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Guillain – Barré Syndrome Support Group New Zealand Trust

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NEWSLETTER June 2017



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Medical Advisory Board



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Dr. Pralene Maharaj Pathology Registrar ADHB And Trainee in Pathology with the Royal College of Pathologists Australasia Member of GBS Support Group since contracting GBS in 2006	Dr. Suzie Mudge Director & Physiotherapist Neuro Rehab Results Senior Lecturer/Senior Research Officer Health and Rehabilitation Research Institute, AUT University
Dr. Dean Kilfoyle Neurologist Auckland City Hospital Auckland District Health Board	Dr. Vic du Plessis Neurologist and rehabilitation specialist. Part time consultant neurologist Dunedin
Kathryn Quick Senior Physiotherapist Neuro ó Services at Auckland District Health Board BSc(Hons) MCSP NZRP	Dr. David Gow Neurologist with Southern DHB
Dr. Annette Forrest ICU Consultant MBChB, BPharm, Dip ag & Vet Pharm PGDIP aeroretrieval Masters Aviation Medicine CAA Medical Examiner PGDIP Occupational Health	

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Dr Matthew Peacey



Dr. John Podd



Chris Hewlett



Meike Schmidt-Meiburg



John Davies



Beverley Whittaker

Meet our Newest Trustee Beverley Whittaker

I was born in Cape Town, South Africa and emigrated to NZ in 2006, becoming a NZ Citizen in 2013.

On arrival NZ I was employed as office manager for Turners Auctions in Napier. I am now a Director and cosmetic consultant of Jeff Whittaker Pharmacy, Havelock North and married to Jeff who is a Pharmacist.

I contracted GBS in May 2014 ten days after a Flu Vaccination. I was virtually paralysed from the shoulders down. I was in hospital for ten days. Eight months later I was walking fairly freely, breathing like normal but still suffering painful episodes especially in my right hand.

We welcome Beverley to the Board.

Editor's Note



Hi everyone

I have been very lucky with articles for the magazine this time around and space is tight so that lets me off the hook.

The conference was a success despite numbers being slightly down. Those that did attend certainly had a wealth of Medical advisors on hand to talk with. A visit from QE Health which included a Chair Aerobics session was very well received. I have to admit that I was not very keen on this but this was a lot of fun and I will be including more on this in the next newsletter as space doesn't allow this time around. Renae Ballø's dance troupe was another highlight for me. What she is doing is really amazing. You can check her story out at:

<http://www.creativenz.govt.nz/news/touch-compass-releases-new-short-film>

I **REALLY REALLY** need some personal stories to publish. Please put pen to paper or send via email. Happy to receive it either way.

Enjoy the magazine and stay healthy over the winter months.

Chris

A few Photos from the Conference



Presidents Report



Welcome to all our readers.

The main item for reflection this quarter is the success of our Bi ó Annual Conference held in Rotorua on 5th, 6th & 7th May.

As president I extend my thanks to all who took the time and expense to travel to Rotorua for this event.

Especially the MBA members without whom the conference would lack true medical substance.

As I have mentioned before the conference is a core activity of the support group and is a once in two year opportunity for everyone to get together and share their experiences and knowledge of the dilapidating syndrome we are afflicted with.

The newsletter contains a number of reviews of the activities and presentations of the day, however two that stood out for me were

Firstly, Renee Ballø's video & Dance Routine of her being afflicted with GBS then her transition through her recovery phase using dance routine as her form of physiotherapy, up to the present where she is back working as a dancer once again. It is an inspirational piece of work that all GBS sufferers should view for its motivational value alone.

Secondly, the end of day open panel discussion with our Medical Advisory Board members, who fielded questions from the floor covering a wide range of issues from our members, I wish to thank them for their direct answers and opinions they gave to the many questions asked. As one member pointed out at the end of the session the information given was priceless for all those present.

One area of concern that Dr Gareth Parry presented is the fact that New Zealand has the highest rate per capita of GBS in the developed world now, 2.53 cases per hundred thousand population based on last year statistics. At this rate we could possibly expect over 100 cases this year.

This could be why our Hospital visitors get a call to see one patient at a rehabilitation unit and on arrival find two others we know nothing about! Hence our need to continue to seek new ways of communicating our existence to hospitals and sufferers. The formation of a social media subcommittee to establish ourselves onto the cell phone networks will be a step in the direction of communicating with the generations who have grown up with this technology. Using it every day as their way of sourcing information and staying in touch with each other.

The Board of Trustees meeting after the AGM on the Sunday introduced two new faces on the Board, I welcome Matt Peacey and Beverley Whittaker to the present governance team.

Our condolences to our Patron Steve Chadwick and her family, on the loss of her husband John who died suddenly at Rotorua Hospital on the 27th of May. Our thoughts are for you and your family at this time Steve.

