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Volume 2; Issue 20

RECOVERY



From the Editor

Dear Members, the GBS Association NSW is really excited to announce a guest speaker at our **next meeting on 25th August at Ryde Eastwood Leagues Club. Associate Professor Arun Krishnan** from Prince of Wales Hospital is undertaking research into CIDP (*details below*) and we are very privileged that he has offered his valuable time to come and talk to our members about his work. Although the focus of his research is into CIDP, we are sure his presentation will be of interest to many of you and all are welcome to join us. To ensure we have sufficient seating would you kindly reply by **1st August** (refer our page 8).

We look forward to seeing you there for this special event.

Special Interest

Articles:

- Guest Speaker 25th August 2012
- CIDP under the microscope

Individual

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Does Fampridine improve fatigue in patients with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)?

Description of intervention(s) / exposure: The purpose is to investigate whether treatment with the medication, fampridine, can help improve the ability to function in patients who have chronic inflammatory demyelinating polyneuropathy (CIDP).

Who is this for? You are eligible to participate in this study if you are ages between 18-80, have CIDP and currently suffer from fatigue and a decreased functional ability. In this study with patients will receiving 12 weeks of Fampridine (active drug) at a dose of 10mg oral tablet twice daily, and 12 weeks of placebo (sham) treatment consisting of lactose tablets, separated by a 4-week washout period.

During the trial, participants will not know if they are receiving active drug or the placebo. Participants will be assessed at baseline followed by 4 weekly intervals to measure fatigue, functional ability and nerve function. Fampridine- PR: Oral tablet, 10mg twice daily for a period of 12 weeks.

The study is a double-blind placebo-controlled crossover study, with patients receiving 12 weeks of active drug and 12 weeks of placebo, separated by a 4-week washout period.

Control treatment: Placebo Glucose tablet identical in taste and appearance to the active drug.

Key inclusion criteria: Definitive diagnosis of CIDP; 18-80 years of age; Able to provide informed consent.

Minimum Age: 18 Years;

Maximum Age: 80 Years

Gender: Both males and females

Healthy volunteers? No

Key exclusion criteria:

- ◆ History of seizures. Current treatment with anticonvulsant medication
- ◆ Pregnancy or lactation. Contraception is required in pre-menopausal female patients
- ◆ History of moderate-severe renal impairment
- ◆ Presence of serious psychiatric disorder (e.g major depression, bipolar disorder) Enrolled in another clinical trial involving an investigational agent
- ◆ Known allergy to pyridine-containing substances
- ◆ History of renal dysfunction

Primary outcome: Six-minute walk test: validated measure that has been used to assess functional capacity in neuromuscular disease. In this setting, it is viewed as a measure of activity-dependent fatigue in patients with demyelinating disease. (*ATS Committee on Proficiency Standards for Clinical Pulmonary Function Laboratories 2002; Kierkegaard & Tollback 2007; McDonald et al 2010*). (*Goldman et al 2008*)

Secondary outcome 1: Peripheral nerve excitability measurement

Secondary outcome 2: Handgrip dynamometry

Secondary outcome 3: Timed 25-foot walk test to assess speed by the time taken

Secondary outcome 4: Nine-hole pegboard test: to assess the time taken to complete a dexterity task

Secondary outcome 5: MRC sum score, assessed as total score and separately for upper and lower limb muscle groups.

Secondary outcome 6: Fatigue, assessed using the validated fatigue severity scale (*Krupp et al 1989*)

From the Chair

Welcome to our winter edition of Recovery. I for one dread the cold weather with hands and feet that never seem to be warm enough. Plus, this will be my second winter suffering from Ulcerative Colitis which unfortunately is exacerbated by cold temperatures. Thankfully, despite side effects from medication my condition continues to slowly improve.

Similarly, the condition of your Association continues from strength to strength. Increasing donations and income from investments has seen a healthy balance sheet. In particular, Mr Peet continues to donate generously and we are very grateful for his continuing support and from all those who have donated over the past 12 months. Of course, there are two sides to a balance sheet and once again our expenses have been kept low. One of our previous main expenses was the printing of Recovery. However, we remain indebted to Sam Khoury and Smartprint for providing these professional printing services for free.

