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## Guillain – Barré Syndrome Support Group New Zealand Trust

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

### NEWSLETTER SEPTEMBER 2014

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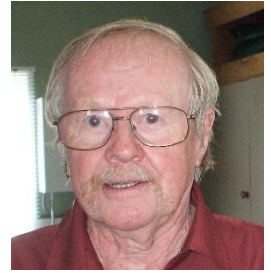
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## Editor's Note

or 3  
Like Tony, Marty and I jetted to escape the rain and cool weather to find some sunshine and warmth. Rarotonga was our destination but we didn't escape the rain and we experienced the coldest winter they have had for 40 years. Having said that I still swam 2 times a day so it wasn't all bad. Came home feeling very refreshed and relaxed. So it has taken me a while to get this newsletter underway. Articles for inclusion are very short so this isn't the meaty edition you have become used to. Please send me in your stories or any other article you think others may be interested in reading.

Each month I receive notifications from Google on how our web site is going. Despite us giving it a fresh new look it doesn't appear to be too successful with 82% of viewers not even bothering to look past the opening page. Any ideas on how we address this? I have put the August statistics later in the newsletter.

Our Coffee Group had another great turnout, this time in Paeroa. Moving the venue around is certainly proving valuable as we are getting to meet more and more members each time. We will be having a Christmas theme for our November meeting which will be held at the Okoroire Hotel near Tirau.

Of course the conference is coming up next year so we need you to mark that on your calendars and give it some thought re attending. Remember if you would like to attend but finances are stopping you we do have a special fund available to assist with your travel costs. This is of course kept confidential. Contact Tony Pearson if you require further information.

As always I'd love to receive your story or any other article you think other members may be interested in.

*Chris*

### **What's in your Magazine this month.....**

Editorial  
Presidents Annual Report  
Correspondence Received  
Secretary's Report  
How's our Web Site Doing?  
Personal Encounter  
BAUD Device  
Notice Board  
BOP/Waikato Coffee Group

Chris Hewlett  
Ken Daniels  
Chelsea Watton  
Tony Pearson  
Google Analytics  
Sue Dixon  
Tony Pearson

Photos by Meike Schmidt-Meiberg

## **A Very Big Thank You to Chelsea Watton**



Hello Jenny

I have just done the ice challenge and want to donate to your charity GBS. I know quite a few people that have been affected by the disease including my father and I want to put back into the organisation.

Thanks,  
Chelsea Watton

## Presidents Report:



There are times when I think I should be paying attention to the astrology column in the paper! The stars must have been in some sort of tremendous alignment last weekend for my family. On Friday night our beloved chocolate labrador dog Queeny died unexpectedly, The oven stopped working, a new granddaughter was born, Judith Collins jumped off her perch and the last day of winter brought unexpected sun and calm to Wellington. What's this got to do with GBS you might ask? Well, it got me thinking of the weird mix of grief, pain, hope and joy, that can surround those with the illness. In my case as with many others life was going along just fine before unexpectedly the devastating paralysis and pain come from nowhere. Then grief followed the realisation that life may never be the same again; then hope that it would and eventually came the dawning of the new world that slowly appeared on the other side of the hill. I must check what the astrologers predicted for me back then!

One of the main aims of our organisation is to offer support to those who are suffering with or have had GBS/CIPD. As you may be aware the confusion and almost overwhelming feelings that follow a diagnosis can be hard to cope with.

Every year somewhere between 40 and 100 people in New Zealand are diagnosed with GBS or a related illness. Many of these new cases do not come to our attention although I am sure that most sufferers or their families will come across our website or that of another support group on the internet. If you know of someone who needs help or support get in touch with them, refer them to the website and if necessary call on the help of other members to help them in this most confusing time.

