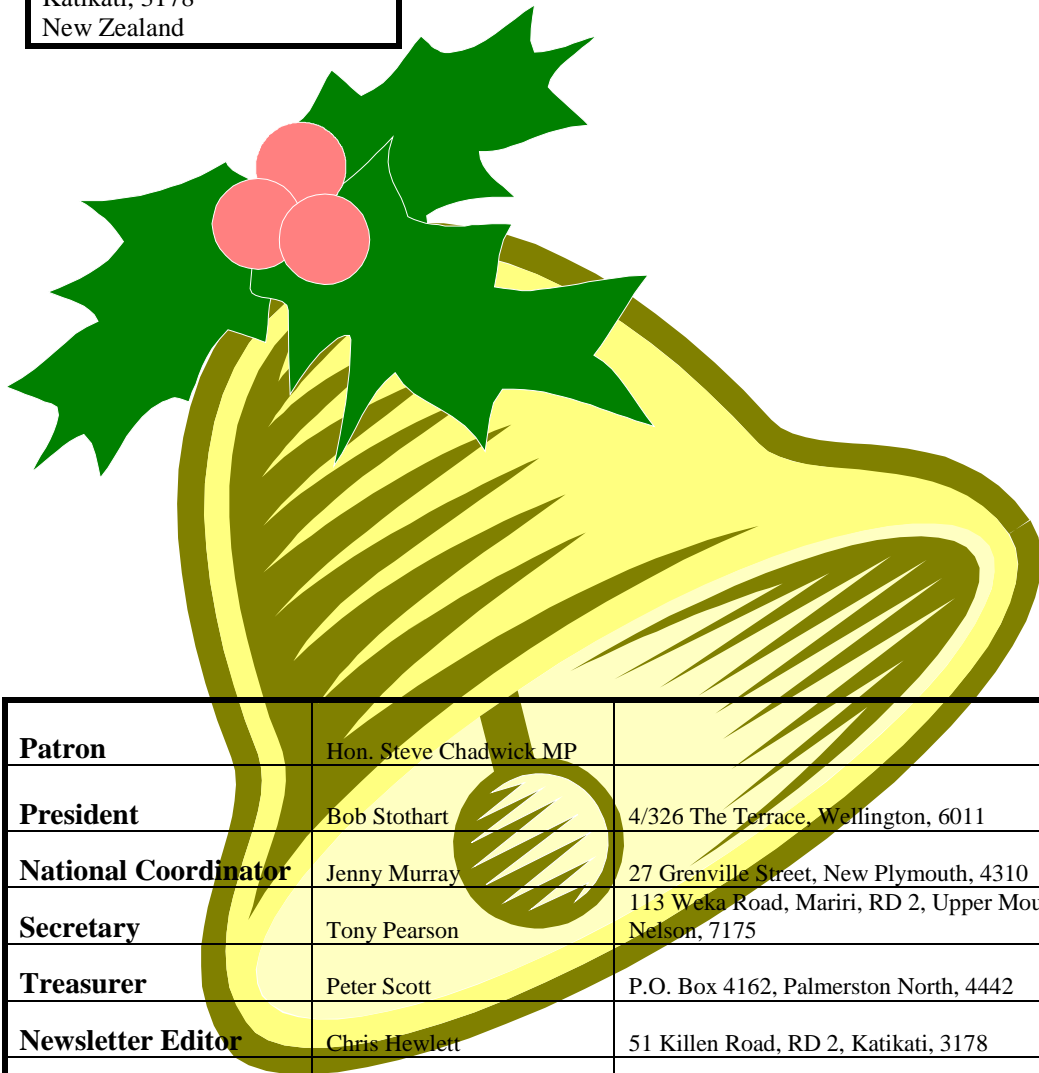


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NEWSLETTER DECEMBER 2010

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Editors Note



It has been a busy year with more new cases of GBS being reported than we would like, but hopefully those that have been affected have made good recoveries and found help and support through our group to make that journey easier.

Through the efforts of many people we have produced an excellent DVD on GBS/CIDP which is available to all. Contact Jenny if you would like one.

The role of Publicity Officer has now been filled thanks to Maria de Cort. Maria has written a small article to introduce herself and her connection with GBS, so please contact her if you have any ideas or projects in mind to promote the Group. Our thanks to Maria for taking on this onerous job. We also welcomed Ken Daniels to the Board of Trustees. He replaces Dr. Forbes Bennett who stood down at this year's AGM. Again our thanks Forbes for your time and input over the years.

I had my brush with GBS 9 years ago and talking to people who have since been struck down, it seems to me the early detection rate has not improved and this has to be a concern. Medical awareness needs to be heightened. We as a Group are continually trying to break down barriers and get communication going with Medical Facilities but it is not an easy task. Their dismissive attitudes highlighted when Jenny sent out over 30 of our DVD's and Dr Parry's book to nursing facilities around the country and only received a couple of replies thanking her for the information.

Hopefully you are all giving some thoughts to attending the Conference next year in Wellington. Information and registration forms are in this newsletter. This is a great opportunity to meet others and learn and understand more about GBS and what it has done to your body. To be able to talk to others who know exactly what you are talking about is very therapeutic. I hope to see many of you there.

On a recent motorcycle trip I managed to make contact with a couple of members in the Hawkes Bay/Wairarapa districts. It was great to meet you guys and thank you Vicky for the scones. They were lovely and set us up for the long ride home.

Last but not least I want to thank all those who have sent me their amazing stories and other contributions for the magazine. It has made the job so much easier.

I wish you and your families a very Merry Christmas and a Prosperous New Year.

Chris

Presidents Paragraph:



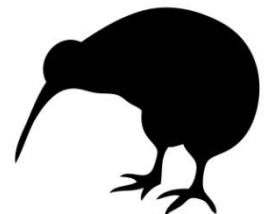
were getting started and we have much to thank her for.

My wife Margaret and I were able to attend the GBS/CIDP Foundation International's Symposium in Philadelphia in early November and it was a great occasion. Estelle Benson, who set the organisation up 30 years ago when her husband Robert got GBS, was stepping down and these gathered for the symposium made it a memorable event. She received a letter from the local Mayor, one from the Governor of the State and most impressively, one from President Obama, all thanking her for her outstanding contribution to the health and welfare of GBS/CIDP patients. Estelle established the benchmark for GBS support groups and saw her vision replicated around the world. Estelle was particularly helpful to our New Zealand group as we

The GBS/CIDP Foundation International funds research in the United Kingdom, in the Netherlands and in America and the recipients of these research grants make presentations relating to their field of study at the Symposium. It is evident that such is the volume and quality of the research activity that new understandings about the treatment and management of GBS/CIDP are emerging. This relates especially to the right kind of medication and the right amount of medication required to treat this perplexing, rare and troublesome condition. Nevertheless, the mantra of 'early identification (of GBS/CIDP) and early intervention of treatment' is the best course of action. It behoves all of us, patients, caregivers, family, recovering and recovered patients to advocate for greater understanding among the health community. Accordingly, the issues raised in the research will be addressed at our conference April 29/30, May 1. I urge you to be there.

