NEWSLETTER OF THE GBS ASSOCIATION OF NSW

June, 2013

Volume 2; Issue 23

RECOVERY

Special Interest Articles:

- Lata Mistry story
- No Laughing Matter review

Individual Highlights:

Meeting dates for 2013

Saturday

- August 31, 2013
- October 26, 2013

Hello Dear Members,

I think we have a wonderful read in store for you this edition and love it when we can bring you personal stories from people to share their experiences. Please read about Lata Mistry on page 3. What a challenge the beautiful young lady was set. Did she succumb? Did she crumble? No, she faced each hurdle head on and is now determined to make the most of her talents and get on with it. Congratulations Lata, you are an impressive and inspiring woman.

AGM Update

Our **Annual General Meeting** was held on Saturday 25th May and we had a very full agenda with a broad range of topics generating interesting discussion. The Committee has been selected and we welcome new recruits Max Humphreys and Attila de Szoeke into the fold. These two gentlemen have been regular faces at our meetings for quite a while now and it is great to have the perspective and contributions of a recovering patient and of a patient partner / carer.

I would like to extend a personal thanks to all the team for their efforts this past year. Each of us has a role and each dedicates their precious time to serving the Organisation. As I heard one Committee member say today, "it is a privilege to help people in their time of need". How true it is and how proud I am to be working with such selfless people.

On a sad note I can not end this editorial without sending our love and best wishes to Ed and Shirley Cooke who have not been in good health of late. Our thoughts are with you both and as part of the team and of our family, get well soon xxoo.

Christine S-M

From the Chair

Welcome to first time readers and particularly to those with GBS/CIDP/MMN and related disorders who aren't travelling so well at the moment. The road to recovery is often fraught with peaks and troughs but, being a member of the GBS Association can help smooth some of them out. I know, I've been there and it does help, a lot.

As some of you are aware I have been battling Ulcerative Colitis for some time and was hospitalised in December with a serious gut infection that not only set off my Colitis but also my CIDP, that had been relatively stable, re-emerged. Whilst I was recovering from this my Colitis flared again but I am now once again on the road to recovery. However, I am taking it much slower this time in order not to stress my fragile systems too much and hopefully ensure a slow but sustained recovery.

Whilst I was in hospital I was put on IVIG once again and attend Westmead Hospital for monthly infusions. For those that don't know the infusions mean you sit in a chair for a few hours while Intragam/Octagam slowly feeds into your body with doses based upon your weight. For some the impact is tangible and they are able to mobilise better etc. and for others the results are more subtle or even no

From the Chair (cont'd)

"It is unfortunate I have acquired CIDP but I am fortunate to live in Australia, fortunate to have access to a first world health system, fortunate to have access to IVIG and fortunate support groups like the GBS Association exist"

discernible change is noted. As we have learnt no two sufferers present the same and no two sufferers respond the same to treatments. There is much to ponder about GBS/CIDP and sitting there getting infusions with other CIDP sufferers and persons with other conditions I often think about the huge cost.

Did you know each IVIG infusions costs about $5,000 and you get 5 initial doses, so the start up cost is about $25,000 and then $5,000 each dose that could be as often as each fortnight for some. The dosage is based upon the weight of the patient. Further, it takes roughly 1,000 blood plasma donations to make 1 dose of IVIG. Currently, Australia does not have enough plasma donated locally to keep up with demand and has to import about 25% of the IVIG, the rest is made by CSL in Victoria. In 2010 IVIG cost the government $160 million or 20% of spending on blood and blood products. More surprisingly is that this accounted for 380 tonnes of donated plasma in 2009.

These figures are staggering and growing each year as IVIG is being trialled on many other conditions. I suppose to those who have never been impacted by CIDP it sounds like a lot of money, especially since CIDP is rarely fatal. It improves quality of life rather than it being a life saving treatment.

However, using my own experience, I was in hospital and both my legs and one arm were virtually useless and I couldn't do anything without assistance. Whilst my stay was complex involving a serious gut infection and Ulcerative Colitis as well, it is likely my stay may have been further extended if not for the IVIG infusions helping me to eventually mobilise with diminishing assistance. I am now living independently, working full time and once again contributing to society. Inversely, without IVIG I may have been a greater burden on the health system requiring perhaps a wheelchair and other aids and more intensive physiotherapy for an extended period of time.