One way to help yourself and others is to learn more about the latest developments in the research, treatment and help available in GBS/CIDP cases. Next year on the weekend of the 10<sup>th</sup> and 11<sup>th</sup> May, we will be holding a conference at the Sudima Lake Rotorua. This is a spectacular venue and we are expecting a full and interesting program of expert speakers, discussion groups and time to swap experiences with other members. The hotel has good accommodation and is on the shores of Lake Rotorua. The Polynesian Spa is almost next door and you may want to allow time to relax those tired muscles! We will be sending full conference details later but it might be an idea to diary the evening of Friday 8<sup>th</sup> May 2015 (registration), the Saturday and Sunday for this major event on our society's calendar.

See you there!

Ken Daniels



### ***In Memoriam***

A donation to the Group is a special way of remembering the life of a relative or friend





## Secretary's Jottings

There is a saying that "All that glitters is not Gold" and that was certainly true of our recent 10 day break on the Gold (well actually Sunshine) Coast of North Queensland. We went looking for a bit of sun and warmth but regrettably found little of either & but what the heck they REALLY needed the rain! The upside was a chance to catch up on some reading so let me impart a few pearls gleaned from that exercise that are relevant to our Group.

Firstly hats off to **John Forman**, the Exec Director of the NZ Organisation for Rare Disorders, who whilst not achieving everything he has been lobbying for has certainly made a big impact on the recent review by PHARMAC of the way they are prepared to allocate funding for the so called orphan diseases & keep up the good work John!

(incidentally GBS is not considered "rare" although getting the DHBs to cough up the required doses of IvIg vaccine might indicate otherwise!)

**Bob Gregory**, one of our Founder members, sent me a link to a USA legal case where a young woman who contracted GBS after a flu vaccination was awarded a US\$4.5m settlement & don't hold your breath for a similar deal in NZ.

**Southern Cross** & probably the biggest Health Insurer in NZ- paid out a whopping \$140,000 in repatriation and treatment costs for a kiwi client who was hospitalised in Asia with GBS and then contracted pneumonia. Want a second opinion on what might be wrong with you? & well why settle for just one! & with the help of **CrowdMed.com** you can send them your symptoms and a nominal fee and dozens of medical professionals, students, and "the man in the street" will share their knowledge and expertise to help diagnose what's wrong with you. Needless to say not every medical professional is happy with the concept both with the credibility of those offering advice and as to the security of sensitive medical information uploaded to the website. I guess you pay your money and take your choice!

And finally & in this "soundbite" section & A recent article in the **Kia Tiaki Nursing Journal** about the experiences of Disabled Nurses struck a real chord with me with the following definitive example:-  
"A person who uses a wheelchair experiences an **individual impairment** as they are unable to walk but becomes **disabled** only when they are confronted by a building without a ramp access as their opportunity to participate in society is thereby restricted. How many of us have been grateful to that Physio or OT who arranged for the raised toilet seat or similar aid that help minimise the disability caused by our GBS impairment .

### Now to more "Secretarial" business

I have just received the BAUD device from the supplier in the USA. We have it on free trial for a couple of months (but this can be extended)- the unit sells for US\$500! Its hand held & like a fat Smart Phone & comes with some pretty straightforward instructions & backed up by an offer of Skype or Phone advice if needed. I have tried it out (using ear buds) and it seems to be a "white noise" generator that you tune to the appropriate volume and frequency to effectively block the brain's signals that are causing the discomfort or desire. The system claims to reduce cravings for food and cigarettes and reduce levels of depression and anxiety but - much more importantly from a GBS perspective - to MINIMISE PAIN SENSATIONS. Four members have already indicated they would like to trial the system so I will start to circulate it. No guarantees & but if you would like to give it a go please contact me.

In the absence (I hope temporarily) of a volunteer to take on the job of the Hospital Visitors Co-ordinator I have agreed to get the job off the ground. I will be contacting all the approved visitors shortly to clarify the requirement for recording visits to sufferers and their carers but, for the record, the Board of Trustees are most concerned that we take proper steps to preserve and protect the integrity of the Group by maintaining a full history of visits made under the umbrella of the organisation. I have also consolidated the remaining small stocks of our brochures and pamphlets & so if you need some to pass on to new GBSers let me know and I can supply you or forward them directly to the new patient or their family.