Money alone does not make a successful enterprise and your Association would not function without the ongoing efforts of the Committee. There were no surprises at the AGM and the Executive remains unchanged although the role of Vice Chair remains vacant. This is a primarily symbolic role and requires the office holder to fill in when the Chair is unavailable. Anyone desirous of this role are encouraged to contact the Association.

Each year 4 editions of Recovery are sent out 4 x 70 = 280 copies to members and associated specialists. Recovery remains our main vehicle to distribute information although technology seems to be superseding print media worldwide and we hope to update our website to reflect these changes. Christine our Editor does a superb job (she is also Treasurer) and is always looking for interesting stories and other content. If anyone would like to help Christine either with Recovery or the role of Treasurer please contact the Association.

Mary and Jane remain our telephone and email contacts, the voice of the Association so to speak and often the first point of call for sufferers seeking assistance. We have received more than 50 documented emails and telephone calls in the past 12 months and despatched 23 GBS/CIDP DVD's.

It should be noted not all phone calls require action or follow up and some are simple incidental inquiries. However, some inquiries are lengthy, in depth, very emotional and require a good deal of personal fortitude to listen to calls for help, maintain composure and provide support.

Often when I listen to Mary or Jane recount a particular inquiry, it takes me back to the dark days when I was first impacted by CIDP and my quest for information and understanding. I was thankful then and now I am the Chair of the Association, although I could not do the job these fine ladies do, day in and day out.

Ronald our Minute Secretary provides structure to our meetings, faithfully recording the proceedings and keeping us on track. As a registered charity we have to submit a return to Fair Trading each year. Further, both Ronald and Glenda conduct hospital visits by invitation where it is thought the support of a fellow sufferer might assist in the recovery of a patient and/or support the family etc. At times they often follow the patient through the recovery process from ICU to rehab. Unfortunately, we cannot control how many visits we do as I believe support from the Association from the earliest stages, just like some of the aggressive medical treatment strategies, facilitates the recovery process.

These fine people are the engine room of your Association and I applaud them for their devotion and sacrifice to provide the services offered by the Association. The role of Chair is made easier with such a great team.

As Chair I continue to liaise with specialists to try and keep abreast of any new treatments and research and petition State and Federal politicians to support disability services, particularly the NDIS. In this regard, A/Prof Arun Krishnan, Prince of Wales Hospital is proposing research into CIDP fatigue issues and setting up a trial. At the time of publishing we are in the process of organising a meeting and presentation with A/Prof Krishnan wherein the issue of potential funding may be canvassed.

In closing I would also like to thank Helen and Russell Hosken and Greg Larkin who travelled from the far north coast of NSW to attend our meeting and also Jade Parsons and Justin Randall. Unfortunately, an AGM can be time consuming and somewhat boring to members and visitors but, they are a statutory requirement. However, we were able to have some frank discussions about fund raising and the services provided by the Association.

There is much we can achieve with new technology. However, these still remain the tools for people to use to improve their quality of life. It is the people that are the strength of your Association and we look forward to a rewarding year.

Kind Regards
Mark.



*"I was thankful then
and now I am the
Chair of the
Association"*

Introducing Glenda Ford our warm and bubbly Secretary



What is your role on the Committee? I am the Secretary and my role is to organise meeting venues and liaison with the Club or hospitals for suitable rooms with the necessary capacity and facilities required for each meeting. I do Hospital Visitations for new GBS and CIDP sufferers and continue to visit them in ICU or hospital wards and later at rehabilitation hospitals. I follow their progress and keep in touch, continuing to give support to both them and their families for as long as they need me. Quite often they become members themselves but not always, as some just want to forget what they have gone through and just get back to living their lives again as best as they can.

I write a report for each meeting and sit on the Board, filling in as Chair or other positions when required.

Can you briefly share your experience? I first suffered severe pins and needles about 18 years ago, after coming down with the flu whilst holidaying on the Gold Coast. I was told not to worry by a doctor and over the years I forgot about the experience.

