Guillain – Barré Syndrome Support Group New Zealand Trust

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NEWSLETTER JUNE 2013

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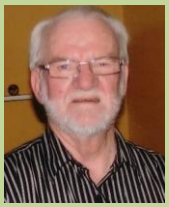

Bob Stothart

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Dr John Podd

John Davies

Meike Schmidt-Meiburg

Chris Hewlett

Dr Gareth Parry answers a question put to the MAB during the conference.
Left to Right: Dr. Michael Baker, Dr Pralene Maharaj, Dr Suzie Mudge, Ex President Bob Stothart, Dr Gareth Parry and Dr Chris Lynch

Editors Note

Well the conference has been and gone and by all accounts was a success. I have heard various comments about it ranging from "scary to the best conference yet, thanks to the guest speakers. It is always interesting to hear of new treatments for GBS, CIDP etc but still disconcerting to hear that the old problem of a quick diagnosis is still not happening in a lot of cases.

The time we had to put questions to the panel never seems to be long enough and some attendees thought their questions weren't answered quite as fully as they would have liked so if you have a question that you still need answers to, send me an email or a note by snail mail and I will forward it onto the MAB and send you their reply plus I will publish both question and answer in the magazine so others can benefit.

It was also great to see lots of new faces and younger faces in audience, proving that GBS is no respecter of age.

I took onboard the advice to exercise more regularly and at work this month organised a 30/30 challenge. At least 30 minutes exercise a day for the 30 days of June. Everyone was given a starter pack, stickers for the chart on the smoko wall, a list of rules, and even a couple of chocolate bars. I also put the challenge on our FB page but am unsure how that is going. Only two out of 14 at work have managed to do something every day and I'm pleased to say I am one, although I am having to go to bed a lot earlier as the month goes on.

Thanks to those of you at the conference who promised articles for the newsletter. I look forward to receiving them. Thanks also to the people who have given me their stories. They will be published in the next newsletter so don't think your efforts have been in vain.

Over the next couple of newsletters I plan to publish the presentations of the conference presenters. These will also be put onto our website.

Congratulations go to one of our members, Gordon Stephenson who has been awarded an honorary doctorate from Waikato University for his lengthy and ongoing contribution to the environment. Unfortunately space does not allow me to reprint an article that was in the Waikato Times at this time. I have to say his achievements are many and this award is well deserved.

Gordon catches up with Dr Chris Lynch at the conference

Chris

What's in your Magazine this month……..

Presidents Paragraph:

Hi Everyone,

This is the first newsletter since our Wellington conference and the first thing I want to do is to thank all those who participated in the event. The numbers where fantastic given the hard times that many of you are facing so thanks to those who were able to attend. A big thanks also to those that helped with the organisation, the speakers, the members of the medical advisory board who gave of their time and also to Bob Stothart, the retiring president and his wife Margaret who have given so much to the group over many years. We have now gained a solid group of hospital visitors from the conference who we will be approaching shortly and who will be available to pass on information and hope to those who have contracted GBS/CIDP and who are going through that initial time of pain and worry.

During the course of preparing for the 2013 conference we noticed that some of our records were not fully up to date. If you have changed your address or phone numbers during the last few years could you please drop us a line, e-mail or phone call to help us keep in touch.

Among the high points of the conference were the stories people shared about their experience of GBS. They gave hope to those who felt that in some way they were alone in their times of disability. It was clear from the discussions at conference that the positive attitude and support of family and caregivers went a long way to assisting a positive recovery. It is possible that in future conferences we will focus a little more on the valuable role of caregivers.

If you have stories to tell, questions to ask or even helpful suggestions for members please let us know.
Thanks to you all. Please remember to keep your details with us up to date. Enjoy this newsletter!

Ken Daniels

The Local Contacts and Hospital Visitor Programme

Thank you to the 17 people who attended the inaugural visitor training at the recent conference. A number of people with existing experience came forward but there were a large number of new faces. We had people from Auckland to Invercargill and many places in between and some great stories were told and experiences shared. The Local Contact and Visitor programme exists to provide support sufferers and their families, both in the acute phase of the illness and during rehabilitation as well as providing continuing support for those with chronic disorders that form part of the group. Local contacts provide an essential service of direct face to face contact with all who need support.

We are currently collating the information from the application forms filled by in our trainee visitors for the identification cards required as part of the programme and will be distributing these in the coming months.

If you think you would like to be part of the visitor programme please contact:

Ken: Ph 04 476 64 323 or

Don: Email: don_martin@xtra.co.nz

Secretary's Jottings

I have reported on the proceedings of the Annual General Meeting elsewhere in the Newsletter but it is always worth noting our thanks for the ongoing support of the ARA Lodge and Lottery which relieves some of the financial pressure of operating the Group and running Conferences. Members like Maurice and Kath Vickers are regular supporters of the Group (this year they raised $600 from their annual Auckland Theatre initiative) and other members make generous one off donations and I would encourage you all to give some thought as to how you might raise some money for the Group – and have fun whilst doing it!

Although I had initial misgivings about the financial viability of the Conference (registrations made a VERY slow start) – all was well in the end with some 76 delegates of which a third were new GBS'ers. This is exactly the reason we continue to hold Conferences – sure it's a great place to catch up with old friends and learn about the most recent advances in GBS "solutions" but it also provides an invaluable forum for new sufferers to learn more about their "little problem", to understand that they are not alone and, fantastically, to be able to talk on a one to one basis with some of the best GBS focused Consultants in the country – if not the world - on issues specific to them. We are most grateful to the members of the Medical Advisory Board who not only gave relevant presentations but were also prepared to participate in this one on one practice. A most satisfactory outcome after (at least for me) a shaky start. Not There??? – well, you missed a great gathering – resolve to mend your ways by 2015!

Shannon Tisbury, the sponsored physio from Nelson Hospital, enjoyed her conference experience and her report is detailed elsewhere in this Newsletter.

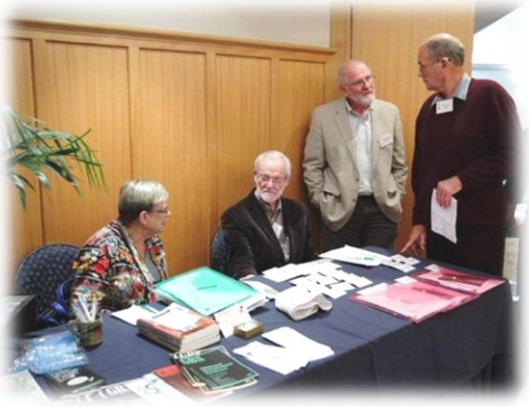
Dr Michael Baker's talk on the statistical evidence for the reduction in GBS cases in New Zealand linked to the major effort to reduce the levels of food poisoning from infected chicken led Gareth to conclude that roughly there are likely to be 100 new GBS cases a year in New Zealand if this is so it would be interesting to know just how many come to the attention of our Group in terms of being able to help with information and support. Something to discuss with Jenny and our Hospital visitors I think.

