

# Guillain-Barré Syndrome

## SUPPORT GROUP NEW ZEALAND TRUST

Registered N.Z Charity No. CC20639 Charities Act 2005



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## NEWSLETTER JUNE 2011

*If undelivered please return to:*

Chris Hewlett  
51 Killen Road, RD 2  
Katikati, 3178  
New Zealand

|                             |                                    |  |  |
|-----------------------------|------------------------------------|--|--|
| <b>Patron</b>               | Hon. Steve Chadwick MP             |  |  |
| <b>President</b>            | Bob Stothart                       | 4/326 The Terrace, Wellington, 6011                      | Ph: (04) 385 0240<br>Email: <a href="mailto:stothart@ihug.co.nz">stothart@ihug.co.nz</a>                 |
| <b>National Coordinator</b> | Jenny Murray                       | 27 Grenville Street, New Plymouth, 4310                  | Ph/Fax: (06) 751 1014<br>Email: <a href="mailto:jenny.gbs.nz@clear.net.nz">jenny.gbs.nz@clear.net.nz</a> |
| <b>Secretary</b>            | Tony Pearson                       | 113 Weka Road, Mariri, RD 2, Upper Moutere, Nelson, 7175 | Ph/fax: (03) 526 6076<br>Email: <a href="mailto:tonypearson@xtra.co.nz">tonypearson@xtra.co.nz</a>       |
| <b>Treasurer</b>            | Peter Scott                        | P.O. Box 4162, Palmerston North, 4442                    | Ph: (06) 357 8436<br>Email: <a href="mailto:peterscott@clear.net.nz">peterscott@clear.net.nz</a>         |
| <b>Newsletter Editor</b>    | Chris Hewlett                      | 51 Killen Road, RD 2, Katikati, 3178                     | Ph: (07) 549 0931<br>Email: <a href="mailto:chrispy57@gmail.com">chrispy57@gmail.com</a>                 |
| <b>Publicity Officer</b>    | Maria De Cort                      | 52 Sandwich Road, Beckenham, Christchurch, 8023          | Ph: (03) 981 5553<br>EMail: <a href="mailto:mandrdecort@clear.net.nz">mandrdecort@clear.net.nz</a>       |
| <b>Medical Advisor</b>      | Gareth Parry<br>ONZM.MDO.FRACP.ChB |  |  |
| <b>Web Site</b>             | <b>Support</b>                     | <b>Education</b>   | <b>Research</b> <a href="http://www.gbsnz.org.nz">www.gbsnz.org.nz</a>                                   |

## Editors Note

The conference is done and dusted for another two years. Despite numbers being down it was a very successful weekend, so a huge thank you to Bob, Tony, Peter, Don and their partners for all the work they put into ensuring it happened.



It was good to meet up with old friends and make new ones. It is also good to talk to people who have experienced GBS and know exactly what you are talking about and have been through. It helps the recovery I'm sure.

I have included two of the presentations made at the conference, one from Dr Ron Paterson the past Health Commissioner on Patient's Rights in NZ and Pain and Fatigue in GBS by Dr Gareth Parry. They are available as a Power Point presentation on request from either myself or Bob Stothart.

I am desperately short of personal stories for the magazine so if you haven't already done so please jot yours down and either post or email to me. It came through loud and clear that those new to GBS and nurses involved in GBS care get an awful lot out of hearing how others have coped with this debilitating condition so don't be shy, put pen to paper and help those new to GBS to see there is a light at the end of the tunnel.

We welcome Ken Daniels and Maria De Cort to the Board. Their expertise will be invaluable. I had hoped to include a small resume from Ken to introduce himself to the group but unfortunately I had not received it in time. Maria of course is our new publicity officer who is doing a sterling job in promoting our group.

I'm looking forward to receiving your stories.....

**Chris**



## Presidents Paragraph:



The fifth national conference has been and gone and although it was less well attended this than in the past, it was still a valuable experience for those who were able to be there. Professor Gareth Parry gave his usual polished performances, loaded with up to date information and presented with authority and humour. The other professor, Ron Paterson spoke at length about patient's rights, the appointment of power of attorney and cases of patients being treated in a less than dignified way. He has an engaging manner of speaking and his presentation was greatly appreciated. One presenter, Lil Morgan couldn't make it as the storms over Hawkes Bay had closed the roads and she couldn't get to an airport. And this was the first conference that Jenny Murray and her husband Ian were unable to attend. They were notable absentees and we missed them very much. An Open Letter to Jenny is printed elsewhere in this Newsletter. This letter was read at the conference by our Patron the Hon Steve Chadwick.

But the main advantage from the conference was GBS and CIDP people getting together, meeting and talking to each other in an environment where everybody understood the issues involved. The regular attendees share a very strong bond and their on-going support for the conference is greatly appreciated. One message for me was how different everybody's story is. Every encounter with GBS/CIDP is a private journey and only other sufferers can really appreciate the journey and the various trials and tribulations for the patient, the family and the prime caregivers.

At the AGM it was decided to return to Brentwood Hotel in 2013 so make a diary note now and if you have any ideas for the programme, please let me know.



**Bob Stothart**



## Secretary's Jottings

After a busy but enjoyable Conference day on Saturday it was pleasing to see that a fair number of delegates managed to hop out of bed on Sunday morning and attend the AGM. Thank you also to the 50 or so of you that sent in Proxy Forms, it is always comforting for the Chairman of any meeting to know that he has the confidence of a substantial proportion of the membership behind him.

