

RECOVERY



From the Editor

Special Interest

Articles:

- Ed Cooke Tribute
- The Blood Lottery

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Meeting dates for 2013

- Saturday October 26, 2013

A very warm welcome to our valued members, we hope this edition of Recovery finds you all thawing from winter's chill. During the period since our last edition the Association has taken a hit with the loss of our dear friend Ed Cooke.

Mary will pay a tribute to Ed inside but I wanted to acknowledge and thank him for supporting the Association since it's inception. As husband to our dear Shirley, Ed has been un-wavering in his support of us and his insights and wisdom will long be remembered. Our thoughts and prayers go out to Shirley and the family, we will miss him dearly.

The Committee rallied and has been busy during the 3 months since our last newsletter. We are in the development phase of designing a new website which is really exciting. It's early days as we pull our conceptual ideas together but we do hope that we can launch it within the next few months.

Our vision is to provide newly diagnosed patients and their families with a user friendly and simple portal, giving them access to



practical and helpful information. We would also like the site to be a source of reference for the medical fraternity, doctors, nurses, physio's and OT's, in fact anyone seeking GBS/CIDP information should find this a 'one-stop-shop'.

Part of this initiative will be to create a new logo for our Association and we would welcome submissions from our members. Obviously our logo is very important to us. It is a symbolic representation of who we are and how we see ourselves. It needs to convey a positive image of recovery, hope and optimism. If you have an idea or design you would like us to consider please email or send to our PO Box, details on page 7. We will obviously keep you up to date with this important project as we bring it to life.

Well I will sign off for now and leave you to get into this Spring edition.

Please remember I am always looking for content so if you would like to share your story just SPRING into action and drop me a line.

Christine S-M



From the Chair

"Never give in. Never give in. Never, never, never, never — in nothing, great or small, large or petty — never give in, except to convictions of honor and good sense."

(Winston S. Churchill, Harrow School 1941)

Perhaps this should be the creed of the GBS Association. We know from experience the majority of sufferers eventually recover and go on. It is not an easy path nor an often travelled path but for those who have had to make the journey it is a well-known path. However, whilst WE who have made the journey know, those afflicted for the first time do not and that is where the GBS Association comes in.

This then brings me to some of the people who have made it all possible, in particular the recent passing of such notables as James Gerrand, David Bryce, Lindsay Peet and Ed Cooke. As Chair I am humbled acknowledging the achievements of these people in support of our cause and am personally enriched knowing they sought not fame and fortune for their endeavours but simply to improve the quality of life of others. They sought the ordinary extraordinarily well and I believe embodied the sentiments of Churchill's words.

Gerrand fought for many, many years to have IVIG recognised as a treatment for GBS/CIDP. As we know this treatment comes with a huge price tag not to mention the pressure on finite donated blood supplies. However, for many it makes a huge difference with few of the side effects of other treatments. Bryce, an early chair of the GBS Assoc., has been a passionate advocate for improvement in disability care and put forward a submission to the Productivity Commission about the formation of the NDIS.

From the Chair (cont'd)

(Continued from page 1)



Interestingly, whilst I never met David, I too put forward a submission to the Productivity Commission about GBS and disability care.

Lindsay Peet, well known in WA for his passionate pursuit of WA history and philanthropy, especially towards the GBS Association of NSW.

Then last but not least Ed Cooke husband of Shirley who has suffered with GBS since the early 1960's. Few knew Ed, as a child, was incarcerated in China at the hands of the Japanese during WW2. Then as a man, married to the girl of his dreams and starting a family, found himself with a wife stricken by a then little known and less understood condition known as Guillain Barré Syndrome. Through the subsequent highs and lows they endured. Ed and Shirley have been stalwarts of the GBS Association since its inception more than 20 years ago. I always viewed Ed as an uncle and listened intently to his sage advice. My parents and grandparents often told me to listen to my elders with the rejoinder, you might think they are talking crap when you are young but you will find when you get older some of it will be pretty invaluable information.

Often when people pass you regret not getting to know them better. I cannot say I knew Ed well, nor Gerrand, Bryce or Peet. However, you just knew by their endeavours they were all good blokes. I should think of no better quintessential Australian epitaph than to have the words, 'He was a good bloke' inscribed alongside their names. Similarly, I would suggest ALL of them would say they did nothing exceptional to warrant acclaim and do not mourn my passing but pick up the baton and continue my work. As Chair I am more than happy to pick up the baton but am somewhat daunted by the bar that has been set. However, when I read the stirring oratory of Winston Churchill, '...Never given in. Never give in. Never, never, never...' the other foot drops and I move forward.

