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Guillain – Barré Syndrome Support Group New Zealand Trust

Registered N.Z. Charity No. CC20639 Charities Act 2005

NEWSLETTER MARCH 2015



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*Chris Hewlett
51 Killen Road
RD 2
KATIKATI, 3178*

Patron	Hon. Steve Chadwick		
President	Ken Daniels	12 Mallam Street, Karori, Wellington,	Ph: (04) 476 4323 Email: espin.karori@xtra.co.nz
National Coordinator	Jenny Murray, QSM	27 Grenville Street, New Plymouth, 4310	Ph/Fax: (06) 751 1014 Email: jenny.gbs.nz@clear.net.nz
Secretary	Tony Pearson	113 Weka Road, Mariri, RD 2, Upper Moutere, Nelson, 7175	Ph/fax: (03) 526 6076 Email: tonypearson@xtra.co.nz
Treasurer	Peter Scott	P.O. Box 4162, Palmerston North, 4442	Ph: (06) 357 8436 Email: peterscott@clear.net.nz
Newsletter Editor	Chris Hewlett	51 Killen Road, RD 2, Katikati, 3178	Ph: (07) 549 0931 Email: chrispy57@gmail.com
Publicity Officer			
Medical Advisor	Gareth Parry ONZM.MD.FRACP.ChB		
Web Site	Support	Education	Research www.gbsnz.org.nz

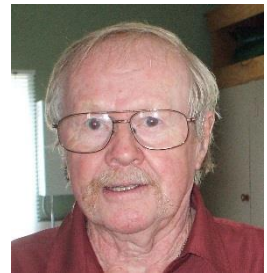
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Editor's Note

I begin this newsletter with an apology. For my tardiness. If you are lucky you will be reading this in March, the designated month but on the other hand it maybe your Easter read.

We have had an extremely busy month, with visitors, motorcycling, tramping, cycling and work that I'm afraid I just put the magazine in the too hard basket and enjoyed the beautiful weather we have had. But it catches up eventually so I have locked myself away in an effort to get this newsletter out to you.

It may not be as ñnewsyö as others but it will still keep you up to date with what the Group is up to.

I hope a good number of members have registered for the Conference as numbers were initially very disappointing and causing the Treasurer a few sleepless nights.

I believe the Board members have all agreed to do another term of office ó if you will have us, so don't be afraid to attend the AGM on the Sunday morning after the conference, you won't suddenly find yourself railroaded into a job. Having said that if you feel you would like to offer your services you would not be turned away. We still require a Publicity Officer and a Hospital Visitor Liaison Officer. Help will be given to anyone who would like to put their hand up for either of these positions.

Dr. Gareth Parry and Dr. John Podd still require people to contact them and take part in a survey project they are hoping to conduct on the benefits of visitors to GBS patients. Their contact details are in the magazine. Results of this could help increase our access to hospitals and new patients.

Our coffee group was very lucky to have Dr. Gareth Parry attend our February get together. We had a record turnout of 30 GBS/CIDP'ers and their partners. A couple of ladies made the trek from Auckland. It was great to meet them and welcome them to our group. A very big thank you to Gareth for taking the time to attend.

When I had GBS I heard of another lady who was in hospital in Tauranga but we never met till the first conference in Wellington. As we each slowly recovered we said we would go cycling together, even contemplating cycling to a conference in Wellington as a fund raiser for GBS but that must have just been the wine talking. However in February we finally got our act together and had a lovely day cycling part of the Hauraki rail trail. It was a long time coming and hopefully the next outing won't take 14 years to organize. Like our GBS recovery we got there slowly.



Looking forward to seeing you at the conference.

Chris



Presidents Report:

Autumn seems to be racing up on us at quite a pace! Despite some of the warm weather we have been having in Wellington there is a decided chill in the air at times and the nights are certainly getting longer. BUT there is a positive side to all that. Cosy nights tucked up in front of the fire or heater, the smell of rain on the summer earth, a hot drink, the sound of rain on the roof at night and the thought of a weekend in Rotorua! Yes the G.B.S. Conference is coming up on the weekend of the 9th and 10th of May at the Sudima Hotel in Rotorua. There are references to this in this newsletter but having seen the program my wife and I are really keen to go. Part of the attraction is the trip to Rotorua and the sights and restaurants of that intriguing place. Please come and join us. I can promise you it will be really worthwhile! (I am sure that you can still sit by the fire, have a hot drink and hear the sound of rain (but hopefully only at night!))