So what happened?:-

We were introduced to our new Publicity Officer Maria De Cort– who later also accepted a nomination to join the Board of Trustees and also Ken Daniels who had been co-opted onto the Board earlier in the year to fill the vacancy left by Dr Forbes Bennett. We farewelled Julie Rivett from the Board with Bob thanking Julie for her sterling support over the past years. Julie will stay involved with the Group in her Hospital Visitor role. The remaining Board members were re-elected.

Bob presented his President's report commenting on the continuing strength of the Group and its developing activities and thanked all those "below the radar" members of the Group that contribute so much to help achieve its aims. Bob reported on his and Margaret's attendance at the USA Group's conference at the end of last year and encouraged other members who can align their travel plans to consider attending their 2012 gathering.

Peter produced another set of robust Accounts backed up by an unqualified audit report and informed the meeting about the \$88,000 legacy that had been received from the Estate of a former GBS sufferer George Hartley Jones. These funds will be invested and the income arising there from will be used to make grants to support research into the causes of and cures for GBS. Subscriptions will remain unchanged for the coming financial year.

Dr Parry advised that the Guidance Rules for the Medical Advisory Committee were in hand and he hoped to constitute the group before too long. Guidelines for Hospital Visitors are currently being finalised and will provide advice on visit and follow up procedures for authorized Hospital Visitors. In an effort to reduce the costs of distributing the Newsletters members will be asked to accept them by e mail but with the option of continuing to receive a hard copy if preferred.

The majority of members have paid their subscriptions for the current year and you should all have received your membership cards. The few outstanding membership renewals will be sent a reminder in the next few weeks.

You may recall the article I wrote in the last Newsletter about the withdrawal of cover for the IVIg and Plasmapheresis treatment of GBS by my private medical insurer. I asked my insurance broker to research an alternative provider so that I could continue to be covered in the event of a relapse of my CIDP only to be told a few weeks later that **ALL** private medical insurers in N.Z. have now introduced this exclusion so to put it mildly "I'm stuffed" – the upside is that Kiwi Saver might be the beneficiary of my otherwise useless insurance premiums!.

As part of this Newsletter you will find a Form of Codicil. If you are so minded this Form will facilitate you leaving something in your Will to the Group as George Hartley Jones so generously did. Any bequest, large or small, will help the Group continue its work to increase awareness of GBs and help ease the suffering of those who fall victim to its attention.

***As always take care***

***Tony***

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## WEBSITE CO-ORDINATOR

For the past few years Lil Morgan has very successfully organized our Website. But due to the need to build a new house and sort a new direction after years of farm management Lil and her man need to focus on matters closer to home.

So we need someone to step into Lil's shoes. You don't have to be a "Techi" or a "Geek" - all that stuff is done by Ben – an employee of the Rare Diseases Organisation – but you do need to be comfortable with your computer – essentially Word and E Mail –and be a bit organized.

The job involves passing stuff to Ben to update our site – latest stories – changes in Trustees etc etc – all provided by me, Chris, Bob "et al" and generally being familiar with the site. I gather we have a Facebook site as well – but don't ask me about that!!

If you would like to give something back to the Group and are keen to have a go – give me a call. I am "holding the fort" in the meantime but in actual fact there is nothing that needs doing right now!

Tony – 03 526 6076 – [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz)

## Publicity Officer's plug



Hello everyone. Great to meet many of you at conference and put faces to names. This was my first conference and I'm pleased to say I felt thoroughly welcomed and inspired. During the course of Saturday's session I jotted down a great many ideas for possible stories to follow up and possible promotional initiatives, which will keep me busily beaver away for a while.

With a number of the things I've flagged to follow up it would be great to get *your* input fellow GBS NZ members. I thought I'd run a few of my ideas by you and if you feel you can help please drop me an email at [maria.gbsnz@gmail.com](mailto:maria.gbsnz@gmail.com).

I have been invited to contribute a piece for *Kai Tiaki Nursing New Zealand* magazine. I would like to cover key messages about specialist care for the GBS or CIDP patient – some dos and don'ts, as well as trying to share patients' experiences in order to raise more awareness of this illness in this key group of medical professionals. I would welcome your input on examples of great nursing care you have received in order to, as Professor Ron Paterson said at our conference, "paint a picture of what great care looks like". You are welcome to tell me the highs and lows of the care you have received, but I will try to accentuate the positives in the article where possible.

In chatting with delegates at conference, who happened to be nurses, I learned of a few great initiatives and activities happening around the country such as former patients being brought in to give seminars to medical staff and a GBS care plan being devised in one DHB intensive care unit, so I am also hoping to give an overview of these developments in the *Kai Tiaki* piece. Anything you can tell me along those lines would be welcome too. Please get your comments to me by mid-June for this one.

Our patron, Labour MP Steve Chadwick, mentioned in her conference opening address that as Associate Spokesperson on Health with responsibility for aged care she attends many Grey Power meetings and tries to spread the word about the support group when she can. To target this audience I would like to profile an older GBS NZ member and submit an article to an outlet such as *Older and Bolder* magazine or the Grey Power bulletin. If you think you might fit the bill and are happy for me to work with you to tell your story, please do get in touch.