New Years Eve of 1999 I felt very tired and went to bed early, missing the celebrations. My legs were very weak and I kept stumbling. On the morning of 1st January 2000, I woke up and was unable to get out of bed. I tried but slid to the floor with no strength in my Legs or body. My hands, feet, and face were suffering from pins and needles.

I had often wondered how sick one would have to be to warrant the call of an ambulance. At this stage I knew instantly that there was something very wrong with me. I called out to Malcolm and he helped me back up onto the bed. The ambulance was called and at my insistence they agreed to take me to hospital. This was the start of my journey that can be read on the [GBS ASSOCIATION OF NSW Website under "Case Histories"](#).

What was the toughest challenge that you faced during your recovery? I went downhill very fast and I did not want to be a burden on my husband and family and having not being diagnosed for a number of days, I did not want anyone to catch what I had and pass it on so pushed them away. To my relief no-one took any notice of what I said. I changed in a way and kept remembering how I used to walk by disabled people in wheelchairs, and promised myself that I would in the future (if given the chance) stop and acknowledge them with a smile and a few words- just so they didn't feel invisible and that some-one cared.

I felt very humbled when I received flowers from friends and well wishers and would cry. I would not think myself worthy



I have recently become a very proud GREAT GRANDMOTHER. Above is a photo of the five generations (I'm centre standing).

of them spending so much money on me. I did not know of the association and did not have any contact with people who could tell me what was going on. The doctors would only say that I would get better. How at that point I craved information.

How did you overcome it? By acknowledging each and every small achievement I was able to accomplish. I was like a child lapping up the praise my husband would bestow on me and the support he gave me was so inspiring. I wanted to make him proud, so I would try so hard to show him how well I was getting. When I was transferred to Balmain Hospital from RPA I enjoyed helping the elderly patients and that in turn helped me. I contacted the GBS Association when I returned home after a neighbour had printed out some information for me. I would have loved to have had a visit from some-one who new what I was going through. I decided to join when I was well enough.

What inspires you every day? I enjoy and appreciate my life, my husband who inspires me daily and I am happy to visit patients and let them see that there is light at the end of the tunnel. I try not to worry about things that might never happen and enjoy and help where I can. After all these years I still ache a lot, have no reflexes in my legs, cannot run anymore and need help pulling myself up when I crouch down, but what I have gained from this experience is well worth all the suffering I have endured.

Do you have anything else you would like to share? I would not wish this illness on my worst enemy. But my experience I believe, has made me a better, compassionate and more understanding person. To look at me to-day you would not believe that I was ever sick.

CIDP Under the Microscope



Re-printed from 'INFORMATION' (Issue 77 / January 2012 --- Newsletter of the INGroup. Victoria, GBS/CIDP Support Group Talk by Associate Professor Andrew Kronberg. Neurology Dept. Royal Children's Hospital, extract of an address given to the INGroup, GBS/CIDP Support Group Victoria Meeting

Dr. Kronberg

So what's happened in the last 12 months? I guess there have been probably 5 things which have been very important and interesting for CIDP in particular.

Over the years I have talked about that CIDP is not really one condition, it's really like Multiple Sclerosis in a way. It is probably many things or many causes that gets you down and it causes the problem that you have in your peripheral nerves.

We know on a clinical level, when we see people with CIDP, everyone is just a little bit different. Some people have more numbness, some more weakness, some more issues with their feet, etc. So there are some differences between people but we treat everyone in the same way. We use steroids, intravenous Gamma Globulin (IVIG), some other medications, combinations, plasma exchange, etc., so we are treating everyone the same rather than looking at what's different

between people and maybe there will be different treatments for different people.

In the last year what's really come out is from the MS information. MS is very common but with MS the reasons why things happen has really been unravelled in the last few years. Where there was one treatment 10-15 years ago, now there is at least 10 different treatments, because people worked out that some people have more problems in this or that part of their immune system.