Each sufferer on the road to recovery draws inspiration from many different sources and the GBS Association is there to offer assistance where we can. We are not trained medical specialists who can diagnose and treat rare peripheral neuropathies. But we do have a wealth of first-hand experience and knowledge and importantly are very good listeners. Mary, our telephone contact and Shirley literally have a lifetime of experience living with GBS. Further, whilst no two persons present the same, there are many who have shared experiences of incorrect diagnoses, interesting and frustrating hospital experiences, the regular travails of pain, strange sensations and for some ongoing medications and at times a painful testing regime.

When I consult with specialists they always stress the need to learn and wherever possible seek to understand the patient experience so they can in turn develop better treatments and strategies of care. Lumbar punctures, nerve conduction, EMG and blood

tests give them the data but what of the patient. How do they feel? That is why I regularly touch on the importance for sufferers to either tell their story in print in our newsletter Recovery and/or come along to a meeting and take the opportunity to share their story with fellow sufferers.

As Chair I am continually seeking new ways in which we as a support group can provide a better level of support to those who come to us for assistance. Every story I hear and read goes to the collective database of knowledge. We have a growing base of medical professionals who read our newsletter and I know from their comments they WANT and NEED to know the 'warts and all' patient experience. If it was good, say why and if it was not so good, why, and what as a patient you might like to see to make the experience better. Each and every sufferer can make a difference and contribute to easing the way for the next person diagnosed with GBS/CIDP.

Currently it is very unlikely there will be an outright discovery of a cure for GBS/CIDP in the short to medium term. However, it is likely there will be incremental improvements in treatments and flow on improvements in patient outcomes and quality of life. Every patient story shared goes to supporting those incremental improvements. Human history is full of occasions when the seemingly impossible is achieved after many years of

endeavour and struggle by many working toward a common goal. The Egyptians building the pyramids or more recently NASA sending man to the moon when JFK famously said in the early 1960's we will send man to the moon and bring him back safely to earth before the decade is out. Coincidentally that was about when Shirley acquired GBS. No doubt both the Egyptians and NASA had their equivalent Gerrand, Bryce, Peet and Cooke.

Life throws up many challenges and it is how we tackle them that helps define who we are. Acquiring GBS or CIDP is not a good thing and there is no current magic pill to cure it. Medical specialists have a range of treatments that may work, may not, or may partially help.

The GBS Association is there to help if we can however, it is the individual who must decide to Until next time. **Mark....**

**Never give in. Never give in.
Never, never, never ...**



When I consult with specialists they always stress the need to learn and wherever possible seek to understand the patient experience so they can in turn develop better treatments and strategies of care.

The blood lottery- so how sick are you?

article written for SMH Weekend Edition 6/7 February 2010

The reprinted article featured below, addresses some of the concerns about the changes experienced by several of our members re the alteration of their usual immunoglobulin product infusions. Some members have found the change to have been to their health detriment, whilst others who have made the switch to the imported product to be of increased physical benefit. Once again reinforcing the realization how important our own Individual responses are to one's medical treatments. Especially for CIDP patients who rely so heavily on IVIg.

Plasma is so useful in treating diseases that almost everyone wants it – and that's the problem, writes Julie Robotham,

How, asks Andrew Kornberg, do you assign a value to helping someone walk again? “When you’ve seen a person who’s been in a wheelchair become a person who can work and contribute ... it’s clearly what we should be doing,” says Associate Professor Kornberg, the head of neurology at Melbourne’s Royal Children’s Hospital.

He is referring to the increasing use of intravenous immunoglobulin (IVIg) therapy for nerve and muscle disorders. Taken from donated blood plasma, the immunoglobulin component which fights infections has long been used as a substitute for people who do not produce adequate immune factors of their own.

More recently doctors have learnt that a blast of IVIg can change the immune response of people whose own systems have gone awry—people with auto-immune diseases, including many of the neurological problems that Kornberg treats. Spectacularly successful in some conditions and light on side effects, if IVIg were a pharmaceutical it would be a blockbuster. But its source in the blood bank means its supply is finite. Ultimately if one group gets it, another may miss out.

Kornberg advises the government on how the resource should be allocated and helped draft the 2007 guidelines that framed the scientific justification for its use in dozens of diseases.