And my final idea to float out there at this stage is this: I have on my radar to look and listen out for food safety campaigns in the media and look at ways we can perhaps "piggyback" on these to raise the profile of GBS/CIDP, with NZ's slightly higher incidence or the syndrome put down to our higher incidence of campylobacter. If you are someone who believes the trigger for their GBS or CIDP was campylobacter I'd be keen to hear from you.

**Maria**

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## Welcome to Our New Trustees:-



Ken Daniels

And

Maria de Cort



## Conference CIDP Survey

A small informal survey of CIDP'ers attending the Conference has produced some interesting, but not surprising, results:-

We were split almost equally into thirds of: - Cured or well into Remission

- Stabilised by current medication
- Active Disease

Most of us in the Cured/Remission/Stabilised categories thought regularly about the possibility of a relapse although not everyone made a point of having, at least, an annual blood check to monitor their White Blood Cell count. Others, like myself, did regular exercises to monitor oncoming muscular weakness.

Most of us rated the performance of our Neurologist highly although clearly it's a bit of a geographic lottery with some respondents feeling they were poorly served.

All of us recognized that CIDP had impacted on our previous lifestyle to a greater or lesser degree with all but one respondent confirming that fatigue and loss of endurance was an ongoing issue. Like me others had experienced problems in getting private health insurance cover and given the choice (at the outset) of getting GBS or CIDP as one respondent said – "I'd toss a coin"!!

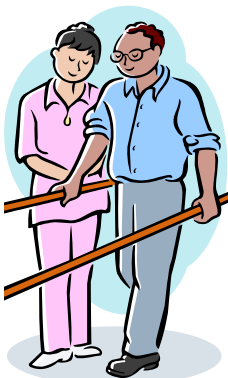
Those of you that receive the USA Group's Newsletter, "The Communicator" will have read the results of their latest very large CIDP survey where 60% of respondents considered their disease was still in the active phase and only 16% said they were stable with no significant disability. I guess we can take some comfort that our American cousins fair no better than us when it comes to meeting up with CIDP.

Tony Pearson

### Links to Disability Services

<http://www.ccsdisabilityaction.org.nz/Support/LibraryampInformationServices/tabid/77/Default.aspx>

<http://www.ccsdisabilityaction.org.nz/> or Library and Information Services form the home page



### Physio Help Available

If you need extra physio help and live in the North Shore area or New Plymouth these physio therapists would be pleased to offer you there expertise.

#### North Shore:

[sue@neurorehab.co.nz](mailto:sue@neurorehab.co.nz)

Neuro Rehab Results **Ph:** 09-4806464

and website

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

#### New Plymouth:

[newplymouth@activephysio.co.nz](mailto:newplymouth@activephysio.co.nz)

Active Physio

and website

**Ph:** 06-7699992

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

# **AN OPEN LETTER TO JENNY MURRAY**

Dear Jenny,

The Board wishes to mark your past continuing contribution to the Guillain-Barre Support Group of New Zealand by sending you this Open Letter.

For the love of your sister Dulcin and your concern for her health, you had the vision which led to the formation of the Guillain-Barre Support Group and you gathered around you people who could help you to realise your dream. You provided the spark, you had the foresight, you brought us together and as a result countless sufferers of Guillain-Barré and CIDP throughout New Zealand have been helped and supported.

Your tact, discretion and compassion are legendary: as is your tireless voluntary work on behalf of other people. You have observed with unfailing integrity the conventions of medical confidentiality while remaining welcoming and approachable to new and existing sufferers and their carers.

Your remarkable contribution has led to the award of the Queen's Service Medal, national recognition richly deserved and applauded by members everywhere.

Your investment of time, effort and ideas for the benefit of others is unparalleled in Guillain-Barre/CIDP community in New Zealand.

We salute you, wish you well and look forward to our continued association.

Bob Stothart  
President  
On behalf of The Board

## **Jenny's Reply**

Dear Bob & Steve, and board members.

I was humbled to receive the copy of the Open Letter that was written on behalf of the committee and read at the conference.

This took me by surprise, and is something I never expected. I wish to thank each and every one of you for such kind thoughts, and recognition.

My original intention was to try and get some support for GBS patients once my sister Dulcie was diagnosed in 1997. I know we, as a family, were completely blown away with her illness and the fear and lack of understanding of GBS. If something could be done to help others then it was worth a try. I fully acknowledge the support I received from people who helped me - people with experience I did not have in respect of being able to fill executive roles, and to have had two very supportive Patrons in Sir William Birch and our current patron Mrs Steve Chadwick.

Dr Gareth Parry is a major factor in our support group, and without him and his expertise and availability we could not function the way we have.

It may have been my vision to have a go - but I have had a lot of support along the way and acknowledge that fully.

Bob Stothart, Tony Pearson and Peter Scott, who have taken the important roles in the group and are doing a fantastic job - thanks guys. I feel very comfortable knowing the group is in good hands, and health permitting, I will be here to do what I can to support future patients and the Board.

Jenny

# Conference 2011



*Patron Steve Chadwick  
Opened the conference*



*President Bob Stothart MC for the  
day*



*Ron Paterson and Gareth Parry were  
the keynote speakers*



*Gareth chats with Gordon  
Stephenson*



*Above: Members whose hard work and dedication made the  
conference happen. Front: Margaret Stothart  
Back left to right: Tony Pearson, Bob Stothart, Don Martin,  
Jos Roebroek (from Holland) and Dr Gareth Parry.*



*Baby Troy came to  
support his mum*



*Left: Gareth ponders on a  
question from the audience*



*Right: Maurice Vickers gives a report  
on the GBS team who manned a stand at  
the "Brain Day" at Auckland  
University.*



*Ken Daniels kept everyone entertained as he told of his personal encounter with GBS*



*Discussion groups are always a popular event*

# ***A Personal Encounter..... A Brief Diary of the Road to Recovery.***

*by Paul Poon. March 2011.*

On the 30th July 2010, I was discharged from the Laura Fergusson Trust Rehabilitation Center. It marked the 315th day since I was admitted to Auckland Hospital on 19 September 2009 with GBS.