Now that is also happening in CIDP. There was a big study done out of Europe, the United States and Australia that has unravelled some of the clinical differences between patients. For example, there are some people with CIDP who come into the hospital and look like Guillain-Barré. They have had this terrible abrupt onset of their condition. We now know that about 15% of people with CIDP present in that way and we are beginning to work out that's what they have got. They have CIDP rather than GBS, we are treating them differently right from the start rather than the ups and downs for a long period of time. We are beginning to group out different patients.

There is a big Japanese study, published in the last year, but it is 3 years worth of information, where they looked at the genes in all people with CIDP and they found some differences in, not one gene, but lots of genes, between people who respond to IVIG and people who don't. That will be, (I think in the next year or two), information as to - where we are - we are going to take off your blood sample - if you have some change in that gene you're going to respond to IVIG so that's what you're going to be on. That's fairly new. Instead of lumping everything together, we have to split everything out because there are more treatments occurring that may actually help this group, but not this other group.

We also know now that in CIDP one third of patients don't respond to anything, or not completely. What is exciting is that now there have been markers identified in CIDP which will allow new treatments to be specifically used for those patients. It is still probably a couple of years away but there are some new anti-bodies which we have manufactured against the thing that is going wrong in those patients. There are expensive treatments but it has happened in MS and it is also going to happen in CIDP.

So in the last year we have had a better understanding of what is different between people. We have now identified groups of people based on their genetics; what they should respond to and now we have actually pulled apart people's conditions and are looking at specific changes in their nerves, etc., which will lead to better treatments. That's really one of the most exciting things. In the last year also at the Children's [Melbourne] we have re looked at all our kids with CIDP and GBS and have identified the same sorts of sub groups in kids as there are in adults. So there is hope for our kids that we are going to have some better treatments.

IVIG. There is plenty of supply. The government has okayed a little bit more (up approximately 14%) for the coming year. There are going to be new ways of giving IVIG. A lot of people go to hospital each month or 6 weeks, to have their infusion, but we are now looking at using IVIG underneath the skin. You have that sort of infusion at home, rather than an hospital. That means, more frequent infusions, but you can do it in the evening times. etc.. so that is the next thing that is about to start happening.

It has been trialled for CIDP. There are at least 3 studies and they are comparable. People who get it subcutaneously, (if given the appropriate dose), will also have benefit at the same level as they would if they had it intravenously. It is a lot cheaper as well as you don't have to come to the hospital. The pump costs a lot of money, but that is a single outlay. It does work. A lot of people may not like it. It is what you prefer. Some individuals if they have to use a huge dose would get a lot of swelling so they won't actually get the medication. We tried with a couple of our children and it does work.



Questions from the floor

Question: Can you tell us about 'Rituximab'? 'Rituximab' was predominantly used for cancers and then for different nerve conditions and it is now finding its place as well in treating CIDP. It is one of the monotonal antibodies. In the 1/3 of patients who don't respond to the normal conventional therapy, about 1/3 of those will respond to 'Rituximab', therefore 10% overall. 'Rituximab' is an expensive medication; it has some side affects, immune issues, but there is now a big trial that has actually shown benefits of 'Rituximab'. It was done by one of my colleagues in the United States. I have used 'Rituximab' in a little girl who has a combination of CIDP and MS. It occasionally happens together and she's responded beautifully to 'Rituximab'. In another patient with CIDP, who failed a lot of treatments, she has responded to 'Rituximab', etc. and I do know that a couple of patients also had that treatment in St. Vincent's and one of my patients at St. Vincent's with a different condition has also responded to 'Rituximab'.

(cont'd over)



So lots of things have been happening and it doesn't seem a lot, but it is, huge amounts of information have happened in the last year. Now that we are beginning to unravel the genetics; why people were different with their therapies and now unravelling why this happened, why the nerve is being attacked, that leads to bigger and better treatments. In MS where there wasn't a whole lot of treatments, they are coming out and every few months we have got a new treatment and it has made a huge difference for the longer term. That is the hope and it will be the same story with CIDP.