See you in Rotorua.

Ken Daniels

YOUR HELP IS URGENTLY REQUIRED.

PLEASE TAKE PART IN THIS STUDY

A study of the impact of a hospital visit on the quality of life during and after recovery for patients with GBS.

Dr. & G Parry and J Podd would like to conduct a study on the above topic and need your help. Initially they would like you to answer these simple questions:

1. Did you receive a visit from a member of the GBS Support Group N.Z. at any time during your initial hospital visit?
2. Regardless of whether you received such a visit or not, would you be willing to participate in a research study? The study will entail answering a series of questions about your in-hospital experience.
3. If you are interested in participating please contact Dr. Gareth Parry at the following e-mail address: gareth.parry@ccdhb.org.nz





Secretary's Jottings

Well Conference arrangements are falling into place and a good attendance looks to be on the cards so now I must turn my mind to the details of the Board Meeting and AGM that sandwich the day of the Conference. A formal notice of AGM is included elsewhere in this Newsletter and I will circulate all financially current members in April with details of the business Agenda. If you have any thoughts/ideas on matters that you think could be constructively discussed at the AGM let me know and we will try to include them in the business of the meeting.

I am heartened by the numbers of members signing up for the Hospital Visitors session on the Friday afternoon. Ken and I will jointly Chair the session and Gareth will add his professional input. I think the guidelines we have are still relevant but it will be a worthwhile exercise I believe to run through them and debate any issues Approved Hospital Visitors have found in their practical application. I will have copies of the Guidelines to distribute to new applicants and it would be helpful for those of you wishing to become an Approved Hospital Visitor to be prepared to give a brief summary of your GBS background to the meeting as well as your reasons for wanting to take on this important role. Could I also ask that everyone attending gives some thought to helping the Group by volunteering to take on the role of Hospital Visits Co-ordinator ó it is not an onerous task ó essentially just maintaining a record of the visits reported in by each Approved Visitor so that the Group can demonstrate, if necessary, that we are running a controlled and organised programme of trained visitors.

I mentioned in the last Newsletter the possibility of Group organised 'informal' one day gatherings in regional centres. I will raise the issue with the Board but it might also be helpful to get an indication of members support for the concept ó I will see if the President can squeeze in a 'show of hands' interlude in the busy Conference programme.

Our Facebook site seems to be gathering momentum ó I have been able to respond (constructively I hope) to a couple of the postings but it seems that the most helpful responses come from those members who have current or recent experience of the issue being raised by the 'poster' ó there is heaps of medical information available on the various GBS and other neuropathy websites but there is nothing like 'first hand' input into the issue that is confronting you NOW ó keep up the good work you 'Facebookers'.

There was an interesting article in the latest Headlines Newsletter from the Neurological Foundation ó about Chronic Pain. According to the research 1 in every 6 New Zealanders suffers chronic pain -17% of the Adult population ó and this rises to 28% when looking at the over 75 year olds! And two thirds of chronic pain sufferers have had to put up with it for 5 years or more! As the article points out chronic pain is clearly a major NZ health issue and as the population ages with more of us living longer it will only get worse. In spite of lots of ongoing research there is as yet no drug to 'fix' chronic pain ó with medication generally only resulting in a 30% reduction in pain. There is no diagnostic test for pain so diagnosis and assessment is purely subjective and involves not just medical input but awareness of physical and psychological issues impacting on the patient as well. Most GBSers will suffer from Peripheral Neuropathic Pain ó one of six recognised categories of pain - which arises from damage or disease in the peripheral nervous system ó and most of us know how that occurs in GBS! I count myself very fortunate to be pain free from my GBS experience ó I know many of you are not in that happy situation and you have my utmost sympathy.

I look forward to meeting many of our old friends and making some new ones at the Conference ó now less than two months away. If you are still undecided whether to make the effort to attend let me dispel any doubts ó you will not regret coming!

As always
Take Care

Tony

GBS – A Personal Encounter – Emily O'Reilly



Hi my name is Emily, I wear hinged AFO splints to walk with, and they have butterfly prints on them. I don't really understand why but mum tells me my experience with a thing called GBS like this.