I contracted a slow Guillain Barré Syndrome right after a flu vaccine on 3 Sept 2009. It started with weak lower limbs that affected my balance while walking, changing trousers and climbing stairs. This eventually moved upwards to my upper limbs and affecting my fingers, vocal muscles, swallowing muscles, taste buds, face muscles, eye sight (double vision), eye lids, chest muscles and sensations throughout my body. I was almost paralyzed with weak arms and legs motion. It is a rare illness. Usually this sickness is triggered by food poisoning or chest infection with a chance of 1 in 100,000. And the chance of getting this syndrome is 1 in 2 million through flu vaccine as described by the consent form "Consumer Medical Information for Fluvax.

After receiving 2 x 5 treatments, Intravenous immune globulin (IVIG) and Plasmapheresis, I was discharged on 5-11-2009 and transferred to Rehab Plus at Point Chevalier. It is a place for intensive rehabilitation. There were special programs tailored made for me by Speech & Language Therapy (SLT), Physiotherapy and Occupational Therapy. There were busy weekly schedules, with Physiotherapy (10 - 15 hr.), Occupational therapy (2 - 3 hr.) and SLT (2 - 3 hr.).

September to December was the worst period in my sickness. I did not have any mobility. I was hoisted around the ward and rehabilitation center. I was fed on NG tube through my nose and afterwards replaced by a PEG tube in my stomach before moving to Rehab Plus. The PEG tube was removed in February 2010.

Information from different sources suggested that recovery could start as early as 3 to 4 weeks after the onset on the sickness. Unfortunately, my recovery had been a slow process too. According to statistics, about 3 % of the patients could end up on the wheelchair for the rest of their life. My family was very frustrated and desperate.

After lying in bed for 3 months, the first sign of recovery began on December. Suddenly I started to make vocal noises as the vocal muscles returned. Swallowing slowly returned and I started my meals with puree food. I started pushing my wheelchair too. It was hard. I could move the wheelchair only a few cm on one push. My fingers and arms were too weak to grab the wheel. In January, I could lift my hands to mouth level and feed myself. This is simple routine turned out to be a great success for me!



In February, my grips and arms were getting stronger. The most significant sign of recovery was making 3-point turn on my wheelchair in a narrow corridor. The technique requires strong grip on the wheels in opposite directions.

In March, I was propelling my wheelchair more than 2 hours every day and travelled over 500 m in Rehab Plus.



Eventually, I was transferred to Laura Ferguson Trust Rehabilitation Center (LFT) in Greenlane on 30 March 2010.

I had a busy weekly schedule too, with physiotherapy (5 hr), going to gym (10 - 15 hr or as much as I could), workshop (4 hr.), occupational therapy (2 hr.), sleeping and eating for the rest of the time.

Progress is promising. In April, toes started to flick and ankle muscles began to move. The range of movement measured in terms of mm. My family was so happy to see those muscles moving again. I was using a walking frame. In May, I was walking on crutches.



## **A Brief Diary of the Road to Recovery**

After 238 nights away from my bed, I finally got upstairs on my bottom for the first time on 15 May and slept on my cozy mattress. That means I could access the shower box in my bedroom, my computer, my books, my softwares, etc.

I was gaining weight. I was 68 kg when I left Auckland Hospital and had gained 4 kg of weight to 72 kg when I left Rehab Plus and then rapidly gaining more weight to 83 kg when I left in July! This is mainly due to muscle gaining through hours of work-out in gym.

In July, my fingers were not coordinated. I type with 2 fingers. Writing and signing cheques was possible but hard. Legs were getting stronger. I was practicing to walk on one stick in Physiotherapy. I discharged on 30th July 2010.

In August, I was walking independently though climbing stairs was hard.

In September, I started driving again. I was doing housework, gardening, typing etc. Life is back to normal.

In the mean time, sensations in my fingers, is much better as compared with 1 year ago. There are very little sensations in my feet and toes. Calf and feet muscles are still weak, but they could support my mobility.

I would describe this as the end of a tunnel. Life had been hard for my family. It would have been a harsh experience for my wife to strive through this Long March without the strong support from all my friends



### **Support Received for the Web Site**

I'm Carol, a registered nurse, I also have GBS.

I have had it for three months following this year's flu vaccine. I also am employed by the hosp board to vaccinate the public and staff with the flu vaccine!!! At least it's a job. I just got unlucky this time.

For me even though I am a nurse, the stories in from your website have provided so much reassurance about the course of the GBS. I don't know if it is getting better, I don't think so. A journey slowly evolving.

Thank you for the work you have done on your website that allow us so much sensible knowledge and through that knowledge reassurance.

Thanks again.

Carol Turner



# Points of Interest from Ron Paterson's Presentation at the recent GBS Conference.



## Overview

- Experiencing illness
- GBS and CIDP patients
- What patients want
- Legal rights in NZ
- When things go wrong
- Complaints

## Illness – a foreign land

For many patients, illness is a journey to a foreign land – the kingdom of the ill. It is a frightening experience and patients look to doctors and nurses as their guides and interpreters.

