

March, 2012
Volume 2; Issue 19

RECOVERY



Special Interest

Articles:

• Mike
Patterson
story
continues

Individual

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From the Editor

Hello everyone, I am really happy to be bringing you another edition of your GBS newsletter and as always hope you find it a good read.

This issue is what I would call a very 'personalised' edition

That is, all of our features have been written especially for you by members or Committee and I hope that makes you feel very special, because you are!!

Without your support in what we do, interest about what is going on in the GBS/CIDP community, and curiosity about research in the medical field, I wouldn't be here preparing this Newsletter.

So from me, THANK YOU !

And thank you to all those who contributed to the March 2012 Recovery, great job!

Christine S-M

From the Chair

Welcome to our first newsletter for 2012. Firstly, our thoughts go out to all those in areas impacted by flooding and especially those living with disability.

I hope everyone had a healthy and restful Christmas/New Year's break. Unfortunately, my Ulcerative Colitis continued to cause some concern and limited my activities. However, I have been able to increase my dosage of Imuran (immunosuppressant) without too many side effects and it would appear to be having a positive impact. Fortnightly blood tests are required to detect any problems. Thankfully, I am once again on the road to recovery.

Due to my ongoing battle with UC I haven't been as active as I would like to be but I have been able to maintain a few contacts and keep up with some developments. A/Prof Reddel (Concord Hospital) has advised he is on the international committee for inflammatory neuropathies. They will be launching IGOS which is a global

outcomes study of GBS being co-ordinated from the Netherlands and hopefully this will be running by year's end. Further, he also advised they need to do a mouse study followed by a human study of Eculizumab which should reduce the damage that occurs in the early attack phase of GBS first in EAN (mouse GBS) then in human GBS but this is financially impossible at present. A yearly dose of Eculizumab reportedly costs over \$400,000. Perhaps I should have considered going into pharmacology when I left school!

It is great to hear there is major international research study into GBS. Hopefully, the Association may be able to contribute in some small way once the study is up and running.

In this regard, I would like to ask the members where they would like to see their Association focus our efforts. Administration of the Association is covered first as the priority and as the platform allowing us to reach out to

From the Chair (cont'd)

*Note: next meeting will be in the "Hawks Room" lower ground level of the Ryde Eastwood Leagues Club — West Ryde.



"As Chair I am both humbled and rewarded knowing people such as these and others make the effort to attend a meeting run by me"

raise awareness and/or foster research etc. Our Recovery newsletter continues to shine and I encourage members, family, friends and medical professionals to share their particular GBS/CIDP story with us either as an article in Recovery or in person at one of our meetings. Each story is important at many levels and adds to our collective awareness of how GBS/CIDP impacts individuals and the relationships around them.

With regard to meetings we are now in the *Rutledge Room at the Ryde Eastwood Leagues Club. The club is situated in Ryedale Road, not far from Victoria Road and the West Ryde railway station, offering convenience for those using public transport. Plus, there is undercover parking and lift access. The room itself is air conditioned and there are all the services you would expect from a large club including a very nice coffee lounge for a nice cuppa, cake and a chat after the meeting. Our next meeting is on Saturday 26 May 2012 and it would be great to see more new and old faces attend.

In this regard, Toni Louttit has twice travelled from Cootamundra to attend our meetings a round trip of over 800 kilometres by train and tell her story and give a demonstration of some very useful aids she uses to help with her GBS. Now that is commitment!!! In fact Shirley Cooke who has been a sufferer since the early 1960's was so impressed with a foot drop aid she gave it a field test around the room. Well, for those who don't know Shirley, she is a mature lady and not normally 'spritely' but when she put on these foot drop aids she took off around the room like she was headed for the London Olympics. You should have seen the look on Ed's face (Shirley's husband) not to mention the huge smile on Shirley's face. We had to keep telling her to slow down. A Kodak moment if there ever was one.