Sure, IVIG costs a lot in anyone's language but what price do you place on quality of life improvements. The very existence of the GBS Association of NSW and other similar support groups worldwide indicates there are many who believe improving the quality of life of sufferers, both the physical and mental aspects, is vitally important. These members know, from first hand experience, the value of being able to walk or use a wheelchair when you were previously bedridden for months, to toilet yourself, to brush your teeth by yourself or get dressed without help. Healthy individuals living without disability often take such tasks for granted, I know I did before I acquired CIDP and UC because I rarely thought of it unless I came across someone in a wheelchair or with a guide dog and momentarily thought how horrible it would be not to be able to walk or see etc. I now have some idea, it is horrible but I am very fortunate compared to many.

There has been a lot about the NDIS in the press lately and the fact the government is considering a levy to pay for the scheme. This is not a new approach and the Productivity Commission put this forward as an egalitarian funding proposal simply because no one knows when they might acquire a serious disability and need to access the scheme.

It is unfortunate I have acquired CIDP but I am fortunate to live in Australia, fortunate to have access to a first world health system, fortunate to have access to IVIG and fortunate support groups like the GBS Association exist.

When people ask why I am the Chair it is because I can and I can because I am fortunate to have received the benefits of many thousands of blood donations both in Australia and worldwide, and as Chair I can give something back, not in kind, because I cannot now donate blood.

A blood donation takes about 15 mins and a blood plasma donation about 1 hour. That commitment by those donors can make a life time of difference to the eventual recipients and it is a renewable resource. Not everyone can Chair a support group, and not everyone can donate blood. However, there are many who can donate. If someone asks you what to give as a gift say donate blood, it is the gift of life and for CIDP sufferers may significantly improve the quality of their life.

Until next time. Kind Regards

Mark

My name is Lata Mistry, I am 20 years old, from London and I am a post-sufferer of Guillain Barre Syndrome. I was diagnosed with the syndrome in September 2005 when I was 13 years old. My case was quite severe and I was lucky to recover at all. Although I was clinically discharged from outpatient care in 2007, the following 5 years were an emotional and physical battle to try and find that 'normal' again. It was only until last year did I feel comfortable in saying 'yes I am fully recovered' and I can admit that this year of 2013 I truly feel proud of what I have achieved and how far I have come. I was told that how you deal with trauma in life is a reflection of how you were brought up. I've always been complimented on my calm, mature approach to GBS and I can say that is due to my strong support group built of family and friends. I count myself very lucky to have these people in my life and understand that not everyone is as fortunate as I am, so by joining the GBS society in New South Wales I hope to share my experience with current sufferers and provide hope and support to those whole are still recovering even though the physical symptoms have gone.

Since 2007, I finished school went to university to study Biomedical Sciences, in my second year got an internship at the Brain and Mind Research Institute which is what brought me to Australia for a year. I dived into physical fitness after all those years of physiotherapy, but I never had the confidence to pursue anything until coming to Australia. I've really love the active lifestyle I have here and being away from the home environment has liberated me to do what I want to do without being influenced by other people's judgements. GBS is a life-changing experience and afterwards your perspective of normal is altered. Having experienced GBS at such a young age I can say this really had a large impact on me and I often felt alienated and alone. I grew up very quickly and coming to terms with my own thought patterns was frustrating, 'why couldn't I be like everyone else?'. I had to learn that I wasn't like anyone else my age and for a while I learnt to be comfortable alone. Over the years this did change and I explained my illness to my friends so they could understand me instead of shutting them out. I've learnt not to hide my illness as I have done enough for it not to be the only thing to define me. I have now accepted it is a part of who I am and have learnt to see it as a strength and not a disability.

Archives of Disease in Childhood 2007;**92**:462-463; doi:10.1136/adc.2006.111369.

BACKCHAT - Experiencing Guillain Barré: a mother and daughter perspective

Taruna **Mistry**, *her daughter*
Syndication Editor, BMJ Publications; h.marcovitch@btinternet.com

One morning last summer, I first felt slight pins and needles in the palms of my hands and the soles of my feet, I didn't take much notice, then when I bent over to tie my shoe laces my back ached and I felt like I couldn't get back up. The next day I felt like I was walking through water, I found it hard going up and down stairs, I felt lethargic and I was really thirsty; my mum said that it could be growing pains.