Finally on a personal note Terry-Ann and I had the pleasure of a visit from our Conference photographer and his partner, Jos Roebroek and Hilde from the Netherlands, at our home two weeks after the conference, they were enroute to visit Stewart Island as part of their NZ tour, it was great that they called in and we would like to offer the same hospitality to any GBS sufferer passing through Invercargill.

Regards to you all.

Doug Young
President.

Annual Report of the Guillain – Barre’ Support Group New Zealand Trust 2017

Introduction

I am Doug Young and I have the pleasure of presenting my first annual report as President. It is very gratifying that the Trust has functioned well over the last year.

People who are serving on the Board or as office holders have carried out their allotted duties with commitment, skill and where required, discretion.

The financial management is sound, enquires and emails have been promptly dealt with. Publicity opportunities of our activities have, when they have arisen, been taken.

All this is carried out by our volunteers.

Medical Advisory Board

Our tireless chairman of the medical advisory board, Dr Gareth Parry has continued to strengthen the structure of this important group of specialist people. They operate within the medical fraternity, thus ensuring a professional approach by our organization to the various hospital area managers who look after GBS patient welfare.

The current members are Dr Parry, Dr Chris Lynch, Dr Dean Kilfoyle, Dr Suzie Mudge, Dr Pralene Maharaj, Dr Vic du Plessis, Dr David Gow, Dr Annette Forrest, and Kathryn Quik ó Senior physiotherapist Auckland DHB.

Our work as an organization is to continue the work of promoting these people to the various hospitals as an important avenue of patient care assistance and advice for doctors and nursing staff of GBS sufferers.

Members

We have 191 members on our books but not all of them are fully paid up.

(A decline of 49 members from 2013 as a comparison)

Hospital visiting

I acknowledge all our hospital visitors members who have put their time aside for carrying out this fundamental part of our operation. As one of our main activities I wish to thank all those who have made hospital visits over the last year.

Communication with health professionals around the 20 plus New Zealand Hospital Boards to enable us to function in the visitor role is variable, and we continue to pursue avenues to improve our contact with them, so our services are made available to GBS sufferers around the country.

We all know the positive effect a past sufferer visiting a new GBS patient can have, providing it is handled in the correct manner. Hence the need for our official hospital visitors to be vetted and adequately trained on how to conduct themselves during these visits. The training sessions held at our bi ó annual conferences are now also an important part of our organization.

Some examples of the invaluable support we can provide is the case of the Hawkes Bay water contamination outbreak and currently three patients in the rehab plus unit Pt Chevalier in Auckland.

Communication

Newsletter

The newsletter goes out to 285 people (126 via E mail & 159 by post) E mail has made a large impact in decreasing our administration expenses for the newsletter.

A further 126 magazines are sent to Medical and support type organizations.

I make special thanks to Chris Hewlett who manages our newsletter every 3 months, it’s our most valuable communication tool at present and without her commitment to this task we would be in a very difficult position when it comes to communication to our members and the various health organizations we mail out

to. Chris has carried out this duty for eight years now and having to co-ordinate several of her fellow board members to meet her deadlines for publication is not an easy task.

All this along with her managing our face book account and involvement in our web site.

Web Site / Publicity / In-formal Meets

Our website is hosted and maintained free of charge by the good offices of the N.Z. Organization for Rare Disorders and we are most grateful for this facility. Day to day updates and changes to the website are carried out by member Lil Morgan in conjunction with Chris Hewlett and Tony ó your contribution is appreciated Lil. With the increasing use of technology to access services such as we provide our website and Face Book account are now a vital part of our service and we will be addressing an upgrade in both these areas in the coming months.

Hopefully we are in a position to provide a publicity support person to assist with wider communication in the near future.

The informal õcoffee groupømeetings appear to be a continuing success in bringing small numbers of members together in their local areas on an in frequent basis - Auckland and Tauranga especially, these informal meetings provide the board members with feedback on whatø happening (or not happening) during the course of the year. Well done by those organizing these mornings.

Sponsorship Thanks to the following

- ARA Lodge No 3481C for the continuing sponsorship,
- Gareth and Cathy Parry for their assisted scholarship donation,
- All members for their annual donation to ensure we continue as an organization.

Trust Board

Over the past year I have formed a respect for the following:

- Tony Pearson preforms all the tasks involved as secretary plus acting as our national coordinator for all enquires and hospital visits

I appreciate the invaluable input from Tony in helping me into this role.

- Peter Scott manages our finances and generally keeps an eye on procedures under the trust deed being followed correctly
- Chris Hewlett newsletter, coffee group, general
- Meike Schmidt - coffee groups, Brain day, newsletter assist, general
- John Podd ó hospital visitors, general
- John Davies ó hospital visitors, Brain day, general
- Dr Pralene Maharaj ó Medical Advisory board
- Dr Matthew Peacey ó (newly co-opted board member) ó research, Publicity
- Dr Gareth Parry ó Medical Advisory board, Research, Publicity, general.