On September 2012, Emily aged 2 years 10 months was sitting at the kitchen table singing Happy Birthday to her little sister who had just turned 1 year old. She complained of sore feet. As a very outdoorsy, never sitting still kind of kid my first thoughts were, splinters, bee stings and pins in needles from sitting on her knees at the table on a big persons chair. All of these scenarios became ruled out. Several days later, the pain began to creep up her legs and she would have bursts/ waves of pain which would progress up her body until she was screaming and as stiff as a surfboard.

I took her into an after-hours clinic in Christchurch (40mins drive) the doctor there witnessed one of the pain bursts and immediately sent us to Christchurch Public Hospital CAA (Child Acute Assessment) ward. Emily had initial observations done and then we were told to hang out and wait. Eventually we

were told that her clinical symptoms were fine, i.e. no temp, so go home and take paracetamol for the pain. We went home and had a hideous night of pain.

Back to CAA, same message- go home the pain will be the aches and cramps of the flu, come back if anything else is concerning. Another hideous night of pain and no sleep. Back into CAA and we were eventually admitted into the Children's ward. We were visited by several registrars who all told us that it was just flu like symptoms.

However I knew we were dealing with something worse. The pain bouts were getting more frequent and intense. The pain had now reached her arms, hands and abdomen. Over the next two days Emily was given Paracetamol, Iprobafen, Codeine and Morphine and none of these did anything for the pain. We were then told to go home (it was a Friday)! I had to carry Emily out to the car as she had no control over her legs. It felt so wrong carrying my child from the hospital, not fixed but worse than she had gone in. After another hideous night of pain and no sleep -where Emily was getting weaker and weaker by the hour I consoled myself with thoughts that the medical practitioners would not send us home if they thought there was something very wrong with Emily. I started to second-guess my mothering instincts and Emily's integrity- maybe she was making it up. But in my gut I knew these thoughts were all wrong- this was real and Emily was not that type of child and too young to know anything but the truth. After toughing out 14 hours of intense pain bursts, she couldn't walk, couldn't hold a colouring pencil and had lost the ability to talk, and was incredibly pale I took her back in and we were once more admitted to the Children's ward. Later that day Emily got a Lumbar Puncture and MRI scan done. When they went to scan Emily she was too weak in the chest muscles to be anaesthetised safely and so therefore was incubated. The results, supported the suspected diagnosis of GBS.

After this the flight for Life team were arranged and at 1am Emily and I were flown to Starship.

Emily stayed in Starship ICU or PICU (pediatrics intensive care unit) for 44 days, where she received testing for Polio, treatments of IVIG, a trachy and 4 plasmapheresis sessions and the most amazing nursing ever.



GBS – A Personal Encounter – Emily O'Reilly.....continued

Two days later she was diagnosed with certainty with GBS. We began to see improvements and the twinkle in the eye return. Although she was improving entertaining her was limited to being read too, talked too and watching Dora the Explorer. An iPad became the next form of entertainment as she was able to swipe with the base of her hand and the look of satisfaction each time was heartwarming. Once she was off the ventilator she was moved to the Neurological ward. Emily spent two weeks here and we became her 24 hr. carers. She was unable to be left as she was too weak to push the help buzzer.

In this time Emily learnt to sit on a box by herself, swallow, eat jelly and slither on the floor like a ssssssnake. Her trachy was removed and this meant that The Wilson Centre would accept her.

The Wilson Centre for Children is the only rehab unit for children in New Zealand. It has six beds available for external patients in Villa 1. The other Villas are for respite care predominately for Cerebral Palsy children. I was able to stay on site in a share accommodation unit with one other family. Emily and I spent 3 months here and the therapists were truly special. She was given a weekly timetable that was divided up into hourly physical therapy, occupational therapy and daytime sleep periods. Once Emily was strong enough to be wheeled around in a wheel chair we would go out on adventures to places like Takapuna Beach and Devonport. Our time at the Wilson Centre was an enjoyable one, as the talented therapists returned our girl to us.

Two years on and Emily has gone from strength to strength. She started and graduated from kindy, is doing too well for the community therapists to continue to have her on their books. Swimming with help from The Halberg Trust with funding and is doing ballet as part of her rehabilitation. School is now the new and exciting thing in her life with the original 3 half days being replaced with 4 full days.