It is information sharing such as this at meetings that helps to collectively improve the quality of life of GBS/CIDP sufferers. Toni is relatively new to GBS but Shirley is a veteran, yet thanks to Toni's commitment Shirley and perhaps many more sufferers may benefit from some improved mobility, more confidence when walking around and thus a better quality of life.

We hope to bring you more information about these aids at future meetings and in later editions of Recovery.

Also, speaking of commitment, Max Trachsler, a long term member, was present at the meeting. Max is vision impaired and when asked how he got to the meeting he matter of factly said he got the train. At that time everyone at the meeting looked at Max in amazement. Now I know speaking with both Max and Toni they would both disregard their attendance at the meeting as anything 'special' but, I am relatively able bodied and can easily get into my car and be at the meeting in 20-30 minutes. Either Toni or Max could have sat at home and said it's too far or too hard but they didn't.

As Chair I am both humbled and rewarded knowing people such as these and others make the effort to attend a meeting run by me. I know many have conflicting commitments, ill health and other activities that might preclude their attendance at meetings. I am often quoted as saying 'family first'.

However, the strength of the Association lies with the commitment of members. Mary and Jane field many inquiries from GBS first timers. A specialist has told them they have GBS and they are left with a vacuum of information. The news has dropped the bottom out of their world and where do they go for information. All too often they Google GBS and get our website. We can help put the bottom back by offering them information and support, to speak with people who have been there and where we can help them on the road to recovery. All these ongoing services flow and grow from a committed membership.

I also would like to revamp our website. Whilst Recovery tends to support our existing membership with information, our website is often the first port of call for GBS/CIDP first timers seeking information so it needs to be user friendly, relevant and up to date.

Any feedback about what features you would like to see on the website are greatly appreciated.

Kind Regards
Mark.

Allow us to introduce the Association's warm, kind, intelligent gentleman, Ronald Nichols, our Minute Secretary.

Committee Profile Page



What is your role on the Committee and what does it entail?

Minute Secretary. Taking and writing up the Minutes for Committee meetings and distributing notices of forthcoming meetings.

Can you briefly share your experience with GBS or CIDP?

How could I ever forget it! It was 3 March 2001 when the pins and needles first appeared in each hand followed by intense pain across my back and thighs. Lying down or walking around did not help. Three visits to Emergency at RPAH before a Neurologist was called who quickly diagnosed suspected GBS and admitted me to High Dependency. Lumbar Puncture confirmed the condition. I was bed bound - could not stand nor walk, there was numbness in various parts of my body. Intragam was administered several times and Morphine to relieve the pain. I lost 15 kilos of muscle tone in three weeks - muscular atrophy they call it. Three weeks were spent in that hospital, then four months in a rehabilitation hospital and nearly a year confined to a wheel chair where I learned to teach my legs to walk and generally recover.

What was the toughest challenge you faced during your recovery and how did you overcome it?

It was the fear that I would not be able to walk again and the floods of tears. I recall writing in my diary (very badly I might say) "I cannot imagine how I will ever walk again" But with intense physio and occupational therapy, slowly but surely the strength and a will to beat this became a reality, not just a dream. I remember one day in the hospital with three therapists close by, I took my first ten steps. A miracle in my book!

Has your GBS/CIDP experience changed your life in any way?

I have said many times how I love to observe people walking and running, particularly down stairs - extraordinary!

What inspires you each day?

The will to live and to share this optimism with others who may be worse off than I am.

Do you have anything else you would like to share?

It is a privilege to be part of the GBS Association in its cause to be there for folk who come down with this mysterious condition.

Mike continues his story from our previous editions of Recovery and we print the last chapter he has filed with us

Member to Member - Mike Patterson

Recovery Update 27 Feb 2011



"I've certainly been improving my work performance and am mentally as sharp as I've been for a very long time."

Its coming up to the 3 year anniversary of my admission to hospital with GBS and its proving to be a strangely emotional period of anticipation. This sense of strangeness was triggered last week by a remark from a co-worker who shares my birthday of January 22. She is much younger. She observed that I was, "a very different man", comparing the before and after me. I suppose you'd hope I'd have to be; that going through the whole business would not have left me untouched, untransformed in some ways. So the remark has provoked a period of intense reflection. I am not going to engage in much of that reflection here. This is more mundane stuff.