The guidelines specified in microscopic detail the qualifying criteria for IVIg use – disease severity, the other drugs the patient must have tried first, the maximum dose and dose interval, and how much improvement was needed to allow the patient to continue. Now those guidelines are under review again, to update them as a result of fast-moving science and to remove residual ambiguities. Andrew Mead, the acting general manager of the National Blood Authority, says the new document for which submissions close at the end of the month, “is not about curbing use.” It’s about the appropriateness of use. But its official context is to limit IVIg use to “patients for whom there are no alternative safe, effective and cost-effective treatments”.

In this rigorous environment, Kornberg and other neurologists find themselves more frequently having to justify their patients’ needs in the face of competing claims – their speciality now accounts

for 42 per cent of use of IVIg therapy and is the biggest factor behind the doubling in its use in just six years. IVIg costs about \$160 million a year: 20 per cent of government spending on blood and blood products. But the fact it stormed through 380 tonnes of donated plasma last year is preoccupying health officials more than the financial impact.



Preparing plasma from blood

In its 2008-09 report National Blood Authority noted that “any changes in the development and use of IVIg can potentially have a large impact on Australia’s blood budget and on the pressures in the system for collection of plasma”.

From a standing start, chronic inflammatory demyelinating polyneuropathy (CIDP) has become the biggest single condition to which IVIg is used. It is not usually fatal but can leave people in pain and horribly disabled for muscle degeneration, while alternative treatments – such as steroids – may carry gruesome side-effects if used long-term.

Kornberg says the scientific evidence for using IVIg is exceptionally strong, but such patients need monthly infusions, indefinitely. Dosing is based on a patient’s weight. For a person weighing 80 kilograms, each infusion may cost about \$5,000 (based on a cost of about \$70 a gram) and some may be required as often as fortnightly.

“If I got CIDP tomorrow I’d want IVIg” Kornberg says. “Sure you could argue about the cost of that but when I think back from the past to now, and the benefits to families and patients ... the stakes are really high.”

Dr Philippa Hetzel, the executive director of operations as the Australian Red Cross Blood Service which collects blood and blood plasma on behalf of the government, says IVIg demand is growing faster than any other blood product, and is becoming the main subject of blood bank planning.

A greater incidence of autoimmune conditions due to people living longer is coinciding with a trend to treat more leukaemia and myeloma patients with bone marrow transplants – they then need IVIg to maintain their health afterwards. The obesity epidemic also inflates IVIg use. Hetzel says because dosing regimens are based on a patient’s weight. Just over half of blood volume is the watery plasma, in which red cells are suspended. Plasma can be extracted from whole blood donations or it can be

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The blood lottery- so how sick are you ?— continued

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taken on its own in a technique known as apheresis in which the red cells are returned to the body.

This yields more than twice the volume of plasma per donation and has the advantage of not risking anaemia in the donor meaning people can donate fortnightly rather than only four times a year. Plasma donors on average give five times a year, while whole blood donors give twice a year. But a plasma only donation takes an hour, rather than 15 minutes for a full blood donation.

“That’s a very big commitment from donors, asking them to stay that extra time,” says Hetzel, who foresees another doubling over the next five and seven years.

Capacity remains in the system, she says, and if the government ordered an increase – the service supplies according to pre-set targets – the first strategy would be simply to open donation centres for longer.

New international rules that have increased the annual volume of plasma a person can donate, from 15 litres to 25, have helped boost supplies of the product and the total donated plasma volume last year increased by more than 18 per cent. – double the increases of other years.

Still more than a quarter of a million plasma donations last year has not been enough to keep

Australia self-sufficient in IVIg as it is in other blood products such as albumin and clotting factors, all processed in Melbourne by CSL Ltd under a just renewed contract that expires in 2017. Last year the country imported 27 per cent of the IVIg it used – the highest since imports began in 2005.

That puts Australia at the mercy of a global spot market. As other countries including relatively poorer ones, increased their usage of IVIg, experts had worried there would be a global shortfall and price spikes last year.

Happily the financial crisis stepped in, according to the National Blood Authority’s assessment: the possible shortage has been mitigated in the short term by the current economic downturn in the United States,, which has increased the number of donors wanting to donate plasma and receive financial compensation.”

Australia’s dependence on imported IVIg concerns doctors like Kornberg.

“What is to stop these companies pulling out of Australia” he says, if a shortage in another market means a temporary higher price elsewhere.