May your summer season be a good one. Be strong and healthy.

Bob Stothart





Secretary's Jottings

Well, now that I have been accepted as a NZ pensioner and have received my Super Gold card (although have been too busy to find out where and what benefits it affords) I shall expect all due respect from the "junior" members of our organization! I get no such respect, however, from my eldest granddaughter (coming up 3 – going on 13! – many of you will know what I mean!!) who regularly reminds me that I am very old and don't have much hair! However, I was paid the ultimate compliment last week when she told me that I was her friend. At the time I was a bit taken aback – of course I am your friend I'm your granddad. But then I stopped to think – whilst I would naturally feel a family bond there was no reason why she should (her Mum and Dad probably being the exception) – I was just this funny old man that came to play with her fairly regularly. The more I thought about it the more I came to realize that her statement was quite significant in her eyes and therefore important to me.

FRIENDS ARE IMPORTANT – GOOD FRIENDS ARE INVALUABLE. I wonder how many of us have been helped through our GBS experience by the bond of good friendship – and indeed have experienced the personal but modest satisfaction of knowing that your friendship has helped someone else in the same boat.

And whilst on the subject of grand children can there be anything more pleasing than watching those first tottering freestanding vertical steps and the sense of achievement in those young eyes? – well in fact there probably is! – and although I am assured that the Physio's "Tilt Board" is a scary piece of equipment - I suspect the sense of satisfaction of being, once again, able to stand on your own two feet after weeks or months of immobility when you were getting use to the idea of being a GBS'er comes pretty close. I know I personally found the whole process of sliding out of bed, crawling to the toilet (and then probably having to be hauled off) and progressing painfully slowly up and down stairs on hands, knees and bottom very frustrating. It's not until something like GBS deprives us of our mobility that we realize just how much we have taken it for granted up to that point.

Frustration is a funny thing. I watched the terrible tragedy of Pike River unfold – as did the Nation- and whilst clearly we all know that mining is, and always has been, a dangerous occupation and the risk of accidents is something miner's families live with daily I had a strong hope at the start that the guys could be rescued – after all the world and I had just witnessed the amazing recovery of those Chilean gold miners. The families of the missing men had that hope a hundredfold. But rapidly that hope was smothered by Frustration – at the apparent lack of rescue activity – and friction began to appear between those involved. Thank goodness that caution prevailed – and in the process probably saved the lives of members of the rescue teams – all itching to "have a go". If I have seen it once I have seen it a dozen times both after GBS and Cancer scares. Initially there is tremendous hope for a full recovery but this quickly evaporates with Frustration at the length of time it is taking for that recovery to occur and perhaps the best advice you, as an occasional hospital visitor or a full time carer, can give is PATIENCE!!

The UK Support Group has a motto.GBS:- Getting Better Slowly –It's not a bad concept!

To end a bit of Admin:-

The Conference is coming and I have already had the first Registration Form in – you will not be surprised to learn it's from our Patron Steve Chadwick! So I look forward to you all making this a record event – Bob has certainly organized a good line up of speakers.

There was NO feedback on your experiences with ACC/WINZ claims/assistance – has NOBODY attempted to get help, financial or physical from them?

Subs for the coming year are now due (from 1st December 2010) but DON'T PANIC. If you are already a financial member I will be sending you a reminder in the next few weeks – in truth I had planned to have done this already but had not bargained on the demands on my time as the Secretary of our local Community Association that a "David and Goliath" battle over a local piece of land considered as a Public Reserve for the last 30 years but now claimed by one of the richest men in NZ - would have on my time.

If you are not a financial member of the Group – but enjoy receiving this Newsletter and the other benefits that the Group offers – either now or in the past – then do PLEASE consider joining up -20 cents a week is not a bad deal! - just let Jenny or me know and we will send you a membership form. Your support is more important than you may realize because when it comes to applying for funds to further our operations Charitable Donors look for strong membership support as evidence of a successful organisation.

Well I had better call that a day – big walk tomorrow into the Kahurangi National Park to a magical place called Silvester Lake where – with a bit of luck if the weather is clear we will be able to look across to the North island and see Mount Taranaki – which reminds me! – good luck with the next phase of treatment

Jenny – the Group needs you to fighting fit!

My "friend" of 40 years (well nearer 50 since we first started dating) has made the cocoa and promised me a heavy night of S.....noring!!

As always - take care

Tony



Introducing Maria - Our new Publicity Officer

My name is Maria. In May this year my husband Roy became ill, with what his GP first thought was “a virus” but was later diagnosed in Christchurch Hospital as Guillain-Barré Syndrome. Roy spent the best part of two months in hospital first at Christchurch Public (Neurology Ward 28 and ICU) and later Burwood Spinal Unit. It was an intensely emotional few months, and that was just for me, the partner/carer. For Roy I believe it was the scariest days of his 45-year life to date.



The night we were given “a name” for what we were dealing with, Roy’s nurse Tony on Ward 28 gave me a GBS NZ pamphlet and in the days following I made contact with Jenny and while we didn’t take up the offer of a support group visitor I really appreciated the contact I had with Jenny, the package of information she sent (including a story to help explain Daddy’s illness to our three-year-old daughter Megan), and we both appreciated the regular cards from members and that knowledge people were out there that really understood and had “been there”.



Roy has made a pretty remarkable and speedy recovery by all accounts but the overwhelming care and support we were shown this year by friends and family had us both wanting to give something back. When we got the September GBS NZ newsletter in the post and I saw the Situation Vacant ad for a publicity officer I decided to put my hand up. I currently work part-time as a Communications Officer at the University of Canterbury and am hoping my journalism skills and experience being by the side of someone battling this rare and pretty darn scary condition will enable me to help raise the profile of the support network and make sure anyone else dealt this hand will know where to turn.

If you have any ideas for ways we can publicise GBS NZ or have a personal story you want to share but need someone to help you tell it please contact me at: mandrdecort@clear.net.nz.

Remember Harry?

Those of you that attended the Conference in Auckland will remember Harry, a lively 2 year old who we believed had GBS. It turned out that Harry didn’t have GBS, but was struck down by some other virus. Harry, now 5, remains paralysed but he is still a very active little boy.

He featured in an article in an Auckland newspaper promoting an event for disabled athletes.

Click the link below to read more.

<http://www.theauckland.co.nz/sport/news/join-harry-in-the-race/3926262/>



A Personal Encounter..... By Jan

"Wait & See"

I was a fit, energetic, healthy, action packed lady who had never suffered ill health.

Three weeks prior to me being diagnosed with GBS, I had spent a day in the garden. I was laden with rubbish and tripped falling flat on my face and my poor neck took the brunt of the fall. The next day I saw the duty doctor in the local after - hours emergency clinic and I was confirmed with a bad case of whiplash.

11/03/2009 - We had been out to dinner with friends and had to come home early due to my back pain.