Thinking of Jenny, as many of you will know, she is not in the best of health presently and our best wishes for a good recovery go to here and husband Ian, who also has his own medical problems at the moment.

Membership renewals have gone well but there are still a few who have slipped through my "net" and I will send out reminders shortly. Newsletters will stop after the September issue if renewal have not taken place by then. This will be my "swan song" as far as membership duties are concerned as Peter is now in a position to take back that responsibility which more sensibly falls under Treasurer responsibilities and the next financial years renewals will be handled by him.

As always take care, winter is now upon us but for most of us at least we don't have to suffer the extremes of climate that our UK and USA fellow sufferers have to endure over their winter.

Tony



Margaret and Bob Stothart ready to welcome members to the conference under the watchful eye of Dr Gareth Parry and Tony Pearson

Report on the proceedings of the 2013 Annual General Meeting

The AGM was rather meagrely attended with only 14 members "signing in" - maybe an indication that we need to re-consider its timing during a conference year with many attendees making their way home on Sunday morning. Or perhaps a free ticket to the Wine and Cheese get together for those attending the AGM – can I hear the Treasurer "exploding" in the background!!

Nevertheless a useful meeting with Ken reporting on a constructive first gathering of the Hospital Visitor Forum and Lil updating the meeting on the progress being made on the "new look" website. Bob referred to the meeting in his retiring President's Report. (which is printed elsewhere in this newsletter).

Peter presented the Group's Accounts for the last financial year which showed a small operating surplus for the year and, as usual were accompanied by an unqualified Audit Report. The ongoing support of the ARA Lodge and a good level of other donations are very important to the Group and whilst our Reserves are robust Peter expressed concern that the ever increasing costs of "normal operations" was now outstripping our subscription income and he proposed that the meeting approve an increase of $5 to individual membership fee, $50 to Life membership and $25 to the Group membership subscription. This proposal was adopted by the meeting so that from 1st December 2013 subscriptions will be:-

Individual:	$15
Life:	$150
Group:	$15

The Memorial Fund continues to earn interest and it should not be too long before we are in a position to make a research award from the accumulated income. A generous legacy of $5000 from the Estate of Mavis Gillies was received this year and the meeting agreed with Peter's suggestion that this sum be added to the Memorial Fund Capital Account.

Maria De Cort's resignation was accepted with regret by the meeting but also with grateful thanks for the sterling work she has done on the publicity front for the group. The Board are reviewing options for filling the vacancy caused by Maria's resignation.

Bob's retirement from the President's role was duly acknowledged with a formal vote of thanks to both Bob and Margaret for their enormous contribution to the growth and development of the Group. Ken was installed as the next President.

Chris reported that steady progress was being made in persuading members to accept the newsletter by Email. This results in significant savings to the Group in both printing and mailing costs and she urged members with Email to consider switching to a digital newsletter if they have not yet done so.

I expressed my relief that following a late surge in registrations the Conference had proved to yet another great success and my earlier thoughts of extending the time between Conferences was unwarranted. It would however be less nerve-wracking to move away from what is clearly a "kiwi" habit of leaving decisions to the last minute!! So there WILL be a conference in 2015 and in the meantime the Board are considering holding the 2014 AGM in New Plymouth.

If you would like a copy of the draft Minutes of the AGM do please contact me.

Tony Pearson
Secretary to the Board

Bob Stothart and Hon Steve Chadwick welcome those members who attended the Friday night Wine and Cheese evening.

Annual Report of the Guillain-Barré Support Group New Zealand Trust 2013

Introduction
I have to report that the Trust is functioning very well. People who have served in various ways on the Board or as office holders (not on the Board) have carried out their duties on your behalf with commitment, skill, tact and discretion. The money is well managed, legal matters are addressed, letters and emails are promptly dealt with, publicity (of our activities) is to the fore and all this is carried out by volunteers. Hospital visiting is a fundamental component of our activities and I commend all members who have been engaged in this incredibly valuable function. We are reliant on communication with health professionals and while this is variable around the country, where it is effective, hospital visiting continues to lift the spirits of patients and families.

Medical Advisory Board
It is with great pleasure that I report the establishment of the Medical Advisory Board, chaired by Dr Gareth Parry.
This group will strengthen our status within the medical fraternity and add status and quality to our organisation. The members (who give freely of their time) are: Dr Gareth Parry; Dr Suzie Mudge; Dr Chris Lynch; Dr Pralene Maharaj; Dr Dean Kilfoyle and Dr Annette Forrest. Dr Parry's leadership in establishing the board is acknowledged and his readiness to help us whenever he is asked is a huge benefit to our organisation. Dr Parry will describe protocol for the interaction with the MAB in a future newsletter.

Thanks/Sponsorship
Special thanks to Ken Daniels who contacted every person on our mailing list, to chat and to interest them in the conference. It was a monumental task carried out with aplomb while observing confidentiality.
Thanks too, to the carrying company Hookers Transport which shifted huge boxes of records from Jenny Murray's place in New Plymouth to Tony Pearson in Nelson. When they heard we were a charity they carried out the job free of charge.
Thanks to the Lotteries Commission and ARA Lodge for continuing assistance.
The Vickers and the Pearson's organised fund raising events. Every little bit helps so others may be inclined to give it a try.
A huge thank you to the late Mavis Gillies who left $5000 in her will to the Support Group.
We thank Maria de Cort who has acted as our Publicity Officer with obvious professionalism achieving great success. Maria has chosen to withdraw and we thank her for her impressive achievements.

Numbers
We have 240 members on our books but not all of them are fully paid up. The newsletter goes to over 400 addresses. Distribution by email is making (and can make even more) a big impact on our administration expenses.

Iron woman Kathy Eggers
Kathy Eggers has CIDP and she completed the Taupo Ironman recently and received quite a lot of publicity which has been great for our organisation. It was a remarkable performance and shows what can be done if one sets one's mind to it.