Sontag, 1978

## Patients are fearful but trusting

We fear pain, disease and disability, and death.

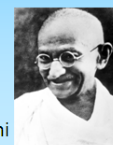
We expect our doctors and nurses to be competent and caring.

## Stand in the patient's shoes

Doctors and nurses need constantly to remember that what is familiar to them – the setting (eg, hospital) and the illness – is unfamiliar to the patient.

"I, too, have felt what I am asking you to feel."

Gandhi



## Emotional healing

"Technology now ensures physical recovery for many who would have died. But having survived severe damage, where is the therapeutic equivalent of intensive care units for the emotional wounds which can leech themselves into a lacerated body'. ... Have we understood that the spirit must accompany and assist this retrieval?"

Tony Moore, *Cry of the Damaged Man* (1991)

## Climbing to recovery

- "It's like I've fallen into a deep, dark hole and can't get out. I feel alone and I'm scared."
- It's a frightening experience. Patients need plenty of encouragement and support from loved ones: lots of hugs, kisses and kind words.
- Coping with uncertainty is one of the most difficult aspects.

## What GBS patients experience

- Lack of understanding – paralysis does not mean no feeling
- Being stranded – meals & drinks left out of reach
- No cradle sides to prevent falling out of bed
- Bells unanswered – waiting to go to toilet
- Lack of respect & decency

## Care and compassion

Patients should be treated with courtesy and care, and shown kindness and compassion.



## Competence

Patients expect "a high level of medical competence – good up-to-date medical knowledge and diagnostic skills, sound technique for medical procedures and awareness of limitations".

NZ Federation of Women's Health Councils, 2006

## Confidence

"Patients need to have a personal sense of confidence in the [health professionals] with whom they are so intimately involved. They need to trust that they will turn out for them, even after hours, if something goes wrong. In an ideal world, the [team] and the patient and [family] will work as a team."

Murray Pfiefer, NZ Herald, 17 June 2005

## The patient's and family's role in patient safety

Patients [and family] should be involved in:

- helping to reach an accurate diagnosis
- deciding on appropriate treatment/management
- choosing a suitably experienced and safe provider
- ensuring that treatment is appropriately administered, monitored and adhered to
- identifying side effects or adverse events quickly and taking appropriate action.

Vincent & Coulter, 2002

## NZ Code of Rights

- No right to access care
- Code regulates *quality* of care
- Consumer responsibilities omitted
- Focus is on local and early complaint resolution, by educational interventions, advocacy, mediation and investigation



## A patient's rights in New Zealand

- Respect, dignity, non-exploitation
- Appropriate standard of care
- Effective communication, full information, and consent
- Support, complaint



### Right to respect and dignity

- Every consumer has the right to be treated with respect.
- Every consumer has the right to have services provided in a manner that respects their dignity.



### Right to good quality care

- Reasonable care and skill
- Services provided in a manner consistent with needs, that minimises potential harm/ optimises quality of life
- Co-operation among providers to ensure quality and continuity of care



### Information and consent

- Effective communication in a form, language and manner that enables the consumer to understand
- Explanation of condition and options
- Every consumer must be presumed competent to ... give informed consent.



### Where patient not competent to consent and no guardian available – Right 7(4)

Provider may provide services where:

- It is in the best interests of the patient
- Reasonable steps have been made to ascertain pt's views and
- Services consistent with choice pt would make if competent, or
- If pt's views have not been ascertained, account taken of "views of other suitable persons ... interested in the welfare" of pt and available to advise.

### Right to support & to complain

- Every consumer has the right to have one or more persons of his or her choice present ...
- Every consumer has the right to complain about a provider and to receive a reasoned, timely response.



### Resource constraints

- (1) A provider is not in breach of this Code if the provider has taken reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in this Code.
- (2) The onus is on the provider to prove that it took reasonable actions.
- (3) For the purposes of this clause, "the circumstances" means all the relevant circumstances, including the consumer's clinical circumstances and the provider's resource constraints.

### Enforcement and Accountability

1. The Code rights are enforceable via complaint system — to providers, HDC consumer advocacy service, and to HDC
2. Most complaints are resolved without need for formal investigation.
3. Serious cases may result in accountability via HDC 'breach' findings, public naming of institutions, prosecution before professional disciplinary tribunals, and (very rarely) civil claims for damages to Human Rights Review Tribunal.

### How does Code address what GBS patients experience?

- Lack of understanding re paralysis – *failure to provide appropriate care*
- Being stranded – meals & drinks left out of reach – *failure to provide services in a manner consistent with needs*
- No cradle sides – *failure to provide services in a way that minimises harm*
- Bells unanswered – waiting to go to toilet
- Lack of respect & decency – *lack of respect for privacy and dignity*

### Wounded patients

"Many patients suffer not physical injury but emotional and psychological wounds in the course of their care ... they seek resolution of an *emotional* injury."

Robin Youngson, 2004

### Left in the dark

Patients are often left in the dark when things go wrong.

Their grief is compounded by unanswered questions and a sense of abandonment.

### A grieving widow

"I still do not know what happened to my husband. The hospital is not giving me detailed facts ... nobody is letting me know what happened."

### An upset daughter

"The rest home played down the whole event and obviously haven't taken it up as their responsibility. I haven't even had an apology, phone call, or any contact since Mum died."

