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Guillain – Barré Syndrome Support Group New Zealand Trust

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

NEWSLETTER September 2016



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In this Issue

Editor's Note	Chris Hewlett
Presidents Report	Doug Young
Secretary's Jottings	Tony Pearson
Report on the 2016 UK Support Groups 'gain2gether'	Tony Pearson
Personal Encounter with GBS	Bruce Kennedy
A Daughter View	Trudy Taylor
GBS Patients in ICU & a Conference Presentation	Dr. Annette Forrest
Waikato/BOP Coffee Group Report	Meike Schmidt-Meiburg
Kathy Eggers Triumphs in Oklahoma	Chris Hewlett
Notice Board	

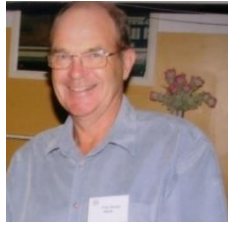
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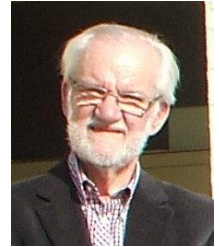
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Dr. John Podd



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Financial Statements

If you wish to see a copy of the Groups Financial Statements these are available on the Charities Website.

<https://www.register.charities.govt.nz/CharitiesRegister/Search>



Editor's Note

Hi everyone

Apologies for the lateness of the magazine and rather hurried compilation. We arrived home a little over a week ago from a wonderful motorcycling holiday in the States and Canada. I achieved my goal of riding my own bike from LA to the Arctic Circle via Canada and Alaska. By the time we returned to LA we had ridden just over 18,000kms. When I was struck down with GBS in 2001 I thought my motorcycling and sporting days were over, but time has been a great healer and always setting new goals helped me on the road to recovery. Never give up and surround yourself with positive people. Focus on what you can do not what you can't. GBS makes strong people even stronger.

Having said that I am finding it a little difficult to adjust back to work and normal life but I'm sure it will happen. Meanwhile I shall be plotting my next adventure.

I missed the Hawkes Bay water drama but it is very good to see that the Group was pro active there.

A venue has been chosen for next year's Conference, and more details will be provided in next month's newsletter. If you have any topics you would like covered by our medical experts please let myself, President Doug, or Secretary Tony know. Your input helps to make these conferences a success.

It seems our Facebook page is growing in popularity with several people seeking permission to join. Thank you Lil for keeping this up to date.

The BOP Coffee group, and cycling group got along great without me so I think I will leave Meike at the helm. She is a great event organiser. I believe the Hawkes Bay Group had weather issues and had to cancel their August get together but I'm sure Lil will setting another date soon. Watch FB for that.

Cheers

Chris





Presidents Report

Hello to all readers of the GBS quarterly magazine, which is a little late with the author being absent due to a road trip holiday in the USA & Canada! ó Welcome back Chris, now all of the magazine contributors have to get into action - as she is on our case.

Firstly I would like to acknowledge the efforts of our committee members who tried to push the GBS -Increased risk possibilityøwith the Hastings health authorities and those effected by the water contamination illness in the Havelock North area.

Dr Gareth Parry & Tony Pearson did their best to contact various people to inform them of the increased risk of people presenting to their GP with GBS symptoms and therefore the GPø needed to have GBS on their -Radarøwhen diagnosing a patient, also the support services we may be able to provide.

My understanding is at present there is 2 cases of GBS as a result of the water contamination ?

Tony Pearson will keep us up-dated on any support services provided by our local people in Hastings.

As a Projects Engineer principally involved in Water Treatment Industry, I will read the findings of the Government Inquiry with great interest.

Another member who has been busy at their respective task is Peter Scott who has confirmed the choice of venue for the next conference at Rotorua. Peter & Robin made a site visit to inspect the different venues and have selected carefully I am sure.

So with Havelock North seeming to have all the attention over the last 6 weeks, I will sign off and hopefully have more to comment on in the next edition.

Regards to you all.

Doug Young
President.

P.S. ó Basking in the Southland fine weather of the last Month ó could you northerners send us some rain please!





Secretary's Jottings

Back in 2015 Vivienne and I and her visiting sister and husband from the UK spent a very pleasant week in the Havelock North/Napier area ó we hired a small cottage just below Te Mata Peak and enjoyed the local beaches and of course the many wineries ! Little did I realise that barely having returned from a couple of months in Europe in July this year this same area would become the focus of a national water crisis with our old friend campylobacter being the villain of the piece! No

one in the Group needs reminding that where there is campylobacter there is a realistic possibility that GBS will follow for an unfortunate few.