Hospital Visiting
This activity is our "shop window" and I thank everyone who has been involved. You make a difference to the recovery of patients. We plan to introduce training for hospital visitors. It has taken some time to set training in motion but I am confident that it will prove to be very valuable. Thanks to Ken Daniels and Don Martin for working on the training programme.

Board
Tony Pearson performs all the tasks involved in being our secretary; Peter Scott manages our money with a frugal eye; Chris Hewlett sends out our informative Newsletter, Maria De Cort has gained us much welcome publicity; Don Martin and Ken Daniels have worked on the training programme for hospital visiting; other members respond when required to various matters of the day; Meike Schmidt-Meiburg; John Podd and John Davies. Although not Board members, Jenny Murray provides on-going service as our national Co-ordinator with great skills and discretion and Lil Morgan looks after our refreshed web-site.

Conclusion
This will be my last annual report as I intend to stand down at the Annual General Meeting in April. I have an unshakeable belief that organisations should seek to renew themselves regularly and to involve fresh ideas and new people. My time as President has seen heartening consolidation of the organisation. As I mentioned earlier, you have been well served by people who have taken on various tasks involved in managing an organisation. In the same way, I have been wonderfully supported by the Board and by members generally. I have been privileged to serve as your President.

Bob Stothart

Bob chats with Hon Steve Chadwick and incoming President Ken Daniels

Chronic inflammatory demyelinating polyneuropathy (CIDP)

(part five in the series by Dr Gareth Parry)

CIDP is a chronic disorder that has many similarities to GBS. The chief difference is that it runs a chronic course but there are also some differences in response to treatment.

What is CIDP and what causes it?

Like GBS,CIDP is an inflammatory, demyelinating disorder of peripheral nerves that is caused by disordered autoimmunity. The trigger for CIDP is unknown; unlike GBS, there is no evidence that C. jejuni or any other infectious agent can act as a trigger. Nor has a relationship to any vaccine been established. It is possible that patients are unable to identify a triggering event because of the slower onset of the symptoms. Although the primary attack is on the myelin sheath there is invariable and often severe axonal injury.

How does CIDP affect you?

The course of the disease: CIDP is a chronic disorder. By definition, GBS stops progressing within 4 weeks of the onset of neurological symptoms and thereafter improves. By contrast, CIDP progresses for more than 8 weeks. There is no consensus on how to define patients whose progression is between 4 and 8 weeks. The course is steadily progressive in about 85% of patients and is usually quite rapid with noticeable worsening from month to month. In the remainder it runs a relapsing course; that is, patients experience intermittent periods of deterioration interspersed with periods of improvement or stability. Rarely, there is a chronic monophasic course over several months; i.e., the patient progresses for a few months, stabilizes and then returns to normal and never relapses. Some patients, especially those destined to run a relapsing course, may present acutely in a manner indistinguishable from GBS. They improve spontaneously or with treatment only to slip back months or even years later; the longest interval I have seen between the initial presentation and subsequent deterioration is 5 years but usually periods of stability or improvement last for no more than a few months. In one study, about 15% of CIDP patients were initially diagnosed with GBS.

Clinical symptoms and signs:

Motor involvement: CIDP is a predominantly motor disorder but the degree of sensory involvement is generally more than is seen in GBS. Rarely, predominantly sensory symptoms may be seen in CIDP. Weakness usually involves both proximal (closest to the spine) and distal (farthest from the spine) muscles although distal weakness usually is most prominent. It always involves both sides but may be asymmetrical. Cranial muscles are rarely affected but facial weakness and weakness of eye muscles can be seen. Breathing muscle involvement is also rare and is almost never clinically significant when it does occur; I have seen only one CIDP patient who required artificial ventilation. Muscle cramps and, rarely, twitching (known as fasciculation) can be seen and may raise a concern about the much more serious condition of motor neurone disease.

Sensory involvement: Sensory involvement primarily manifests as imbalance. Weakness can also affect balance but in CIDP there may be imbalance of a much greater degree than can be accounted for by weakness alone. In some cases there is a condition called sensory ataxia where balance is severely impaired and it is much worse in the dark or when the eyes are closed. Patients with sensory ataxia will notice that they tend to fall if they need to get up in the night or when they close their eyes while showering. Loss of skin sensation occurs but is not usually severe. Tingling sensations, called paraesthesias, may also occur. While weakness affects both proximal and distal muscles the sensory loss is confined to the distal areas with feet being generally more affected than the hands.

Pain in CIDP: Unlike GBS, pain is not usually an early feature of CIDP. The aching pain (nociceptive pain as described in part 2 of this series) in the back, between the shoulder blades and around the hips and shoulders that occurs in about a third of GBS patients does not occur in CIDP. However, as the disease progresses and the degree of axonal injury increases, neuropathic pain often emerges. This pain is similar to that suffered by GBS patients. It is felt in the feet mainly with much less frequent involvement of the hands. It seldom spreads further up the limbs. It typically has a burning, prickling quality but there are over a hundred different adjectives that people use to describe neuropathic pain. Treatment of neuropathic pain is challenging but has improved over recent years and there are now more than a dozen medications that have been shown to offer some benefit.

Other features: Like GBS, CIDP almost invariably results in loss of reflexes. While this has no effect on the patient's function it is a critical finding that can help to distinguish CIDP from other neuropathies as will be discussed below. Autonomic involvement, which is so common in GBS, can often be found in CIDP if specific and sensitive testing is done but, unlike GBS, it is not clinically apparent. Rarely, the central nervous system (CNS) is involved and patients with spinal cord and optic nerve involvement have been described. Abnormalities of the MRI scan may also occur. It has been suggested that this is due to a shared protein between peripheral nerve and CNS but in a study that we did we concluded that it was no more than a coincidental association, a position also supported by others.

Chronic inflammatory demyelinating polyneuropathy (CIDP)

How is CIDP diagnosed?

CIDP is a neuropathy and neuropathies are generally quite easy to recognize. However, there is low recognition of CIDP as a distinct entity; many if not most general practitioners and even non-neurology specialist physicians are only vaguely aware of the condition. This frequently leads to delay in diagnosis and diminishes the probability of a good response to treatment. Unlike GBS where the diagnosis may be delayed by a few days, CIDP diagnosis may be delayed years and may never be recognized unless the patient is fortunate enough to see a neurologist. The average CIDP patient may be checked for diabetes and asked about alcohol intake and is then told that they have an "idiopathic neuropathy" which simply means that no cause has been found. There are three clinical features of CIDP that should alert any physician that this is not a typical diabetic, alcoholic or idiopathic neuropathy. Firstly, most neuropathies are predominantly sensory whereas CIDP is predominantly motor in its manifestations. Secondly, when weakness does occur in other neuropathies it is invariably confined to distal muscles, usually just affecting the feet, whereas weakness in CIDP affects both proximal and distal muscles. Finally, other neuropathies often result in diminished or absent ankle reflexes but do not affect the knee or arm reflexes whereas CIDP generally affects all reflexes to some degree. Any patient with any of these features which are atypical for other neuropathies should be referred to a neurologist for consideration of CIDP.