## What are patients looking for?



Colleen Poutsma

- Restoration
- Communication
- Correction
- Sanction

### Responding to medical error

The majority of patients say 'yes' when asked if they would like to know about medical error.

Hingorani et al, BMJ 1999

What do patients want? Open disclosure. Rae Lamb, 2004

### Candour & the Code

Code of Rights affirms duty of candour –

Right to the information that a reasonable patient, in that patient's circumstances, would expect

### Honesty is the best medicine

- Acknowledge: explain what happened and the consequences for the patient
- Empathise: express sorrow for what happened
- Make amends: take whatever corrective actions are appropriate

### Why do people complain?

- Uncertainty
- Hurt
- Grief
- Frustration
- Anger

### How does HDC resolve complaints?

- Complaints are usually resolved by informal, low level intervention
- Advocacy, mediation and referral back to provider (with HDC as back-up) are often successful
- Formal HDC investigation reserved for serious cases where there is a need for accountability and an opportunity for sector learning

### Providing closure



"Completion of your investigation allows us to put another part of this sad incident behind us.

We trust that no other family has to go through the same experience that we have."

Letter to HDC from patient and his family

### Outcomes benefit others

"Thank you for your report regarding my complaint. I wholeheartedly appreciate all the work you put into your report ... it brought tears to our eyes. We are grateful for your 'recommended actions' enabling less stress on future patients and whanau."

Gisborne family, April 2004

### Building a fence at the top of the cliff



- Individual complaints offer a valuable window on serious threats to patient safety
- HDC plays a key role in linking dispute resolution with improvements in patient safety

### The value of complaints

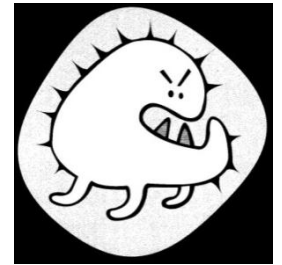
"When complaints are freely heard, deeply considered, and speedily reformed, then this is the utmost bound of civil liberty attained that wise men look for."



John Milton, Areopagitica, 1644.

**A full copy of Ron Paterson's power point presentation is available via email upon request to either the Editor or Bob Stothart.**

# **Campylobacteriosis Cases Halved Following Controls On Chicken Meat**



*Press Release by University of Otago, 16 May 2011.  
Forwarded by Hon Steve Chadwick*

New Zealand's success in reducing its food borne campylobacteriosis epidemic is receiving international attention. In a paper just published in the journal, *Emerging Infectious Diseases*, NZ scientists report how both notified and hospitalised cases of campylobacteriosis declined by more than 50% following interventions to reduce campylobacter contamination of fresh chicken meat.

"This decline in campylobacter infection is one of the largest drops in disease incidence ever recorded for a national epidemic of this type," says Associate Professor Michael Baker from the University of Otago, Wellington.

Campylobacteriosis rates started rising in NZ in the mid 1980s and peaked in 2006 with 15,873 notified cases. This gave NZ the highest rate reported internationally for this disease at 384 cases per 100,000 population. Rates declined rapidly in 2007 after the New Zealand Food Safety Authority and the poultry industry introduced a range of regulatory and voluntary measures aimed at reducing levels of campylobacter on fresh chicken meat.

"Following the introduction of these control measures, there were 9,000 fewer reported cases in 2008 than in 2006 and 500 fewer hospitalisations. We also estimate there are now 70,000 fewer unreported cases in the community" says lead researcher, Dr Ann Sears from the University of Otago, Wellington.

Despite the success of this control programme, NZ still has amongst the highest reported rates of campylobacteriosis in the developed world at 168 cases per 100,000 population, compared with Australia at 108 per 100,000 and the USA at 13 per 100,000. Fresh chicken meat remains the dominant source of infection in NZ.

"This is by far the largest food borne epidemic in NZ's history. It was created by producing and consuming increasing amounts of contaminated chicken meat," says Associate Professor Michael Baker.

"We need to learn from this experience. Firstly, this success shows the importance of high quality disease surveillance, effective research, and strong regulatory agencies. We need to keep strengthening these areas," he says.

"Secondly, investing in prevention can save NZ a fortune. Controlling this epidemic costs little compared with the estimated savings of \$40 million a year from reducing rates of this disease."

"Thirdly, we can do better. NZ initially delayed tackling this epidemic for several years, despite evidence highlighting the role of fresh chicken meat. Even now, our campylobacteriosis rates are still too high, so more work is needed. As a food-producing country we must be leaders in food safety to maintain the trust of countries we export to as well as domestic consumers."

The package of interventions that have been successfully used in NZ to reduce chicken contamination include: setting mandatory targets for producers to reduce campylobacter contamination of chicken meat, better hygiene practices during chicken processing, and changes to the chilling processes.

"Campylobacteriosis is more serious than a minor stomach upset," says Dr Ann Sears. "That's why it's important to bring down our high disease rates."

Symptoms of campylobacteriosis include diarrhea, stomach cramps, tiredness, fever, nausea and vomiting which typically last about a week. Most of those affected take time off work and school. Some have severe symptoms requiring hospital treatment and develop life threatening complications.

A multidisciplinary group of scientists contributed to this research, including researchers from the University of Otago, Wellington; Massey University, Palmerston North; ESR (Environmental Science and Research Ltd); and the NZ Food Safety Authority (now part of the Ministry of Agriculture and Forestry).