With Dr Parry in the vanguard we did our bit to ensure that the medical authorities in the area were up to speed with the GBS possibility and particularly understood the importance of early diagnosis as key to a more speedy recovery process and had contact details for the Support Group. Our local authorised Hospital Visitors Erika, Beverley and Jeff were on full alert to provide support and information when requested.

We also learned that Dr Michael Baker ó the NZ expert on campylobacter ó was assisting the local authorities. Some members will remember Dr Baker presenting his ground breaking research to an earlier GBS Conference wherein he established a clear link between undercooked chicken and the incidence of campylobacter infection and went on to demonstrate a clear relationship between reduced cases of that infection and the number of GBS diagnosis over the same period.

Over a normal winter the PN area might expect see 1 or 2 GBS cases but with some 5000 plus residents reported to have been infected by campylobacter there was (and potentially still is) a real danger of a spike in GBS diagnosis which could seriously overwhelm local medical/ICU facilities. So far to date our worst fears have not materialised with only one confirmed case in the DHB area and another in Wellington that might have been sourced from Havelock North and at this stage no requests for assistance from the Group. Fingers crossed the crisis has passed ó although as far as I am aware the source of contamination of the water supply has yet to be discovered/announced.

During our holiday in the UK in June we attended the 100 year celebration of the discovery of GBS held by the UK Support Group in Glasgow ó I have penned a separate summary of the proceedings at that event but it was also an opportunity to meet the officials of that Group and to hand over our New Zealandised versions of their information brochures and to seek their approval to our publishing and using them in NZ. I am happy to say this was forthcoming and we are now in the final stages of preparing the brochures to use on our website and as part of our hard copy information pack.

A fortnight ago I decided to pop into the Nelson Hospital to renew contacts in the Neuro and Rehab wards and whilst I was there decided (for the first time) to visit the ICU ward ó had to negotiate the security systems but once the charge nurse recognised I was approved she led me to see a guy who had been admitted a week before and had been subsequently diagnosed with GBS. Mark (in his early 50s) had been visiting Nelson to attend a friend's wedding ó and developed all the classic symptoms very quickly. He was making a good recovery and hoped to be back home later in the week but was very pleased to have someone to talk to about his condition and readily grabbed the pack of brochures and Gareth's book that I had with me ó an unexpected bonus but one that demonstrates the potential benefits of a regular cold call to your local hospital if you are an Authorised Hospital Visitor.

A couple of bits of Admin- we need nominations for the Board vacancy that currently exists ó if you think you can contribute to the running of the Group ó or even just think it's time to shake up the old guard (it is election time anyway!!) then put your hand up ó no need to wait for the AGM ! It's not an onerous job but it can bring great satisfaction to know that you are giving back something to the Group that helped you during your relationship with GBS.

AND we still need that elusive PUBLICITY OFFICER ó I had a shot (with Gareth's help) at issuing an Open Letter to the residents of Havelock North advertising the help available from the Group ó I emailed it to the local papers in the area but I don't know if it got published ó but I guess there are more efficient/certain ways of getting our existence on the wires. If you can help PLEASE let me know ó even if you don't want the job but know how it's done ó I am happy to continue my amateur efforts but need to know the hints/tips and contact points of how to send out a Press Release.

And lastly Chris talked about a possible sponsored bike ride during the next Conference at Rotorua ó I'm up for that ó or a sponsored walk ó if you are interested let Chris or I know and we will see what is possible ó nothing too energetic but there are some lovely walks and rides around Rotorua.

As always

Take Care

Tony

100 year anniversary of the seminal work of Drs Guillain and Barré

The diagnosis of GBS

On 25th June 2016 Vivienne and I attended the UK Support Group's *gain2gether* gathering in Glasgow to mark the 100th anniversary of the diagnosis of the condition we now know as GBS. Just to put the record straight we did it on the way to see our longtime friends from our òEgyptian daysò who now live in Aberdeen !!

We all know the GBS òdiscoveryò story so I won't repeat it ó but why celebrate it in Glasgow? (like me most of you will think of Glasgow as a grubby, violent, run down city that lost its magic when it stopped building giants of the ocean) ó how wrong we are !! Glasgow has re-invented itself and is now a vibrant hub of education arts and culture ó don't miss it if you go to the UK !!