Once a diagnosis of CIDP is suspected it is generally quite easy to confirm, at least if the patient is seen within the first 2 years of the onset of symptoms. Just as in GBS, nerve conduction studies are the cornerstone on which a diagnosis of CIDP rests. The details of the nerve conduction abnormalities in GBS are outlined in part 3 of this series and the findings in CIDP are essentially identical with slowing of the speed of conduction being the most easily recognized feature. Challenges in making a diagnosis arise when there has been a delay in consideration of the diagnosis until there is severe associated axonal degeneration. At this late stage, which is usually seen only after several years of CIDP, it may be difficult to recognize the features of demyelination because the majority of the axons have degenerated.

Examination of the spinal fluid is no longer a routine part of the diagnostic assessment of CIDP patients but it can still be useful in atypical cases. Like GBS, the protein level is usually high but there is no inflammation. Other laboratory testing assumes a more important role in CIDP because there are a number of medical conditions associated with CIDP and there are several demyelinating neuropathies that closely resemble CIDP but that are treated differently and have a different prognosis. The blood proteins should routinely be measured; an elevation of the gammaglobulin component may indicate an important bone marrow condition, either a condition with the clumsy name of "monoclonal gammopathy of undetermined significance (MGUS)" or, less commonly, a type of bone marrow cancer called multiple myeloma. Complications of "connective tissue disorders", diseases such as "lupus" and rheumatoid arthritis, can superficially resemble CIDP and laboratory testing is usually done to exclude these.

How is CIDP treated and what is the outcome?

There are similarities to GBS but also important differences in the approach to treatment. Since both conditions are autoimmune, the foundation of treatment is some form of immune therapy. While supportive therapy such as physiotherapy and occupational therapy and management of pain are important they play a smaller role than in GBS. Nor is there need for respiratory support. This review will, therefore, be restricted to treatment with immune therapies.

Treatment with corticosteroids ("steroids"): Unlike GBS in which steroids such as prednisone are not beneficial and may even be harmful, treatment with steroids in CIDP should be the first line of management. Most neurologists treat with daily prednisone which is certainly an effective strategy but one that is plagued with adverse effects such as weight gain, skin changes, diabetes, hypertension, osteoporosis, cataracts and many others. To ameliorate these adverse effects while preserving the beneficial effects we have been treating CIDP patients with "pulsed" steroids for more than 10 years. The treatment consists of a very high dose of steroids administered as a "pulse" once a week. This treatment regimen essentially eliminates the most common steroid adverse effects like those listed above. Osteoporosis can occur so if long-term treatment is given (more than 6 months), regular bone density measurements should be done and bone preserving treatments should be given. The other adverse effects listed rarely, if ever, occur with this treatment regimen. The most common adverse effects are psychiatric; about 70% of patients become irritable, rarely to the point of psychosis, and about the same number have insomnia. These adverse effects are restricted to the treatment day and the night following so most patient tolerate it quite well. About 30% of patients have indigestion or heartburn but it rarely is sufficiently severe to warrant treatment. With this treatment regimen we have found that about 60% of patients go into remission and treatment can be stopped after 1-2 years. Other patients need longer term treatment but the dose can almost always be reduced. The most reliable predictor of remission with this treatment is the duration of disease; patients treated within 2 years of onset are much more likely to remit than those treated later.

Chronic inflammatory demyelinating polyneuropathy (CIDP)

We start treatment with methylprednisolone (a steroid closely related to prednisone but about 25% more potent) at a dose of 500mg once a week. As soon as improvement begins the dose is reduced and tapering of the dose is continued until the treatment is stopped or relapse occurs.

Treatment with intravenous immunoglobulin (IVIg): This is the most frequently used treatment in the US and is also widely used in NZ. However, I regard this as second line therapy to be used in those who do not benefit from steroids (rare) or those who cannot tolerate the adverse effects. IVIg is a blood product that contains the antibody fraction of normal human plasma. It is thought that these naturally occurring antibodies eliminate the harmful antibodies that are causing the nerve damage in CIDP. A group of CIDP experts from the GBS/CIDP Foundation International have recommended a standard approach to therapy consisting of 400-500 mg daily for 2 consecutive days every 3 weeks. As with steroids, as soon as improvement begins the dose should be tapered. It is best to reduce the dose but maintain the interval between treatments although some doctors continue the same dose but increase the inter-treatment interval. The treatment is as effective as steroids but has fewer adverse effects which makes it attractive to many doctors and patients. It has the disadvantages of being inconvenient, requiring intravenous infusions for each treatment, and extremely expensive; in the US it costs $10,000-$20,000 a month. Headache may occur during the infusions but is generally mild and can be managed by reducing the infusion rate. Rarely, a drug-induced (allergic) meningitis occurs which necessitates stopping the treatment permanently. Other allergic reactions can also occur. Rarely IVIg can cause blood clots leading to heart attacks, stroke, kidney failure and pulmonary embolism (blood clots to the lungs) so it needs to be used with great caution in older patients or those with diabetes or kidney problems. While effective in controlling CIDP, IVIg never produces remission so treatment needs to be continued long term, often for decades

Treatment with plasma exchange (PLEX): PLEX was a very commonly used treatment for CIDP in the past but has been largely superseded by IVIg because of the greater convenience of administration. PLEX and IVIg are equally effective. During PLEX treatment blood is withdrawn from the patient, the plasma is separated from the cell components of blood which are then returned to the patient with either donor serum or a synthetic serum. Since antibodies are contained within the plasma fraction it is thought that the harmful antibodies are removed. The procedure requires expensive and cumbersome equipment and access to major veins, usually through an implanted catheter in the upper chest. Because of this PLEX and IVIg are about equally expensive. PLEX is occasionally used as short term treatment in CIDP but rarely life-long. Like IVIg, it never induces remission.

Other treatments for CIDP: Not all patients respond to the treatments listed above or may respond but continue to require high doses with the inevitable attendant adverse effects or staggering costs. To reduce the dependence on these other treatments various other immune therapies are used. These include azathioprine (Imuran), mycophenylate (Cellcept) methotrexate and even cyclophosphamide which is a potent form of chemotherapy. These drugs are rarely used in isolation but as adjuncts to steroids, IVIg or PLEX.

