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Guillain – Barré Syndrome Support Group New Zealand Trust

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

NEWSLETTER DECEMBER 2014



Patron	Hon. Steve Chadwick		
President	Ken Daniels	12 Mallam Street, Karori, Wellington,	Ph: (04) 476 4323 Email: espin.karori@xtra.co.nz
National Coordinator	Jenny Murray, QSM	27 Grenville Street, New Plymouth, 4310	Ph/Fax: (06) 751 1014 Email: jenny.gbs.nz@clear.net.nz
Secretary	Tony Pearson	113 Weka Road, Mariri, RD 2, Upper Moutere, Nelson, 7175	Ph/fax: (03) 526 6076 Email: tonypearson@xtra.co.nz
Treasurer	Peter Scott	P.O. Box 4162, Palmerston North, 4442	Ph: (06) 357 8436 Email: peterscott@clear.net.nz
Newsletter Editor	Chris Hewlett	51 Killen Road, RD 2, Katikati, 3178	Ph: (07) 549 0931 Email: chrispy57@gmail.com
Publicity Officer			
Medical Advisor	Gareth Parry ONZM.MD.FRACP.ChB		
Web Site	Support	Education	Research www.gbsnz.org.nz

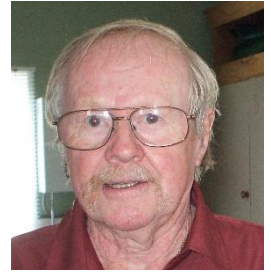
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Editor's Note

This is the final newsletter for the year. My, it has come around fast.

I have found it a little hard to get out of holiday mode and into work mode as we have been away quite a bit over the last few weeks. One of these was a jaunt to Adelaide for some motorcycling and then to Melbourne to see our eldest son and his partner. While in Melbourne I was lucky enough to catch up with Kath Donaldson who has set up some amazing FB sites for GBS sufferers. I managed to get her to write her story for the magazine and this includes the FB links so don't forget to take a look. I was particularly impressed with the Turtles for Kids page. Something we should get involved with I think. Anyway, with luck, Kath and her husband Rob will be at our conference so we can chat about this some more.

It's time to pay your subs again. I hope that you will all rejoin as it is these funds that allow us to print and send information to new sufferers. With the internet being so available now and everything being so accessible sometimes we don't see the need to continue as a financial member, but the bottom line is that without financial members we cannot continue to support families when their loved ones are struck down. So please make the choice to stay a financial member of the group.

It was with much sadness that I heard of the passing of Jenny's husband Ian, in October. Our sincere condolences to Jenny and her family. Ian was always there to support Jenny as she tirelessly worked to raise awareness and support those with GBS. Something she continues to do despite her own ill health.

Dr. Gareth Parry and Dr. John Podd are looking to conduct a study and need your help. Details are in the newsletter so please contact them and help them with this project.

You are probably all tired of hearing and seeing our BOP/Waikato Coffee Group but I have to say we had a wonderful get together last month with a record 22 attending. Our next get together will be in February and we are very very lucky to have Dr. Parry coming to join us. So if you want to come along, check out the details later in the magazine. If you are coming can you please flick me an email or phone. This is just to make it easier on the caterers.

Finally, the conference has been all sorted so get your registration in. If you would like to attend but finances are tight we have a fund that may be able to assist you. Details of this also in the magazine. Please take the opportunity to use this if it means attending or not attending the conference. All enquiries are in strictest confidence.

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

Have a wonderful Christmas and a prosperous New Year.