Obituaries

Itø with great sadness I have to acknowledge the passing of two of our organizations early members.

Founding member:-

Jenny Murray - at New Plymouth on 13th December 2016. It is 20 years ago this year since Jenny put her enquiry letter in the New Zealand Womanø Weekly magazine looking for other GBS sufferers, this was the start of our present organization. Without the tireless efforts by Jenny to coordinate and form this group none of us would be here today. Jenny was acknowledged in the honors list for her volunteer work in forming this organization.

Early board member - Bob Stothart at Wellington the beginning of November 2016, Bob was one of the original committee members going on to become president for a number of years, his enthusiasm and energy as one of the main driving forces helped to develop the organization to its present day status.

Obituaries for both Jenny and Bob were given at the conference in Rotorua 6th May 2017.

Major Involvements For 2016

1. Havelock North's Water Contamination caused 5000 people to come down with severe illness due to campylobacter contamination - which we all knew would lead to some GBS cases down the track. Thanks to Gareth and Tony for their efforts to inform the local Ministry of Health Officials, Doctors and medical staff to be made aware of the possibility that patients may present with GBS symptoms. Gareth's fear was that the worst case scenario, of possibly as many as 10 or 12 GBS cases, would swamp the local Napier hospitals ICU capability.

As it progressed only 3 cases eventuated that we are aware of.

2. The Board's decision to provide seed funding for research into a New Zealand native plant that may contain a unique compound that will alleviate pain in GBS sufferers.

The funds will be made available from the interest earned by the G.H. Jones and Others Memorial Fund, and is allocated through Section 3c of the Trust Deed rules we operate under.

Gareth Parry and the MAB will monitor research results and report on progress to the board twice a year.

3. Tony and Gareth are fielding inquiries from several different avenues.

For example we dealt with an inquiry for transport and support for wheelchair bound invalid just to get to a specialist appointment. This meant the Board was involved with WINZ, caregivers and several different government departments.

Gareth had an inquiry from India for support from a mother with a child with possible GBS.

Therefore this indicates to me our organization is being effective in some areas that we never thought we would be in, however there is still a lot of work to be done in promoting ourselves.

This completes the Presidents Report for 2017



To have the Flu Jab or not??

Dr David Gow, a new member of the MAB and senior Neurologist at Dunedin Hospital gave a succinct review of the historical statistically records of GBS events occurring (or reoccurring) after a Flu vaccination at the Rotorua Conference. In a nutshell, except in very specific cases, the medical profession's conclusion was that the risks of getting a severe infection from the flu were significantly greater than the chance of contracting or re-contracting GBS.

If there is space in future Newsletters I for one would be very pleased to see the slides of that presentation for future personal reference but for now here is what I brought away from that presentation.

1. If an individual has no history of GBS/CIDP and no other obvious health compromises it's a no-brainer to get a Flu Jab!
2. For everyone else (including GBS/CIDPers) Dr Gow presented a risk strategy table:-

Did the initial illness occur following a vaccination	YES	Did the initial illness occur following a vaccination?	NO
Did the illness occur following Flu	NO	Did the illness appear following Flu	YES
Are there clear factors to suggest that vaccination would usually be recommended	NO	Are there clear factors to suggest that vaccination would usually be strongly recommended	YES
RISK PROBABLY TO HIGH		PROBABLY RISK IS JUSTIFIED	

The overall conclusions were:-

- Although Flu vaccine changes year on year the historical problems of mass vaccination causing a spike in GBS occurrences has not been consistently replicated
- Flu can cause GBS
- On a population wide basis the balance of risk favours vaccination



Secretary's Jottings

Well the Conference has been and gone ó if you attended you don't need me to say how fulfilling it was ó if you weren't there is a brief summary of events ó and of the AGM - included elsewhere in this Newsletter. Try harder to get there next time ó you won't regret it. Organising a Conference takes a lot of effort on the part of a few dedicated officers of the Group and I know for a fact that sometimes our Treasurer Peter Scott - who took on responsibility for the management of registrations as well as sorting out the physical and financial arrangements of our room accommodation, presentational areas and equipment as well as our dining arrangements with the Hotel - sometimes felt as though he was swimming uphill through treacle as he tried to get others to understand and comply with his requirements. It all worked brilliantly Peter ó a big WELL DONE!!