Long term outcome of CIDP: CIDP is a disabling but not fatal illness. Without treatment very few patients are able to continue their former physical activities. Spontaneous remission does eventually occur in many patients but they are generally left with significant disability. Introduction of effective treatment has changed this rather bleak prognosis, especially if treatment is started with 2 years of symptom onset. As mentioned above, with pulsed steroid treatment 60% of patients in our study were normal or stable for at least 2 years on no treatment. All patients whom we were able to contact remained in remission 5 years later. Some of these did have some residual problems such as fatigue, mild weakness or imbalance but most had an excellent quality of life and many had returned to prior activities, including one who returned to his extremely physically demanding work as a fireman! Even though neither IVIg nor PLEX induce remission they are effective in controlling the disease and many patients are able to function extremely well on these treatments. Like GBS, fatigue, unrelated to the degree of weakness, may plague CIDP patients who are otherwise doing well. Pain may also be persistent and require treatment long term.

Kathy Eggers, probably our most "famous" CIDP'er speaks about her Iron Man Experience.

(I think we all thought she was a little crazy to want to do it. Ed)

A Personal Encounter: Living with CIDP

I have Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). My condition was originally diagnosed as Guillain-Barre Syndrome (GBS) following a nerve conduction test (the thoroughly unpleasant procedure which I describe as the 'cattle prod' test). My subsequent clinical history led to a revision of the initial diagnosis.

When I first became ill, I was in hospital for two years (from late in 2002 until early in 2005). Almost one year of this time was spent in Intensive Care. Five times during those two years I made it out of Intensive Care only to boomerang back. Sometimes I got as far as the neurology ward, sometimes to rehab and once I was discharged for a few weeks. But I kept returning to Intensive Care. Clearly my condition was 'chronic', hence CIDP.

While I understand what chronic means, I naïvely imagined that after two years and five recurrences the disease had finished with me. One of my neurologists seemed to confirm this idea when he said that he thought the condition had 'burnt itself out'.
I went off to New Zealand with my husband Peter to the NZGBSSG Conference in 2007 confident in this opinion. I was horrified to hear during the conference that CIDP is never finished: it can come back at any time. I discussed this issue with Lindsay Haas, an old friend from my university days. Not only do I think that he was a brilliant neurologist, I also knew him to be a very kind man. When I told him that I was sure that my CIDP was finished, he smiled and said, 'You believe whatever you want to believe, Valerie.'
I continued with my misguided view for another year. Then, in 2008, I was persuaded to have tendon transfer surgery on one of my crippled hands. It was a fairly serious operation, taking about five hours. The plastic surgeons were very pleased with the results of their work, but I noticed when I was in rehab after the operation, that the familiar and dreaded paralysis was returning. I ended up back in the neurology ward seriously ill.

It reminds me of the old joke about surgeons: 'The operation was a splendid success; it is just a pity that the patient died.' This operation was *not* a success (my hand may look better, but the function is worse than before) and I didn't *quite* die, but I nearly did.
After this episode I had to come to terms with the fact that my CIDP could recur. In this instance it was clearly brought on by the trauma of the surgery. We knew after this that we had to do everything we could to minimise trauma in my life.

Frighteningly, the next recurrence in 2011 had no cause that we could identify. There was nothing more than usually stressful in our lives and I hadn't had any discernible illness or infection. But there were unmistakable signs that the neuropathy was back.
With more experience, I am now better able to read these signs. As the paralysis slowly proceeds, I have a corresponding loss of function. I have drawn up a strength/function chart which lists things (functions) that I am usually able to perform readily. These include examples like: can lift my hands to my face to feed myself or to put on my sunglasses; can stand to walking frame and walk (well, in my case, shuffle in an ungainly crouched position) about twenty steps; can hold my head up; can breathe all day without ventilator assistance. Then against each of those I mark whether I am *able* to perform each function, whether I have *difficulty* performing each function, or whether I am *not able* to perform each function at all. Deterioration is clearly indicated as the marks move across inexorably to the 'not at all' column. I know that things are getting grim when I need a straw to drink my nightly sauv blanc (but that's not on my chart!)
My strength/function chart is my attempt to be objective about my condition. The neurologists have their own way of measuring the depredations of CIDP. They do what I call the 'Push me/Pull you' test. It goes something like this: 'Lift your knee, trying to resist my downward pressure; lift your elbows and hold them out, again resisting my pressure; push your hands away from your body while I push them in the opposite direction etc.' They give a numerical value to each action and then add it all up to get an overall picture. It ends up being quite a serious workout for me! This test is also a little subjective (it depends a bit on which neurologist is doing it), but it sure beats a nerve conduction test! I am always very grateful that my neurologists believe me when I tell them that the CIDP is back and, rather than wasting time on unnecessary tests, get on with treatment straight away.

It is a bit tricky, because I don't think I look too sick in the early stages of a new episode. I remember once when I was in hospital my granddaughter was very distressed about what was happening to me. I was pretty paralysed at the time, but Peter and a nurse helped me get out of bed, wrestled me into my dressing gown, propped me up on a chair, wedged a pillow behind my head to stop it flopping around and folded my hands decorously in my lap. My beautiful Laila sidled into the ward behind her mother with her big brown eyes wide open. She looked me up and down and then declared, 'You don't look too sick to me, G'ma!' Mission accomplished: granddaughter reassured.

A Personal Encounter: Living with CIDP

The CIDP came back again in 2012 and this time the cause was very clear. I got the flu and this precipitated the neuropathy. I had thought carefully about whether to have the flu injection and was so frightened by the possibility that it might bring about a recurrence of the CIDP, that I decided not to have one. Of course I got the flu and had to be admitted and cared for in the Intensive Care Unit. I was discharged after ten days and then, after one uncertain and miserable week at home, I was back in hospital to get treatment for CIDP.
This year I decided that I should have the flu injection. Surprise, surprise! It brought about another episode of the CIDP. The phrase 'Can't win!' comes to mind.

Each time I have an attack of CIDP, I get increasingly paralysed to the point where I am unable to get out of bed, can barely lift my arms off the mattress, can hardly chew and swallow and, annoyingly, find that my speech becomes so slurred that it is hard to communicate.