12/03/2009 - I had been to my doctor twice, once in the morning and later in the afternoon. My husband (Ray) had to wheel me into the Doctors surgery in a wheelchair as I was unable to walk. The doctor advised "there was nothing he could do for me" but due to my hectic lifestyle he recommended I take Anti Depressants which I declined.

13/3/2009 - In the early hours of Friday I asked my husband to ring for an ambulance as the pain was horrendous. I was admitted to hospital, with a 5 day history of back and neck pain, decreased power in my lower limbs & difficulty walking. CT, chest x-ray, 2 x lumbar punctures, blood test, proved negative.

16/03/2009 - I had an MRI scan and that evening I was confirmed as having suspected GBS. I was transferred to ICU and they commenced Immunoglobulin IV. I was in ICU for 7 weeks and my first week and a half was in an induced coma.

17/03/2009 - Incubated and ventilated, developed aspiration Pneumonia, treated IV antibiotics. Nasogastric feeding commenced. Required blood transfusions.

23/03/2009 - Minitract inserted 04/05/2009 - Nasogastric removed yay!

24/03/2009 - Tracheostomy placed, ongoing issues with pain and hypersensitivity, and requiring more RBC transfusions etc!

In ICU my family covered my room with pictures of my family, ferns, paua, rolling grass, the beach and colourful flowers. I am a Kiwi and just love the outdoors.

As I was paralysed from the neck down and unable to speak or even breathe for myself, my only form of communication was through my eyes. My family learnt very quickly how to decipher what I wanted but unfortunately it didn't work all the time and was very frustrating for all concerned. I remembered wanting some water or Red PowerAde and not that horrible mint stick that they lubricated my tongue & lips with. Mind you it kept me from choking.

My daughter (Nikki) would groom my eyebrows and cut my nails. Even though I didn't know what was going on she kept them immaculate as she knew I would be mad if that job had not been kept up to date. My families' endless dedication was amazing but it was my job to be the "mother". I do the caring and the nurturing. I love a challenge but this was ridiculous.

The doctors in ICU told my family to start a scrapbook as I would be in a coma for a long time. They could express their feelings or write down things that were happening on a day to day basis. This was therapeutic for the family and also something for me to read at a later date.

Excerpt from scrapbook written by Ray:

"I have been going up to the hospital 3 times a day and giving Jan a kiss and holding her hand sometimes with tears in my eyes. For the past week we all feel so helpless and wait for the time when we can talk to you "I love you. Jan" I tell you always. We missed our Wedding Anniversary but your brother and sister-in-law made a lovely dinner and I made the bed properly that morning."

26/03/2009 I kissed Ray for the first time. Ray writes *"I think Jan thinks I am a male doctor"*

Hee hee looks like I was having fun!!!!

October 2010 I am reading the diary for the first time and it brings tears to my eyes. Do you know, I am the luckiest woman in the world to have the most amazing caring family who have supported each other through this devastating time!

Little excerpts from the diary:

- *Unironed sheets on the beds and no tablecloth on the dining room table, my goodness!! That's bad!!*
- *My brother (Jim) did my garden, my god he's ruthless who authorised him that job!!!*
- *My son & daughter write "We have worked out that you know when we are there beside you. We say hello & give you a kiss and your blood pressure goes up slightly which means you are acknowledging us."*
- *My step daughter (Sue) arrived from Aussie and the family had a lovely pork roast with veggies. After dinner there was no dessert, my specialty. There was a knock on the door and my neighbour had brought a banana cake over. Even when I am not there the family can organise dessert, greedy little piglets.*
- *I was given a facial and my hands massaged. Yeah and I blimey missed all the attention!*
- *My son & daughter in law (Scott & Kaye) & my 4 grandchildren. Scott writes "We found 3 TV remotes and one telephone in the washing machine this morning all gone through the wash". I wonder who the culprit was.*
- *Nikki writes "I will never forget that moment when I walked into ICU and saw your eyes open. I cannot begin to describe how I felt; it was the most magical moment in my life. I looked into your eyes and you looked back at me with your eyes so wide open, just sparkling and glowing and full of love. I could see the relief, you knew you were safe and you were going to be okay."*

I was turned every hour and one day I asked if there was any possibility of having a shower. I love swimming and was craving to be under the water. To be shifted off the bed was so painful but it was worth it. Off we went to the bathroom. I had two male nurses looking after me this day, one was washing my hair and the other was washing my legs. When my husband came looking for me and opened the door...what a sight!!!! We had a great laugh.

In ICU I suffered from terrible nightmares which I was advised was normal and was drug related. One I will never forget involved my family and two nurses. I thought the nurses were out to kill me. They were actually two very special people and sadly I missed out on their excellent nursing skills but luckily there were many more to look after me.

One night I was very distressed as I was missing Nikki. My favourite nurse stood over me as I tried to relate "Please tell Nikki I love her". She rung Nikki and unbeknown to me Nikki's father-in-law had passed away suddenly and the funeral had taken place that afternoon. I did not know this but somehow I knew she needed to hear those words.

Another night I was sleeping and I got tapped on my shoulder, it felt so beautiful but no-one was there. Two nights went past and I received another tap, I think it was my guardian angel.

After many many days there was a tiny speck of light. Just before Mother's Day I was able to feel a little tiny expression of wind. "Awesome" I am on the mend. My Mother's Day card this year related to that incident and we had lots of laughs.

At last my lungs were clear and my lovely physiotherapist didn't have to put the tube down my throat anymore.

22/05/2009 I was transferred to a medical ward which was very frightening as previously I had two nurses by my bedside 24 hrs a day. I celebrated Mothers Day in this ward. My two step daughters (Kaz & Wendy) gave me a day to remember for the rest of my life. They arrived at 2 o'clock and said "we are going to give you a bath." Hot water, yummy!!! They located a sliding board and wheeled me through the corridor to this enormous bathroom and did I have a ball wallowing in hot water, shampoo, soap, massage you name it I got it. I came out squeaky clean and never have been the same again. So there are huge benefits to being paralysed once you forget your inhibitions (I had to lose those pretty quickly!!)

25/05/2009 - Transferred to Rehabilitation & Aged Concern Ward. What a huge wakeup call!

- My family were advised that they were only able to visit during normal visiting hours as I was going to start rehab. As I was told, the tears flooded down my face. I was so scared and could not stand to be alone.
- Did this mean that I would go hungry as I was unable to feed myself? How would they know if I needed help? How would I ring the bell and would they come?? Did they know how sick I was? Did they know how much constant pain I suffered at even a touch?)
- I lay in bed in terrible pain for hours waiting for my next dose of pain relief.
- I dreaded being put in the sling hoist to go to the shower as any tiny bit of movement caused me excruciating nerve pain and some of the nurses didn't understand what was happening to me
- The dietician telling me if I didn't eat they were going to put me back on the feeding tube. Yeah right!
- Pulling out the catheter while I was in the sling hoist with the balloon still blown up Ugh. I can tell you it was never put back.
- Being up in the sling hoist over a potty to try and make gravity work.
- Not having a shower everyday and the lick and a promise of a bed bath
- *I am chuckling while I write this as it was all a day's work.*

The good bits were:

- *Getting breakfast in bed and not starting work at 6'clock*
- *Having some terrific nurses & Health Care Assistants (HCA) who will hold a special place in my heart for ever.*
- *Having beautiful homemade food delivered.*
- *Receiving massages on a regular basis*
- *Taken out for coffee*
- *Catching up with family & friends*
- *Having time to reflect that I had packed a lot into my life and I had no regrets*

I have always set goals for myself and in ICU the goal was to get all the tubes out and learn how to speak. Scott came to visit for the day and he said "I have set a big goal for you, which is to climb Mt Everest. It might take some time, but you will get there." He put a picture of the mountain on the wall with inspirational sayings alongside. Since I couldn't move I had to look at them, so there was only one way up.