BUT for the UK Group Glasgow has a special significance as it is the home of their funded research centre into the causes and cures for GBS ó research is led by Professor Hugh Willison and, in a nutshell, the Conference was a chance for Hugh to showcase the work he and his proteges have done in GBS research. The programme ó held in a glorious old University Hall ó was fast and furious ó 15mins max for a presentation ó 11 in all as well as òsocialò interludes.

We learnt about new and experimental treatments:

Compliment Inhibitors Treatment ó molecular mimicry - EQUILIZUMAB ó (Gareth spoke about this at our last Conference) it is apparently a treatment that slows or inhibits the development of the immune system attack on the nervous system ó VERY expensive at present but with luck will become a regular available treatment in due course.

SIDGBS ó how to treat a patient who does not respond to Ivig when first given.

Dr Rob Hadden a consultant neurologist at Kings College Hospital in London spoke on the importance of the formation of **PATIENT GROUPS** (perhaps our Coffee Group equivalent ?) for Education/Support/Research/Advocacy with websites, social media, fundraising and public awareness ó supported by a creditable MAB being at the forefront.

Another of the Gain funded Doctors gave an update on the international IGOS study ó which has recruited a 1000 plus GBSers around the world to partake in clinical research. I hope our MAB can update on the latest outcomes next year.

Further presentations followed by very well qualified presenters ó advocating the importance of managing fatigue and sensible building of post GBS strength and personnel management programmes. We learnt about the massive challenges faced by doctors in Bangladesh treating GBS without any funding and how they are pioneering work in the area of small volume Ivig treatments.

AND there were some lighter sides !! Did you know that dogs and chickens get GBS but cats rarely do!! ó We had a stunning dance performance from a guy who had GBS and his partner that tells his GBS story in dance ó and they hope to take this national in the UK and beyond ó I invited them to NZ!!

To wrap things up we had a presentation from an Oxford University academic who was asked to look forward 100 years and envisage how we might be treating GBS then ó to summarise his speech he said that now we attack the Syndrome with a sledgehammer ó hoping to wipe out what is causing the problem ó but doing a lot of other damage in the process ó in 100 years time we will use the equivalent of an electron microscope to specifically eliminate the problem antibodies ó a thing to look forward to but perhaps not in our time!!

During the course of the Conference ó and the enjoyable dinner at the end ó we met the founder of the UK Group Glennys Sanders and her equivalent in the USA, Estelle Benson and made a lot of international friends and put faces to names only òmetò by Email previously. In all a very enjoyable 24 hours and I have come away with a number of organisational ideas that I hope we can implement at next year's Conference in Rotorua.



100 Year anniversary of the seminal work of Drs Guillain and Barré

The diagnosis of GBS

Tony got to meet and share ideas with these ladies:

Right:	Caroline Morrice, Director of UK Support Group
2nd from Right:	Estelle Benson, Founder USA Support Group
Left:	Patricia Blomkwist-Martens, Founder of Netherlands Support Group.



NZ GBS SUPPORT GROUP CONFERENCE 2017

WHEN: 5TH ó 7TH May 2017

WHERE: Novotel/Ibis Complex Rotorua

More details and registration form will be in the December Newsletter.

GBS A Personal Story..... Bruce Kennedy

Resident Whanganui – Age 82 years.

I have been outdoors all my working life as a nurseryman.

In February 2015 I was feeling unwell. Slight cough, tremors and fever, so I went to my GP who sent me for an Xray, Scan, and blood test. Two days later I went back but they had not come to any conclusions. The weekend followed. On the Monday I drove to the hospital and after an examination they admitted me with a chest infection. I do not remember a lot after that apart from a series of challenging nightmares. I remember waking and a visitor was there but I would drop off to sleep with them still there. I was told that one stage there was a note pinned to the sheet reading (Please wake me I would love to see you).

Two weeks later I was more conscious of my surroundings and I was informed I had got GBS.