The treatment I have to have each time is horrible. The only thing that seems to have any lasting impact on my condition is Cyclophosphamide. This is given intravenously. It is a very toxic drug and has unpleasant side effects, including nausea. It makes my already thinning old-lady hair even thinner and, because it suppresses the immune system, makes me very vulnerable to infections. While it does work, it takes up to a month to take effect. While we are waiting for the Cyclophosphamide to kick in, I usually have to have plasmapheresis. This involves inserting an access line. Sometimes they use a permacath which, in spite of its name, is anything but permanent. For me, with my compromised immune system, it always gets infected and has to be removed after a couple of weeks. Sometimes they use a more temporary solution, a vascath, which they insert usually in my groin or jugular. I dread the procedure, which is done without a general anaesthetic, and I hate having a bouquet of tubes sprouting out of me, particularly when it is from my neck.

The disease (and treatment) is very debilitating. When I get home from hospital after each episode, I struggle with rehabilitation. As I get older, I find that it is increasingly difficult to get back to what Peter and I consider as my baseline. It is hard to get the balance right between pushing myself to exercise and getting enough recuperative rest. As all people recovering from CIDP or GBS know, too much exercise is counter-productive. On the other hand, you can't sit around doing nothing all day. Each time I have to climb, that rehab hill seems to get steeper and steeper!

Not only am I getting older, so too is Peter on whom my whole quality of life depends. He retired when I first got sick to care for me. When I was in Intensive Care last year, in the same bed and in the same room I had been in when I first got sick, I looked at him sitting on a chair beside the bed and thought, 'You did this all ten years ago, but then you didn't have an artificial heart valve, a pacemaker or prostate cancer and you were only in your 60s not your 70s.' Still, he continues to be my rock.

With Peter's loving support, I have come to terms with the disability with which my illness has left me. After those first two years in hospital I have to have nocturnal ventilation and I have a trache to facilitate this, my mobility is seriously limited so I spend a lot of time in a wheelchair, and I have very limited function with my crippled hands. I am lucky because Peter cares for me with tenderness and devotion and remarkable good humour. You can cope with being a cripple when you are waited on hand and foot!

I have a lot in my life for which to be grateful: the support and love of Peter and my family; a wide range of wonderful friends; a lovely apartment in a beautiful city; marvellous support systems in place and the fact that when I got sick I was in my late fifties and I had already had a full and interesting life.
None of this however makes it any easier to live with the uncertainty of this horrible disease. I am frightened because I never know when it's going to come back, I hate the thought of being paralysed again when it does, I dread the treatment I know I will have to have, and I despair about being able to recover from future setbacks. I seem to lack the resilience I once had, and it is becoming increasingly difficult to be positive and optimistic. This is the reality of living with CIDP.

Happily I don't waste too much of my time reflecting on this reality. Mostly I just get on with my life, enjoying my very pleasant day-to-day existence.

Valerie Simpson
June 2013

A physiotherapist's perspective by Shannon Tisbury

Firstly I would like to thank Tony Pearson and Murray Brown for arranging for me to attend this year's conference in Wellington. It was very generous and very much appreciated. All the previous courses or conferences I have attended in the past are targeted at physiotherapists or other allied health professionals specifically. So it was very refreshing to be part of a conference whose target audience was for those who have been directly affected by GBS, CIDP and Miller-Fisher Syndrome.

Whenever I attend a conference I try to reflect on what I have learnt and identify how this will change my practice and my patient's journey. Having mostly worked with GBS in the past I now have a better understanding of CIDP and have been introduced to the Miller Fisher Syndrome which I had not heard of before. The programme outline was comprehensive and the topics were very relevant and informative for all the participants. Fatigue is often an issue that persists despite a good physical recovery and I have always found it challenging to be able to assist my patients in managing this. I have always wondered how much I should advocate exercise when someone reports high levels of fatigue. As a physiotherapist exercise is often the cornerstone to rehabilitation but how much is too much is often the question? This is a difficult question to answer as each person presents differently and as Dr Mudge highlighted there are many factors which impact on a person's ability to participate in activity. Professor Parry advocated exercise as an important part of managing fatigue and made the point that fatigue may be also contributed to by an element of deconditioning and weakness associated with a change in activity. The amount of activity that is recommended will depend on so many variables and during rehabilitation this requires a close dialogue between those affected and the professionals who are supporting them through their recovery.

I was very impressed by the organisation and professionalism of this year's conference. I shamefully was not fully aware that such a support group existed in NZ but now having attended the conference and having met with the GBS Support Group Committee I will now make it routine to introduce the concept of this group to my future patients. I would also recommend the conference to other professionals who work with persons with GBS, CIDP and Miller Fisher Syndrome to improve their knowledge and understanding of these rare conditions.

Shannon chats to long time supporters of the Support Group, Maurice and Kath Vickers.

The Mobility Assistance Dogs Trust

The Mobility Assistance Dogs Trust (Mobility Dogs) is a registered charitable trust established in 2003 with the mission: "*to enhance the lives of people living with long term physical disabilities by providing mobility dogs to increase independence, confidence, self-esteem and participation in New Zealand communities."* Mobility Dogs are trained to provide assistance with everyday tasks: retrieving dropped items, opening doors, refrigerators, cupboards and drawers pressing lift and pedestrian crossing buttons, barking for help and much more. Mobility Dogs are partnered with people living with long term physical disabilities such as (however, not limited to): cerebral palsy muscular dystrophy multiple sclerosis spinal cord injuries. Some Mobility Dogs are partnered with people in wheelchairs; others provide balance and stability whilst walking. Mobility Dogs working teams span a wide age range from children through to retirees. Alongside providing assistance with everyday tasks Mobility Dogs offer companionship, a greater sense of security and a feeling of connectedness to the community.

For more information contact:

Jody Wilson - General Manager
Mobility Assistance Dogs Trust and
Puppies in Prison Programme
P.O. Box 300-563 Albany Auckland 0752
M: (027)7007017
E: jody.hogan@mobilitydogs.co.nz
Join us on Facebook: https://www.facebook.com/mobilitydogs

Dr Suzie Mudge gave this presentation at the conference on Rehabilitaion.

It is also available to view on our website.

