



# RECOVERY

GBS / CIDP  
GUILLAIN BARRE SYNDROME  
CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY

## Funding for CIDP Research

### Research into all aspects of CIDP will be based at RPA



The National Health and Medical Research Council (NHMRC) has announced a grant for the research into the treatment of CIDP. The research team will be headed by Professor Matthew Kiernan, (pictured left).

Research Fellow Dr Nidhi Garg was a special guest speaker at our February meeting. Dr Garg is completing her PhD at Royal Prince Alfred Hospital with Professor Kiernan.

I posed a series of questions to Dr Garg in relation to the research.

**1. Who is on the research team?** The research team consists of a combination of neurologists, neurophysiologists, scientists and research assistants. Neurologists that are heavily involved include Professor Matthew Kiernan, Professor John Pollard, Professor Con Yiannikas, Professor Steve Vucic, Dr Judy Spies and Professor Arun Krishnan. However, many other neurologists have also contributed to the research so far. In addition, we have several highly qualified scientists working on the neurophysiological and immunological techniques that are part of the study.

**2. What does the research entail?** The overall aim of the research is to better understand different types of inflammatory neuropathies, including disease mechanisms. The research involves clinical assessments, nerve studies and blood tests. In patients who are on intravenous immunoglobulin (IVIg), we would like to determine whether there are changes in nerve studies or blood markers associated with IVIg and whether this may help determine the response to IVIg and guide dosing regimens.

**3. Where will the research be carried out?** The research is conducted at the Brain and Mind Centre in Camperdown. The research institute is a part of The University of Sydney and Royal Prince Alfred Hospital.

**4. When will the research begin?** We started our research protocol approximately one year ago and have enrolled around 35 patients with immune-mediated neuropathies.

**5. Will the research be open to participants outside the metropolitan area?** Yes, definitely! We have seen patients from interstate and even overseas.  
*continued page 2*

*Guillain - Barré  
100 Years*



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**Next Meeting:** Saturday 7th May 2016

'Susan Schardt Conference Room' L1  
Royal Rehabilitation Centre Sydney  
235 Morrison Road, Ryde

9:30 - 11:00 Committee business and administration

11:00 - 12:30 Open Forum for members and family / guest speaker

Visitors are welcome to both sessions or the Open Forum only if preferred



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## Funding for CIDP Research *from page 1*

**6. Has similar research been carried out before?** Not that I am aware of. We are closely looking at the clinical features and neurophysiology of each patient. Although the immune-mediated neuropathies such as CIDP and MMN are grouped together, there is a lot of variability in presentations and treatment response and we would like to look at this more closely.

**7. Will there be regular updates on how the research is progressing?** We will present our research at local and international conferences as well as through peer-reviewed journals. Patients will also be kept updated on any relevant results directly and through communication with their neurologist.

**8. How can our members find out more details?** Details about research carried out through the Brain and Mind Centre along with contact information, can be found on the website: <http://sydney.edu.au/brain-mind/patient-services/forefront-mnd-clinic/clinical-studies.php>



Dr Nidhi Garg (4th from left) with committee members.

## ZIKA VIRUS AND GUILLAIN BARRE SYNDROME

NARBERTH, Pa., Jan. 26, 2016 /PRNewswire/ -- The GBS|CIDP Foundation International and its Global Medical Advisory Board is closely monitoring the suspected link between the Zika virus and the onset of Guillain-Barré Syndrome (GBS).

GBS is a rare inflammatory disorder of the nerves outside of the brain and spinal cord with an incidence rate of 2 per 100,000 individuals. The syndrome is characterized by a rapid onset of numbness, weakness, and often paralysis of the body. It is an autoimmune disorder usually preceded by a viral infection.

Recent reports from Brazil suggest the Zika virus may cause an increase in cases of GBS. According to the United States Centres for Disease Control and Prevention the Zika virus is spreading in Latin America and other countries through mosquitos. The virus includes symptoms of fever, rash, conjunctivitis and headache.

"The reports on Zika virus and GBS now coming from South America follow those from French Polynesia in Dec 2013," say members of the GBS|CIDP Foundation's Global Medical Advisory Board. "We are in touch with doctors in South America and doctors from the CDC who are investigating this now. They have offered whatever assistance is needed given their expertise. At the moment it seems that Zika virus is one of many agents that can lead to GBS, but we eagerly await more information."