"Redefine a meaningful accomplishment"

"Cut yourself some slack"

"One step at a time"

"Realise the power of your thoughts"

"Think of your problems as potential teachers"

"It is not the mountain we conquer, but ourselves"

"It's easier to go down a hill than up it but the view is much better at the top"



One morning the Health Care Assistant came into my room to give me a bed bath and said "My god, are you growing a forest?" I missed her point and she cracked up and said it's about time your legs had a wax. I almost died of embarrassment. So my daughter was not up to the eight ball after all, she had missed this job in ICU and it had not been done for months!!!

Four months had passed and my hair was looking disgusting. My step daughter (Sue) made another trip from Aussie to see me and said enough is enough!! She came with dye and scissors. She had to plan her visit between me getting my medications and also being quick enough so that I could last the distance sitting in my wheelchair. She put me in the shower to wash my hair and luckily the shower hose did the trick. I sure felt like a million dollars and a drowned rat all at the same time.

I wore moon boots for 2 hours on and 2 hours off and at night they put hand splints on to try and open my fingers. In the early hours of the morning I used to rip the velcro off with my teeth as I felt like I was in a straight jacket.

Losing my appetite was a problem, but Wendy came in with a 12 volt chilly bin, which sat beside my bed. My family & friends kept it full and enticed me with goodies. It was awesome.

As I could not use a toothbrush, the nurses would clean my teeth for me which was difficult for them. They suggested I use an electric toothbrush so Ray purchased one. It was awesome even though it was difficult to turn off. To this day I get toothpaste down my clean t-shirt but at least I don't have to gag while my tonsils were getting cleaned instead of my teeth.

One night I heard a clinking noise up the hallway and it was Wendy. Her husband had been out fishing. She was carrying a tray all set up with china and silver cutlery. Here was this beautiful fish meal. Pan-fried Snapper, Kumara Patties and a Side Salad. A glass and a baby's plastic cup. Guess what was in the plastic cup? Black Rum to go with the coke. It nearly blew my head off.

A few weeks later my grandson had been fishing and he went home and pan-fried some more fish for me and brought it up in tinfoil for my afternoon tea. Was I spoiled, I sure was.

Scott, Kaye & the kids once again made the journey to see me with lots of home baking, books and new pictures for my wall. It was the middle of winter and they wrapped me up warm and off we went down the road in the wheelchair. It was scary as the road entrances were unfriendly. We crossed a pedestrian crossing and low and behold I nearly fell out. Scott grabbed me by the shoulder. Wow wee! Have you ever felt powerless and have no control over your body, so scary.

The Occupational Therapists were one out of the bag:

- Teaching me to hold and drink out of a cup without spilling it; it was so embarrassing when you have done it all your life without a hiccup. Ray came in to see me and I was so excited to show him I could drink water. As he entered my room I spilt it all down my front.
- Brushing my hair
- Learning to get dressed
- I was so excited to stand for the first time in the standing frame but it was pretty scary especially on the tilt board.
- We played various games and did jigsaws for the development of my hands. My OT and two HCA's brought me in gorgeous beads so that I could make bracelets and try and fine tune my fingers.
- My favourite therapy was cooking and this was just fabulous. In the end I cooked all the time, making afternoon tea for the ward and had fun swapping recipes. This was a major help in keeping me sane.
- I made modern flower decorations for the tables in the dining room and they are still being used.
- I had to learn to hold a pen before I could write again.

I was given a bigger room to help with my rehab. I would be put in the wheelchair for a short time and I would have to try and move around the room which was difficult as I had no power in my hands. My sister-in-law (Marilyn) was a cyclist so she took me down to the local bike shop and bought me a pair of cycling gloves. I was away, yay! I built up the strength in my arms quite quickly as I would go up & down the ward getting stronger and stronger by the day. The physiotherapists did a great job and because of the extreme pain, I am sure they were very apprehensive about me and my capabilities. My two youngest grandchildren were just learning to roll over, crawl and later walk. So the race was on. The only trouble with me is that I had to try and tell my brain to do the movements and then as the muscles had degenerated it was a tough ask. I kept watching all the stroke patients on the parallel bars and said to myself one day it will be me and it sure was.

Kaye gave me a subscription for two magazines. My friend sat and turned the corner of each page and then I had to try and turn a page. It was a good trick, really hard for me to do but I eventually managed.

I didn't fit into the criteria of being able to have taxi chits to help with my home visits but a friend contacted CCS and they were able to help me and have supported me ever since.

On the home front, my family kept up the housework just in case I arrived home at anytime. They tried to have it just like I would or as close to. They used to laugh and say it was never quite up to mum's standard!

The first time I had a home visit it was full of mixed emotions. The family put on the most beautiful luncheon for me but I was unable to help with anything and I felt like a stranger in my own home. I was very sad when I had to return to the hospital after 2 hours.

Ray and my neighbour brought Tammy (our Samoyed) up to see me in hospital and I was so excited. Tammy was more interested in smelling the grass and getting lots of attention from the nurses. I thought enough was enough of being ignored so I gave her a command and she was beside me like a shot. **Awesome!**

I was allowed home for the day on my 60th birthday, I was so excited. I wanted a pot luck lunch with my family & friends. We had a great day filled with so much fun and laughter. It was a special day that I will remember forever.

As I got stronger in my wheelchair my friends were able to take me for walks up to the rooftop garden. It was scary being out in the real world but exciting too. I had my first excursion to the supermarket. There were so many beautiful colours in the supermarket that I have never noticed before. We normally rush in on the way home from work and rush out again. I bought some goodies to go in my locker. It was interesting to see how I was treated differently just because I was in a wheelchair. At times I felt like I was being ignored which I found rather sad.

One day on my two hour pass, Ray & I got a taxi to the water front to share fish & chips with his family. I had my catheter in but all of a sudden I thought I was going to burst. Oh boy, all over the footpath and in my slippers. We couldn't stop laughing. Can't take me anywhere! I had the jolly thing turned off.

One Friday afternoon I came back from a home visit and was feeling a little low. Friday's were quite hard for me as this was normally the day when patients would be discharged along with their brown paper bags full of their belongings. Was it ever going to be my turn? I got back to my room and here on my bed was a beautifully wrapped parcel. Inside the card read "SURPRISE" and here were the tiniest, lacy G strings you have seen. One purple & and one hot pink for myself and my friend. We cracked up and one night my friend put her's on and when the nurse came to put her to bed... no need to say anymore.