A week later, I went to Accident and Emergency (A&E) where they said it could be Guillain Barré syndrome (GBS). I was sent up to a children's ward and two doctors explained what GBS was and said that it could get worse but I will recover – I didn't really realise how bad I could get and just thought I'd be out by the end of the week. They decided to give me immunoglobulin to slow the virus and to stop it from spreading. I had one hour observations for the rest of that day including at night which was annoying, so I didn't sleep much but I was really restless anyway. The next day I got worse. My face muscles went slack and it felt like my face was drooping, even my eye lids were weak, they felt really heavy and I couldn't close them properly; my lips were slightly swollen and I couldn't close those properly either and so found it hard to eat. o get off my bed I had to slide my legs off one at a time mainly using my hands to lift them, I had to use my mum to get up and then found that I couldn't walk so I had to use a wheelchair. I had another dose of immunoglobulin ten days later.

By then I don't think I could use my legs at all and my arms were getting weaker; my peak flow had dropped from 250 to 150. During this time I just wanted my mum to deal with the doctors and all the questions asked of me, I just wanted to go through it and be done with it. At times, mainly at night, I was in pain and it felt like I just needed to stretch all the time. It wore me out because I couldn't sleep and I was always very thirsty. After a while this would upset me, I felt more angry then upset, I wanted the doctors to tell me what to do, how to make everything better, just to make it pass quickly. Every time I needed the loo or anything I had to call the nurse and if it was a new nurse I had to tell them how they were to help me – I found it so tedious when they couldn't do it correctly.

I looked forward to visitors because I was not alone, and they were someone new to talk to about something different and not about me. Sometimes I found the visitors annoying when they would either just sit there in silence not saying anything but occasionally glance at my legs as if they were trying to see the virus in me, or when they would constantly ask me questions. It annoyed me because I had the same-ish questions from the doctors everyday and my answers were always the same. The slightest thing, like having a bad visitor or nurse, could decide whether I had a good or a bad day.

Another thing that didn't help was the nutritional value of spaghetti hoops, as that was the only thing that tasted ok and that I could eat from the menu. The food was disgusting, even the doctors and the lunch ladies admitted that it was gross! I had practically memorised the menu off by heart as it was the same every week. My mum had to go out

everyday to either buy food, make it or tell my dad to attempt something. I was very disappointed because for my illness nutrition was very important. It was the only medicine. How were any of the children in the ward supposed to recover successfully if they didn't have any real food?

The first time I went out of the hospital was probably around the end of the 2nd month. I was in a wheelchair and my physio decided to take me out to show mum how to control the chair (up and down kerbs, etc). We had a bit of difficulty at the beginning because the kerb outside the hospital is steep and there was no way of crossing the road unless you tilt the chair (of course with me in it) at a 45 degree angle down the kerb, turn me around, cross the road then turn me around again and tilt me forwards (this was when I thought I was about to fall out or fall forward which I had done before and it was the most terrifying experience that I had ever had) to get back onto the pavement. Being just outside the hospital was OK because there were other disabled people too sometimes, but as we moved further along the road more people could see me.

Everything was different because I could only look at things at my eye level which was a lot lower because I was sitting down. This also meant that if people were to look at me they would have to look down to see me or just not look at all. Sometimes I would see people I knew but it would be different, they would crouch down to talk to me or if they were talking to my mum I felt uncomfortable because I couldn't see them, I didn't know what was going on. I also felt odd because you can't see who is pushing you so it feels like you're alone. Because the chair was obviously a lot wider than me standing up, people moved out of the way more, and seemed to be further away from me. When we got back to hospital and my physio had left I started crying. I thought going outside would be nice, but I hated it. I felt like I was living in someone else's body. I didn't want to go out again anytime soon –I was too scared. I soon got used to it, but I didn't need to because I was on the path of recovery and soon I was using a walker when I went home and was able to transfer in and out of a car, and then crutches later.

Now I can walk unaided with just a few minor problems which will go in time.

PARENT/CARER'S VIEW ... Lata's mother

As a parent, my first feeling was just like my daughter's: we would get to the hospital, get some medication and go home to rest and recover.

When they started taking extra blood samples for more tests and saying that we needed to be admitted immediately, fear began to settle in. We had never heard of GBS or what such an illness entails. Though I had a thousand questions to ask, my immediate thought and request was for the doctors to assess her and treat her. Every moment we waited she got worse. They said the illness could take several different paths and this would dictate the intensity and severity of it.

How long it took to peak and then stop would then also have an effect on her and on recovery.