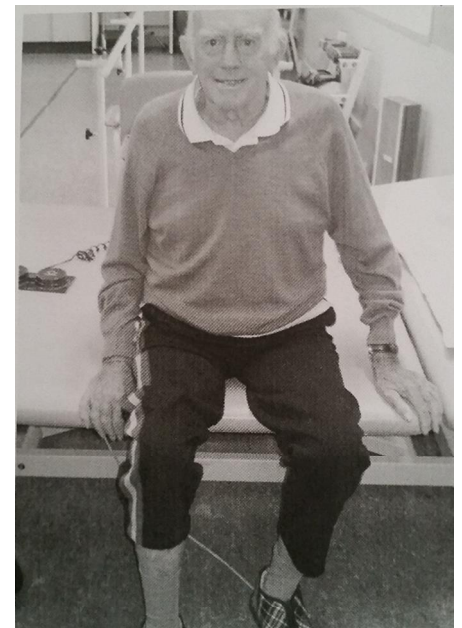
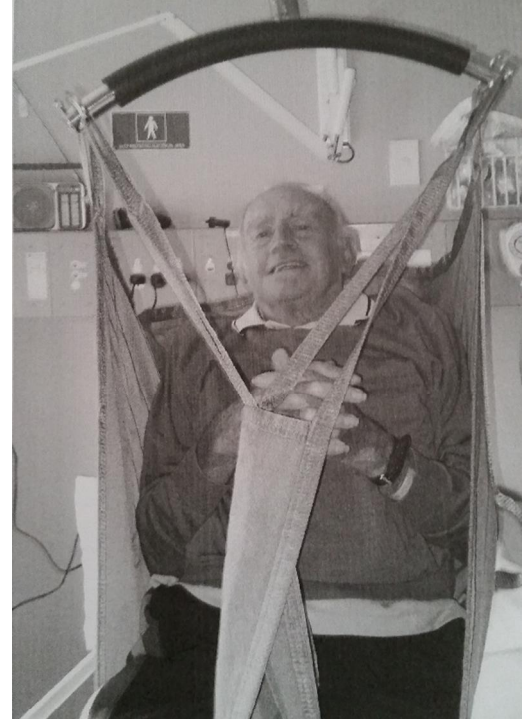
I could not move my hands, arms or legs and had trouble with speech. I was paralysed from the neck down.

At this stage I was transferred to the rehabilitation ward where there was a hoist for lifting me out of bed.

The Dr. who admitted me went on 3 weeks leave a short time after my arrival. On his return he was checking his patients one evening when he looked in my room and said ,~~am~~ pleased to see you ÷ I looked at him in surprise. He said when I left I gave you less than a 50/50 chance (of survival).

I spent the following weeks gaining small achievements such as feeding myself and managing the toilet.

The Physiotherapist lady spent that time getting me on my feet and walking again with the help of the sling to get me out of bed and various walkers etc. I am very thankful for all the help I got in that ward.



In all I spent 3 months in hospital.

On leaving I lived with my daughter for two months as I was having a new house built.

I am now in my new home, still having minor problems with balance but am back to golf with the help of a golf cart and am coping OK

I try to do a lengthy walk twice a week which seems to help the balance problem.

A daughter's view of GBS

Dad was living with my husband Lindsay and I while building his new unit, when he started feeling unwell. Dad had an essential tremor for years, progressively over a week, in early 2015, that essential tremor became worse, along with what appeared to be a chest infection. Dad being a typical kiwi bloke kept things to himself, he let us know he had gone to the GP but we didn't know he had taken himself off to the hospital until he phoned to see if we could take in a few things for him as they were keeping him in. When we arrived he said just leave the car in the car park I can drive myself home tomorrow.

The first few days were very uncertain as test after test showed no results and Dad progressively got worse. GBS was finally diagnosed by process of elimination of everything else. When the doctor started talking about GBS a whole lot of information about the syndrome came flooding back, I did some research in GBS when I was doing my paramedic training after treating a patient with the syndrome. I knew straight away how serious this could be. I knew that many people survive GBS but there are some that don't and at 81, age was definitely not on his side.

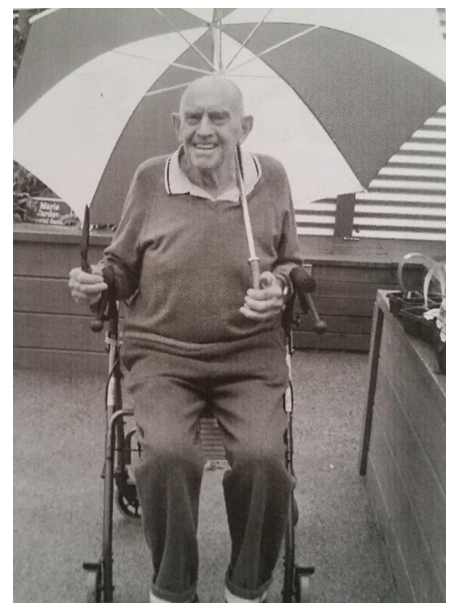
As Dad started losing the use of all the muscles in his body, he became more and more dependant for everything. The medical staff were amazing, but our family tried to be with him at meal times to feed him. Dad never lost his appetite through the whole thing. But the loss of muscle mass saw him lose a lot of weight.