Then came Saturday night - not another night in isolation. I was used to spending Saturday nights at the Speedway with Ray. With the help of my friend and her electric wheelchair we decided to have our own Speedway fun and had races up the main corridor. **Burn ups!** We were like naughty little school kids and in the end we got caught. We were told off and put to bed early but boy did we have fun and slept well that night.

There were so many happy evenings eating Subway, Chinese, Fish 'n Chips and the occasional cold beer so I guess this meant I was on the mend and getting up to no good. The only trouble was the old body was so slow in responding. The GBS recovery time being a millimetre a day.

My sister-in-law (Donna) is a great musician and came and played the piano and piano accordion for the patients in the Rehab ward. It was excellent and some people sung while others tapped their feet. At the end she played Abba's "I Have a Dream" - well did the flood gates open. I sobbed and sobbed but I guess it was my big release. My dream came true.

I now refused to have the Clexane injection in my tummy. This happened right on bed time. No kiss good night just a jab. I had had 217 injections and was totally over it. My poor tummy looked like a pin cushion.

The last couple of weeks in hospital involved staying in the hospital flat and me having to look after myself. Nikki and Lyn would come for sleepovers. Ray would come for tea but he wasn't staying over - he wasn't giving up his comfy bed, cheeky monkey.

My specialist is fabulous and I have a great admiration for her. She not only shows interest in my progress but we have had some great meaningful discussions about all sorts of things that have cropped up over my many months in hospital.

31/10/2009 FINALLY.....Discharged from hospital.

Since I have been home I have been to a Hydro pool which has been excellent therapy. As I was a good swimmer, I have also visited the hot pools but found this difficult as my upper body was the only part working at the time. The worst problem is standing on concrete as my exposed nerves are unbearable on rough services.

Ray managed to get me out in the garden and once down on the ground I shuffled along on my bum. The smell of the flowers, the dirt and the grass and the shine on the leaves was just heaven.

The cold legs & feet are a big problem and I just can't keep socks on. My dear mum of 90 has knitted me some gorgeous TV socks with a draw string and they are working magically.

Sometimes I feel I am trapped in my own body. My brain is on full alert but the body does not respond. I am not and will not be on the scrap heap!

I am attending a rehab gym 3 times a week. It is just fabulous and slowly I have got stronger and am now going for small walks around the house unaided. I was told I would spend the rest of my life in a wheelchair, never say never.

Just recently I have been able to tie my shoe laces and just manage to get my socks and undies on. I have trouble doing up my bra - aren't men lucky? Rolling over in bed is still hard and I get sore in my hips and lower back. My hands are still numb and it is very strange doing some personal care when you can't feel what you are doing. I will say no more! My legs are heavy and I get very little sleep but I have nearly weaned myself off the medication.

It has been wonderful that I can now babysit my grandchildren and I am enjoying every minute of it. My kids bought me a book "Don't Sweat the Small Stuff" which has been like my bible.

I named my story "Wait & See" as I am still completing my journey. "Wait and See" - I will be back to 100% !



EXPERIENCES COMMON TO GBS/CIDP PATIENTS

As raised at the GBS/CIDP Foundation International Symposium

Anxiety, Depression, Guilt, Poor bladder control, Constipation, Weight loss, Pain, Pins and needles, Unable to concentrate, being too warm, unable to sleep, Problems swallowing, Impatience, Double vision, Blood pressure variations, Worry about the future, Not wanting to be alone, Cramping and muscle spasms, Financial worries, Swollen feet.

EXPERIENCES COMMON TO CAREGIVERS

Anxiety, Depression, Guilt, Fear, Isolation, Weight loss or gain, Worry about today, Worry about tomorrow, Separation anxiety, Vulnerability, Physical exhaustion, Frustration, Loss of interest in activities previously enjoyed, Sleeping problems, Impatience.

The upcoming Conference in Wellington next year is a great opportunity to meet with others and discuss these issues and discover new ways and strategies to deal with them.



Bay of Plenty members - (left to right) Noel, Glenda, Meike, Jan, hubby Ray, Chris, Zelda and her friend and carer Joy enjoyed meeting for coffee and sharing their experiences recently.

Next get together is January. Check the details on the "Notice Board"

New to Caring?

Information for people who provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

This article has been reproduced with the kind permission of the author, Carers UK and GBS UK. I have omitted information specific to the UK welfare, pension, social services that do not directly apply to NZ.

Selfish?

Looking after a family member, partner or friend is something that will happen to most people at some point in their lives yet it remains one of those things people don't talk about. A few years ago I wrote a book about caring called *The Selfish Pig's Guide to Caring*. The title was deliberate. I wanted people to recognise that far from seeing ourselves as unsung heroes or selfless angels, as for many of us caring brings a mass of confusing and conflicting emotions.

Many carers feel they are selfish because they never wanted to be a carer, they resent it, or they feel guilty about their reaction. Exhausted and isolated, carers are so worried about the person they care for, and for the standard of care they are providing for them, that they forget about themselves. If that sounds like you, then don't be so hard on yourself!

In the long run this isn't good for you or the person you are looking after. People who have been caring for a number of years tell us how important it is to maintain a life outside of caring – keeping up with friends and family, staying in work. This isn't easy to achieve and you'll need all the help you can get. Life goes on – you have to pay the bills; you have to keep healthy.

Battles

Carers UK, who have produced this article, are an organisation of carers battling to get carers the financial, practical and emotional help they need. And battling is something that all carers have to get used to – endless benefit forms convincing professionals to take you seriously, arguing over the help you and the person you care for need. There is no doubt that caring can be a battleground. If I have one piece of advice – if I only knew then what I know now – it is easy to make sure you are as well informed as you can be. There is help out there, but you may have to fight to get that help.

I'm sure by now you feel like running for the hills – but it isn't all bad news and there is a positive side. Caring for someone else can be very rewarding personally. Carers now have a small but growing set of legal rights, hard won by organisations like carers UK. With each year that goes by, caring is gaining more recognition as one of the key issues facing our society in the 21st century.

This article contains all the basics you need to know – and there is a wealth of help out there. There are thousands of carers' organisations and groups across the UK that can offer practical help and support. I hope this guide will reassure you that you are not

alone and help you prepare for what might lie ahead.

Hugh Marriott

Author of *The Selfish Pig's Guide to Caring*

The Emotional Impact of being a Carer

However much you like or love the person you care for, the emotional and physical demands of caring can be extremely stressful.

It can be especially frustrating if you feel you spend all your time and energy looking after someone else, and they do not seem to appreciate your help. You may also feel as if you're letting down the person you care for by not doing enough to help them.

As well as dealing with a new caring role, you may also have to come to terms with a change in family relationships – suddenly having to do everything for your parents, who have always looked after you, may mean that you have lost one of your biggest sources of support. If you're caring for a spouse or partner then the change in that relationship can be especially hard to cope with.