To watch a very active teenager loose mobility so quickly was horrific. Despite being very close to my daughter, I have little understanding of the sheer terror and fright she must have felt. I feel ashamed that I could not relate to her feelings and could only comfort her with words and hugs, but soon we could not even hug and my words were not sounding strong. At this point the doctors told me that I had to project a very positive image and keep her calm and optimistic.

Now, a year in I can say that they were right, this illness does pass, though it seems unbelievable when it first happens. My anxiety was there, I needed solid proof, but who can do that but the one above? I made demands on the medical staff for reassurances and more facts. I felt that things would feel better the more I knew. However, not all facts are easy to digest, so all I can say is that a good support team is essential.

As much as the doctors comforted and reassured us, they also had other patients to see. As this is a rare illness, we were very lucky that one of the nurses had dealt with such a case before, and continual advice from her was priceless. She helped us to pass the day; she was able to advise me how to help with all the basics like changing clothes, toileting and eating. Our time of greatest trauma and need was when we came in to A&E. It is particularly important that the diagnosis is made correctly and immediate action is taken with a care team set up of experienced staff who are able to deal with the crisis and also be supportive. I have and I continue to thank God for the blessed support team in A&E, who were followed up with an equally excellent team of staff in the ward. I wanted the relevant staff to do what they are experienced to do and at the same time I continually sought reassurance and emotional support. It was a lot of "I want!" and I realise now that I had become my daughter's spokesperson.

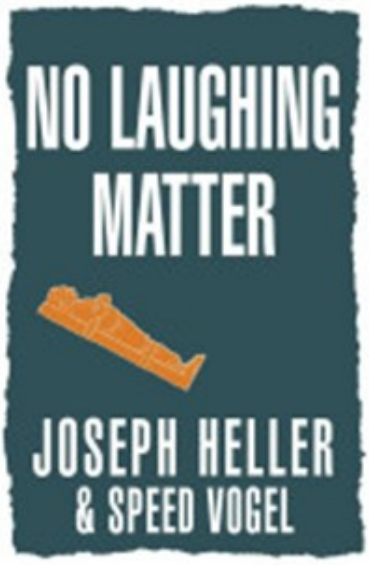
Maybe because she was so young, or so scared, she wanted me to deal with all the daily questions and details. She just wanted to be told what to do and that she would get better. She wanted no more facts about the illness and I now realise that if I told her all the details I had been given, it upset her a lot. At times she was frightened, at times she just cried, at times she was very angry, it seemed endless. I must give praise to her because in public she was always very brave and only got upset in private. Such a young child to be so much in control!

Before we went home, the most important thing for us was that there should be continuity of care. We were to have a community support team but this needed setting up. She was doing so well and so we wanted to continue this at home, but it was a battle with the authorities to set up and maintain all the systems until complete recovery. It should not be like this! Sometimes (or should I be honest and say most of the time) it was lack of funds that hindered any plans and finding ways round this was the hardest thing. It is not fair on the medical professions to battle with red tape when their services are so needed concerning the real issues of their normal working day.

The last stage (I write this one year on) is what I call the aftermath. My daughter is about 90% back to herself, though sometimes she still get aches and pains and fatigue. Now she is physically stronger, the reality of what has happened is taking its toll. She is crying and grieving at the time lost and also angry at why it happened to her. These are healthy emotions of course and we are dealing with them. I had to resort to private finance in the period after coming home as the only way to maintain my daughter's rehabilitation because there was limited support from the NHS due to lack of funds! As already mentioned, continuity is very important at this final stage. It is very sad that despite several attempts from the consultants they could not find a rehabilitation centre that would accept her.

At this stage you wonder where all the contributions you have paid have gone and about the true state of the NHS. We have survived with emotional scars to show, but we hope that future patients can receive all the relevant care and their needs be properly acknowledged.

ACKNOWLEDGEMENTS *- My most sincere thanks to the dedicated team we had, with whose help we are now in this state of reasonable good health. We would like to thank Dr Alistair Sutcliffe for helping us with this submission.*



Member to Member

BOOK REVIEW OF 'NO LAUGHING MATTER' BY JOSEPH HELLER AND SPEED VOGEL

Joseph Heller is most famous for writing 'Catch 22'. While I really enjoyed reading this anti-war novel, my favorite Heller book by far is 'No Laughing Matter'. This book documents Joseph Heller's journey through GBS as only this insightful writer can tell his story. It's funny, yet insightful and touching. The unique feature of this book is that alterative chapters are written by the patient and the carer - so you get both perspectives.