A copy of the article is available online at: <http://www.cdc.gov/ncidod/eid/upcoming.htm>

# **Points of Interest from Dr Gareth Parry's Presentation on Pain and Fatigue in GBS**

*This presentation is available in power point via email from either Bob Stothart or the Editor*

## **Pain in GBS**

- Pain is a greatly neglected feature of GBS.
- Occurs in 15% - 85% of patients

## **Types of Pain in GBS**

- Pain accompanying the acutely evolving paralysis
- Pain related to immobility
- Pain occurring as paralysis improves
- Pain associated with rehabilitation
- Emotional pain.

## **Pain During Acute Paralysis**

- Occurs in 30 -50% of patients
- Maybe the first symptom of GBS
- Pain may exacerbate autonomic instability
- Pain is nociceptive, not neuropathic
- [Nociceptive Pain](#)  
An appropriate physiologic response to painful stimuli
- [Neuropathic Pain](#)  
An inappropriate response caused by a primary lesion or dysfunction in the nervous system

## **Location of Pain:**

- Pain is typically poorly localized
  - Low back
  - Buttocks, hips, posterior thighs
  - Neck and shoulders
  - Interscapular
  - Rarely distal

The pain is usually felt deep within the body rather than on the surface.

## **Character of pain:**

- **Aching quality**
  - Muscle stiffness
  - Cramping, etc; etc
- **Shooting pain – especially with movement (passive or active)**
- **Rarely burning, stinging, throbbing**

## **Patients often have difficulty describing pain.**

- Pain is usually mild
- Pain is generally proportional to weakness - severe weakness is more likely to be accompanied or preceded by severe pain.
- Pain typically peaks during the first few days of weakness and then subsides or is replaced by a different pain.

## Treatment of Pain:

- Non-narcotic analgesics appropriate only for mild pain.
- Narcotic analgesics
  - Oral
  - Parenteral
  - Epidural
- Narcotics should be used with caution in patients with compromised pulmonary function.
- Narcotics may induce or exacerbate autonomic instability.
- Treatment of GBS with plasmapheresis or IVIg may improve the pain.
- Steroids do not improve GBS but may improve pain.
- **ASK...** It is critical to ask patients whether they are suffering, especially if on respirator.
- **REASSURE...** Make sure that the patients know that you understand that they have pain.
- **TREAT...** Do not hesitate to treat with appropriately potent analgesics.

## Pain with Immobility

- **First-rate nursing care:**
  - Egg-crate or air mattress
  - Frequent changes in position
- **Physical Therapy** (may help exacerbate pain):
  - Passive range of movement
  - Stretching

## Pain During Recovery

- More likely to occur if there has been pain accompanying paralysis
- More likely to occur if there is axonal degeneration.
- Proportional to the severity of the weakness

## Location of Pain:

- Usually distal or distally accentuated but may be widespread.
- Easily localized and often on the surface rather than deep.
- Neuropathic rather than nociceptive pain.

## Character of Pain:

- Burning
- Tingling
- Cold
- Stabbing

## Severity of Pain:

- Mild to severe
- Often worse at rest after exercise
- Often worse at night
- Allodynia

## Evolution of Pain:

- Emerges as nociceptive pain and paralysis improve
- May increase in severity for months.
- Prognosis is usually good
  - Typically lasts for months
  - May last for years or even be permanent

## Treatment:

- Simple analgesics (non-narcotic and narcotic) only modestly effective.
- Narcotics may result in habituation but the risk is low. Long acting narcotics are preferable.
  - Tramadol
  - Oxycontin
  - Methadone
  - MSContin
  - Fentanyl patches

## Medications for Neuropathic Pain:

- **Tricyclic Antidepressants** (beware of autonomic instability):
  - Nortriptyline
  - Desipramine
- **SNRIs:**
  - Duloxetine (Cymbalta)
  - Venlafaxine (Effexor)
- **Anticonvulsants:**
  - Gabapentin (Neurontin)
  - Pregabalin (Lyrica)
  - Carbamazepine (Tegretol)
  - Oxcarbazepine (Trileptal)
- Combination therapy is frequently necessary.
- By combining drugs with different side effects it may be possible to achieve the desired beneficial effect without intolerable adverse effects.
- Gabapentin and pregabalin may be preferable to other drugs as a “platform” drug because of the extremely low incidence of interactions with other drugs.
- Duloxetine maybe a good choice because it doesn’t cause sedation and may actually reduce fatigue.
- With all drugs “start low and increase slow” to minimize the risk of adverse effects.

## Emotional Pain

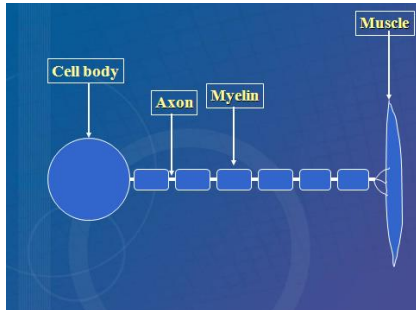
- Fear of loss of control
- Fear of death
- Indignity of ICU
- Fear of recurrence
- Depression

## PAIN IN GBS:

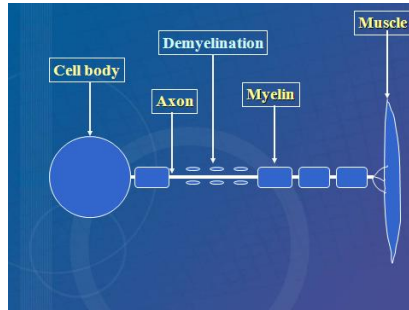
- Is a common and under appreciated symptom in GBS
- Is generally mild but may be severe and occasionally disabling
- May occur at all stages of the disease.
- Needs to be recognized and, when severe, aggressively treated.
- Generally has a good prognosis.