If you live with the person you care for you may feel you have no time to yourself to relax and unwind.

The feelings you have about your caring role may change from day to day, or even from hour to hour.

You are not alone!

Everyone reacts differently to the stresses of caring, but when carers get together they often find that they share many of the same feelings. It can be very reassuring to talk to other carers and discover that your feelings are very similar to others in your situation. Some of the most common feelings carers describe are:

- Frustration
- Resentment
- Guilt
- Anger
- Fear
- Loneliness
- Depression

Get Help from:

1. Your friends and family – talk to them about what's going on, and ask for their help, support and advice.

2. Your local carer's group or centre – other carers maybe the best people to understand the situation. Find out if there is a condition –specific support group for carers, e.g. through organisations like GBS Support Group, MS Society, Alzheimer's Society, and Cancer Support.

3. Social Services can tell you about local support groups and services or maybe able to provide break services to help you get some time to yourself. (see practical help section)

4. Your GP may be able to refer you to a counselling service

5. Your Local College - see if they run stress management or relaxation courses



Looking after your health

There is no doubt that without the right support caring can damage your health. You'll need to find the balance between caring and looking after your own health needs. It's not an easy balance to find, but remember – the better your physical and emotional wellbeing, the better you will be able to cope with the demands of caring.

We could fill a book with advice about your health but here are three things to remember...

1. Tell your GP

As soon as you begin caring tell your GP that you are a carer. If they know you are likely to be under pressure at times, they will find it easier to diagnose and treat you and offer the support and advise you need. As a carer, you will probably carry on regardless through coughs, flu, stomach upsets and worse; but don't put off seeing your doctor if you feel ill.

2. Watch your stress levels

Stress is a fact of life for most carers. One carer put it like this: "when a dog goes to sleep, it's got one ear up. That's what it's like to care for someone." Not being able to relax has long-term detrimental effects on your health. It's easier said than done but it's vital that you learn to recognise the signs of stress and take action.

3. Look after your back

You may find that lifting the person you care for, helping them dress or move around places a strain on your back. It maybe impossible to avoid lifting and handling the person you care for but you can get advice and guidelines that may reduce the risk of injury. (ACC would be a good starting point here in NZ)

Social services (and/or ACC) may also be able to tell you more about training available in your area, and many local care centres offer training on how to lift without harming your back. You can also get equipment and aids that minimise the strain.

Laura Collins is a carer.

“I believe that keeping well and strong is so important for carers. So, how do we stay sane and manage the stress of caring? When there just aren’t enough hours in the day how is it possible to get all our caring tasks completed and still have time to ourselves? The answer is – to think smarter, not work harder. Here are my tips which have worked for me”.

Here she shares her tips for coping with caring:

1. Time spent worrying is wasted. Instead make your decisions by first making a list of the positives and negatives, and once you have made the decision do not spend time worrying about the consequences.
2. Don’t put things off. Make a list of all the tasks you need to do. Schedule the worst tasks first and plan free time for yourself.
3. Give yourself a treat, no matter how small. This brings a sense of control over your life and reduces feelings of stress. My reward might be an afternoon spent gardening or just spending some time with my cats!
4. Get help from friends and family. It can be difficult to ask, but remember you can’t do everything yourself. A burnt-out carer is of no use to the person you care for.
5. Tidy house, tidy mind. Reducing clutter in my life makes me feel able to cope so much better.
6. You must learn to ask for help and be prepared to accept it.

Getting some practical help

You maybe many things, but you are not superhuman. Caring can be physically and mentally exhausting and every carer needs help and support. Getting practical help could be:

1. Someone to come in and help with the practical tasks you have to do, e.g. personal care, bathing.
2. Adaptations or equipment for your home to make it easier for you to help the person you care for, or to enable them to do more for themselves.

3. A few hours break to give you some time for yourself.

4. A more substantial break of a week or more where the person you care for goes into residential care.

Employment

Working and caring can feel like holding down two jobs. After a hard day’s work and a long journey home, the last thing you may feel like doing is looking after someone else.

On a bad day giving up work may seem like the easiest solution. But before you do this, take some time to think about what you might lose by giving up work and consider your options. As well as an income, work can also give you the opportunity to socialise, a different set of skills to the ones you need as a carer and an escape from your caring role for a few hours a day or week.

Around 3 million carers combine work and care – this means that 1 in 8 employees (UK) are carers, so the chances are that you are not the only carer at your workplace.

Support at work

It’s a good idea to check your company’s policies for supporting carers in the first instance. You do not have to tell your employer about your caring responsibilities, but you might find that if you inform your manager or personnel officer about your situation they can help you manage your two roles.

Having an understanding employer or manager can make juggling work and care easier, but as an employed carer, you do have some rights that all employers must adhere to that could make it easier for you to manage your work and caring responsibilities.

Your employer should be able to tell you about:

1. Your right to take time off in an emergency, e.g. to arrange alternative care if the care package you have in place breaks down.
2. Your right to ask for flexible working, e.g. to work part time, flex-time, to do some or all of job from home.

3. Their own policies for carers in the workplace, e.g. career breaks, early retirement.

You could also ask your employer for more practical help that they could give such as access to a phone – perhaps in a private space – so that you can contact the person you care for if you need to, or for more information about support services they can refer you to.

Remember that you have the right to choose – and that means choosing to give up work as well as staying.

Having a life of your own

Caring is an incredibly valuable role, but it can all too easily become isolating. Your time can be spent thinking about the wellbeing of someone else rather than your own. It can be hard to keep up with friends.

Because you are worth it...

Having some time to yourself, away from caring, even for just a few hours can make all the difference to your own quality of life. Many carers say that having a life outside of caring helps them to feel more able to cope with the ups and downs of caring.

Food for thought...

Time for you might be catching up with friends, doing a spot of gardening, pursuing a new interest or learning a new skill or hobby. You might want to do a course at an adult education centre or college or a course through the internet. Some carers' organisations have activities for carers – outings, pamper days and opportunities to make friends who share similar experiences and understand your situation.

Facing the future

Nobody knows for sure what their future holds but for some carers there are some certainties that you have to be prepared for. With caring nothing ever stays the same and it is almost certain that the disability or illness of the person you look after will change over time. Don't assume that professionals like your GP or social worker will know about these changes. You may need more

help. Let them know and ask for a re-assessment of your situation. Likewise there may also be changes to benefits that you or the person you care for can receive.

You may also find that your need for emotional support changes once you have been caring for a while. Contact with other carers who know what you're going through may become more important, or you may find it harder to get out to meet up with other people or go to events.

Contact your local carers centre to find out if they can help you.

Residential care

If the person you care for moves into residential care, your situation will change dramatically. You may be living on your own for the first time, you have to get to know the staff at the care home and establish your role in this new set up, and your benefits are likely to be affected. Whilst you may no longer be a 'carer' in the eyes of the benefit system or social services, you may still be caring for your loved one. Some carers find they spend more time caring when the person they care for leaves home because as well as visiting (and often still helping with practical tasks like washing and dressing); they also have to spend extra time travelling to and from the care home.