We had a constructive Hospital Visitors Workshop on the Friday afternoon before the Conference with 23 members attending. Lots of exchange of ideas and experience that I have yet to distil into a proper feedback report ó it's on my to do list! BUT what was very clear is that we desperately need representation in Christchurch and Wellington ó two of our biggest cities with not a single Authorised Hospital Visitor between them. If you are reading this and are based in those areas DO PLEASE put your hand up and help. It's not a difficult task but does involve a commitment to visit and talk to patients either in Hospital or at their homes (costs covered by the Group!). Beyond doubt it is one of the most important services this group provides. Time and time again I get feedback from new sufferers telling me what a lift they got from talking to a recovered fellow GBS/CIDPer.

A little light on the Publicity Officer horizon with a couple of people offering to share their knowledge and experience ó helping but not taking on the role!. We still need that special person who has that background experience to help us get the Group's presence and message out there. HOWEVER there may be a new way! ó apparently it's called "SOCIAL MEDIA" not something an old coger like me indulges in but I am told that it is taking over from the printed news as the way to get our presence out there. Fortunately we have people on our Board of Trustees who understand this stuff and they have formed a sub-committee to move this platform forward. In my own defence I have now signed up to our Group's Face Book site and will endeavour to contribute useful input although I have to admit to being somewhat frightened to learn (as soon as I joined Face Book) that I have 100's of friends who want to talk to me and share their sites but, without seeming rude, "thanks but no thanks!!"

Back on a platform I do understand we now have 7 new Brochures printed that cover the main GBS/CIDP topics ó a few more to do but we are well on the way to having a completely updated set of information to impart to new sufferers and their carers. Many thanks to Chrisson Matthew Hewlett for the very smart covers and to John Podd for organising the printing of the proofs prepared by the MAB.

For the first time for a number of years the Board of Trustees is up to its full complement with Beverley Whittaker from Napier and Matt Peacey from Nelson joining us at the AGM ó and yes they both came with Smart Phones/iPads welded to the right hands so ensuring that us older members on the Board are dragged into the 21st Century!! I bought a Smart Phone last week after months of badgering by my daughters ó it's sat beside me now and scares the beebbers out of me every time it burps and rings telling me its updated something or other. I have learnt how to answer a phone call ó swiping not tapping!! ó and it came loaded with 33 Apples or something which óas yet I haven't dared tap (or swipe) on!! But I'm getting there!

Brain Days: These events are run by the Neurological Foundation of NZ and provide a show case for organisations such as ours ó with accompanying seminars and presentations by notable physicians in the Neurological field. For the last few years they have been run in Auckland and our stand has been faithfully manned by John Davies, Maurice and Kath Vickers and Meike Schmidt óMeiburg. We debated our ongoing support for this event at the AGM and although attendances have been decreasing it was pretty much universally felt we should continue to attend and next time we hope to have members of our own MAB along as well.

Lastly a couple of snippets of news:

Subs: With effect from 1.12.17 membership of the group will be free ó we will continue to seek donations from members and others to fund the operations of the Group but cost will no longer be a barrier to membership. **Future Events:** What would you like our future gatherings to be like? and where? ó there is no monopoly on fresh new ideas ó so let me know and we can discuss them at the Board.

As always Take Care

Tony

Report on the 2017 Rotorua National Conference and Annual General Meeting in May

With the forecast of a fine weekend for the Rotorua region some 60 members of the Group assembled at the Novotel Hotel for a busy but enjoyable weekend focused on all things GBS.

On the Friday afternoon the Hospital Visitors Workshop was well supported with 22 members attending and exchanging experiences and ideas to improve our capabilities. Without exception everyone agreed that their visits to patients and carers both in and out of Hospital had been very well received and clearly provides a very valuable service. Tony reported that during the past two years (since he took over the role of National Co-ordinator) he had received 60 referrals for information or requests for visiting. Dr Parry said that statistically New Zealand has about 120 GBS/CIDP cases each year (we have one of the highest rates per head of population in the world!) ó So that equates to 240 cases over the same period ó where are the other 180? Everyone agreed we MUST do something to increase the rate of referrals from Hospital staff particularly nurses and other support staff as it seems the Doctors and Consultants are disinclined to pass on a referral. The wine cheese and chat gathering later that evening provided a suitable start to the 'official' Conference proceedings and as always a very pleasant hour or so was spent conversing with old friends and making new ones.

The Conference got underway proper on Saturday morning and was opened by our Patron the Hon Steve Chadwick who gave us priority of her time before rushing off to officiate as Mayor during the Rotorua Marathon which took place on the Saturday as well.

The day proceeded in its established format of presentations by members of the Medical Advisory Board on various aspects of interest in the GBS/CIDP world. This year saw an emphasis on the 'Variant' forms of GBS ó MMN, Miller Fisher and even rarer forms. Of particular interest to many members was the presentation by Dr David Gow (a new MAB from the UK and now working as the Neurologist in Dunedin) who provided very good explanation and advice on the old chestnut of having a Flu vaccination or not ó hopefully we are all now in a position to determine our own position on this perennial question.