# FATIGUE IN GBS

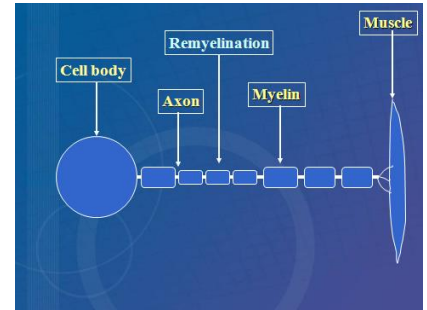
- Fatigue is common following GBS:
  - 50-80% of patients who have had GBS subsequently suffer fatigue.
  - Fatigue is not necessarily related to the residual effects such as pain and weakness but it is certainly more common in those more severely affected.
  - Fatigue can persist for several years, even when recovery seems otherwise complete.



**A Healthy System**



**System under Attack**



**System Repairs**

## Fatigue is not necessarily a direct consequence of having had GBS:

- Concomitant physical illnesses such as anemia, low thyroid function, diabetes, heart disease and chronic lung diseases may contribute to fatigue.
- Sleep disorders are common and can contribute to fatigue.
- Medications used to treat many conditions may exacerbate fatigue, especially pain medications.
- Untreated pain can contribute to fatigue.
- Depression is common following GBS and can manifest primarily as fatigue.
- Deconditioning is an important contributor to fatigue.



## Management of Fatigue in GBS

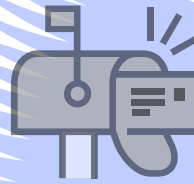
- Remember to make sure that there is not some other cause of fatigue.
- Cornerstone for the management of fatigue is exercise.
  - Establish the habit of exercise, even if it seems trivial at first.
  - Light aerobic exercise.
    - Goal is to exercise 4-5 days a week
    - Increase pulse by about  $\frac{1}{3}$  and maintain it at that level for 15 -20 minutes
- Weight Loss
- **Judicious use of stimulants:**
  - Amantadine which is used in MS-related fatigue does not seem to benefit GBS patients.
  - SSRI/SNRI medications are mildly stimulant and have the added benefit of elevating mood.
  - Methylphenidate (Ritalin), dextro-amphetamine (Adderal) and modafinil (Provigil or Nuvigil) have not been formally studied in GBS but clinical experience suggests that they can be beneficial.
  - Importance to use on an as needed basis to avoid tolerance.



Radio NZ interview .Hear Professor Parry being interviewed on One in Five with Mike Gourley.  
<http://www.radionz.co.nz/national/programmes/oneinfive/20110417>

# Notice Board

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](http://www.gbs-cidp.org)



Want to receive your magazine by Email?

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

Not only would you be saving a tree but also be helping to reduce the costs of publishing and posting the magazine.

## NZ Facebook Support Group

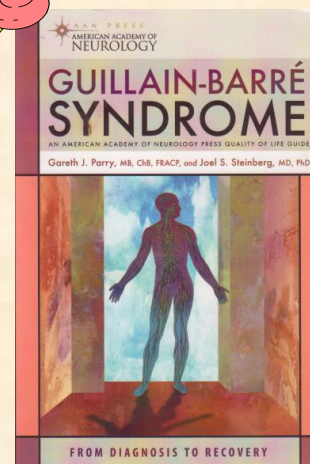
Lil has set up a support Group on Facebook under the section 'common interest and health and well being'. If you are on Facebook join up and start some discussion going.

Guillain-Barré/CIDP Support Group

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



Moving House? Don't forget to give us your new address.



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.



# Codicil to an existing Will

If you have already made a Will you can still help the Guillain Barré Syndrome Support Group by adding a codicil to your Will.

If you would like further information or would like to talk to a Trustee of the Group about making a bequest to the Charity please contact us on 03 526 6076.

**We do advise consulting with your legal advisor before completing this codicil form**

**Please take this form to your legal advisor**

I ..... (Name)

of .....

..... (Address)

Declare this to be a ..... (first/second) codicil to my Will dated ...../...../.....

In addition to any legacies given in my said Will I give to the Guillain Barré Syndrome Support Group New Zealand Trust, of 113 Weka Road, Mariri, RD2, Upper Moutere, Nelson 7175 (or any other premises which the Support Group may hereafter occupy) a charity registered in New Zealand No. CC20639,

A share of ..... of my estate or the sum of NZ\$ ..... and/or  
..... (a specific sum)

to be used for general purposes and I declare that the receipt of the Treasurer or duly authorized officer shall be full and sufficient discharge. \*

In all other aspects I confirm my said Will and all other codicils thereto.

*\*please complete as required and cross out those options not required.*

Signed .....

Signed by the above named in our presence and witnessed by us in the presence of him/her and each other

**Witnessed by:**

Signature.....

Name .....

Address.....

.....

.....

Occupation.....

Date...../...../.....

**Witnessed by:**

Signature.....

Name.....

Address.....

.....

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Occupation.....

Date...../...../.....