Chris

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

Editorial	Chris Hewlett
Presidents Annual Report	Ken Daniels
Secretary's Report	Tony Pearson
Conference Details	Peter Scott
Personal Encounter	Kath Donaldson
An Ingenious Device	Patricia Blomkwist-Markens
BAUD Device	Tony Pearson
GBS Study ó Participants needed	Dr. Gareth Parry
BOP/Waikato Coffee Group	Photos by Meike Schmidt-Meiberg
Conference Registration Form	Peter Scott
Subs Renewal Form	Peter Scott

Presidents Report:



I was in a café recently having a quiet latte with my wife when an old business associate wandered in, looked lost and went out again. Initially I wasn't sure that it was the person I had once worked with as he was slow both in movement and in the reasons he came into the shop. A few minutes later he returned, looked slowly at the food cabinet and was almost ready to exit the café when I got up and re-introduced myself. We spent the next quarter of an hour chatting about old times and what we were both doing these days. My friend told us that he had retired a year before and spent his day sleeping in, going for the occasional walk and generally just doing nothing. He was physically well but believed that retirement meant that he no longer had to do anything. He had started to quietly fade away.

I was very sad to see this once active man slip into inactivity and quiet oblivion by an attitude that told him that as he was now retired his life as he knew it was finishing.

The thoughts that followed when my friend sauntered out of the café centered on the people who are starting a new and different life after GBS. There is often a radical change of physical and mental environments after such a serious illness. Legs and fingers may not work the same, people may look at you when you walk flat footed and the onset of fatigue can make you feel as if you have to explain why you appear lazy.

You see, a lot of the changes are as much mental as physical. Sure your legs may not work, but the way you face the world often has more to do with your attitude than your legs. A positive belief that you are now different but nevertheless still there can relieve a lot of the stress and anxiety associated with radical changes of life. Resilience is sometimes a worthwhile skill to learn along with your physiotherapy and medication. Treatment and getting your head in the right space are both difficult in the beginning but both can make for a better outlook in the end!

I am really looking forward to the conference next year. It promises to be a positive experience for both those who are members of the GBS club and their families.

Have a positively happy Christmas and I look forward to seeing you in Rotorua!

Ken Daniels

"Always Laugh when you can. It is Cheap Medicine"





Secretary's Jottings

As we gear up for our 2015 Conference and AGM in Rotorua next May the UK Group, now known as GAIN (**G**uillain-**B**arre & **A**ssociated **I**nflammatory **N**europathies), who had to cancel their May 2014 Conference for lack of support have held a survey of their members and based on the responses received may decide not to hold any more Conferences but to focus on Regional one day events. As I have said previously I think we

have got our Conference õset upö about right ó every two years and a one day event but there is something to be said for considering Regional Gatherings of a less formal and more social nature (held perhaps in a non-Conference year) and, based on a suggestion coming from our Christchurch membership, we will give this some serious thought at our next Board meeting. Christchurch have put their hand up ó what about Auckland, Hamilton or Dunedin?

A couple of other snippets from the UK Group's Autumn (our Spring!) magazine:-

Subcutaneous immoglobuin (SCig) is now being considered as an alternative to the usual intravenous (IVig) by some UK clinics for CIDP patients requiring regular õtop upsö. If my understanding is correct it is administered by injection at the patient's home ó sounds a lot more convenient than an extended stay at Hospital for the IVig treatment. Not sure what N.Z's position is on this ó perhaps a question for the Panel of Experts at the Conference!

To Jab (Flu) or not! ó an independent Canadian survey has determined that there is a million to one chance of your contracting GBS from a flu jab ó but a one in 60,000 chance of getting GBS if you contract the flu!! ó pretty clear choice I think if you are in one of the so called õrisk categoriesö i.e. Those aged over 65, Pregnant women, People with an underlying health condition- particularly heart and respiratory problems and People with weakened immune systems. As always- if in doubt talk to your GP.

Where do you go to find out information on a new subject or issue? ó go back 10 years and most of us would resort to an Encyclopedia, ask a friend or contact a professional in that or a related field for advice. Now we have the WEB and with the aid of Google and similar õsearch enginesö the scope of accessible information and knowledge is virtually unlimited.