Highlights of the day included a moving presentation by Renee Ball of the impact of GBS on her dance career and her amazing road to recovery culminating in a video showing of her own dance routine depicting that journey and then a live performance by Renee and her support dance troupe.

Our post lunch stupor was interrupted by a Chair Aerobics session given by the staff of the re-invigorated QE Health rehabilitation centre in Rotorua followed by a presentation of their ambitious plans to carry forward the amazing work of this centre dating back to the Second World War.

The ever popular Break Out sessions provide an opportunity for members to share the ups and downs of their experiences and to learn 'hints and tips' from others about how to deal with the challenges brought on by the Syndrome entering our lives. A summary of the conclusions and findings of those sessions will be published in a future Newsletter.

A lively 'Ask the Experts' panel concluded the proceedings with topics ranging from the cause and effects of the Havelock North water crisis to the potential benefits of medicinal cannabis! We are as a Group so very fortunate to have this direct access ó both in the panel session and throughout the Conference proceedings ó to such a knowledgeable and forthcoming group of neurological experts and owe a debt of gratitude to them for giving so freely of their valuable time and of course to Dr Parry for assembling the Medical Advisory Board and persuading them to attend.

Feedback has been very positive but an undeniable fact is that over the past few years the numbers attending the Conference have been diminishing and the Board will be addressing potential new formats to ensure that the Group continues to provide an opportunity for members to meet face to face with each other and perhaps the best brains in the Country on our 'open' topic.

Annual General Meeting.

Usually judged as 'boring affairs' the 25 members who attending the Group's Annual General Meeting on Sunday morning were rewarded for their effort by learning about developments for the Group including the decision by the Board to abolish membership fees with effect from this coming December and the award of a \$25,000 grant to a new research project investigating the potential pain relieving properties of the native Onga Onga Stinging nettle. Two new members of the Board of Trustees ó Dr Matt Peacey from Nelson and Beverly Whittaker from Napier were elected and the Medical Advisory Board has been expanded to include two additional neurologists one based in Southland and the other living in the Bay of Plenty area. Our Treasurer Peter Scott presented a robust set of audited accounts and our President summarised a good and active year's progress for the Group in his annual report.

Personnel Story: CIDP Survivor Val Simpson

I was first diagnosed with CIDP fifteen years ago. That's a long time to have been living with a chronic condition.

After an initial two years in hospital (plenty of time to get used to the new reality!) Peter and I have been mostly living at home in our lovely apartment in inner Melbourne. I say 'mostly' because there have been many regular forays to outpatient clinics and several more admissions. I even made it to Wellington in 2007 for the Support Group's annual meeting that year.

I thought the CIDP had finished with me after the first two years. I remember telling lovely Lindsay Haas this. He said gently, 'CIDP is never finished with you.' I had the temerity to contradict him saying, 'No. Mine has burnt itself out.' He just smiled kindly and said I could believe that if I liked, but I was wrong.

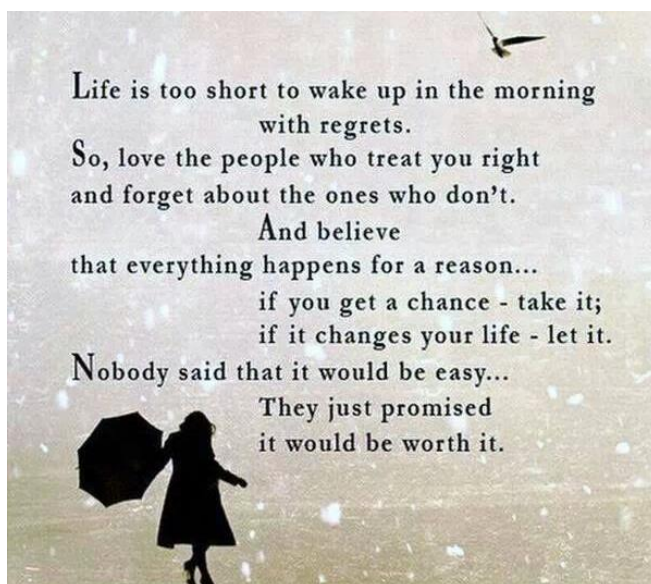
Of course I was wrong. Since 2005, I have had eight more episodes (every year now for the last six years). Each episode has involved hospitalisation, slowly increasing paralysis usually until I am bed-bound, and then treatment with cyclophosphamide and (usually) plasma exchange.

The treatment on which I depend has unwelcome side effects. Just this year I have been referred to Urologists and to Gastroenterologists to follow up on some of these side effects. Just two more specialty areas to add to my list that now includes Neurologists, Respiratory doctors, Dermatologists and Intensivists. I fear that soon I shall have to add Ophthalmologists to that list. Something funny is going on with my eyes.