Some very good things have been happening, and two things have had powerful affects upon me.

The first is, I am have driving more and more. The car is bliss to drive [2002 BMW 320i] and as I have driven more that old sense of ease of driving and pleasure in doing so has been coming back. For a time I was worried that the sheer effort in driving would remain and the pleasure would not come back. I spent weeks behind the wheel in a hyper-vigilant state feeling discomfort in ways that were very unfamiliar to me. My spatial sense was fragile so I tended to hug the left side of the road. My confidence in my feel of the car was weak, and I was tense and anxious. But last week on a flex day I went off for a solo drive and just paid attention to driving. I headed off down to Wallerawang, about 50 kms away. It was a destination I was familiar with in a previous role. There is a licensed boarding house there and I'd not been near the place in over 4 years. I went to visit. By the time I got home I'd crossed a watershed and I was now on the pleasurable driving side. I'm almost ready to drive work cars in city traffic.

The other good news is that I've changed my job. I was offered an opportunity to become a special projects/trouble shooter working directly to my senior management. I am still carrying some responsibility for emergency response stuff, and will continue to do so until the end of March. As a result life gets slightly frantic at times. But I am having a ball, so much so that most days I am reluctant to go home. This is a huge change. Twelve months ago I was dragging myself through each day and hanging out for the chance to work at home two days a week. Now I am building up flex time and full of energy. True, some weekends I just veg out and get my energy back.

I had a supervision sense with my senior manager last week and he sounded out my interest in an acting manager role. I had to pause a moment and wonder whether its time in my recovery cycle to take on the additional challenge. I think it is, in the sense that if I don't give it a good go I'll not know. Besides I feel mentally and emotionally up to the challenge. I've been a bit of a gold-haired boy lately and I'm enjoying the praise. I've certainly been improving my work performance and I am certainly mentally as sharp as I've been a very long time. But the other thing is that we've had some very good changes at the level of senior and executive management, and these two things have come together to my advantage.

The job change over has disrupted my gym routine and I've been okay about that during the hot days. Between the heat and work pressure I've not been keen to head off the gym at the end of the day. That's about to change as the weather becomes more respectable.

Mike's story continues

I have finally stopped researching, at least so far as the book is concerned. At present I need to overcome the mindset that has prevailed and move to actually pulling it all together. There's an odd sense of modesty that creeps in and I have to consciously remind myself that I really am an expert.



On the physical side there is continuing incremental improvement across the board. Its slow but folk who don't see me for awhile remark on the improvement. I've been chalking up a few nice 'firsts' – walking with hot drink in one hand and plate of food in the other and sitting down in the lounge without spilling anything, standing up with glass of wine and walking, driving up the street to buy bottle of wine [my first casual instance of nipping up the street to buy something], adjusting clothing and dressing whilst standing without supports [involves a lot of movement but I neither fall over nor lean]. At work I carry my own coffee to my desk. The mug gets hot and I do risk dropping it before putting it down and giving my poor fingers a break. My down trip by train from Katoomba to Parramatta or to Central is entirely unaided.

Now I can drive I take myself off in the early mornings on the weekends to take some photos and/or go to a café. I've even put petrol in the car all by myself. I am at the stage where I can drive up the road to the supermarket and do some serious shopping, but other than buying some toothbrushes I've not done that yet.

All in all life is going quite nicely. I am reading when I get the chance and have about half a dozen books I need to finish off. My time on the train and walking to and from the office is devoted to pod-casts – politics, philosophy and current affairs mostly. I really want a few more days a week and a few more hours a day. Most days I am lucky to be asleep by 10.30 and I'm up at 4.30. I sleep or doze for an hour on the train. I get to Parramatta by about 7.05 and usually get a half hour in my café over a coffee and some food and start work at 8.00. Usually I'm back in town by 6.30 but often 7.00. It can be a punishing routine for me at the moment.