Our GBS world is no different and more and more patients, their family and carers are resorting to the various websites run by Groups around the world such as ours to glean information about this strange sounding thing that they or their loved ones have been diagnosed with. It may be a co-incidence but if you type in õGuillain-Barre Support Groupsö into Google ó of the 82,600 references it comes up with the top 5 are links to our web site! ó then the USA Group followed by the UK Group. Now I'm not saying our website is better than theirs ó goodness knows how much professional help they pay for to run their õwhizzyö sites whilst we rely entirely on the volunteer input of our Webmaster's Lil Morgan (within the Group) and Ben Chapman at NZORD ó BUT there is no monopoly on good ideas to improve our site and if you have an idea or suggestion do PLEASE let me or another Board member know and we will do our best to incorporate it if it will raise our game.

CARERS:- A few months back I read an article from the USA about the stress of being a carer for a chronically sick person ó it was scarily honest about feelings of anger, resentment and critical of the chronically sick partner who contributed little to a busy family life ó followed by overwhelming guilt and intense love. Of having to come to terms with õnothing is going to get betterö ó there's nothing to beat ó it will only deteriorate. It's hard for us õwellö people to understand what that situation must be like. Fortunately for our GBS/CIDP carers there is usually hope of a good, although perhaps not perfect, recovery of our loved one but nevertheless it ain't easy. Vivienne can now talk objectively of the stresses she had thrust upon her when her õheroö fell off his perch ó a victim of CIDP - but it must have been tough at the time! ó So guys and gals in the Carers situation we take our hats off to you ó we couldn't have got through this õthingö without you.

I am looking forward to catching up with old friends and meeting new faces at the Conference ó see you there ó if it could be your first time then, believe me, you will not regret it!

Tony

Conference 2015

2015 Conference and Annual General Meeting.

This will be held at the **Sudima Hotel 1000 Eruera St Rotorua** over the weekend **8-10 May 2015**.

A Registration Form is enclosed with this newsletter- please note the deadline for registering so as to be entitled to the discounted registration fee.

You will need to book your own accommodation with the Hotel either by

E-mail reservations@sudimarotorua.co.nz or
Phone 0800 783 462

The Hotel has 2 accommodation blocks. One does not have lifts, so those with disabilities (i.e. climbing stairs) will need to make this known to the Hotel at time of booking. The hotel are holding 50 rooms for us, so book early to ensure you get a room (further rooms may be available but the sooner you book the better). When booking you will need to quote the Reference No 1332434 to get the Conference rate.

There are a number of options

Superior Room	\$120 per room per night
Superior Room and Breakfast-single occupancy	\$140 per room per night
Superior Room and Breakfast-twin occupancy	\$160 per room per night
Standard Room	\$110 per room per night
Standard Room and Breakfast-single occupancy	\$130 per room per night
Standard Room and Breakfast-twin occupancy	\$150 per room per night

Conference Assistance Fund

The Trustees of the Group are keen to encourage members and their families and supporters to attend the May Conference in Rotorua but understand that the cost of doing so may place this beyond the reach of some. Accordingly a Fund has been set up to assist people wishing to attend the Conference who might otherwise be unable to attend.

Applications for assistance should be made to the President Ken Daniels who will determine if assistance is warranted. Please write or e mail Ken at the address following. You are assured that your application and any award will be treated in strict confidence.

Ken Daniels, President, GBS Support Group N.Z.

12 Mallam St. Karori Wellington 6012

espin.karori@xtra.co.nz



HOSPITAL VISITORS

As you will notice from the details of the Conference programme published elsewhere in this Newsletter we plan to hold another meeting of accredited Hospital Visitors on Friday 8th May at 1500hrs.

All current Hospital Visitors are urged to attend but we would also welcome those members, whether GBSers, CIDPer or Carers who feel they could contribute to this very important area of the Group's activities to come along. If you are wanting to volunteer contact Ken or Tony before the meeting with a brief history of your 'GBS experience' and also the name of the Hospital/s that you would be willing to visit.

The meeting will provide an opportunity for an update on training and, most importantly, provide an opportunity for Hospital Visitors to provide feedback on their experiences over the past couple of years.