Wonderfully, all these people have kept me going. All these specialists and Peter. While I am disabled and ventilator dependent, I plod (metaphorically) on. I don't really know if the health problems I have are related to the CIDP or to the treatment I have to have for it. Maybe it is just because I am getting old. I'm certainly often tired and fatigued. This I know is a classic symptom of CIDP.

This year I am hoping to avoid my annual bout of CIDP. My neurologists at the Royal Melbourne Hospital are going to try a preventative approach they describe as a 'maintenance treatment'. They are going to use a drug called Rituximab. Initially it will be given intravenously in two sessions, a week apart. The hope is that this winter I will sail through without another episode of the paralysis. Wouldn't that be wonderful!

I hope to stay strong enough to keep doing the things that make my life rich and rewarding. I love being a Grandma. I love swanning around to local coffee shops and cafes. I love the volunteer work I do at the Royal Melbourne Hospital. I love reading and talking about books, both at my Book club and informally with a wide group of bookish friends. And I value the joy and happiness of my life with Peter and our marvellously supportive family and friends.





BRAIN DAY 2017

Report by John Davies

Brain Day in Auckland has come and gone for another year. It would not be one of the most successful Brain Days by any means. Attendance was down considerably on past years, although the lectures seemed to be well attended.

Our GBS Support Group stand was once again manned by the stalwarts who have given willingly of their services over a number of years, namely Maurice and Kath Vickers, Meike Schmidt-Meiburg, Margaret and myself, regardless of our call for volunteers to come and join us for this worthwhile opportunity to publicise and promote our existence. We were fortunate that our stand was really in a prime position at the end of a row, and near to the lecture theatre, which the majority of visitors could not help but notice as they passed by or otherwise.

Our stand looked reasonably professional with the large banner prominently displayed, and with an interesting collection of new and old brochures on show - as Meike's photographs will undoubtedly reveal. We had the usual number of "tyre kickers" or "collectors" turn up, whom we were able to steer away without too many publications being uplifted. But regardless of the lack of numbers of interested visitors stopping to talk - which was the same complaint with all thirty-four stands, it turned out to be a worthwhile exercise for the five of us. We were also able to catch up with numerous acquaintances from other support groups that we had fostered over the years and compare thoughts, experiences, advances in treatments, and results.

Our one and only serious visitor didn't even know that there was a GBS Support Group, but was enthusiastic to talk to us about her teen-age daughter's encounter with GBS two years ago, thereby enabling us to give her wise council, someone to talk to and give her some little re-assurance, and to supply her with as much information as she needed, and above all a contact for the future.

In conclusion I have to say that a bit more support from the Auckland contingent would have been very welcome. However those of us who serve will continue to battle on for another day.



Margaret, Meike, Maurice and John man our stand



Margaret, Kohn and Maurice share a joke with Sir. Richard Faull a presenter at Brain Day



Several members asked at the Conference whether or not they were able to donate blood. Teri- Anne Young made inquiries with policy writers at the NZ Blood service.

This is their reply:

GBS has potential for passive transfer of auto-antibodies (can be passed on)

***Single episode only.** Donor will be deferred for 2 years from recovery.*

***If persistent** – auto immune neurological disorder, **if recurrences, relapses etc**, Donors are deferred permanently.*

If a donor is not happy with this they can request a meeting with a Medical Officer to further discuss. Each Main site has one.

Travel Insurance and GBS

During the Conference "Ask the Experts" session at the end of the day the following question was asked:-

When applying for Travel Insurance do we have to declare GBS as a "pre-existing" condition?

The experience of the Questioner being that having done so the Insurance Company whacked a premium and conditions on their cover.

The "wisdom" of the Experts was that as GBS was almost invariably a "one off" ACUTE condition and once the patient had recovered it was over and done with it did not present a risk to the client or the Insurer and so does NOT need to be disclosed.

CIDP is however a different matter as it's a CHRONIC condition as can flare up again at any time and hence IS a risk to both client and Insurer so SHOULD be disclosed and the increased premium/conditions consequences accepted as or declined and cover for an unexpected re-occurring CIDP event whilst on holiday be a "self-insured" item.

A good friend is an independent Insurance Broker specialising in obtaining cover for "difficult" cases so I asked her for her views on this topic.

She agreed without comment to the CIDP situation requiring full disclosure BUT as far as GBS was concerned her recommendation is that it SHOULD be disclosed but the point made to the Insurer that it was an acute event with negligible likelihood of a relapse as and if necessary back this up with a medical opinion.

Her reasoning was that these days Insurers in the travel field face potentially enormous medical costs if a client takes ill abroad and will "wriggle" to avoid meeting any such costs if there is the smallest possibility of a non-disclosed related condition giving them an "out".

At the end of the day it's an individual decision but ALL insurance policies are based on "full disclosure" and "absolute trust" so in my case I would hesitate to part with a premium knowing that it could be lost and the policy voided by failing to meet these undertakings.