Question: When you say people are improving with specific treatment. what is actually happening to those people? Is there less inflammation in their bodies? Are the nerves being repaired? How are they actually improving? I get a lot of fatigue. Will that go away? The other thing in the last year is that we now have better measures to say whether someone is better or not. With a big international collaboration we have now looked at these parameters to see if you are actually better or not and that is for studies.

When you are treating a condition which is chronic, which is there all the time and we know that the problem is inflammation of the nerve and secondary damage to the nerve, a treatment stops that inflammation and damage, the next phase is that there has to be regeneration or new nerves being laid down. I think I have said this before; a nerve regrows at millimetre a day, so if you can stop whatever is causing it, then you get regeneration at 1 mm per day. Now I'm not that tall so it wouldn't take me as long as it would some of you tall people here, but 1mm a day takes a long time. And it is going to be one fibre here and one fibre there. What that means is that you get stronger and your muscles are stronger and you have a little less in the way of fatigue. Fatigue is the hardest thing to treat, because people with Guillain-Barré Syndrome ten years later they are running, playing tennis and everything is all better, but they have profound fatigue and unfortunately we haven't been good enough or smart enough to understand why they are fatigued and we know in MS fatigue is a big problem, we know in GBS it is a big problem and also in CIDP it is a big problem but we haven't got great treatments for that yet.

There is a new medicine that has helped nerves work a little bit better. It's not on the PBS at the moment. It costs about \$700 for a month's supply. Hopefully that gets funded and that may very well help with fatigue, but it is not readily available at the moment.

What is it called? Fampridine SR'. It is specifically for patients with MS. That is where it was developed. It is better for walking, etc. How it works would work very nicely in nerve problems such as CIDP but we have to work on getting a study done so that it can happen.

Peter: I was getting 'Intragam' every 2 months for years and in June my neurologist decided to give me the 5 day treatment and then infusions every month. I had a nerve conduction test in March. Last Thursday I had another nerve conduction test after having the treatment described. There has been an improvement in my nerve conduction test, so would that say that I have a little bit of regrowth, or is it just the time that it takes to react with me?

Ans: It is an important point that you bring up. We assume when we give IVIG that we need to give it about a month apart. We believe that you replenish when you get a big hit of IVIG and it takes 21 days for it all to go away and that's where the 28 days or 4 weeks comes about. There are some studies, particularly with the Dutch, where the same total dose, but more frequent injections, may actually make a difference in the longer term. Maybe you are one of the people who respond to more frequent but lower doses and we know that IVIG doesn't cure the underlying condition but it blocks antibodies and that's probably why you have improved. But that's the importance of working out who responds to IVIG and whether you need it more frequently. Subcutaneous injections, given more frequently, may be beneficial to you, but we don't know as yet.

Question: Can you use the two in combination. intravenous and subcutaneous? It is either all or none at the moment. It may be that there will be people who get combinations of treatments but overseas, particularly in the Netherlands where a lot of this work has been done, most of them are either all subcut. or all IVIG. If you did subcut. and you did that every week; it would work out the same total dose so an intravenous dose is not worthwhile.

Question: What sort of volumes could you deliver with subcut? You need to have high concentration of the IVIG so when it was 5 - 60lo IVIG it is really hard to deliver that, so the new subcut concentrations are somewhere between 12 and 20%, so then you are using much lower volumes for that number of grams. So that is where things are going.

Question: What would the maximum be that you could deliver with subcut? Ans: Probably, the maximum you can actually deliver in one site is 100mls. When you get subcut you actually have multiple sites going. 100 mls. at each site. It balloons up and then quickly dissipates.

Question: Can you deliver an equivalent of 100 grams IVIG? You can but you would probably have about 4 sites. If you are getting 100 grams every month, that would be 25 grams per week would be what you would infuse in that week. You might do it 2 or 3 times in that week. You get the same total dose but rather than in one hit, you are getting it in small doses all the time. It probably is the way to go with chronic conditions because it is not really the level of IVIG it is probably other factors. A lower dose more frequently (like with Peter) is probably the way to go.

Question: Is it into the vein? It is administered just under the skin. It is like if you have diabetes. It just goes under the skin, into your tummy, so it is actually underneath the skin, into the layer where there is a little bit of fat and it goes in and gets absorbed.