Rehabilitation and beyond…

Suzie Mudge
Dip Phys, MHSc, PhD

Background

NEURO REHAB RESULTS

- Director and physiotherapist
- Private rehabilitation clinic in Auckland specialising in neurological conditions
- Experience is with clients with GBS who are living in the community
- www.neurorehab.co.nz

AUT UNIVERSITY

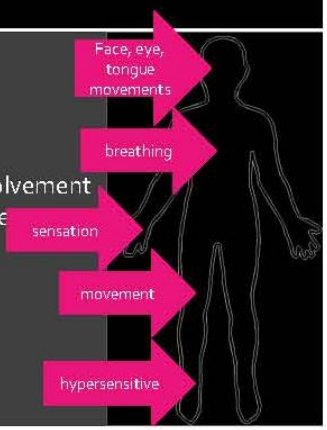
- Post doctoral research fellowship funded by Waitemata DHB
- Person Centred Research Centre
- Research interests include
  - what improves walking (and other function) in the real world?
  - How do we need to work differently to be more effective?

Outline

- Physical symptoms of GBS
- Rehabilitation (physiotherapy) for GBS
  - What we know
  - What we don't know
- What are peoples' needs beyond rehabilitation
  - What can be done about them?

What are the problems after GBS?

- 100% motor impairment
- 83% sensory loss
- 74% respiratory muscle involvement
- 64% cranial nerve involveme
- 22% hypersensitivity



What do we know about rehab for GBS?

- Not a lot from good quality studies!
- But what evidence there is suggests that in the short term:

High intensity rehabilitation

Improved functional ability

Improved social roles

Khan et al, 2010: Cochrane review

General rehab principles

Physiotherapy has been shown to

- Increase strength
- Increase fitness
- Improve function
- Improve quality of life
- Decrease fatigue

Khan and Amatya, 2012

So what don't we know?

- What the content of care should comprise
  - But also, how much, how long and where?
- What are the longterm issues
- How to best address psychological issues
- How should we treat pain?

Khan et al, 2010: Cochrane review

How much recovery?

- Most people make substantial improvement
- Two-thirds achieve 'good' recovery
- Most people are walking by 6 months

Khan et al, 2010: Cochrane review; Davidson et al, 2009

But…

- 20% have residual significant disability
- 68% have not returned to previous level of mobility
- 60% with pain
- 60% with fatigue
- 16% report moderate to extreme impact on major life areas (work, family, leisure and social activities)
- 22% report impact on satisfaction with life, mood, confidence and ability to live independently

Davidson et al, 2009; Dennis & Mullins, 2013; Kahn, Pallant, Ng & Bhasker, 2010; Khan, Amatya & Ng, 2010

And beyond…

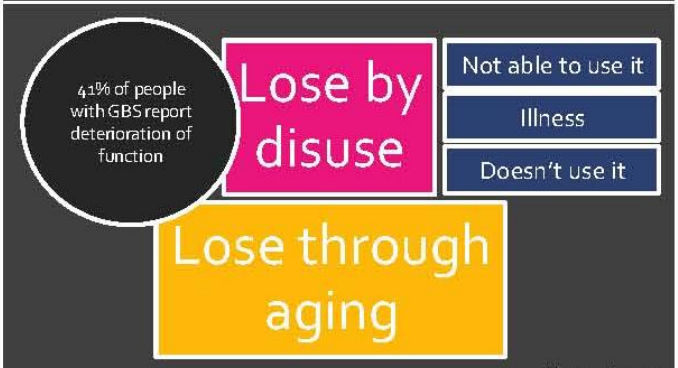
Most improvements are made in the first year after onset.

And after that?

- Modest improvements (in mobility, self care and positive impact on relationships) still possible after 1 year with intensive rehab
  - 2-3 sessions/week
  - 12 weeks
  - Control group received home based exercise programme: exercises, education and 30 min physical activity programme 2X/week

Khan et al, 2011

Can you lose function?



Khan et al, 2011

What happens with aging?

PRIMARY genetics

SECONDARY experiential

- Our muscles become weaker, slower and tire more easily
- We become less flexible
- We are slower to process sensory input (e.g. vision and sensation)

- Exercise
- Nutrition
- Pathology
- Insults

Shumway-Cook & Woollacott, 2012

Can we reverse these changes?

Lose by disuse

- Not able to use it
- Illness
- Doesn't use it ✓

Lose through aging

- Genetic factors
- Exercise ✓
- Nutrition ✓

Khan et al, 2011

Physical Activity and Healthy Eating

5+ a DAY fresh fruit & vegetables

Rongoā Kākāriki GREEN PRESCRIPTION

HEHA

Pretty simple really

PHYSICAL ACTIVITY

- **Adults**
  - at least 30 minutes per day of moderate physical activity on at least 5 days per week.
- **Children and adolescents**
  - At least 60 minutes of moderate to vigorous physical activity daily.
- **Older adults**
  - as for adults as abilities or conditions allow.
- Add strengthening of major muscle groups 2-3 times per week for all groups.

HEALTHY DIET

- Low fat diet
- Increase fruit and vegetables
- Limit/discourage consumption sugar-sweetened beverages

Department of Health and Human Services, 2008; Haskell et al, 2007; Lau et al, 2007; Swinburn et al, 2004; WHO, 2009

Guidelines for Disabled People

- Limited research
- Current recommendations
  - Based on general population guidelines
  - Within limits of individual conditions
  - Progression may be slower
  - Careful monitoring recommended

Department of Health and Human Services, 2008; Ministry of Health, 2003

But is it really that easy?

Living Well with a disability: needs, values and competing factors

Suzie Mudge, Nicola Kayes, Verna Stavric, Alexis Channon, Paula Kersten and Kath McPherson

on behalf of the Living Well Project Team

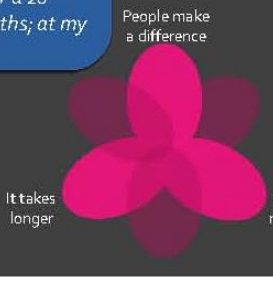
PCR Person Centred Research Centre

AUT UNIVERSITY

Findings

And I had a really kind friend who came with me and cause I needed my care for things at home. I only had 10 hours a week at that point, care. So I needed my care for keeping things going at home so a friend came with me. And it was a whole morning's effort to go for a 20 minute swim. And I did 20 lengths; at my best I could do 20 lengths.