The GBS|CIDP Foundation International is the preeminent global non-profit organization supporting individuals and their families affected by Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes through a commitment to support, education, research, and advocacy. The Foundation has more than 35,000 members throughout 47 countries and has a 26 member Global Medical Advisory Board comprised of the world's leading physicians in peripheral neuropathy research and patient care.

### NDIS: NSW Housing Innovation Showcase

Like all Australians, participants in the NDIS need access to affordable, appropriate and secure housing. The NDIS will offer many participants their first opportunity to plan to live more independently and to think about different housing options.

Hear from housing and support providers about some of the innovative housing and support models that are currently available and growing across Australia. Presenters include not for profits, parent cooperatives, housing organisations and support providers. There will also be a small trade show with exhibitions from the presenters.

Entry to the event is free.

**Where:** Waterview Bicentennial Park, Olympic Park, Sydney

**When:** Wednesday 6 April 2015

**Time:** 10.00am – 3:30pm

# Message from the Chair

Welcome one and all to the first edition of Recovery for 2016; the centenary year for GBS. As some of you may be aware it was in 1916 that 3 French doctors Guillain, Barré and Strohl made their now famous observations that eventually lead to the name Guillain Barré Syndrome. Why Strohl was left out of the 'kudos' is not really that clear. However, some information suggests Guillain and Barré were quite well known at the time, Strohl to a lesser extent and their seniority meant they received more acclaim.



Further, this might also explain to some extent why Landrys much earlier work was not mentioned that much and Georges Guillain was quite adamant that his work was sufficiently different to that of Landry as to be considered a new discovery. So that is the brief history lesson of how our peripheral neuropathy came to be called Guillain Barré Syndrome.

Why is it important that we reflect on this discovery 100 years ago? Well, as you will read in other articles in this edition and on our website, funding has been provided for specific research into CIDP. I am advised the type and extent of research to be undertaken is world class and in fact no other countries are doing this type of research. Australia punches well above its weight in many areas of medical research and this has been a long time coming. Many years ago when the Association was considering where to provide support and in what form, Professor John Pollard indicated that CIDP research was lacking. However, when we looked closer we noted funding just one full time researcher was \$100,000 per annum plus; well beyond our financial scope. But now we have this new research project 100 years after Guillain Barré and Strohl's discovery and we can but hope for resultant better models of treatment and even greater discoveries beyond the current main treatments of IVIG and plasmapheresis.

On another note I continue to advocate through my State and Federal representatives to increase the supply of age appropriate housing for those living with a disability. Recent data indicates there are in excess of 6,000 young Australians living with disability housed in aged care facilities for there are no other options at present. In truth there are some for whom such an arrangement is suitable but I would argue for the majority their all-round quality of life would significantly improve if they were provided with other accommodation options such as group and/or other supported housing arrangements with person/s of similar age and outlook. Further, it is my belief the acceptance of those living with disability within the wider community would be greatly enhanced by day to day contact with the rest of their community and not shut away or confined as is often the case.

In this regard, some may be aware that I work in Education and I recently became an inaugural member of the Department of Education DEN (Disability Employee Network). DEN is a support group within the department set up to help facilitate employment of those living with disability. From that group association I have become a member of NSW Government ASG (Advisory Sub Group). ASG is made up of 15 employees from across all of government with a lived disability and advises the DEAC (Disability Employment Advisory Committee) looking at employment of those living with disability across all of government. The ASG has its first meeting on 9<sup>th</sup> March and I have been invited by the Minister for Disability Services to attend the official launch of "Upholding the Rights of People with Disability: A Training Package" on 10<sup>th</sup> March at Parliament House in Sydney.

As a member of the above groups not only will I be able to have a greater involvement in improving the lives of those living with disability but as the Chair of the GBS Association I can raise awareness of GBS/CIDP to a wider audience.

I would also like to think my recent submission to the IG committee in Canberra, one of the few 'lay people' to make a submission, the vast majority were medical professionals, may have in some small part influenced the recent funding for CIDP research which may result in more targeted treatments for those with CIDP and less reliance on IVIG which at 457 million dollars per annum is the 3<sup>rd</sup> highest recurring treatment in the national health budget. It is my fervent hope that in the medium to long term, for such research takes time, perhaps a few short years from now we will be bringing you news of great advances and even hope of stepping stones to a cure.