On the weekends I like to get a day just to veg and catch up on some telly watching, as there is no real time during the week. Mercifully there's mostly rubbish on so there's not a lot to catch up on.

So that's how things are going at the moment. The next six weeks are going to be interesting. I'll be booking the 13th out and I plan to visit the local hospital to pay my respects to the staff. I am also planning to write something quite strong on the fact the same hospital actually held a meeting and freaked my family out with the proposal that I be deposited in a nursing home. That was in July 2008 after I came out of ICU and transferred to rehab in Katoomba. I was lucky Emma had the fierce determination to put paid to that idea. I want to remind those who were tempted to do that just how utterly wrong they were to even contemplate such a thing.

I will not write in anger or scorn but form the clear sighted knowledge of what I have achieved, and the idea that they thought to consign me to the waste bin before I got really going scares me for those who may not have had an Emma there to speak and act on their behalf.

My best wishes for your well being.

Michael

Phoning a Friend

When Christine our Editor of Recovery suggested a new item for our GBSCIDP newsletter called *Phoning a Friend* to share the general nature of the telephone calls and the questions we receive, I wondered if it would breach any privacy obligations. I think not, and it provides the opportunity to share similar circumstances which you too maybe facing.

The suggestion made me think about the role we each play as being part of the GBS/CIDP family. My own role as a "Friend", being at the end of a GBS/CIDP telephone line, was not one that I had previously viewed myself as being in those terms exactly. The idea provided me with the thought; -- "well yes, I hope I am". However, more importantly, I do hope the callers to the Association should also feel they do have a "friend" at the end of our telephone line. Someone who has the time, the understanding and the knowledge and possibly some insight into their concerns, no matter how troubling they may seem to be to the caller at the time..

Not all telephone calls are from new patients, over the period of a month there are usually about ten or twelve calls and perhaps as many emails. No two calls will be exactly alike in their content. During the last months one particular call raised the fortunate position we enjoy in Australia with the availability of hospitals and access to suitable treatments for both GBS & CIDP.

The situation arose of a family member presently living in Australia with a niece living in Indonesia who had contracted GBS. That hospital was not able to provide either plasmapheresis or any IVIG treatment to this patient, although it was necessary.

The family member was hoping to purchase IVIG in Australia and export it to his niece's doctors to administer to her. Resulting enquiries by our Association to Red Cross and CSL found that the Australian product, Intragam (IVIG) could not be purchased or in any way exported out of Australia although some IVIG products which originate from overseas can be purchased and exported.

The realisation of how fortunate we are to live in Australia, was just overwhelming. Still another question rose from a caller in Cootamundra, who has had GBS 14 or 15 months about pain management? Is it usual for pain to be still managed at this stage of her recovery? Also do others have a "tremour"? Would other GBS people call or write and comment about this?



And then there was David Bailey who lives in SA, and I give his name because he wishes other GBS people to write to him. (*his address is available for those who would care to write to David*). His own recovery over 9 years has been hard won, and his journey is still his personal challenge..

Although all calls are of an individual nature one challenging question occurs fairly frequently from the families of GBS patients who may have a slow or limited recovery and the pressure by Hospitals to discharge such patients to Nursing Homes instead of suitable Rehab. Centres.

Obviously this situation is not ideal for still recovering patients. Our present rehabilitation centres are hard pressed to accommodate the needs of all who require their help. Many patients prefer to go home and seek the help of ancillary services and their immediate family's care than enter the Nursing Home alternative.

These are but a handful of those who have called GBS/CIDP NSW, we hope you find this addition to Recovery of some interest....from your GBS Telephone Friend...March 2012

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

the Annual General Meeting of the GBS Association of NSW Inc

26th May 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 this 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

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

Email: smorgan8@bigpond.net.au

Men do less than they ought, unless they do all that they can

Thomas Carlyle

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

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)

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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:

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