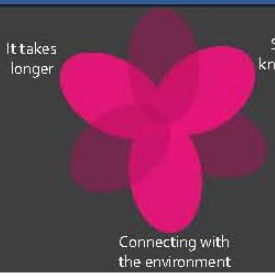
Michelle* (adult with physical impairment)



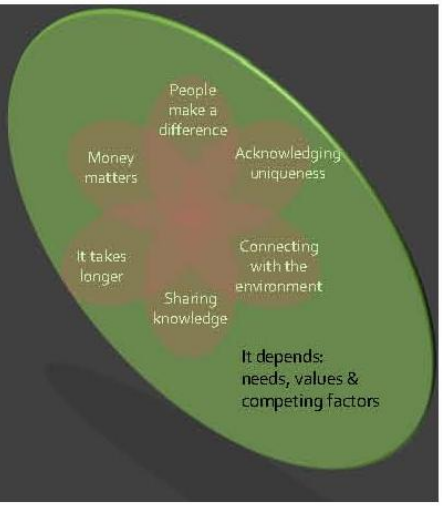
*pseudonyms used throughout presentation

It takes time, for example, if I want to join Zumba, I need to find somewhere that's close and local for me, I need to meet the trainer, the person that's providing that, I need to talk with them, explain I'm deaf, I need to be there early to be at the front so I can lip-read them well, and follow them well. So all that takes time.

Sue (deaf adult)



Findings



Needs or choice?

...it's a lifestyle choice for a lot of people... but for you and I... we've got to do it. It's a matter of life and death, really.

Nina (adult with physical impairment)

I think for a lot of people it's [physical activity and healthy eating] *not on their priorities. It's only at a level that maybe, there are a lot more things that are crucial. You know, being fed, as simple as that. House and those things.... [when you're in] a place where you can take time out to focus on, you know, getting a good pair of abs. And then things in your life are pretty good all around.*

Tony (from advocacy/service provider group

Values

- Challenging oneself
- Pushing limits
- Taking risks
- Being competitive

I'd rather be included in with these muscley guys and the everyday work that comes from the gym... Today when I go to the gym, they know who I am. So we form different relationships outside of the fact that I'm disabled.

Matt (young people group)

Competing factors

Yeah well like it can depend on whether they've actually slept, it can depend on the weather, it can depend on transport... I suppose you could say it's like looking into a kaleidoscope.

Liz (adult with physical impairment) referring to the ever-changing lens

Main messages

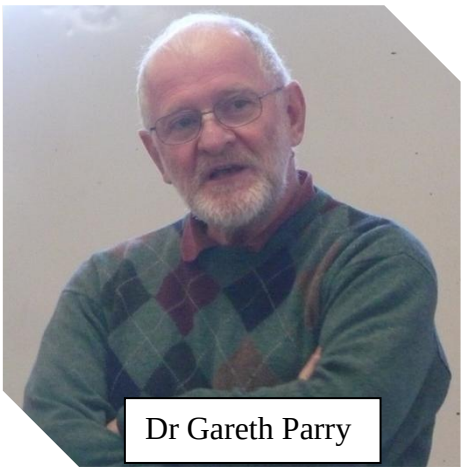
- Lots of factors impact ability to take part in living well
  - Realise it's not simple
  - Go easy on yourself if you're not meeting guidelines!
- Sometimes a health professional may be helpful to help address barriers

Summary

- The impact of GBS may be reduced with rehabilitation both in the short and longer term.
- Aging and disuse may reduce function.
- Some of these effects can be reversed with exercise and activity.
  - Sometimes it's not that simple to exercise
  - Sometimes a health professional may help
- But doing something is better than doing nothing!

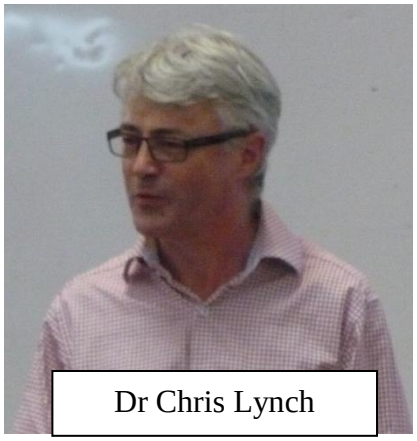
Attendees at the 2015 Conference.

Presenters at the Conference



Dr Gareth Parry

Hon. Steve Chadwick



Dr Chris Lynch

Dr Dean Kilfoyle

Dr Pralene Maharaj

Dr Michael Baker

Dr Suzie Mudge

Kathy Eggers

Peter Scott

Lil Morgan

Letter to the Editor

Hi Chris

Good to meet everyone at the GBS/CIDP conference on Saturday.

When my husband, Scott was diagnosed a few weeks ago with CIDP that's all we were told was that he had CIDP – it took some googling and was quite serendipitous that the conference was about to happen in Wellington.

My Dad has Secondary Progressive Multiple Sclerosis so we had just kinda compared what Scott had with that and thought oh well at least this disease has a treatment.

We were both quite blown away hearing all stories about people ending up in ICU on ventilators followed by months of rehab. We think that Scott has been rather lucky so far.

One thing that really touched me was Peter Scott's story about having to alter his bathroom to suit his needs – he was lucky a plumber mate was able to step up and help him out.

When we were in our groups – I was in the carer group and one lady from Invercargill explained how her CIDP husband had been sent home with no consultation and had to sleep on the couch downstairs as there was no other option in their house and the health services hadn't even checked out the situation before discharging him

I'm an architectural designer and have a lot of experience both personally and professionally (I used to do Summerset retirement villages) with disabled bathrooms, ramps etc.. I'd like to pay it forward and offer my experience and services to those who might find themselves in a hard situation (as if being sick isn't hard enough). If people need advice they can just give me a call and if they find they need plans drawn I'll do what I can to help.

Regards
Rochelle Dennis

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Website
The International Foundation has made some changes to its website. Several links to the websites of international chapters are now listed : http://www.gbs-cidp.org/home/get-support/international-chapters/

We aim to add more as they become available.

PADDY MARIE LTD

Who are you? You direct credited $50 to our bank account on the 28 April, unfortunately I cannot relate this to a membership. Please contact me: peterscott@clear.net.nz.with your name.

Dear Friends,

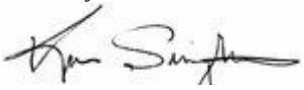
The Foundation continues to want to share our newsletter, *The Communicator*, with everyone who is interested in receiving a copy. In an effort to reduce our mailing costs, we are beginning the transition to emailing *The Communicator* to every recipient who has an email address.

Below is a link to the GBS/CIDP FI Spring 2013 Newsletter. I encourage you to comment on receiving this newsletter by email.
I can be contacted at ken.singleton@gbs-cidp.org.

http://www.gbs-cidp.org/wp-content/uploads/2011/11/Spring-2013-Newsletter.pdf

I look forward to hearing from you.

Sincerely,



Bay of Plenty / Waikato Coffee Group.

Venue: **Kaimai Cheese Company, 2 Hawes Street, Waharoa (just off St Highway 27)**

Date & Time: **12.30** **Friday August 16th**