In closing I would like to congratulate Trish Brice for volunteering to be our new phone a friend support person. As mentioned in previous editions Mary is scaling back her involvement. Change is inevitable in an organisation that has been going for more than 20 years and whilst no one is indispensable, Mary's lifetime of GBS experience is priceless and indeed she will still be around for sage advice. However, Trish also has a font of knowledge with lived disability and with every change I look forward to the personal touch each new individual brings to their role.

Kindest Regards, Mark



## Talk by Associate Professor Andrew Kornberg at IN Group Annual Luncheon 15/11/2015

It is nice to join you at the end of another year here at The IN Group with lots of old friends and some new friends. I was just talking to John at our table as to when the first time I spoke and it was in 1999. 1998 was when I first actually met someone from the group and it was the founder of the group, James Gerrard, who came to the Royal Children's Hospital years and years ago.

Today I wanted to bring everyone up to date with regard to inflammatory nerve conditions.

There is an organisation called the Peripheral Nerve Society that we are a member of and it is an international group that looks at conditions affecting the peripheral nerves. These are all the conditions that have affected many of the people here, such as Chronic Inflammatory Demyelinating Poly/peripheral Neuropathy, Guillain-Barre` Syndrome, Multi Focal Motor Neuropathy, etc. The good news is that each year The Peripheral Nerve Society meets as a group and we are actually planning different studies to understand what is going on in these disorders, but also talking about treatment trials, etc.

Just talking amongst ourselves at the table brought up two of the things that we were studying over the last year. One of the studies was in fact people who ultimately get diagnosed as having CIDP who present like Guillain-Barre` Syndrome. That is one of the studies and it was published in one of the Journals a couple of years ago; looking at how can you predict what someone is going to have when they first present?

I don't know the story per se, but that comes from putting a lot of information together to try to understand when someone comes into the hospital and has



A/Prof Andrew Kornberg

some weakness, how do you know what they have got? Part of that is the clinical data that you actually get. Has this happened before? Is it slowly progressive? Are there nerve studies? What do they look like? This actually helps to predict to that person what is going to happen in the future. Sometimes when you come in and it is all scary, you do want to know what is going to happen in the future. That comes from some of the research that the PNS is actually doing.

One of the big studies that actually happened is the ICOS 1000. It sounds like a funny name but it is an international Guillain-Barre` outcome study and they are trying to actually get 1000 people into that study. People have been followed in many of the large centres in Melbourne. The usual talk when someone has GBS is they know you have an 85% chance of being completely normal, 15% chance of having some disability, (5% really quite severe, but the other 10% are really functional), etc. This study is being done at the moment and there are 800 people enrolled and all our children from the Royal Children's Hospital are enrolled.

We are beginning to understand things that happen 10 years down the track about fatigue and what you can actually do about fatigue. Also from that study we are picking out that there are some people who present with GBS who are very severe right at the start, within hours, or within a day, but what's different about them compared to someone who is less severe?

The importance of understanding that is; should we be using combination treatments or some other sorts of treatments if we can pick who is going to be more severe? That is some of the information that is coming out.

There is also a trial being done in GBS. Some of you have had GBS, (most will have had CIDP), but whether you should be given the second dose of IVIg. It doesn't sound much but it can actually make a big difference to that person in the longer term. These are the sorts of things that are actually happening and I have 12 studies that we are a part of and doing in multi centres round the world.

The one that is most important is the ICOS study where we are studying the outcomes of CIDP. When we look at lots of people who have CIDP and they are on IVIg and it is thought to be life long, it appears that probably 40% could come off IVIg at some stage. That is because either:

1. The condition is cured – goes away by itself.
2. Their nerves have had damage and the condition has burned out or some better treatment has eventuated. Those people can actually be switched over to some other treatment.

I have talked about monoclonal antibodies and other things like that and people are beginning to use that more often rather than coming in every 4 – 6 weeks, every 2 weeks in some cases to get an IVIg. Now that doesn't sound a lot but that is 2 days of your time every month and it really hampers what you can actually do.