When Heller came down with GBS he had recently separated from his wife of many years and was going through an acrimonious divorce. As he had never done anything in the way of looking after himself in all his years of marriage – he was at a double lose as a GBS patient…..having to look after himself and cope with his diagnosis.

As this was beyond him - enter Speed Vogel, a close male friend, to save the day. Speed became Heller's 'wife' and his link to the outside world. He collected Heller's mail, paid his bills and looked after him generally throughout his journey

In addition to the main storyline, the progress of the disease and Heller's gradual recovery, there are other stories and famous people who come into the book. Mel Brooks, for example, was a close friend of Heller's and part of the all male gourmand eating club where stuffing yourself was the rule and a requirement of membership. Mel Brooks, as it transpires, was also Heller's only friend who was fully au fait with his GBS diagnosis – being a complete hypochondriac.

Heller eventually married his nurse, Valerie, who we meet in the course of the book. When I read the book I wanted to thank either/or both Heller and Vogel for the gift of sharing their journey to which I fully related – but unfortunately both were no longer alive. I did, however, write to Mel Brooks and Valerie Heller. I never received an answer. I hope they received my letter but will never know.

In conclusion, I really recommend this book – regardless of whether or not you've been on this journey.

Jane Rothman - 22/4/13

Wikipedia says -

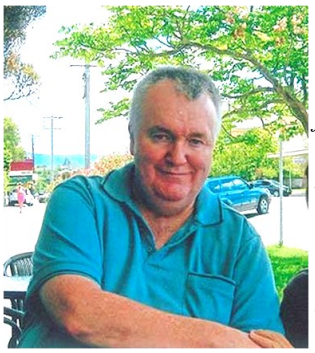
On Sunday, December 13, 1981, Heller was diagnosed with Guillain-Barré syndrome, a debilitating syndrome that was to leave him temporarily paralyzed.[1] He was admitted to the Intensive Care Unit of Mount Sinai Medical Hospital the same day (Heller 1986, pp. 23–34), and remained there, bedridden, until his condition had improved enough to permit his transfer to the Rusk Institute of Rehabilitation Medicine, which occurred on January 26, 1982 (Heller 1986, pp. 170–174).

The book reveals the assistance and companionship Heller received during this period from a laundry list of his prominent friends—Mel Brooks, Mario Puzo, Dustin Hoffman and George Mandel among them.[2]

Heller eventually made a substantial recovery. In 1984, he divorced his wife of 35 years, Shirley, to marry Valerie Humphries, the nurse who had helped him to recover.[2]

Speed Vogel writes of helping Heller, his friend for twenty years, through his rehabilitation. The pair write alternating chapters, which amusingly chronicle Vogel's rise through society as he the stands in for Heller, even traveling to the Cannes Film Festival, while at the same time Heller is becoming more helpless. Although Heller's disease is debilitating, the book is full of humor and never self-pitying. Heller's only lament is letting an insurance policy lapse, resulting in his out-of-pocket expenses of $120,000 in medical costs.

Author(s)	Joseph Heller & Speed Vogel
Country	USA
Language	English
Genre(s)	Autobiography
Publisher	G. P. Putnam's Sons
Publication date	1986
Media type	Print (Hardback)
Pages	335 pp (1st edition)
ISBN	978-0-7432-4717-7
OCLC Number	57666812



David Brice:

The present GBS Association and its formation, plays tribute to David who with a handful of other dedicated GBS persons, and the University of Sydney in 1989/1990 determined the vital necessity to form a support group for GBS afflicted persons. Those early beginnings were steered through, with determination by David Brice who was elected President at our very first unofficial meeting. It was David who subsequently guided the fledgling group through the intricacies of the process of be coming an Incorporated Charity. A handful of those from that early group, Ursula, Shirley, and Mary are still actively involved with the present GBS Committee. We have seen many changes since then but none will deny how many hundreds of GBS and CIDP folk have benefited by those early struggles to get our support group established. On behalf of those unknown countless people I dedicate our sincere respect and grieve the loss of a remarkable man, David Brice

David Brice argued for the national disability insurance scheme and believed it would work.

David Brice was a fighter for the rights of the disabled who understood the basic issues because he was living with a disability. He had Guillain-Barre syndrome, a rare autoimmune condition that causes spreading paralysis.