Dad was put into the high dependency unit as GBS took over his body; he was constantly supervised in case he stopped breathing and had to go on a ventilator. The pain appeared to be excruciating. Fortunately the GBS didn't stop him breathing and after 3 days he was transferred back to the ward, but at this time we were not sure he would survive. It was hard to think there was no treatment for GBS, they gave Dad plasma product for which they believed may reduce recovery time.

Dad never lost consciousness, and would talk often very quietly, but he does not remember anything for several weeks. That could be a fortunate thing as some of the hallucinations appeared to be interesting; he saw a dog sitting on the shelf at one stage. The syndrome had started affecting the synapses in the brain. He had no memory and often didn't recognise people that visited, but Dad was always polite and never let on he didn't know people. As soon as you left he had no idea you had been there.

Dad has a large network of friends and he had many come to visit, bringing him baking, magazines and just stopping to chat. Even though he didn't remember them I am sure it is what kept him going. I printed out an information sheet on GBS and left it in his room, so visitors could understand what he was going through. Because everything was so exhausting for Dad he slept a lot, but the friends visiting meant so much to him that I left a note telling visitors to wake him.

The rehab ward at Wanganui hospital was amazing; there was a network of people to help Dad through every step of his rehab, it was a slow and steady progress that got him from bed ridden to a wheelchair, into a gutter frame to a normal walking frame and eventually a walking stick. The physio was relentless and just as dad mastered something she would make it harder. Dad always had his sense of humour and there were often lots of laughter at his rehab sessions. We are very fortunate Wanganui A T & R ward has a garden area which the patients have input into the gardening, Dad just loved this as he has been a nurseryman all his life. He didn't think much of having to sort buttons to get his fine motor skills working again. However getting him to plant some seedlings and prune a bush was right up his ally. They got him to sort the extensive old record collection, which he enjoyed and again improved his fine motor skills and cognitive skills. But some of them were older than him and in not much better shape he told me.



A daughter's view of GBS ...continued

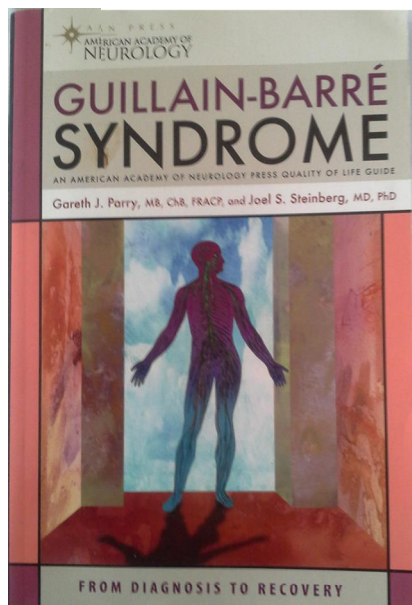
Dad and I already had in place a power of attorney for health and finance, thankfully I managed to get the passwords for his bank accounts from him before he lost that memory. I could manage his finances and make the decisions about his new unit that was being built. I also had to look after mum's affairs as she had advanced Alzheimer's and lived in a care facility. Thankfully everything was already set up for her and the staff at the rest home did a wonderful job of looking after Mum, it was one thing we as a family didn't have to worry about. The rest home staff would visit Dad on a regular basis to see how he was going; they missed his regular visits to them.

The only good thing about the GBS was he had no essential tremor, unfortunately that returned as his nerves started to repair. Dad is still improving and now has his driver's license back, even if only for daytime. He has returned to doing most things he did before GBS. He still has some lost feeling in his feet but is slowly coming back. Dad is still very frustrated he can't do some things and I constantly remind him he is lucky to be alive so suck it up and make the most of life.

In my job on ambulances, I always fully appreciate life as I know in an instant how that can change, it always brings that home when it's your own family. It is over a year post Dad contracting GBS and late last year Mum died. Mum and Dad travelled the world extensively through their life but one of the things on Dad's bucket list was to do a safari, so in May this year my husband Lindsay and Dad are doing just that, a trip to South Africa. I think there is plenty of life left in the old boy yet!

If there is anything that can be learned from this, make sure you have an advanced care plan for all of your family, so you know exactly their wishes. Have your power of attorney sorted well before you think you will ever need it. In rehab encourage and stimulate as much as possible. Don't be scared to ask questions at any point, some of the things the medical people do may not make sense to you but there will be a reason behind it, they always have the patient's best interest at heart.

Trudy Taylor
Bruce's daughter
Wanganui



New Stocks of this easy to read and enlightening book are now available.