Muscle fatigue and cognitive fatigue are Emily's great battles. She has a sensitivities diet which at different times during the day allow her to stop, relax and regroup before getting to -wired and then behaving badly. This plan has given Emily lots of strategies to recognize and then reduce her arousal rate. She uses these techniques at school, at home, in the car and in other situations such as the mall where the stimuli are too much for her.

Emily seems to touch something inside everyone who has crossed her path and somehow made them laugh with her and enjoy her special determined and courageous positive outlook on life.



Conference 2015

The 13th AGM: 0900hrs Sunday 10th May 2015. Sudima Hotel 1000 Eruera Street Rotorua

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all financial members of the Trust in early April. Everyone is welcome to attend the meeting but only financial members are eligible to speak and vote at the meeting

Members who are unable to attend the meeting may nominate a Proxy to vote for them, either our President Ken Daniels or another member of their choice.

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

Conference Assistance Fund

The Trustees of the Group are keen to encourage members and their families and supporters to attend the May Conference in Rotorua but understand that the cost of doing so may place this beyond the reach of some. Accordingly a Fund has been set up to assist people wishing to attend the Conference who might otherwise be unable to attend.

Applications for assistance should be made to the President Ken Daniels who will determine if assistance is warranted. Please write or e mail Ken at the address following. You are assured that your application and any award will be treated in strict confidence.

Ken Daniels, President, GBS Support Group N.Z.

12 Mallam St. Karori Wellington 6012

espin.karori@xtra.co.nz



HOSPITAL VISITORS

As you will notice from the details of the Conference programme published elsewhere in this Newsletter we plan to hold another meeting of accredited Hospital Visitors on Friday 8th May at 1500hrs.

All current Hospital Visitors are urged to attend but we would also welcome those members, whether GBSøers, CIDPøers or Carers who feel they could contribute to this very important area of the Group's activities to come along. If you are wanting to volunteer contact Ken or Tony before the meeting with a brief history of your 'GBS experience' and also the name of the Hospital/s that you would be willing to visit.

The meeting will provide an opportunity for an update on training and, most importantly, provide an opportunity for Hospital Visitors to provide feedback on their experiences over the past couple of years.

GBS – A Personal Encounter – Linda Bannister

My journey began in late 2010 in the year of the ōSwine Fluö. We were on our way to Napier to celebrate our son and daughter-in-law's birthday in the first week of August. We had just passed a sign saying ōwelcome to the wine countryö only somebody had put an ōSö in front of the wine and saying Welcome to the Swine Flu Country. I laughed and pointed it out to my husband.

I felt fine on leaving home, then on our approach to Napier I started to sneeze. This became worse into the evening and soon I was bedridden for 5-6 days and taking cold and flu tablets and Neurofen trying to ward off the flu virus. It was this Noro Virus which occurred 3 times and by the week before Christmas when we had gone to a wedding in Rotorua that I noticed my legs were weakening and I was becoming unsteady on my feet. It seemed I had to have my husband at my side to support me on every step. Christmas came and went and on Boxing Day we went to a local Picnic Race Meeting. Well I saw the first race and then feeling tired went to sleep under a tree. I woke up around 6pm. Everyone had gone but my husband was still there reading his book and told me I had missed all the races. I thought I must have been so tired with all catering we had done from November onwards in our business.

Each day the weakness worsened and I had excruciating pain in my spine. I could not sleep as my back was too painful to lie on. The lounge floor was the only place I could grab a few hours sleep on my stomach with a pillow under my head. I went to see my Doctor and then a physio who thought I had sciatica.

In desperation with pain I went to an after-hours medical centre. I was given an x-ray and then sent home. New Year was spent at home as I was not well and then at midnight decided to dance on the deck with my husband to the music of Mama Mia. My legs felt so weak!

When I walked out onto the deck in the morning my legs gave way. We called an ambulance and went to hospital. (The next day we were booked on a flight to the Gold Coast but we cancelled our trip and I was very thankful we did not go.) It was a Friday and a Dr. on duty luckily diagnosed Guillain Barré Syndrome. I was immediately given Plasma over 5 nights. The pain continued with intensity and nursing staff tried me out sleeping on a Lazy boy chair. I was not comfortable anywhere. I was sent home on the 7th day in a wheelchair.

My husband struggled to get me into the house over the stone chip driveway. The next day I was in the shower and noticed the paralysis had spread from feet up legs onto torso in lung area. My breathing had been affected and I needed a fan next to my bed. I returned to hospital but was sent home after midnight with a list and told to come back if I got worse.