CONFERENCE PROGRAMME OVERVIEW

FRIDAY 8 May

3:00pm Training for Hospital Visitors and Local Coordinators

4:00pm Registration

5:30 - 7pm Wine, Cheese and Chat with conference members

(Own arrangements for dinner)

SATURDAY 9 May

8:45am Official Welcome and Conference Opening

An interesting program has been arranged for the day including addresses by the following members of the Medical Advisory Board:

Dr Dean Kilfoyle

What's new in GBS

Dr Chris Lynch

Pain

Dr Suzie Mudge

Fatigue

Kathryn Quick - Senior Physiotherapist-Neuro

Role of PT in ICU

Dr Annette Forrest

GBS in ICU

Penny Sender - Clinical Psychologist

Psychological Impact of GBS on Patient & Family

There will also be a personal story, breakout session and the popular Panel Discussion to end the Conference.

7:30pm Conference Dinner (optional)

SUNDAY 10 May

9am

AGM

Please try and attend this



2013 Conference
Group Breakout
discussion groups
and the 'Ask the
Panel' question
time were very
popular amongst
conference goers.



GBS – A Personal Encounter – Kath Donaldson

Thank you for allowing me the opportunity to contribute to your December Newsletter.

I was diagnosed with GBS in August 2011.

When I was discharged from hospital, I searched for support groups, but couldn't find any that suited me. There were plenty out there, but the groups I came across had too much negativity, so I decided to start my own. Guillain Barré Syndrome - Australia was born in approximately March 2012.

<https://www.facebook.com/GuillainBarreSyndromeAustralia>

In around July 2012, in conjunction with 4 other support pages, predominantly in the United States, we started Turtles 4 Kids. This page started because there were parents with children joining the pages, seeking advice. Turtles 4 Kids send soft plush turtles along with colouring books, to kids worldwide. We are lucky as we have sponsors that provide the turtles and one of our turtle sponsors works for a transport company and they very kindly donate the paper and photocopier for the colouring books. To date, Turtles 4 Kids has sent out 33 turtles and colouring books worldwide to kids diagnosed with GBS & CIDP. We've sent one to a little girl in New Zealand. We get great satisfaction when the kids receive their packages and we get photos back of the kids, which are then included in our Turtle Hall Of Fame. There's a photo of Zoe with her turtle and book which we sent out in December last year. Turtles 4 Kids also works closely with a UK based kids support page, Guillain Barré Kids and we reciprocate with referrals.



<http://www.facebook.com/groups/GuillainBarreKids/www.facebook.com/Turtles4Kids>

In November 2013, GBS/CIDP EXERCISERS GROUP was born. This highly motivated group comprises people who want to exercise and improve their strength whilst still having regular infusions and even the occasional relapse. It's a group full of empathy, humour and motivation. Anyone having a rough day, come and visit us and we'll soon have you smiling.

<https://www.facebook.com/groups/GBSCIDPEXERCISERS/>

In February 2014, I was appointed as another Liaison Officer for Melbourne, by the GBS-CIDP Foundation in the U.S.

Last but by no means least, we've recently started GBS & CIDP SUPPORTERS & CARERS, a self-explanatory group which was set up specifically to help families, friends, and colleagues, get a better understanding of GBS & CIDP

<https://www.facebook.com/groups/GBSCIDPEXERCISERSUPPORTERS/>

I'm truly blessed with the most amazing co-administrators for all the above pages and without them, there's no way I could do it all. Superwoman I ain't.

We'd love to welcome anyone from New Zealand to come along and join our groups if you'd like to.

I'm hoping that my husband and I can get house and dog sitters for a few days in May next year to come to your conference. Would love to meet you all.

Until then my Kiwi friends, I'd like to wish you all a very Merry Christmas from my family to yours, and a safe, happy and prosperous 2015.

Warmest regards from across the ditch



Simple & Ingenious Communications Device

The device in the picture below was designed and built by the family of a patient here several years ago. He (the patient) was in the hospital for several months and totally incapacitated. The family gave it to me when he finally checked out for rehab.