If you would like to purchase one contact:

Chris Hewlett: chrispy57@gmail.com

Or

Tony Pearson: tonypearson@xtra.co.nz

GBS Patients In ICU

By Dr. Annette Forrest , Conference Presentation

DEFINITION

- No clear definition
- Clinical presentation varies widely
- Commonly is a progressive ascending paralysis caused by nerve demyelination by macrophages

INCIDENCE IN TERTIARY ICU NEW ZEALAND

- Two to four patients a year
- Data from last 10 years

CAUSES

- Infections
- Acute illness
- Surgery
- Vaccination
- Miscellaneous

CLINICAL FEATURES

- Paraesthesia
- Back pain
- Symmetrical ascending weakness in legs, arms, respiratory muscles and facial muscles
- Diminished or loss of deep tendon reflexes

THREE PHASES

- Acute
- Plateau

DIAGNOSIS

- No specific test
- Combination of patient history, clinical symptoms, excluding other conditions,
- nerve conduction studies,
- Lumbar puncture to rule out other conditions



50 % of patients present following a prodromal respiratory or Gastrointestinal infection
Infectious causes include viral, bacterial and parasites
Common infectious agents include campylobacter jejuni and mycoplasma

Paraesthesia often described as numbness, creepy crawlies, tingling burning

Acute: onset of first symptoms, progression until no further symptoms develop. Acute phase can be rapid where patient progresses over a 24 to 48 hour period or lasts up to 4 weeks. Normal nadir for muscle weakness is about day 10
25 to 30% of patients will require intubation in this acute phase
Plateau Phase: symptoms remain but don't worsen can be days to weeks
Recovery from a few weeks to 2 years

LP normally has an elevated protein with no increase in lymphocytes. Investigations can often lag behind symptoms by a week
Albuminocytologic dissociation of LP i.e elevation of CSF protein with only a few wcc

GBS Patients In ICU

By Dr. Annette Forrest , Conference Presentation

MANAGEMENT

- Symptom Management
- Prevention of Major Complications
- Treatment : Plasmapheresis and intravenous immunoglobulin

INTUBATION AND MECHANICAL VENTILATION

- 30% require intubation secondary to respiratory failure
- 25% require intubation secondary to oropharyngeal muscle weakness

Guidelines say FVC < 15ml/kg or Maximum inspiratory force < 25 cm H2O, actually more interested in tiredness, is the carbondioxide rising . Hypoxia is not generally the reason for intubation. If a patient is heading towards intubation, try to discuss with them and their family that there will be an early tracheostomy

VENTILATOR



INDICATIONS FOR ADMISSION TO ICU

- Respiratory Failure
- Oropharyngeal muscle weakness
- Autonomic dysfunction

*Respiratory failure secondary to respiratory muscle weakness, mainly diaphragm with phrenic nerve paralysis
Oropharyngeal muscle weakness leads to impaired swallowing of secretions and aspiration*

NON INVASIVE VENTILATION



Bipap not often used in GBS because of secretions but can be used temporarily while deciding whether intubation necessary

TRACHEOSTOMY

- Early
- Cuffed to protect from aspiration
- Different types
- Several changes with improvement

Annoying but not as bad as an ETT

TRACHEOSTOMY AND NASOGASTRIC TUBE



TRACHEOSTOMY TUBE



Example of the tracheostomy we use, short length cuffed

FLANGE TRACHEOSTOMY



Another type of tracheostomy we use, soft, and pliable

AUTONOMIC DYSFUNCTION

- Common
- In up to 70% of patients
- Commonest is Sinus tachycardia and hypertension
- Blood pressure labile

Can get big swings from high blood pressure to low paroxysmally so need to use agents that can be adjusted quickly

GBS Patients In ICU

By Dr. Annette Forrest , Conference Presentation

HAEMODYNAMIC MONITORING



CARDIAC ARRHYTHMIAS

- Tachycardia
- Bradycardia
- Heart block
- Cardiac arrest

*Some patients require temporary pacemakers
Suctioning can cause vagal episodes with bradycardia*

PACING BOX



ILEUS AND CONSTIPATION

- Common to get constipation,
- Adynamic ileus

*Start laxatives from day 1
Nasogastric tube*

URINARY RETENTION

- Urinary catheter

GENERAL SUPPORTIVE CARE

- Enterally feed
- Analgesia
- +/- sedation
- Thromboprophylaxis
- Ulcer prophylaxis
- Glucose control