Mead from the National Blood Authority, acknowledges that but argues international product can be cheaper and says Australia needs continuing relationships with overseas suppliers in case our own production were to fail.

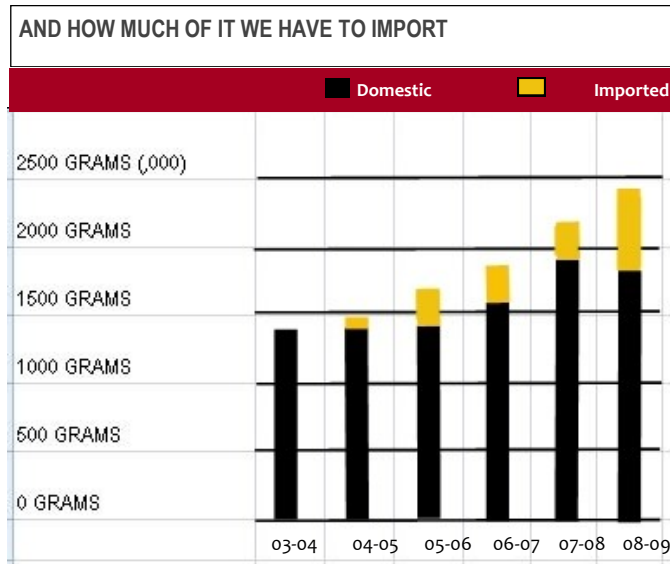
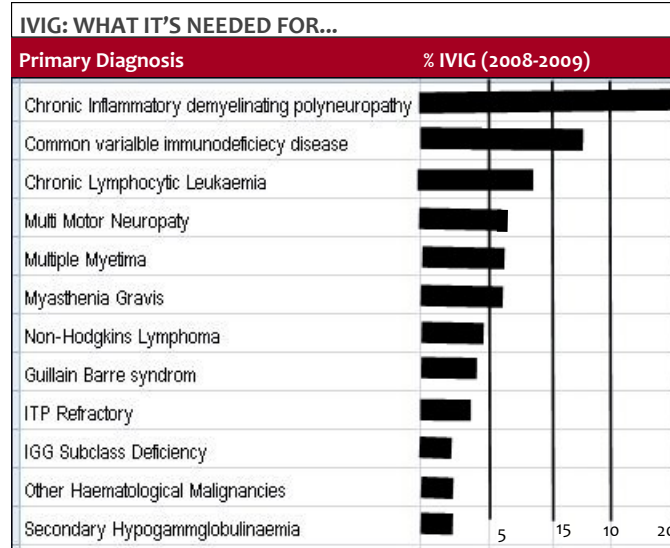
Meanwhile new potential uses for IVIg keep on emerging. Just last month, Australian doctors published a paper showing it may reduce the severity of a rare form of anaemia found in babies, caused by the mother’s immune response to foetal blood.

But the big one is still to come. Baxter Healthcare Corporation in the US will complete a trial of IVIg in Alzheimer’s patients this year. In theory, its immune-resetting function could help the

body fight the protein plaques that clog the brains of people with Alzheimer’s.

If it partially reverses the disease or even halts it in its tracks, then all bets would be off, since Alzheimer’s – affecting one in 100 people – is hundreds of times more common than the neurological disorders that are already putting the IVIg supply under strain.

Associate Professor John Ziegler, the chairman of the NSW IVIg user group, says: “If Alzheimer’s became an indication we’d. just have to go back and start again. The current system just would not cope.





Member to Member

Farewell, Dear Ed Cooke,

It is with my own sense of personal grief and sincere regret that I inform the members and friends of the GBS Association of the death of my dear friend and long serving Committee member Edmund “Ed” Cooke. Ed, husband of Shirley, father of Janet, Paul, & Cathy, and grandfather, of their children, and brother of Joyce, died on the 1st June 2013 in Hospital, after some months of challenging and long standing health problems.

To all of Ed’s Family, and most especially to Shirley his loved wife of more than fifty-five years, we send our deepest and heartfelt condolences to you all, from your GBS/CIDP Family of Friends.

Shirley and Ed Cooke have been active members of the GBS Assoc. since its inception in late 1989. Shirley has been a Committee member since that time, and Ed a financial supporter for all those years. I don’t believe Shirley has missed more than a handful of Committee meetings since our first official meeting in 1990. However it always appeared to me that although it was Shirley who had GBS, it was Ed and Shirley who shared between themselves an intrinsic bond of mutual supportive strength which gave their marriage a partnership of loving compassionate and caring values. I am sure those who knew both Shirley and Ed thought of them as a team, strong, reliable and concerned, not only for their own family but also for the extended GBS family as well.