More Conference Photos



Chronic Immune Mediated Neuropathies

A conference Presentation by

Dr. Gareth J Parry

- What does immune-mediated mean?
 - The normal protective functions of the immune system are hijacked resulting in disease.
 - Inflammatory cells (lymphocytes) and antibodies attack healthy tissues.
- Auto-immune diseases are triggered by an invasion of the body (viruses, bacteria) leading to a normal immune response that becomes misdirected against healthy tissue.
- Dysimmune diseases occur when the body loses control over a clone of inflammatory cells that expand and attack healthy tissues. There is no identifiable trigger.

Immune-mediated neuropathies

- GBS is an autoimmune neuropathy:
 - An antecedent infection (e.g., C. jejuni) triggers an immune response that secondarily attacks nerves (molecular mimicry).
- CIDP is probably an autoimmune neuropathy although no consistent trigger has been identified.
- Other immune-mediated neuropathies are probably dysimmune.

Chronic Immune-mediated neuropathies

- CIDP is the commonest:
 - Prevalence is ~3/100,000 (range 1-9/100,000).
 - ~130-150 patients in NZ.
 - About 5% of patients initially diagnosed as GBS turn out to have acute-onset CIDP.
 - About 15% of patients with CIDP have this form.

Dysimmune neuropathies

- Multifocal motor neuropathy (MMN, Parry's syndrome).
- Multifocal (acquired) demyelinating sensory and motor neuropathy (MADSAM, Lewis-Sumner syndrome).
- Distal (acquired) demyelinating sensory neuropathy (DADS):
 - With antibodies to MAG.
 - Without myelin-specific antibodies.
- Paraproteinemic neuropathies:
 - Benign; i.e., with no associated blood cancer.
 - Associated with malignancy, usually myeloma.
- CANOMAD.

Multifocal motor neuropathy

- Multifocal: Affects multiple individual nerves.
- Motor: Only affects motor functions.
- Neuropathy: A pathological condition affecting nerves.
- MMN is a chronic disorder that develops and evolves slowly (months to years).
- Usually begins in the arms but may eventually become very widespread.
- Has some similarities to MND with weakness, cramps, muscle twitching and muscle atrophy (wasting):
 - MND is untreatable and invariably fatal, usually in 3-5 years.
 - MMN is benign and treatable (although not curable).

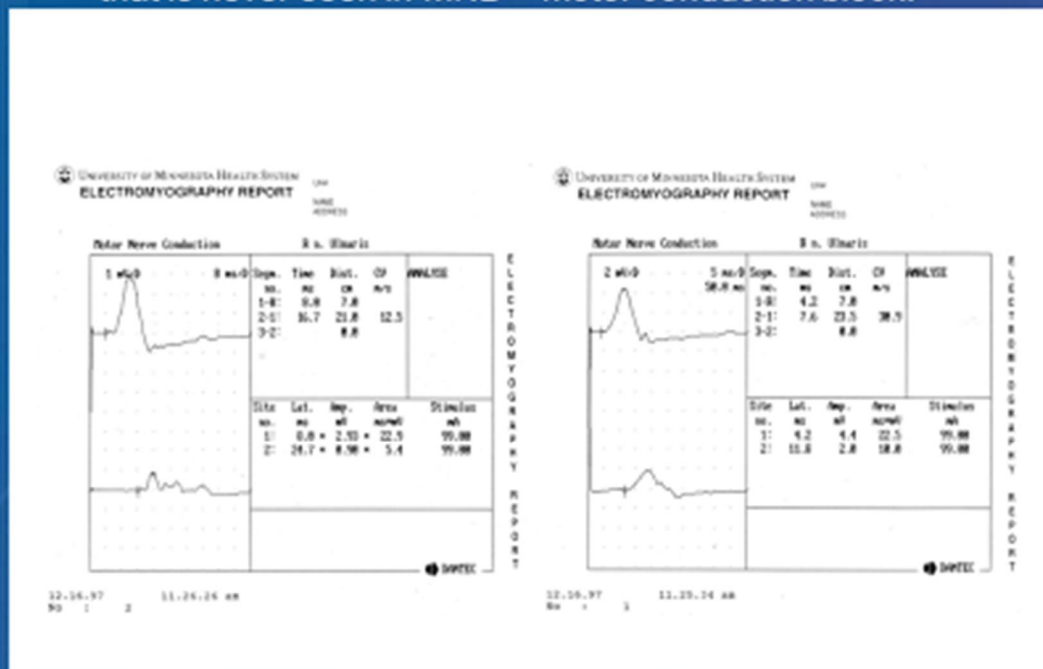
Multifocal Motor Neuropathy (MMN) with conduction block

27 y.o. man with progressive hand weakness:

- 1983 – weakness, wasting, fasciculations and cramps in the R forearm and hand.
- 1984 – weakness in a more widespread but very patchy distribution in both UE's.
- No bulbar, respiratory or lower limb symptoms.
- No sensory complaints.