From that ICOS study what is really coming out is that some groups of people who have CIDP – what they should be on or whether they can come off IVIg. There are also some newer drugs being used in CIDP, but also some drugs that are used in MS now being trialled in CIDP. This is because Multiple Sclerosis is a condition where you have white matter problems in the central nervous system, whereas CIDP is in the peripheral nervous system, but the way that drug works in MS, it should work or could work in CIDP. It is a once a day tablet, that's all it is, so wouldn't that be great?

Having this Peripheral Nerve Society where we are all members and now part of all these sorts of trials will add lots of information and give us more and more information as to who should be treated with this drug, what is their outcome and in particular, are there newer drugs which are being used for other conditions that could be used in CIDP or GBS.

There are 12 studies going on right now with all these conditions and also outcomes which are very, very, important.

The things that you should know is that I might not be able to come and tell you that this year I have got a magic medication, or anything like that, but it is like the little Turtle on The IN Group newsletter, "Slowly but Surely" we have little bits of information, more data, that will ultimately make a huge gain and an outcome for everyone affected with these conditions, in particular everyone here.

That's all I've got. Anyone who has a question, I am happy to answer them.

**Question:** In the diagnosis of CIDP do you look for blood test type antibodies to confirm you have got these conditions, because that would be fairly specific as well as the nerve conduction test?

**Andrew:** In GBS there are antibodies that typically do recur. In CIDP it tends to be a whole variety of different antibodies as I think CIDP is not one condition, one disease, it is really the end point of many different factors.

I did a lot of research on antibodies for CIDP and GBS. We found a couple of antibodies in CIDP but the antibodies were not in everyone. If someone had a particular antibody it would be a predictor, but it is actually very, very difficult to do that antibody. At the moment it is a clinical diagnosis with the blood test. Typically it is how the person appears, their examination.

The nerve conduction studies are still the most important. Sometimes a lumbar puncture, sometimes an MRI, but the antibodies are not that helpful.

**Question:** What about 'T' cells?

**Andrew:** Any condition where you have auto-immunity, where your body is fighting your nervous system, you have increases in different "T" cells. It is not specific. It is just what you can actually see that would go along with autoimmunity. You have these changes. You would see that in MS. You would see that in Myasthenia Gravis (MG). You should see that in lots of other conditions where there is auto-immunity. It is not that helpful. It helps the Doctor to decide it is auto-immune and not a genetic problem, but it is not that good.

**Question:** I have a severe case of GBS. I had a second dose and I found it a great help at that particular time in rehab. It meant that I could get going on exercise and get out of there.

**Andrew:** The problem is that we know in individuals it looks like you need a second dose or a third dose or whatever because it hasn't treated the fluctuations, but the question really is whether everyone should have a second dose. You know there are always difficulties with getting IVIg and it is quite expensive too. You have to ask yourself, are you being efficient. Not to say you don't deserve a second or third dose, but the studies will tell us, in a person who has some treatment fluctuation and they come down to this level, they are the ones who need to have a second dose. The vast majority of people get their dose and that's all you need, but a group of people will need a second dose. So these studies could be very important.

*With thanks to The Inflammatory Neuropathy Support Group of Victoria Inc (IN Group) for this article.*

## GAIN Address by Rob Poppleton

An excerpt from an address given at the GAIN (*Guillain Barré & Associated Inflammatory Neuropathies*) third regional event held at York (UK), 10th October 2015 by guest speaker Rob Poppleton, a Consultant Clinical Neuropsychologist from Christchurch Group, based at Hunters Moor in Birmingham. He is a respected neuropsychologist with a particular interest in outcomes measurement and the management and assessment of those with complex brain injury.

In response to two people who spoke very highly of the service they had received in terms of physiotherapy and neuropsychology at 2 different hospitals, Rob said that the outcome often depended on a number of factors, including the personality of the patient, as well as the amount of support from their family. Not everyone is able to benefit from family support of course, and Rob acknowledged that this can have an effect on a person's recovery.

There was a great deal of discussion amongst the audience as to how much physiotherapy a patient should receive.