I got it back this morning from another patient (Jesse) who was totally incapacitated and who will be leaving for rehab on Tuesday after 66 days in the hospital. Jesse told me they would have been lost without it...both family & nurses.

Interestingly enough, both patients also had a complete set of our communications cards and both preferred this device.



Front and back are identical making it easy for the family member/nurse/doctor standing behind it and looking at the patient to quickly narrow the letter choice down to a group and then a single letter by pointing over the top with the patient choosing with an eye movement, blink or some other cue. Much, much faster and easier than selecting one letter at a time from the entire alphabet. Plus quick numbers and a "Yes" or "No" feature.

An added piece of advice: write down what has been spelled on a whiteboard!

Article sent by:

Patricia H. Blomkwist-Markens

Voorzitter Diagnosewerkgroep GBS/CIDP van Spierziekten Nederland

www.spierziekten.nl

Regional Director and member of Board of Directors GBS/CIDP Foundation International

www.gbs-cidp.org



UPDATE ON THE BAUD DEVICE

We received the Baud Device in early September & I gave it a trial operation (although not a real test as I have no ongoing pain issues) and started it on its circulation to the 5 members who had registered for a trial & two weeks each.

Whilst I am not a techiö as far as I could determine it operates on the similar basis to the TENS devices & essentially using sound and vibration waves to block the nerve transmission pathways that are otherwise carrying PAIN signals to the brain. Operation is either through a set of headphones or earbuds for the sound therapy or by direct contact through microphones to a painful area & e.g. knee joint.

Feedback to date from 4 members is as follows:-

First and foremost a 2 week trial is just not long enough to do justice to establishing if the device is going to work for you & but with a purchase price of US\$500 & it's NOT a frivolous purchase item. My thoughts on this are that maybe the Group should BUY one and then hire it out to members for a few dollars a month say with a 6 month limit & if it does work for them then a purchase is an obvious route.

Some older members found it difficult to tuneö & clearly the inventor recognises this as he is keen to use SKYPE or telephone calls to coach and advise people on a one to one basis on how to get the best use from the equipment & again something that probably is not do-able on a 2 week trial but may well be sensible if you know you have the kit for 6 months on hire.

The bottom line is that during their trial period nobody experienced anything more than very small and often transitory improvements to their GBS symptoms. Certainly nothing like the almost miraculous improvements reported by a Swedish GBS sufferer but as the inventor himself admits this is not a typical improvement & so clearly the device impacts on different people in different ways and it takes time to become familiar with its operation and for the effects to show themselves more positively.

So where does that leave us? & I will talk to Dr. Parry as Head of our Medical Advisory Board and see if he supports a Support Group purchase for extended trial use & and then, of course, I have to persuade our Treasurer!

A worthwhile experiment I think but regrettably no N.Z. miracles to report.

Following contact with the Inventor about this lack of positive results from our trial he has offered to extend the loan to One NZ GBS Support Group member who is suffering significant pain or ongoing symptoms for a further period of time provided they agree to a session of öCoachingö via Skype (1 to 3 sessions) & to use the system for up to 5 sessions for 15 minutes at a time over a period of several weeks. If this doesn't see a significant improvement he will eat his hat! If you would like to have a shot at this get in contact with me.

Tony.



Christmas Get Together at the Okoroire Hotel



Sue Dixon digs deep

Fran McKay, John Dixon
Celia Stephenson,
Chris Hewlett



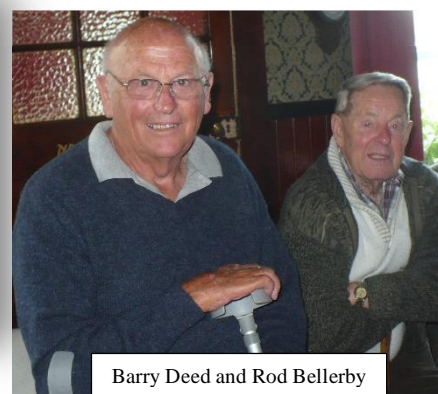
Marilyn Turnwald



Bette Blance and Jan Gribble



Mike and Janet Greenall



Barry Deed and Rod Bellerby



Back: Ken and Julia Ardern, Fran McKay and John Dixon
Front: Rex and Karen Soppet



Meike Schmidt-Meiburg and Judy Deed



Time to unwrap the pressies



Sue Dixon



Table One ready to eat



Ken and Julia Ardern



Kohuroa Ruwhiu



Warren and Marilyn Turnwald, Grant McKay and Gordon Stephenson



Meike plays Santa again

A study of the impact of a hospital visit on the quality of life during and after recovery for patients with GBS.