When caring ends

There will come a time when caring will end and it is important that you are prepared. In a few cases this may be because the person's health has improved and they have regained their independence. However for most carers this will be in sadder circumstances – caring usually ends because the person being cared for had died. When your own life has been focused on someone else, in the case with many carers, it can be extremely hard to adjust to a life after caring.

Suggested Contacts in NZ:

Local CCS Branch
WINZ
Your GP
Citizen Advice for support Groups in your area

Garden Tips for Summer



I always mention to customers that plants are like people – feed and water them regularly and they stay healthy. This is especially so when under stress (would you agree?) Summer is a time when your plants will be under stress due to the heat and in many cases lack of water and nutrients. Deep watering is important to gaining success with keeping plants alive during the summer. By deep watering I mean that rather than give your plants a five minute wetting every night give them a half hour soak 2-3 times a week. By soaking I am not suggesting that you flood the garden. The best way to deep water is to either leave your hose on the ground beside each plant with only a dribble of water coming out, or purchase a “weeping hose” from your local garden centre. By doing this the water is soaked deep into the soil and does not dry up quite so quickly. The deeper the moisture the deeper the roots will go and the higher the survival rate through a hot summer.

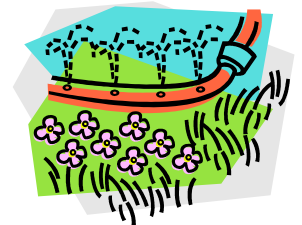
Slow release fertilisers are the best to maintain nutrients within the soil. However, occasionally you may need to give your plants a bit of a boost. This is when you would use a liquid fertiliser or granulated fertiliser. If we think again of the analogy of people, look upon the slow release fertilisers as the main meals with the liquid and granulated fertilisers as the occasional treat such as an ice cream or piece of chocolate.

These tips will help in your flower beds, shrubberies and veggie garden. I Hope this helps you to have a successful summer garden with lots of colour and a bountiful harvest.

All the very best for Christmas and the New Year. There is always something new around the corner, approach it with confidence and you will succeed.

Terry Watton

Paeroa Garden Centre (and fellow GBS sufferer)



Something from Jan's Kitchen

Broccoli Salad

This is a favourite family recipe, awesome with ham and barbies
Great for visitors over the holidays, left over real yummie the next day
Make it as big or small as use wish

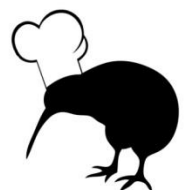
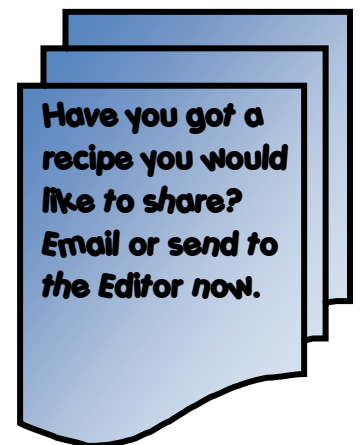
1 large bunch of broccoli chopped up
1/2 lb (500gm) bacon chopped into pieces
1/2 cup sunflower seeds
1/2 cup raisins
1/2 cup grated cheddar cheese
1/2 cup chopped red onion

Sauté the bacon and sunflower seeds in a little bit of butter or oil

Dressing:

1/2 cup of Best Foods mayo - it is a little bit expensive but worth it
3 tablespoons wine vinegar
3 tablespoons sugar
Beat the dressing with a spoon until sugar is mixed in.
You can add more sugar or less vinegar to your desired taste

Mix all together and chill in fridge for a couple of hours before eating as flavour goes through.





The Benefits of Bananas

Never, put your banana in the refrigerator!!!

Bananas contain three natural sugars - sucrose, fructose and glucose combined with fiber. A banana gives an instant, sustained and substantial boost of energy.

Research has proven that just two bananas provide enough energy for a strenuous 90-minute workout. No wonder the banana is the number one fruit with the world's leading athletes.

But energy isn't the only way a banana can help us keep fit. It can also help overcome or prevent a substantial number of illnesses and conditions, making it a must to add to our daily diet.

Depression: According to a recent survey undertaken by MIND amongst people suffering from depression, many felt much better after eating a banana. This is because bananas contain tryptophan, a type of protein that the body converts into serotonin, known to make you relax, improve your mood and generally make you feel happier.

PMS: Forget the pills - eat a banana. The vitamin B6 it contains regulates blood glucose levels, which can affect your mood.

Anemia : High in iron, bananas can stimulate the production of hemoglobin in the blood and so helps in cases of anemia.

Blood Pressure: This unique tropical fruit is extremely high in potassium yet low in salt, making it perfect to beat blood pressure. So much so, the US Food and Drug Administration has just allowed the banana industry to make official claims for the fruit's ability to reduce the risk of blood pressure and stroke.

Brain Power: 200 students at a Twickenham (Middlesex) school (England) were helped through their exams this year by eating bananas at breakfast, break, and lunch in a bid to boost their brain power. Research has shown that the potassium-packed fruit can assist learning by making pupils more alert.

Constipation: High in fiber, including bananas in the diet can help restore normal bowel action, helping to overcome the problem without resorting to laxatives.

Hangovers: One of the quickest ways of curing a hangover is to make a banana milkshake, sweetened with honey.. The banana calms the stomach and, with the help of the honey, builds up depleted blood sugar levels, while the milk soothes and re-hydrates your system.

Heartburn: Bananas have a natural antacid effect in the body, so if you suffer from heartburn, try eating a banana for soothing relief.

Morning Sickness: Snacking on bananas between meals helps to keep blood sugar levels up and avoid morning sickness.

Mosquito bites: Before reaching for the insect bite cream, try rubbing the affected area with the inside of a banana skin. Many people find it amazingly successful at reducing swelling and irritation.

Nerves: Bananas are high in B vitamins that help calm the nervous system.

Overweight and at work? Studies at the Institute of Psychology in Austria found pressure at work leads to gorging on comfort food like chocolate and chips. Looking at 5,000 hospital patients, researchers found the most obese were more likely to be in high-pressure jobs. The report concluded that, to avoid panic-induced food cravings, we need to control our blood sugar levels by snacking on high carbohydrate foods every two hours to keep levels steady.

Ulcers: The banana is used as the dietary food against intestinal disorders because of its soft texture and smoothness.. It is the only raw fruit that can be eaten without distress in over-chronicler cases.. It also neutralizes over-acidity and reduces irritation by coating the lining of the stomach.

Temperature control: Many other cultures see bananas as a 'cooling' fruit that can lower both the physical and emotional temperature of expectant mothers. In Thailand , for example, pregnant women eat bananas to ensure their baby is born with a cool temperature.

Seasonal Affective Disorder (SAD): Bananas can help SAD sufferers because they contain the natural mood enhancer tryptophan.