Question: What is a Nerve Conduction Test? There are conditions where it is mostly motor nerves and there are conditions where it is mainly sensory nerves, but in CIDP you typically have both affected, on nerve conduction tests and on clinical levels and we believe it is the same problem in both. When we actually take nerve biopsies, (we don't do that often) we actually take a sensory nerve to have a look underneath the microscope. The more disability in the vast majority of people is in the motor, because that is what you do, you are walking, climbing stairs, etc., but the sensory is also affected and both respond to these treatments. A nerve conduction test is for measuring both the motor and sensory nerves.

Question: Will there eventually be an oral medication for CIDP? There are already medicines that you can take orally but many of them have quite a few side affects. IVIG out of all of the therapies probably has the least side affects, but you know 'Prednisolone' the steroid can be taken orally. It does work but there are issues if you have been on it a long time. But there are some new oral agents which have been developed, initially for MS for the same sort of immune conditions so they will also be able to be used in CIDP. They have not been studied as yet

P h o n e a F r i e n d

Whenever the GBS/CIDP telephone rings, I realise the person I am about to speak to, has very probably some real concerns which may be troubling them. Indeed many callers have delayed speaking of these apprehensions to their families, preferring to be silent about their problem, reluctant to seek or ask for their help. GBS/CIDP persons no matter at what stage of their recovery, often find it is difficult to know what is to be tolerated or expected, or is there something which could be done to enhance or improve their worries? Sometimes just speaking over our concerns lessens the anxiety; maybe they might be of a recent nature, or they may have been troubling for some time. Contacting the GBS/CIDP Assoc. by email or by telephone and just speaking or asking someone who has been down a similar path takes a positive step in expressing their concerns. Obviously as much as we would prefer it otherwise — not all concerns can be swept away by just talking, however talking it over, may at least settle small concerns, larger ones are more difficult to manage.

Since our last edition of Recovery, more than fifteen people have called our Association and more than double that number, have emailed for advice or spoken about their concerns.

Several of the telephone callers did not actually have diagnosed cases of GBS, never-the-less the callers had some previous knowledge of the condition which concerned them now, harbouring and fearing in their minds, a strong possibility they may develop GBS. One caller was a nurse from ICU who understood very well, the trauma of having GBS, having nursed patients in ICU. The caller described they were under huge personal strains and unrelenting stress, the question was, is it possible to develop GBS from stress? Another caller was from a young single mother with a very young child, having initial GBS-like symptoms, and very fearful of what might happen to herself and her child if she developed GBS/CIDP? Both callers reflect the trauma which can surround having GBS. One cannot pretend that this is not so, it certainly is.

In the cases mentioned, one can only suggest that a visit to a hospital who may have a Neurologist in attendance hopefully such consultations, may be able to dispel their worrying concerns, or perhaps even more troubling confirm their worst fears.

Stress has often been quoted as a possible contributing factor with GBS and CIDP, however this has not yet been totally confirmed. So here are but two examples of the mystery of both GBS and CIDP which can provoke real or otherwise concerns.



The question of why at some point in our lives GBS or CIDP may develop, be you young or old, male or female both conditions can and are, non discriminative, the question remains, why?

Neither GBS/CIDP conditions will tick neatly into descriptive boxes. What might apply to one GBS case, may not necessarily be similar to your case. Keeping that in mind, all persons whether it is the patient or their families, wish to know what to expect now and in the future? how long will recovery be? how fully will I recover? why is it after having IVIG, or plasmapheresis, I, (or they), do not make a full recovery? how long will I need these pain killers? how long will I have this tremor? None of these questions will have a definitive answer. Each case will be separate to the other in their personal recovery journey. Therefore it is unwise to compare one recovery case with another.

Receiving GBS telephone calls with such questions, requires encouraging the caller to keep the positives upper-most in their attitudes to their goals, coupled with the understanding that time and intervention treatments given whilst in hospital do give quite positive outcomes for most people of to-day who may develop GBS.