Drs G Parry and J Podd would like to conduct a study on the above topic and need your help. Initially they would like you to answer these simple questions:

1. Did you receive a visit from a member of the GBS Support Group N.Z. at any time during your initial hospital visit?
2. Regardless of whether you received such a visit or not, would you be willing to participate in a research study? The study will entail answering a series of questions about your in-hospital experience.
3. If you are interested in participating please contact Dr. Gareth Parry at the following e-mail address: gareth.parry@ccdhb.org.nz

Links to Internet Articles:

From Charlene Chamberlain - I would like to share a story how the healing power of music helped a dear friend with GBS recover.

Tell the Wind I'm Calling

https://www.youtube.com/watch?v=z_XQLV0eXv0

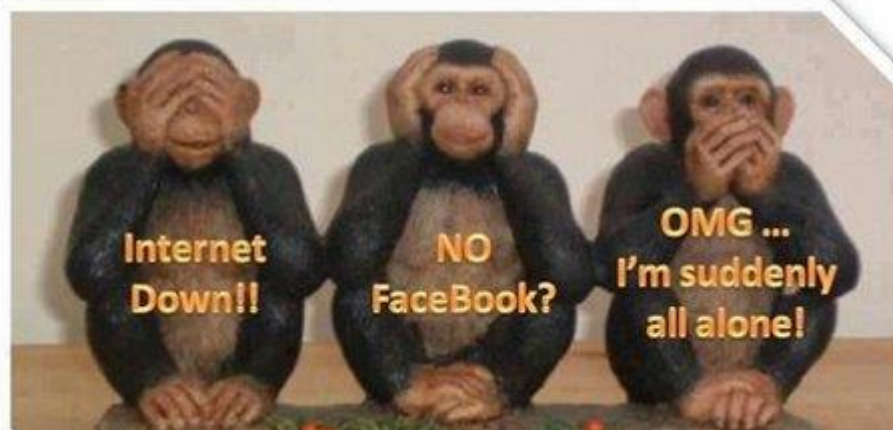
<https://www.youtube.com/watch?v=IgPfeZ3QHws>

How to Repair Myelin Sheath with Food

http://www.ehow.co.uk/how_7894361_repair-myelin-sheath-food.html

A Personnel Story by Michel Daniek

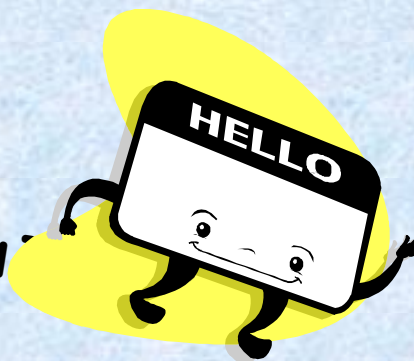
<http://michelgeschichten.blogspot.com.es/2013/03/english.html>



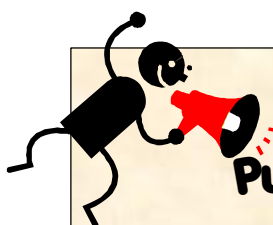
Conference 2015.

Where: Rotorua – Sudima Hotel

When: Friday 8th May to Sunday



Registration Form attached to this newsletter.



Wanted

Publicity Officer and Hospital Visitor Coordinator

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

Their contact details are on the front page of the magazine and they'd love to hear from you.