There is information elsewhere in the Newsletter about the Conference and AGM in Rotorua next May but you may be interested hear a summary of the results of a poll the UK Support group took recently of its members concerning the ongoing desire for their annual Conference ó attendance at which had been falling significantly over the past few years:-

90% of respondents had attended a Conference- three quarters of those had been between 1 and 5 times. Of the 10% who had not attended half cited travel distance as the main deterrent to attending.

Asked whether future Conference should be held Annually or every two years ( as we do) there was a marked preference for a two year timing although some 30% of respondents thought a Conference was not necessary at all and a better option would be to increase the number of regional or national Social gatherings. 50% thought a one day Conference was about right.


As is the case with our Group three quarters of conference delegates were 55 years old and over and an average delegates fee of around an NZ equivalent of \$150 seemed to be acceptable to some 60% of respondents.

These are all just approximate figures and the detailed results will be on the UK Group's website [www.gaincharity.org.uk](http://www.gaincharity.org.uk) shortly but these results say to me that we have got our Conference organisation just about right ó and I look forward to seeing you all again in Rotorua

As always ó take care

Tony

## How is our Web Site Doing?

Google Analytics				
Visits		1302		
Average time On Site		01:44		
Average pages Viewed in session		2		
<b>Bounce Rate</b> This rate shows how many people leave our site without visiting any other pages on the site		82% 		
Who Visited				
USA	NZ	UK	Australia	India
651	174	90	80	57

# **GBS – A Personal Encounter – John Dixon**

## **Told by His Caregiver Wife Sue**

John has asked me to write up his story as he doesn't remember very much of it at all, particularly the earlier parts.

On Sunday, 1<sup>st</sup> September, 2012 we celebrated Father's day by going out for a meal. The following morning John said he had a terrible stomach-ache. He hadn't been able to sleep much during the night. It thought it must have been something he ate. All day Monday he was restless and uncomfortable and sleepless on Monday night. On Tuesday he told me he hadn't done a poo since Sunday. I dosed him with laxative but when by Wednesday nothing had happened I took him to his G. P. Dr Lydiard prescribed more laxatives and said to ring him Thursday morning if they hadn't worked. He would then organise for a District Nurse to give John a fleet enema. The laxatives didn't work and neither did the enema. We had an appointment to see him Friday morning (7<sup>th</sup> Sept) but when he learned there had been no bowel movements he organised for John to have an x-ray and then bring the x-rays to him. The x-ray showed a massive bowel blockage. Dr Lydiard told me to take him straight into Tauranga Hospital and he would let them know to expect us.

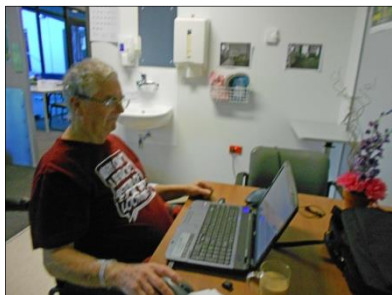
In **A. & E.** he was given two enemas; neither worked. He was then admitted to Ward 3a, the surgical ward. They worked on him to clear the bowel sufficiently to perform a colonoscopy. The second colonoscopy, (Friday 14<sup>th</sup> Sept) worked sufficiently to find there was absolutely nothing wrong with his bowel. It just didn't work. While he was in Ward 3a he had had several falls. It was noticed that the strength in his legs was failing but no one knew why. He had had some falls at home but they were few and far between and attributed to cartilage wear on his left knee. If he had had tingling in feet and toes it was too slight and for too short a time to mention it. The diagnosis of Guillain Barré Syndrome was mooted, but not taken seriously. There were two different schools of thought emerging. Apparently there are no signs of infection with G.B.S. and John's blood tests showed an infection.