COMPLICATIONS TO AVOID

- Pneumonia
- Sepsis
- DVT and pulmonary embolism

Patient is supine, not moving not clearing secretions and on a ventilator

HAND HYGIENE FOR STAFF AND VISITORS



HYGIENE TO AVOID INFECTION



THROMBOPROPHYLAXIS

- Enoxaparin injections
- Sequential compression devices

SCD's can cause pain in legs with squeezing

SEQUENTIAL COMPRESSION DEVICES



PAIN

- Can be very difficult to treat
- Early on it can be deep and achy
- Later it is more neuropathic and burning feeling
- Involves trunk and limbs
- Can be very severe and overwhelming

ANALGESIA FOR PAIN

- Treat aggressively
- Opioids
- Gabapentin
- Tricyclic antidepressants
- Cutaneous stimulation
- Ice
- Heat
- Distraction
- massage

GBS Patients In ICU

By Dr. Annette Forrest , Conference Presentation

NUTRITION

- Enteral feeding from day 1
- Nasojejunal tube
- Problems with tube feeding :
 - excessive gastric residual
 - diarrhoea
 - constipation

*Nasojejunal tube is smaller and more comfortable, bypasses stomach
Have decreased gastric motility with decreased gastric emptying. Start a prokinetic such as metoclopramide and erythromycin early*

SKIN INTEGRITY

- Prone to skin breakdown
- Watch for pressure areas
- Change position regularly
- Speciality air mattress

*Regular wound skin assessments
Changing position every 2 hours but for ventilation and skin but causes pain*

PREVENT JOINT CONTRACTURES

- Range of motion exercises
- Physio/nursing staff and family
- Proper positioning for joints

ROM important but again can cause pain, splints and orthotic devices to keep joints in a neutral position pain also

COMMUNICATION IN ICU



COMMUNICATION

- Difficult but very important
- Patients are often anxious and fearful about what is happening to them
- Being unable to communicate leads to frustration and feeling of loss of control

*Lip reading is very difficult, patient has to exaggerate lip movement and speak slowly
If they have facial muscle paralysis will be unable to communicate in this way
Some phones are easier than others, eg iphone and itouch easier to press
Patients get fatigued easily with speech*

COMMUNICATE HOW?

- Lip reading
- Letter and picture boards
- Non verbal options such as blinking and tongue clicks
- Computer (pad on pillow) needs head movement
- Apps on Phones such as Yes/No app from smartears
- Tracheostomy Passy muir valve or take cuff down

PASSEY MUIR VALVE



On tracheostomy can be used as part of weaning , for communication and gives a small amount of peep

MOBILISATION

- Tilt boards
- Chair when able
- Move bed outside

*Tilt boards are frightening, tiring and can cause hypotension
Patients can be taken outside on beds when ventilated
Can be moved down to windows*

TILT BOARD



PSYCHOLOGICAL

- Anxious
- Stressed
- Fearful
- Feelings of despair
- Feelings of helplessness
- Pain
- Depression common

ONE OF OUR MANY LINES



Procedures are multiple and lead to psychological issues

DELIRIUM/ICU PSYCHOSIS

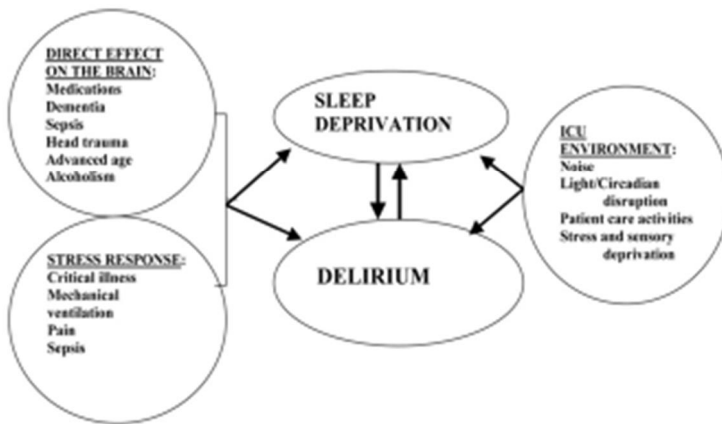
- Secondary to sleep deprivation
- Changes in how the patient perceives the environment
- Feel "trapped"
- Hallucinations
- NOISE
- Ward rounds

*Sleep deprivation often due to noise caused by machinery and staff, neighbouring patients. GBS visitors help
Loss of sensory input changes how you perceive your environment*

GBS Patients In ICU

By Dr. Annette Forrest , Conference Presentation

SLEEP DEPRIVATION



SOLUTIONS TO SLEEP DEPRIVATION

- Establish a sleep routine
- Take down to where there is natural light, or outside to establish a day night pattern
- Try to keep noise down, stop signals