Ideally, following discharge, a patient should expect ongoing physio at their local hospital or at community level. It may be possible to access NHS-funded exercise programmes at the local gym or swimming pool, so it is worth asking your GP if this is available. Rob stressed that rehabilitation is not a spectator sport, and you must put the effort in order to gain the most benefit. However, it is also important to rest, as overdoing it and pushing yourself too far may prevent you from being able to exercise for the next couple of days. Physiotherapy should be 7 days a week, so even if you only have access to a physiotherapist once a week or once a month, make sure you have exercises you can do yourself between visits. If your entitlement to guided physiotherapy has come to an end, it is important to keep motivated and keep doing the exercises. You don't need special equipment, improvise with tins of beans or bags of sugar!

In order to combat fatigue (physical) and build stamina (mental), structure and planning is key. Little and often is best, and if you learn to pace yourself and structure your day, you will find that stamina and fatigue levels will gradually improve. Remember the 5 'Ps' (more often extended to 6 'Ps', but shortened here to 5, so as not to cause offence!); **Prior Planning Prevents Poor Performance.**

We all have limits. You had limits before your condition, and now you have different limits. If you live with the condition, not through the condition, you can put yourself in control and not be ruled by it. Ignore what you can't change. Do what you can, instead of dwelling on what you can't, but at the same time know your limits.

Recovery from serious illness or living with a long term, life-changing condition can produce the same emotions as grief. The 5 stages of grief are DENIAL (can't be true, this isn't happening), ANGER (why me?), BARGAINING (if you can manipulate the situation it will go away), DEPRESSION (it's all hopeless; my life is over) and ACCEPTANCE (re-structuring and living life within new limitations).

There is more than one type of depression and not all types of depression can be successfully treated with medication. Severe illness or disability, along with many other factors, can cause reactive depression, which is a response to something bad happening. Unlike endogenous depression, which is caused by a chemical imbalance that can be corrected, reactive depression often won't respond successfully to medication, which is why neuropsychology plays such a vital role in recovery. Behaviour might change and a patient may feel worthless and want to avoid people altogether, which isn't good for recovery.

Socialising should be encouraged. Regular exercise can improve mood as well as fitness levels, but look out for the early warning signs of 'overdoing' it, such as aching muscles, etc. Eating a healthy diet can also help.

Maintaining a positive mental attitude helps a lot, especially in conjunction with the support of family, and having a good laugh really does take some of the pressure off.

A question was asked: What happens to a relationship when a partner becomes the carer?

There seem to be positives and negatives, with some couples becoming closer and stronger, and others breaking down. Statistics show older, more established couples fare better whereas younger couples don't do so well. Although the theory would suggest it is better that the partner doesn't become the carer, in reality, it often works out that way, either by choice or necessity.

Rob finished by saying patients should think of coming through rehab as The New You. You are living through and surviving a tough situation. Take credit and be proud of yourself.

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# Feedback

*The views expressed in this publication should not necessarily be taken as the GBS Association of NSW policy. Whilst every care is taken to provide accurate information, neither the Association, the editor nor the contributors take responsibility for errors or omission*

Hello Ken,

Welcome to your new role as Editor of "Recovery" - you are certainly already busy in the interests of GBS folk and we wish you well as you assist those directly impacted and also promote the Association far and wide (A.C.U.).

We do find the stories of other people (e.g. Eliette) both interesting and inspirational, so please do share your own story too.

You have a wonderful sub-Editor in Mary McAlister - she is a real gem!

I notice that Mark mentioned (June newsletter) that 1916 is the centenary of GBS. Could you perhaps print an article on the three gentlemen and their discoveries relating to GBS? At the moment I really don't know how this anniversary could be commemorated in a meaningful way - other than for someone to identify the cause(s) of GBS and how it can be eliminated forever! But on a more realistic note, perhaps as an international effort, if each country represented by a GBS association of some nature could contribute an update from their perspective of things like e.g. research and/or what is being done for patient wellbeing in their country, it could all be collated and shared. I think there is strength in numbers and it may be a way of bringing GBS into greater prominence. Just a thought anyway, but I'm sure other people could well have more viable ideas.

As well as the more well-known health problems, it seems there are also many more obscure and/or serious illnesses out there, so many that people are feeling at saturation point in trying to come to terms with how to help....

On a different subject, I was wondering if GBS is on the rise, decline, or are there any trends in Australia for better or worse? Are some areas 'hotspots'? Is there any trend age wise or within different ethnicities?