After his colonoscopy on Friday, which showed that surgery was not required, he was moved to Ward 2b, a medical ward. He was there for 3 hours. Apparently they had started treatment for G.B.S. but he was one of the unlucky ones who had a bad reaction to it and developed cerebral meningitis. He went from Ward 3c to 2b to HDU on the same day. That week was a horror week. He was totally paralysed from the waist down, had no control over bodily functions and was away with the fairies. He talked non-stop and very little of it made sense. He was having terrible nightmares and calling out and crying in his sleep. On Friday 21<sup>st</sup> we had a family meeting. Two young female doctors told us that they didn't really know what was wrong with him, they didn't know how to treat him and they didn't know if he would survive. We were a pretty miserable family group going home that afternoon. That night my daughter-in-law, Diane, came into hospital with me. John was sleeping peacefully for the first time and I just knew he was going to be okay. The doctor called us aside and told us that John was being treated for G.B.S. and it seemed to be working. I went home feeling much happier and rang all the family with the good news. I think Dr Spelacy, our G.B.S. specialist, had been consulted at this stage. She was wonderful all the way through. One of the very few things that John remembers about this time was a doctor speaking to him on Saturday morning. He said, "You're a very lucky fella. Last night we were taking bets as to whether or not you would be here today."

Shortly after that John was transferred to Ward 3c. He was frustrated that he still couldn't move, wasn't getting physio therapy and didn't seem to be progressing. He just wanted to go home. For a couple of years before he was admitted to hospital he had been on a very high dosage of Efexor-xr for depression and Post Traumatic Stress Syndrome from his army experiences. He had suddenly been taken off these and was probably suffering from withdrawal symptoms. He was still having nightmares so they put him in a room of his own and psyche service visited him for a chat a couple of times. He was in Ward 3c for 2 weeks while waiting for H.I.A. to be cleared of the **Noro Virus**.

## **GBS – A Personal Encounter – John Dixon Told by His Caregiver Wife Sue**

Once he was in H.I.A. things didn't happen as quickly as he wanted and he was still frustrated and grumpy, having nightmares and talking rubbish. He still needed the cradle hoist to get him into a wheelchair and was totally dependent on the nurses for absolutely everything. Then he gave us the first real scare. He started shaking uncontrollably and violently. It appeared he had two severe urinary infections. They took the catheter out and put him into isolation and he had to use a bottle.



1. John at his computer in H.I.A. lounge
2. John making scones with the O.T.
3. John on the standing hoist with the physio. It was good to be on his feet.

The next thing he complained about was that his false teeth had become too loose and he was getting ulcers. He was on three meals a day, with three meal supplements, morning and afternoon tea and supper with extra protein and was still losing weight. I organised taking him by wheelchair taxi to the dental technician at 2<sup>nd</sup> Avenue on about the 25<sup>th</sup> October. His birthday was coming up on the 31<sup>st</sup> October and this was to be a trial run to see if I was going to be able to take him home to celebrate. The whole operation ran like clockwork. They used the cradle hoist to put him in a wheelchair and we were off; his first day out of the hospital in 7 weeks. After we had returned John was sitting talking to his doctors when he said, "I don't feel well." Then he went white and collapsed. His doctors were part of the "crash team". Other doctors and specialist nurses appeared from nowhere. He does have some memories of this. He thought he was in a train station because there was so much movement around him. Somebody said, "Everybody out!!" That worried him. He thought everybody was just going to leave him there at the station. Then somebody said, "Where's the sandpaper?" He stopped trying to make sense of it. What had actually happened was the portable x-ray machine had been brought in and everybody sent out of the room while it took its pictures. Then they put the electronic sensors on him. Some of his skin was sweaty and the sensors didn't stick. They prepared the skin with wipes they called "sandpaper". The sensors monitored all his vital functions and the info was sent up stairs to I.C.U.