EARPLUGS FOR NOISE



OUTCOME

- 80% of patients will make a complete recovery but of these 65% will have persistent problems such as foot drop or distal numbness
- There is a 3 to 5% mortality
- Will require intense physiotherapy and rehabilitation
- 20% will have multiple medical issues

LONG TERM PSYCHOLOGICAL EFFECTS OF ICU

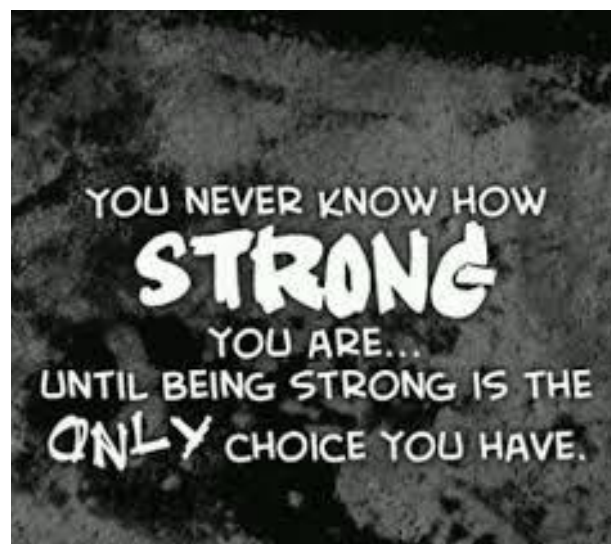
- Nightmares
- Sleep deprivation at home
- Flash backs and PTSD
- Increased anxiety
- Difficulty getting back to work
- Family believe you should be over it

PATIENT COMMENTS

- My wife of 36 years told me that I was just "feeling sorry" for myself and I needed to get on with life
- I felt isolated and excluded at work, no one wanted to be around me
- It has been two years and I am still trying to sort out what was real and what wasn't

ICU DIARY

- Scandinavian
- Nurse and family write in from day 1 with photos
- Particularly good with long term patients



BOP/WAIKATO Coffee Group August Get together



Left to Right: John and Sue Dixon, Meike Schmidt-Meiburg, Karen Soppet, Barry Deed, David Powell, Yvonne Powell, Rex Soppet, Judy Deed, Grant McKay, Fran McKay, Ken Ardern, Julia Ardern, Shanti Singh

Kathy Eggers Shines in Oklahoma

At the 2013 conference Kathy Eggers gave us an inspiring talk on her battle with CIDP and her desire to compete in an Ironman Event. She was the star of a TV program which followed her preparation and ultimately her participation and completion of this gruelling event.

Kathy hasn't slowed down and in August she was in the NZ team that competed in the World Championship Long Distance Triathlon in Oklahoma USA. She proved once again what sheer grit and determination can do. She was placed 5th in her age group in a time of 8hrs 56.09.

The race consists of a 4km swim, 120km cycle ride and a 30km run. Not for the faint hearted.

Congratulations from us all Kathy you are a truly inspirational person.



Left: Kathy slogging it out on the gruelling 120km cycle ride.

Right: Off the bike and a quick 30km sprint to the beer tent



NOTICEBOARD

WAIKATO/BAY OF PLENTY COFFEE GROUP

23 November 2016



Where: Nourish Cafe, Te Puna

When: 23rd November

Time: 11am onwards

As this is our Christmas get together and final meeting for the year we will be having our 'Secret Santa' bag so we ask that you bring along a small gift to the value of \$5.00 (Not compulsory)



Please let Meike know if you are attending so she can confirm numbers with the Café.

Email: schmidtfarm@xtra.co.nz

Cell Ph: 027 3250369

**Everybody
welcome.
See you there.**

What's Your Story?

Urgently needed are your stories to publish in your magazine.

Please take the time to write about your GBS/CIDP (and or other Variants) and post or email to me – your editor. Details on the front of the newsletter.

Bob Stothart is happy to assist anybody to write their story. Contact him by email:

stothart@ihug.co.nz

PUBLICITY OFFICER WANTED

We are looking for someone who would like to take on this role.

If you think you have what it takes please contact:

Doug Young: devoungs@xtra.co.nz

Or

Tony Pearson: tonypearson@xtra.co.nz

Your Ideas Wanted

What topics would you like the MAB to cover at the next Conference?

Send your wish list to the Editor

Email: chrispy57@gmail.com