CIDP callers, too often find huge time delays in confirming their diagnosis. At least two callers were in this situation, more than 2 years of deterioration had occurred in each case. Yes, for both, a relief a diagnosis was finally made, however treatment was for these cases delayed and the consequences of such delays might be more challenging to arrest. Perhaps the answer in these cases is for Neurologists to have a better grasp on the possibility of the circumstances of persons developing CIDP and providing supporting treatment much sooner.

The situation re availability of Rehabilitation Centres, was also raised by yet another caller who was a GBS patient with a poor recovery — indignant and angry that GBS patients often had to spend their rehabilitation in unsuitable nursing homes, instead of the more appropriate Rehab. Centres. This type of call is repeated far too often. There seems to be no answer to this vexing question at present. We hope the new Disability Scheme soon to be implemented may go some way to provide the answers in the near future.

To finish, may I just emphasis that in talking through our concerns, we may not always receive the answers to our anxieties, but most times it will and does help considerably to just talk them over with someone who understands, whether it is family, doctors, or the GBS/CIDP Association we are willing to listen, and even may suggest some options which might help.

Best Wishes to the GBS/CIDP family, from your telephone friend...

Bits n Pieces

GBS Association of NSW

**A NON-PROFIT VOLUNTEER
ORGANISATION**

Registered Charity No. CWD295

Incorporation No. Y13693-18

COMMITTEE

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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.

MEETING VENUE



We are still looking for a permanent home, until we do lets get together at

Ryde Eastwood Leagues Club

25th August 2012 at 10.30am

117 Ryedale Road, West Ryde NSW 2114

the club is on the Eastern side of the rail line – it is walkable from West Ryde Station, which has lifts. We will be in the “Hawks Room” on the lower ground floor which has a lift to the floor plus lifts from the 2 level car park underneath the club. The room is booked in the name of the GBS Association.

Meetings commence at 10.30 am - to 1.30 pm

Help support your Association, get involved, come to a meeting, share your experiences, help others like they helped you.....reward yourself !!!

Financial Year 2012

Members are reminded the Association's financial year is

1st January 2012 to 31st December 2012

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 or 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 spiralling insurance 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 me, Christine Simpson-Morgan:-

Mail: 8 /36 Mobbs Lane EPPING NSW 2121

Guest Speaker Associate Professor Arun Krishnan

Ryde Eastwood Leagues Club - Hawkes Room

25th August 2012 at 11am

Please RSVP by **1st August 2012.**

Cut out this slip, complete your details and sent to **PO Box 572 EPPING NSW 1710** or via email to **info@gbssnw.org.au**

Please reserve seats for name(s)

Please indicate below how you think you may be able to help:

☐ Hospital or home visits to new sufferers **(REMEMBER how you felt)**

Preferred areas:

☐ Telephone contact **(Be a GBS or CIDP friend-by-phone)**

Preferred areas:

Or send us YOUR STORY for the newsletter. How about doing all three?

We need your help to really make our Group 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 PHONE email

ANNUAL SUBSCRIPTION / DONATIONS

Financial year from 1 January 2012 to 31 December 2012

NAME:

ADDRESS:

ADDRESS:

PHONE / MOBILE PHONE email:

ANNUAL SUBSCRIPTION / MEMBERSHIP RENEWAL \$ 20.00 (includes GST)

DONATIONS \$

TOTAL \$ - please do not send cash

CHEQUES PAYABLE TO:

The GBS ASSOCIATION of NSW Inc"

PO Box 572, Epping, NSW 1710

NOTE: Donations of \$2.00 or more are tax deductible. Registered Charity CWD295.

☐GBS ☐CIDP ☐DOCTOR/MEDICAL ☐RELATIVE

(Please tick the appropriate box)

Publication of name in newsletter ☐YES ☐NO

IF YOU WOULD PREFER TO HAVE YOUR "RECOVERY" FORWARDED PER AN ATTACHMENT TO YOUR PERSONAL EMAIL ADDRESS; PLEASE TICK THE BOX AND PROVIDE YOUR EMAIL ADDRESS BELOW

email address:

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