So why did he collapse? Apparently his blood pressure dropped dramatically and normally the heart rate would speed up to compensate. Thanks to G.B.S. it didn't. His body was just going to shut down. They had two IVs going into him simultaneously with a pump on one to build up the blood pressure. Everyone was so in control, knowing what they were doing, I didn't feel particularly apprehensive at the time. It was later on when I thought, "What would have happened if he had collapsed in the taxi or at the dental technicians?" I wouldn't have had a clue what to do apart from call an ambulance and I think by the time the ambulance had got there and back to hospital it would have been too late. Once again, the angels were with us. And his teeth were fixed.

The following day we had a family conference scheduled that John should have also attended. He wasn't allowed out of bed. Things did start to improve from there on mainly because John's attitude changed. He was able to be got out of bed and into a wheelchair and so get himself around. I brought in his computer and a netstick, he made scones with the OTs and a big day came (Friday, 2<sup>nd</sup> November) when he started to use the standing hoist instead of the cradle. Best of all he had some control over his bowels.



# **GBS – A Personal Encounter – John Dixon**

## **Told by His Caregiver Wife Sue**



We were going to celebrate John's birthday on either the Saturday before or the Saturday after the 31st. Due to John's episode after his trip to the dental technician we chose the latter and no way was I going to risk taking him home. Tauranga H.I.A. had a lovely private garden area. We brought extra tables, everybody brought food and our friend Gordon decided that as no Dixon birthday was complete without a BBQ he would barbeque the sausages, mushrooms and chicken at home and then bring them. It was a fantastic day and a real morale booster for John. Just about all our family and friends came.

Shortly after his birthday John was transferred to a room with four beds. Opposite him was a man who was to become a really good friend, Ken Ardern, who also had G.B.S. These two competed with each other for progress. John was assisted from the bed to the wheelchair and then to the walking frame. By the 17<sup>th</sup> November he was able to sit up in bed, manipulate his legs over the side of the bed, stand up using the walking frame and go for a short walk. Freedom came when he could get to the bathroom unattended.



1. John learns to walk again.
2. John uses a walking frame.
3. The physio checks him walking with callipers.



On 24<sup>th</sup> November John came home for a visit for the first time. We had put in a lot of thought on how best to get him home. We had a Mistu half-tonne flat deck truck. The seats were higher and easier for him to get in than the car. It had been mentioned that the physios would give him some practice in getting in and out of a vehicle. However, the day before he was due to come home that hadn't happened so my son Jonathan and I brought the truck in so that we could practice. While I went looking for John and for a physio to let them know what we were doing, John, who was in the gym, saw the truck and went out the side door to Jonathan. By the time the physio and I got out to the truck John was sitting in the passenger seat, laughing. He got his hand smacked for that because he had used upper body strength to swing himself in and he was supposed to be learning to use his legs again. But we got him home.

# **GBS – A Personal Encounter – John Dixon**

## **Told by His Caregiver Wife Sue**

On 30<sup>th</sup> November he was allowed home for the weekend and Sunday 2nd December went to Anoushka's engagement party. His social life had returned. On 5<sup>th</sup> December we went to the H.I.A. Christmas party in the gym.

On the 20<sup>th</sup> December John finally came home to stay after 15 weeks in hospital. He came home with two callipers, a walking frame, a shower seat and lots of extras. We had our own wheelchair. The following day, the 21<sup>st</sup>, was my 70th birthday. Once again most of our family managed to come. There were so many people there who had visited John and had helped me over the last three months. On the 25<sup>th</sup> December we had Christmas at our place.

The only real problems John was having, was with his right leg that would not obey instructions. Watching him try to get socks and shoes on was painful. Watching him try to put his underpants on was hilarious.

2013 saw physiotherapy once a week for 6 weeks. It was supposed to be for 10 weeks but after 6 weeks they said he had improved so much they couldn't help him much more. By then he was using just a walking stick. He was back doing the cooking and as much as he could around the house.