Over those years now in excess of twenty years since our foundation as a support group, GBS/CIDP has been continually enriched by the presence and the active participation of our dear friends the Cooke’s. Ed always adding wise counsel to many contentious matters which may have faced the Association.

Although retired these many years, Ed lead a very active life in the business world. Initially employed in the Banking area, later becoming a Stock Broker. His family life with Shirley and the children, were years of personal involvement, participation and on some occasions, adventurous holidays for them all. Shirley, as Shirley would, was equal to (and is) to all Ed’s plans, no matter how challenging they may have been for herself. The children remember these holiday adventures with fond and great memories of both their Dad and Mum, never daunted by their many misadventures..

As a boy Ed’s life was a challenge as well, his parents business people living in the North-West of China in Tsingtao in the 1940/s were caught up with thousands of others in the second World War, The Cooke parents, with Ed and his older sister Joyce were interned by the Japanese in the Weihsein Compound an Internment Compound in China, including the families and individuals of the allied nationals of the War, a mix of European, Dutch, American, Australian persons, and many other nationalities, brought together from about December 1941 to August 1945. Most internees were always hungry, food was scare, clothing, shoes, medicines, even water, were almost non existent. Life was hard. Nevertheless the community organised church services, school, sport, even a scouts group, and created many other activities to involve the internees as much as possible in some type of normal life, under difficult circumstances. The Cooke family were amongst the first to be interned. Ed was then nine years old, and was 13 years old when liberated by parachuting US Para troop group — such a grand and great moment for all, I have heard this story from Ed myself. I am sure we all gain self-reliance from our deprivations, and grow stronger as a result, I feel as though Ed did.

Later Ed and his family were to migrated to Australia in 1946. Ed. completed his schooling begun whilst in Weihsein at the Marist Brothers High School at Parramatta. Married his love Shirley; and have three much loved children— farewell for the moment Ed.

To dear Shirley we send you and the family our love and blessings from the GBS/CIDP family.



***“I know for certain that we never lose the people we love, even to death.
They continue to participate in every act, thought and
decision we make.***

Their love leaves an indelible imprint in our memories.

We find comfort in knowing that our lives have been enriched by having shared their love”

Leo Buscaglia



Call a Friend segment in this edition of Recovery reflects a snapshot of just one call to the Association. It concerns the interaction between a new GBS patient, and her immediate family, and that of a former GBS patient who became her visitor. I trust you will all find the conclusion inspirational. I did.

Saturday 20 July, from a mother, Brid, with her husband had previously had an emergency dash from Ireland to be with their daughter Danika, a patient in a Sydney Hospital at the end of June 2013.. the following are exactly her words..

"She first went to Emergency on the Tuesday night and again on Wednesday night (sent home both times told she only had flu). Went back by ambulance on Friday morning as she was unable to walk. Again told she only had flu like symptoms and she would be home on Monday. Well on Monday morning (3 am with us in Leitrim [Ireland]) she rang in panic that she could not breathe. I told her I would ring Neurology Ward and speak with staff which I did. I rang back and was told by a nurse that her breathing was ok, she was fine, that it is was only anxiety. 24 hours later we got a call from a friend of Danika to say she had been rushed to ICU as she was having breathing problems." "They only started treatment on Monday, (now over 4 weeks ago) which was almost one week from her 1st attendance at Emergency. She is on a ventilator all the time, so we have a letter board to communicate "

"I told Danika about your telephone call and she is really looking forward to "talking" with a former GBS person. She had a better day to -day but cried in the evening. When we took out the letter board she got us to spell out—All I want to do is to be able to talk -. It was a pity the hospital did not pick up on GBS sooner and start treatment"

Readers of Recovery may recall in our last edition we featured a GBS story from two aspects, the patient's and the patient's mother. The patient was a young English lass, presently completing a year's Internship with the Brain & Mind Institute in Sydney, in the Parkinson's Research Clinic. Lata came to one of our GBS/CIDP meetings last year.