I was able to walk at first with the walking frame, firstly across the room to a chair. I placed chairs all around the house as the days passed. The pain went on for about 4 months in my spine. I had painkillers to ease this. I started exercising in the hospital pool and later on in our local swimming pool.

My balance was badly affected but I was determined to get on the road to recovery.

I wanted to feel useful so began making jams, chutneys, preserves etc sitting on a high stool in the kitchen stirring the jam on the stove. I was pleased with my efforts and had a nice display in my pantry cupboard.

I could not go back to work for about 5 months and then only an hour or two at first. I decided it was time to give up work when my husband semi-retired. We managed a trip overseas and then turned our home into a Bed and Breakfast and my husband Rex drives the school bus 4hrs a day. This has suited us very well. I am also able to groom dogs as a hobby sitting on a hair chair and using a hydraulic table.

It is now four years since I contracted GBS and I am thankful I found the Support Group. It was almost a year before I found it after I was told one day that I would be hard pressed to find a Doctor in our local medical centre whom would have been able to help me with GBS.

GBS – A Personal Encounter – Linda Bannister

.... continued

Thank you Dr. Parry for your book ó it has been a God-send in times of sickness and thank-you Jenny Murray for your help in the early days.

I still get the flu virus every winter and some of the symptoms return. I have some residual symptoms, tiredness, tingling in the ends of my hands and toes. My balance is still a problem but one day on a day when I had a bad flu and breathing problems I decided I needed to exercise so I looked up on the internet and found Nordic Walking. The poles have been a great support to me with walking. I can now walk the Hamilton lake Circuit. We have taken the poles overseas and apart from some strange comments I have been able to enjoy walking longer distances.

I had also been ballroom dancing for four years prior to GBS and now enjoy the odd social dancing.

I also appreciate the café morning to catch up with others with GBS.

GBS was my 2nd big challenge in life as I had Malignant Melanoma when I was 34 years old. GBS struck when I was 57.

I am now proud to be 60 and regard everyday as a òNew Dayö to be enjoyed. My husband has been my biggest supporter. We have 5 grandchildren to spoil. It really is the Golden Years.

Special Guest Attends Coffee Group Meeting



Ann Moring and Julia Arden



Grant McKay, Barry and Judy Deed



Warren and Marilyn Turnwald



**A big turnout
at Feb. coffee
group
meeting to
meet and talk
to Dr. Gareth
Parry.**

Jan Gribble, Dr. Gareth Parry and Jenny Ackroyd



Jan & Ray Morrow and Eileen Jacobsen



*Meike Schmidt-Meiburg, Fran and Grant McKay,
Barry and Judy Deed*



*Karen Soppet, Dick & Christine Wilton,
Rex Soppet*



John & Sue Dixon, Ken Arden



Ray and Linda Bannister



*Meike Schmidt-Meiburg, Ray Morrow,
Eileen Jacobsen and Glenda Ryan*



Rod Bellerby, Gordon and Celia Stephenson



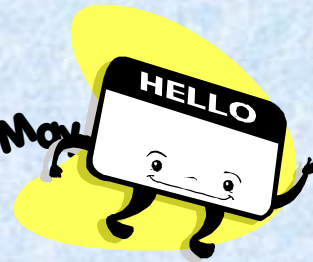
Everyone enjoyed the question and answer session held at the end of a very convivial meeting



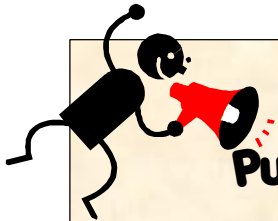
Conference 2015.

Where: Rotorua – Sudima Hotel

When: Friday 8th May to Sunday 10th May



You will need to book your own accommodation with the Hotel either by
E-mail reservations@sudimarotorua.co.nz or Phone 0800 783 462



Wanted

Publicity Officer and Hospital Visitor Coordinator

If you think you have what it takes to promote our Support Group or be the liaison person for our hospital visitor program please contact Ken Daniels or Tony Pearson.

Their contact details are on the front page of the magazine and they'd love to hear from you.

WAIKATO/BAY OF PLENTY COFFEE GROUP

July 2015

Where: To be announced

When: To be announced in June
Newsletter



See you there.
Everybody welcome.