1. John and Diane washing the dishes at home.
2. Putting the washing out. His walking stick is hanging from the clothes line.
3. The campervan he drove in Australia.

In April we went to Levin. I drove but while we were there John sat in the car and practiced shifting his right foot from accelerator to break. By June he was driving around town and had driven to Whakatane and to Huntly for functions. In July we went to Australia and John drove the campervan from Brisbane to Sydney. That thing was way too big for me to drive.

He had some setbacks. He was put on a heavy dose of Prednisone to cure a renal problem and withdrawal from that presented its own difficulties but he is now almost back to where he was before he contracted G.B.S. He is not as fit and tires very quickly sometimes needing 12 or more hours sleep in a night. He has sizable blocks of memory loss. This isn't totally a bad thing. Most of the bad memories from the army no longer concern him.

We have so many people to thank for their help, prayers and good will during that time. Things are not quite the same as before we met G.B.S. but we both have our lives back.

# BAUD

As Tony mentioned in his column he now has one of these devices for members to trial. Please contact him if you wish to do so.



For further information about the BAUD system please check [www.BAUDtherapy.com](http://www.BAUDtherapy.com) or [www.mybaud.com](http://www.mybaud.com). You will see that it is a very easy system for the average person to use.

Best

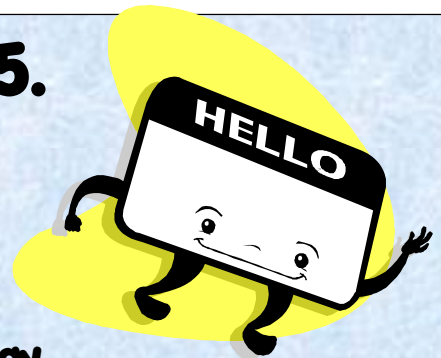
Claus Zimmermann Pedersen

**President and founder of the Swedish GBS/CIDP Patient Support Group**

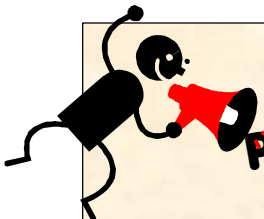
## Conference 2015.

**Where:** Rotorua – Sudima Hotel

**When:** Friday 8<sup>th</sup> May to Sunday 10<sup>th</sup> May



**Full program and cost details will be in the next magazine.**



## Wanted

**Publicity Officer and Hospital Visitor Coordinator**

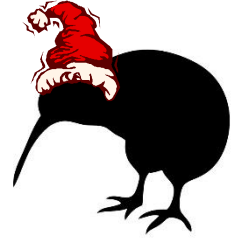
If you think you have what it takes to promote our Support Group or be the liaison person for our hospital visitor program please contact Ken Daniels or Tony Pearson.

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 CHRISTMAS LUNCH



## Where:

Okoroire Hotel  
Somerville Road, RD 2 Tirau

[www.okohotel.co.nz](http://www.okohotel.co.nz)

## When:

Friday 14<sup>th</sup> November 11.30am

**Bring: Small wrapped gift. Maximum value \$5.00**



### Standing:

Brian and Dawn Bennett (Cambridge), Debbie Allison (Morrinsville), Grant McKay (Matamata), Jan Gribble (Morrinsville), Chris Hewlett (Katikati), Mike Greenall (Cambridge), Jack Singh (Te Kauwhata), Meike Schmidt-Meiburg (Waitakaruru), Lenore Clement (Thames), Barry and Judy Deed (Tauranga), Celia Stephenson (Waotu)

### Sitting:

Sue and John Dixon (Tauranga), Shanti Singh (Te Kauwhata), Janet Greenall (Cambridge), Fran McKay (Matamata), Gordon Stephenson (Waotu), Stuart Clement (Thames)  
Taking the photo: Marty Hewlett (Katikati)