Thanks to all the Committee and everyone who contributes to our fine Newsletter. It is ever evolving and a real credit to all of you! Kind regards,  
**Barbara Phillip (former GBS patient).**

Dear Mark,

I was advised to contact GBS. So I phoned Mary McAlister who was a wonderful help to me at a time I was feeling very unwell. Mary was so reassuring and gave me some very helpful hints, which has been so much help. Thank you Mary.

I was hoping to be able to attend your meeting on Saturday but still feel very weak and think perhaps I'll wait until warmer months and maybe I could attend your following meeting in November.

The weather is so cold as you could all relate to. It would take us 4 hours to travel to Sydney.

I am enclosing \$20 to join membership, plus \$100 donation (for) a very worthy cause.

I would like to receive any information on GBS or CIDP by mail to my address.

If I could help people in the Upper Hunter, Murrurundi, Scone and Muswellbrook I would be very pleased to help when I recover fully.

In closing I wish you all the best for your meeting on Saturday 01-08-2015. (I) look forward to your newsletter, 'Recovery' and any information. Thank you.

Kind regards,  
**Betty Brooks.**

This is your column where you can give your views on any subject that is of importance to you. It is especially good if you can give, but is not exclusive to, comments on articles that appear in Recovery or that you would like to see in Recovery.

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or mail:

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PO Box 572  
Epping NSW 1710

G'day Ken,

Tim Pickering here. I think it was you who visited me at Nepean Hospital between Feb and May this year?

How are you?

I'm out of hospital now and living in Kellyville. Still not 100% as I wear ankle/foot orthotic's (still don't have any movement in my ankles) but otherwise getting there day by day.

**Tim Pickering**



# Back Page Bits 'n' Pieces

## GBS Association of NSW

A NON-PROFIT VOLUNTEER ORGANISATION

Registered ABN: 59 166 877

537 Incorporation No. Y13693-

### COMMITTEE

#### PATRON:

Ursula Carlile

#### CHAIRMAN:

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## ANNUAL SUBSCRIPTION / DONATIONS

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GBS

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Doctor/Medical

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Relative

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**Annual Subscription Renewal**

\$ 20.00

**Bank Account:** St George 161403610 BSB: 112-879

**Donation**

\$

Cheques payable to: **The GBS Association of NSW Inc**

**Total**

\$

PO Box 572, EPPING NSW 2121

*Note: Donations of \$2.00 or more are tax deductible. ABN: 59 166 877 537*

### Please let us know if you would like to volunteer for your Association

*We need your help to really make our Association supportive and effective. We are here for you – all on a volunteer basis. Can you be there for those who are going through what you did, or are still going through?*

Name:

Address:

Address:

Phone / Mobile:

email address:

Hospital or home visits to new sufferers (remember how you felt)

☐

Preferred area:

☐

Telephone contact (be a GBS or CIDP friend by phone)

Preferred contact number:

### Committee Meetings

All are welcome to attend the GBS Association of NSW Committee meetings. Newly diagnosed and people recovering from GBS and CIDP will appreciate the contact, encouragement and support from fellow members.

#### 2016 Meeting Dates

6th February	7th May AGM	6th August	5th November
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#### Financial Year 2016

Members are reminded the Association's financial year is

1<sup>st</sup> January 2016 to 31<sup>st</sup> December 2016

GBS NSW would appreciate your continued support.

### Disclaimer

Information presented in "Recovery", GBS Newsletter is intended for information sharing and general educational purposes and should not be considered as advising, diagnosing or treatment of the Guillain-Barre Syndrome or any other medical condition. Views expressed in articles and letters printed in Recovery are those of the authors and do not necessarily reflect the opinions or Policy of the GBS Association of NSW Inc.

### Public Risk

The Guillain-Barre Association of NSW would like to inform all members, friends, guests and readers that the Association no longer has Public Risk insurance covering association meetings or association functions. We regret that due to increased costs we were unable to renew our Public Risk Insurance.

### Contact the Editor

Do you have an interesting story to share with your fellow members? Perhaps you would like to share your experience with GBS/CIDP with us by writing your story for 'Recovery'. Maybe you just need some more information on an article appearing in the Newsletter? Whatever it may be you can contact Ken Brooke:

**Mail:** 16 Corio Drive ST CLAIR NSW 2759

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