Brice was unusual in that most people with GBS have only one attack. Brice had five, the first when he was 14. Each meant stays in intensive care, recovery in the ward and major rehabilitation programs. The staff at Prince Henry, Prince of Wales and Concord hospitals were crucial in his treatment and the teams at the Queen Elizabeth II and Royal Ryde rehabilitation units became an important part of his life.

He was a senior advocacy officer for Spinal Cord Injuries Australia (SCIA) from 1980 to 2003 and was its president from 2006 until 2011. He was also president of the Physical Disability Council of NSW (PDCN) in 2002 and 2003.

David John Brice was born in Paddington on February 26, 1950, the second son of Jim Brice and his wife, Myra (nee Barlow). He grew up in Paddington and went to St Francis of Assisi Primary School and Christian Brothers, Bondi Junction. After high school, he joined the public service.

About 1979, Brice moved in to the Australian Quadriplegic Association (now SCIA) operated from Ashton House in Maroubra as one of its early residents. He soon joined AQA's advocacy department. His time in the public service proved to be a great asset in campaigns against government injustice or when writing to ministers and senior bureaucrats about the provision of - or, rather, lack of services for people with physical disabilities.

Brice was involved with campaigns for the introduction and maintenance of the National Attendant Care Scheme, for increased funding to the Home Care Service, for the expansion of the program of Aids for Disabled People, for improvements in the provision of accessible taxis and for many other programs and services.

As president of PDCN, Brice spoke out, at the risk of funds being cut, for the agenda of the Spinal Cord Conference in Sydney to include not only medical issues but also social inclusion issues.

His Legacy:

David Brice argued for the national disability insurance scheme and believed it would work.

The gamble he took paid off, and some weeks later he received thanks from the then premier Bob Carr for helping to reshape the conference agenda.

The letter was delivered to the intensive care unit at Concord Hospital, where Brice was being treated. He smiled when the nurses told him no patient in ICU had ever received official mail like that before.

One of the happiest events in Brice's life was in 1993, when he met Trish Carey at a social function. They were married in 1997, in the Coast Chapel, Prince Henry Hospital - a scenic and accessible venue for all guests.

Brice never let his disability define his life and he never complained.

He loved sports, and had a passion for the NRL's Sydney Roosters and racing. He also went to the cinema every week.

Recent highlights at SCIA for Brice included the Walk On program, launched by the Governor-General, Quentin Bryce, in 2010, and presenting a submission on behalf of SCIA to John Walsh at the Productivity Commission regarding the national disability insurance scheme (NDIS) in 2011. Brice believed such a scheme would become operational, perhaps funded by a Medicare-type levy.

Brice attended last year's rally by the Every Australian Counts Campaign, where the Prime Minister and the Minister for Disability Reform, Jenny Macklin, pledged support for the NDIS.

Brice's last attack of GBS proved fatal, following his fourth tracheotomy. A message of condolence sent by the Governor-General said: "David was a source of courage, support and inspiration to me and to so many people and a truly lovely man. I was always uplifted by my conversations with him - always shining through that generous warm spirit. He leaves a powerful legacy - a life that made a difference."

David Brice is survived by Trish, brother Garry, sister- and brother-in-law Mon and Brian, nephew Matthew, aunt Iris, close friends Cath and Steve and Barlow and Brodie family cousins Douglas, Christine, Ken, Kathleen, Pat, Greg and Loretta.

Mon Bright and Trish Brice

Read more: http://www.smh.com.au/national/obituaries/advocate-improved-lives-20130117-2cw0b.html#ixzz2S0rxcizl

Bits n Pieces

GBS Association of NSW

A NON-PROFIT VOLUNTEER ORGANISATION

Registered Charity No. CWD295

Incorporation No. Y13693-18

COMMITTEE

PATRON: URSULA CARLILE

CHAIRMAN: Mark Kunach

DEPUTY CHAIR:

Attila de Szoeke

TREASURER & PUBLIC OFFICER:

Christine Simpson-Morgan

SECRETARY:

Glenda Ford

MINUTE SECRETARY:

Ronald Nichols

GENERAL

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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 10.00 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:

⇒ August 31st 2013
⇒ 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

"Just know, when you truly want success, you'll never give up on it. No matter how bad the situation may get." - Unknown

ANNUAL SUBSCRIPTION / DONATIONS

Financial year from 1 January 2013 to 31 December 2013

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: .....

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