- Diagnosed with MND and referred for a 2nd opinion.
- Nerve conduction testing showed a specific abnormality that is never seen in MND – motor conduction block.



Multifocal motor neuropathy - diagnosis

- Clinical pattern of involvement:
 - Patchy distribution of weakness (cf: MND).
 - No sensory involvement (cf: CIDP).
- Nerve conduction studies.
- Antibody testing:
 - About half the patients have abnormal antibodies against nerve proteins.

Multifocal motor neuropathy - treatment

- Most patients (~80%) respond to IVIg.
- Ig can be given subcutaneously.
- Treatment needs to be long-term (?life-long).
- Strength is improved but not to normal.
- In the long-term, strength slowly declines despite short-term improvement with each infusion.
- Because response to treatment with IVIg is suboptimal other strategies have been tried:
 - Chemotherapy.
 - Rituximab.

Multifocal motor neuropathy - treatment

- Since MMN is thought to be a dysimmune neuropathy with a clone of lymphocytes producing antibodies that attack the nerve it seems logical that giving a treatment that kills these cells may be beneficial.
- Chemotherapy (cyclophosphamide) is a broad spectrum cell toxin that is used to treat cancer.
- Inflammatory cells, like cancer cells, divide and reproduce more rapidly, making them more susceptible to chemotherapy.
- Chemotherapy has been shown to help MMN but is very toxic and seldom, if ever, justified for a disease that is not fatal.

Multifocal motor neuropathy - treatment

- The inflammatory cells that produce the antibodies that attack the nerve are called B-lymphocytes.
- B-cells have on the cell surface a marker specific for that cell (CD20) and an antibody (rituximab) against that marker has been developed that kills the B-cells.
- This antibody does not attack any other kind of cell and is, therefore, much less toxic.
- Does rituximab help patients with MMN and other dysimmune neuropathies?

Multifocal motor neuropathy - treatment

- Several anecdotal reports suggested that rituximab could help MMN patients.
- Larger controlled clinical trials were unable to recapitulate those findings.
- I have had a number of patients who have benefitted but no one has been cured.
- It is very difficult (?impossible) to get PHARMAC to approve rituximab for MMN patients.

Rituximab treatment for other dysimmune neuropathies

- Several anecdotal reports suggested that rituximab could help some patients.
- Larger controlled clinical trials did show a modest benefit for some patients (anti-MAG neuropathy).
- I have had a number of patients who have benefitted, occasionally dramatically.
- It is somewhat easier to get PHARMAC to approve rituximab for the dysimmune neuropathy patients.
- Since these other neuropathies can be very disabling and do not respond to other treatments a treatment trial is worthwhile.

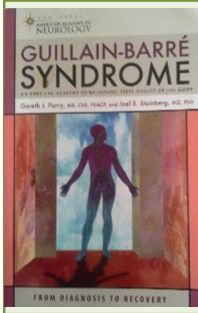
Chronic Immune-mediated neuropathies

- CIDP is an autoimmune neuropathy and is the commonest and easiest to treat.
- Dysimmune neuropathies are rare and difficult to treat:
 - IVIg helps in MMN.
 - Chemotherapy may help but is very toxic.
 - Rituximab may help in some instances but is difficult to access in NZ.



Dr Parry speaking at the 2017 Conference

NOTICEBOARD



New Stocks of this easy to read and enlightening book are now available. \$30 including P & P. If you would like to purchase one contact:

Tony Pearson: tonypearson@xtra.co.nz



If you would like a copy of this book please contact Tony Pearson who has a few complimentary copies available.

Publicity Officer

The Group **desperately** needs a Publicity Officer ó someone with the experience to help us get our message ó indeed our very existence ó out into the public domain via the media.

Do you have the skills to help us?

The Board has approved the payment of an **Honorarium of up to \$1000pa** (depending on the level of skill and experience demonstrated) to encourage someone to step forward ó could it be you!

Contact the President or Secretary if you are interested.



What's Your Story ?

Urgently needed are your stories to publish in your magazine.

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

WAIKATO/BAY OF PLENTY COFFEE GROUP

Where: The Club, 601 Mackay Street, Thames

When: Wednesday 6th September

Time: 10.30am onwards

Parking: Behind and in front of the building and across, near and around Thames Hospital.

Please let Meike know by Monday 5th if you are attending so she can confirm numbers with the Café.

Email: schmidtfarm@xtra.co.nz

Cell Ph: 027 3250369

Ph: 07 867 3163

**Everybody
welcome.**



Want to receive your newsletter in **colour**, online please contact the Editor.