Smoking & Tobacco Use: Bananas can also help people trying to give up smoking. The B6, B12 they contain, as well as the potassium and magnesium found in them, help the body recover from the effects of nicotine withdrawal.

Stress: Potassium is a vital mineral, which helps normalize the heartbeat, sends oxygen to the brain and regulates your body's water balance. When we are stressed, our metabolic rate rises, thereby reducing our potassium levels. These can be rebalanced with the help of a high-potassium banana snack.

Strokes: According to research in The New England Journal of Medicine, eating bananas as part of a regular diet can cut the risk of death by strokes by as much as 40% !

Warts: Those keen on natural alternatives swear that if you want to kill off a wart, take a piece of banana skin and place it on the wart, with the yellow side out. Carefully hold the skin in place with a plaster or surgical tape!

So, a banana really is a natural remedy for many ills. When you compare it to an apple, it has four times the protein, twice the carbohydrate, three times the phosphorus, five times the vitamin A and iron, and twice the other vitamins and minerals. It is also rich in potassium and is one of the best value foods around. So, maybe it's time to change that well-known phrase so that we say, 'A banana a day keeps the doctor away!'

Participants wanted in Auckland Region for Medical Study

The School of Nursing at the University of Auckland is carrying out a study to understand the experiences of people living in the Auckland community with a long term condition. The emphasis is on non medical factors such as community and social support, practical ways people have adapted to living with their condition on a day to day basis and the frustrations and challenges of living with a long term health condition. Participation involves two interviews of about an hour each by two 2nd year nurse trainees either at home or wherever else suits between March and May next year.

If you would like to participate please contact Michelle Honey the Study Co-ordinator

Ph: 09 373 7599

E Mail: m.honey@auckland.ac.nz



Can you Help?

JON ANDA

Jon, a member of the Group, based here in Motueka (you may recall his story in the May 2009 Newsletter) has continued to suffer a deterioration in his condition. He has been diagnosed with CIDP – the very rare “anti Mag version which Gareth, who has met Jon, has described as “progressive and disabling”.

For the past 15 months Jon has been undergoing monthly chemo sessions with progressively more and more aggressive drugs including the latest Rituximab that Gareth described at our last conference – but to no avail. Jon has therefore elected to try a stem cell transplant treatment – as a kill or cure solution - and has been accepted as a viable patient at the Western Memorial Hospital in Chicago USA with a target to commence treatment as soon as possible in the New Year. The cost of the treatment, after care and flight/accommodation extras is huge – up to NZ \$250,000!! Jon hopes to raise the bulk of this by selling/mortgaging his assets and from very generous loans and donations from his brother and a close friend but he still needs all the financial help he can get.

If you feel moved to help Jon with a donation, no matter how small please, send it to me and will ensure it gets to Jon.

Thank you - Tony Pearson

Jon's plight was reported in our local paper last week and you can review it at the following links :-

www.stuff.co.nz/nelson-mail/news/4423762 and also 4423844

NZ GBS SUPPORT GROUP BI ANNUAL CONFERENCE

Where: Brentwood Hotel, Kilbirnie, Wellington

There is a Brentwood Hotel courtesy car. A taxi ride is a short journey as Brentwood is close to the Airport.

Please specify if you require an accessible room i.e. wheelchair accessible and bathroom accessible when you book in.

When: Friday April 29th 2011 to Sunday 1st May 2011.
Registration forms in this issue.

What's on:

Friday night: Wine and cheese, meet and greet

Saturday: Full day of interesting key note speakers including:

Professor Gareth Parry, neurologist at the University of Minneapolis, a distinguished New Zealander, and world authority on GBS/CIDP: he will make two presentations, one on up-dating us on recent developments and one on pain and fatigue.

Professor Ron Paterson, former Health Commissioner, and now Professor of Health Law at Auckland University: he will speak on patients' rights.

Lil Morgan and Ken Daniels will give a personal presentation's on their encounters with this perplexing neurological condition.

AND

Ask the Experts Forum where conference goers can ask questions and seek answers.

Discussion groups where people can share and compare their own experiences with GBS/CIDP.

Saturday Night: Dinner and further chance to chat to fellow members

Sunday Morning: The AGM

Stay and offer your thoughts and ideas on how we can provide more and better support to GBS/CIDP sufferers.



Notice Board

Want to receive your magazine by Email?

Just email the Editor and your colour copy will be on its way.

The GBS/CIDP Foundation International's magazine is now available online. Anybody who wants access to this magazine can get it online at:
www.gbs-cidp.org

NZ Facebook Support Group

Lil has set up a support Group on Facebook under the section 'common interest and health and well being'. If you are on Facebook join up and start some discussion going.
Guillain-Barré/CIDP Support Group

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

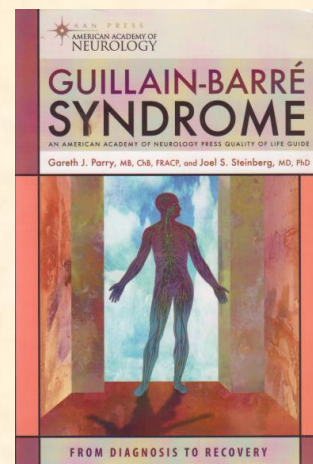
Coffee Morning for BOP members Or any others wishing to attend

When: Monday 17th January
Where: The Manor Café
514 Cambridge Road, Tauriko, Tauranga

Time: 10.30am
Please let Chris know if you can make it (07 5490931)
We have a table booked and the café is looking forward to hosting us. Hope to see you there.

SUBS ARE DUE

RENEWAL NOTICES WILL BE IN THE POST SHORTLY.



Jenny now has a new stock of Gareth and Joel's book.
Cost \$35 plus p&p

Written in an "easy to read and understand" format for the layman, it covers a wide range of topics including symptoms and diagnosis, caregiver guidelines, rehabilitation and much more.

If you or any of your family members want a greater understanding of GBS then I strongly recommend this book.

REGISTRATION FORM

Guillain-Barré/CIDP Conference April 29/30 1 May 2011

Name.....

Address.....

.....

Phone.....

Email.....

Please enclose Registration fee with this form and post to:

**Tony Pearson, Skylark Ridge
113 Weka Road, Mairiri, RD2
Upper Moutere, Nelson. 7175**

\$100.00 full registration

\$60.00 for Saturday only

\$50.00 for second person in a family

\$30.00 for full-time students

\$40.00 conference dinner. This is optional

Conference fees \$.....

Dinners \$.....

TOTAL \$.....

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

**Reserve your own accommodation at the Brentwood Hotel, 16 Kemp Street, Kilbirnie, Wellington:
Phone 04 920 0440 and quote the Reference Group number 70912 to obtain the GBS special rate.
(\$135.70 per room).**

You will need to specify any disability requirements.

.....
.....

If you are a first time attendee, please tick here.....

The conference fee covers venue hire, the Wine, Cheese and Chat session, the morning and afternoon teas, lunch on Saturday, postage, travel expenses for speakers and other administrative costs. It does not include the Saturday dinner.

We have worked hard to keep costs to an absolute minimum.