WAIKATO/BAY OF PLENTY COFFEE GROUP

February 20th 2015

Where: Fairview Golf Course Café Katikati
Sharp Road, RD 2 Katikati

When: Friday 20th February 11.30am

Special Guest: Dr. Gareth Parry



**See you there.
Everybody welcome.**

GUILLIAN BARRE SYNDROME SUPPORT GROUP NEW ZEALAND TRUST

2015 CONFERENCE AND ANNUAL GENERAL MEETING ROTORUA 8-10 MAY 2015

I/We will be attending the Conference as follows

				No Attending
FRIDAY	8th May	Hospital Visitors Meeting	3pm	_____
		Registration	from 4pm	_____
		Wine,Cheese and Chat	5.30pm-7pmish	_____
		Dinner (optional) at own cost	7.30pm	_____
SATURDAY	9th May	Conference	8.45am	_____
		Conference Dinner (Own Expense)	7pm	_____
SUNDAY	10th May	Annual General Meeting	9am	_____

REGISTRATION COSTS

		<u>If paid by</u> <u>28-Feb-15</u>	
\$120	Full Registration	\$100	_____
\$90	Saturday Only	\$80	_____
\$60	For 2nd person in family	\$50	_____
\$30	Full Time Students	\$30	_____
	Dinner (Optional)	\$42 ph	_____
	TOTAL		\$ _____

Special Dietary Requirements (ie GF etc)Please advise _____

ARRIVAL METHOD & ESTIMATED TIME

Friday/Saturday/Sunday Please circle which day)
Estimated time of arrival _____am/pm
Method Car/Plane/Other (Please circle one)

PLEASE NOTE THAT YOU WILL NEED TO MAKE YOUR OWN HOTEL BOOKINGS DIRECT TO THE HOTEL

Sudima Hotel 1000 Eruera St Rotorua 0800 783 462 or www.sudimahotels.com
quoting Reference No _1332434_____

NAME _____
ADDRESS _____

CHRISTIAN(Nick) NAME (S) for name tags _____

PLEASE RETURN TO GBS PO BOX 4162 PALMERSTON NORTH 4442 WITH YOUR PAYMENT. IF PAYING BY DIRECT CREDIT INSURE THAT YOU SEND THIS FORM TO THE ABOVE BOX NUMBER. REGISTRATIONS RECEIVED AFTER 28 FEBRUARY 2015 WILL NOT BE ENTITLED TO CLAIM THE EARLY REGISTRATION DISCOUNT

Guillain Barré Syndrome Support Group Trust N.Z.

Registered Charity No CC20639 www.gbsnz.org.nz

INVOICE

2014-2015 MEMBERSHIP ANNUAL SUBSCRIPTION

Subscriptions for membership of the Group for the financial year commencing on 1st December 2014 are now due and your ongoing support would be appreciated to help further the important roles the Group plays in supporting new and existing sufferers of this devastating syndrome.

Please detach the bottom section of this page, complete the information requested and send with your remittance to the address detailed below.

Subscription Rates

Single Annual \$15.00

Single Life \$150.00

Medical Group \$75.00

*Subscriptions can be paid Direct Credit the Group's Bank Account
Taranaki Savings Bank (TSB) Moturoa Branch New Plymouth
Bank Account No:- 15 3949 0339362 00*

Be sure to reference your name on the transfer

You can also now receive the Group's Newsletter by e-mail (thus helping us with the cost of stationery and postage) if you would like to take up this option and have not already notified our Editor Chris Hewlett please e-mail her at (chrispy57@gmail.com) or add your e-mail details below and we will arrange for this to happen.

Thank you on behalf of the Board of Trustees.

**Please detach and post this remittance advice with your subscription to:-
Peter Scott PO Box 4162 Palmerston North 4442**

NAME(s) í .

MEMBERSHIP NUMBER(s) (if known) í í í í í í í í .

SUBSCRIPTION(s) PAID í í í í í

DONATION í í í í í

TOTAL =====



If your address or contact details have changed recently please make a note of the new details hereí .

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