I knew from meeting her and later reading her own story, that she would instinctively be the "right" person to visit Danika. Not all people feel totally comfortable as "visitors" to new GBS patients; so I understood when I initially contacted Lata re visiting Danika there was just a second or two of hesitation, the hesitation I understood completely. Nevertheless, Lata said "yes I need to do it for Danika and myself". I had no doubt in my mind exactly what Lata meant. It does take courage to face the trauma, the fears we all harbour about GBS. I knew well the amount of personal courage and conviction that Lata would need to be a Visitor to Danika. I was anxious for Lata's decision, certainly I did not wish to persuade her into any action for which she was not emotionally ready...

The results were inspirational.. for both Lata and Danika. The visit to Danika, was a total success, for mother Brid, and Danika, and not the least for Lata herself. With Lata's permission, I have included her last email to me this week, I am sure you all will be inspired by a two most remarkable women, Lata Mistry, and Danika ...as most certainly I have been!

Monday 26 August 2013 from Lata Mistry

I haven't been back to visit Danika, I have sent emails to Brid updating her on my whereabouts and giving motivational advice for Danika but have not received anything back in a while. I will continue to send messages but I don't think I will see Danika again in Australia. I was supposed to visit once more before I left the country and Danika set herself a target for the date. It was a fairly optimistic target and although her recovery so far of course has been excellent, she may be feeling frustrated that she is not at her desired stage. So I'm more than happy to take a step back and let Danika progress in her own time.

When I describe my story to friends I end up explaining that my year in Australia feels like a year of complete recovery, my recovery. Entering the real world again after having GBS is beyond explanation. You have a unique perspective which is hard to share and often leaves you feeling lonely and frustrated. Most of the time you wish you didn't have it so you could be happy with whatever everyone else finds entertaining. You have a constant desire of wanting more and a feeling of am I enough? This year in Australia I've discovered that I am enough. I've learnt to embrace my unique perspective and use it as a strength instead of a weakness. Being a new 21 year old my judgement and opinion was often ignored by older peers and even worse ignored by myself. Now I learnt that I can trust myself and I've done enough to prove it.

The first feeling of recovery came when I had a bad bout of Sciatica in May 2012. Now having Sciatica is never really a sign of a healthy recovery but I had developed the condition because I was doing so much exercise and not allowing myself to rest. I had gone from too under, to too over. Ok, sign number one of needing to relax. Second sign was joining the GBS society in Australia and going to a support group meeting. I had never had much of an active input in the UK as I don't think I was mature enough or ready to go. This was the first time I met other GBS patients, some at the beginning of the recovery to some who are 40 years recovered.

The third and final step of my recovery was meeting a young GBS patient who was still suffering. This year in Australia I've been coordinating a Parkinson's Research Clinic at the Brain and Mind Research institute of university Sydney. Now this internship will without a doubt help me academically but additionally it prepared me on how to approach people who are still suffering. We've been there we know what they want and what they don't want. After the meeting with a GBS patient I was surprised at how calm I felt afterwards. I wasn't traumatised or upset but relieved and happy. Of course the patient has a long road ahead but recovery is achievable. It was the moment where I realised I was not the patient anymore and I can do a lot more good being who I am than trying to be someone else.

I'm now on my way out of Australia and back to London. Its certainly been a memorable year and I'd like to thank the GBS society for being a part of it. I hope to keep in touch with the team here and perhaps meet that GBS patient again to celebrate her own complete recovery.

Lata Mistry

May I conclude by mentioning Lata is now back in the UK with her family. To, Lata, Danika and Brid, on behalf of GBS/CIDP.NSW our sincere and heartfelt appreciation for sharing your individual journeys with us ... Mary

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

Ryde Eastwood Leagues Club

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 all levels of car park underneath the club building. The room is booked in the name of the GBS Association.

Meeting dates scheduled for 2013

Administration Section of Meeting commences at 9.30 am –11 am

Open Forum/ Guest Speaker 11.00 am to 12.30 pm

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

Meeting dates for 2013 are; the last Saturday of the following months:

⇒ **October 26th 2013**

Financial Year 2013

Members are reminded the Association's financial year is

1st January 2013 to 31st December 2013

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

Email: smorgan8@bigpond.net.au

*Our greatest glory is not in never failing,
but in rising up every "time we fail."
- Ralph Waldo Emerson -*

ANNUAL SUBSCRIPTION / DONATIONS

Financial year from 1 January 2013 to 31 December 2013

NAME:

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

DONATIONS \$

TOTAL \$ - please do not send cash

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☐ 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:

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:

With thanks to Smartprint for printing, labelling of our Newsletter and also to the Sitemanager
for the generous donation and management of the GBS NSW website