



Message from the Chair

Welcome to our Spring edition of Recovery. What wonderful weather we have been having of late which helps to defrost fingers and toes that never seem to fully thaw during the winter months.

I am fortunate where I live to look out over Parramatta Park toward the east and experience beautiful golden sunrises over the CBD skyline most mornings. These sunrises always

remind me of our logo; the light emerging out of the darkness. This coupled with the knowledge we have committed committee members ensuring the GBS Association is there to support those impacted by GBS/CIDP and related disorders encompasses the symbolism that is our logo.

However, we are much more than a logo. You may be aware we have raised concerns at both the State and Federal levels about the treatment of person/s over 65 suffering from GBS/CIDP and the length and extent of treatment they may or not receive. In particular, we know from experience, that there is a much better chance of long term positive outcomes for patients at any age, let alone those over 65, if they obtain the correct diagnosis, receive the appropriate medications/treatments and very importantly sufficient intensive Occupational Therapy to allow them to eventually go home rather than be sent to an aged care facility where they are most unlikely to receive the intensive OT necessary for recovery.

We have been reassured in writing there is no policy to cut off those over 65 suffering from GBS/CIDP from the necessary treatments that are more likely to see them go home and not to an aged care facility. Further, the response from Canberra indicates there may be provision within the emerging NDIS for some sufferers of GBS/CIDP and there is a facility called the 'My Access Checker' within the NDIS website, that can provide an indication whether you are able to access resources under the NDIS. I would encourage sufferers who believe they may fit the criteria for support from the NDIS to access the 'My Access Checker' and to please provide the Association with feedback about your experience using this service and dealing with the NDIS overall. The NDIS is slowly evolving and developing. As such it is vitally important the services are driven by those living with disability and not just accountants. Your feedback is crucial to making the NDIS a success.

I am advised there is a push from government to change the composition of the current NDIS board effectively reducing the number those either with a disability or close connection to those living with disability to those reportedly with greater business acumen. Interestingly the NDIS is operating well within budgetary guidelines and a cynical person may reflect there may already be attempts to rein in the scope of the NDIS, contrary to the findings of the Productivity Committee's investigation that led to the inception of the NDIS.

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Next Meeting: 7th November 2015
'Susan Schardt Conference Room' L1
Royal Rehabilitation Centre Sydney
235 Morrison Road, Ryde

9:30 - 11:00 Committee Business and Administration
11:00 - 12:30 Open Forum for members and family / guest speaker
Visitors are welcome to both sessions or the Open Forum only if preferred



website: www.gbs-cidp-nsw.org.au
email: info@gbs-cidp-nsw.org.au

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For decades those living with disability, their carers, family and friends have fought for a better model of treatment from the health systems within this great country to enable those living with disability the same opportunities and aspirations that 'normal' Australians often take for granted. The GBS Association was formed many years ago for the same reasons. The NDIS has been designed to help create a more equal playing field for those living with disability but it is not a done deal and there are many years to come to get it right or at least a much better system than that which saw many living with disability closeted away focussing on the disability but never looking at the potential ability that lies within us all if only provided with the opportunity to shine.

The GBS Association continues to grow and evolve just like the NDIS; and to explore new avenues where we can support, influence and advocate for better models of treatment for those impacted by GBS/CIDP. I am sure the work of the GBS Association is now well known to the NSW Minister for Health and no doubt when she or her staff see correspondence from the GBS Association and/or with my name on it, it will receive due recognition.

Looking forward to meeting both new and old visitors and members at our next meeting.

Kindest Regards

Mark.

My Story - Ken Brooke

Where do I begin? It was Saturday March 1st 2008. I was not so unlike many men my age (having recently turned 55), working long hours, eating poorly and drinking too much. So when I woke up that morning with blurred vision and a weakness in my arms I wasn't too distressed. The alarm bells began when I got into the shower and had difficulty raising my arms to wash my hair.

A trip to a local doctor (not my usual GP) and I was diagnosed with having suffered a TIA (a mini or warning of a stroke) and was told to go home and rest for the weekend and if no better on Monday to have a brain scan. Saturday afternoon I had trouble walking when I presented to Nepean ED, at the insistence of my wife and son, and by about 7 pm was diagnosed as having developed Guillain Barre Syndrome (GBS). I'd never heard of it.



*State of the Art communication
device 2008 ICU style.*

So after having CT Scan and an MRI by midnight I was in ICU. In the early hours of the morning I had a spinal tap but the needle didn't go where it was supposed to, so it was tried again and again. The next night, apart from the big toe on my right foot, I was completely paralysed and intubated. Because I had movement in my big toe a speech therapist set up a communication device (pictured left), consisting of a toy bear drummer that also blew a whistle. This allowed me to gain a nurse's attention. Unfortunately, in the early days at least, once the nurse arrived I couldn't indicate my needs.

I spent 241 days in ICU, 14 days in a ward and a further 116 days in rehab as an inpatient, followed by more than 4 and a half years as a rehab outpatient.

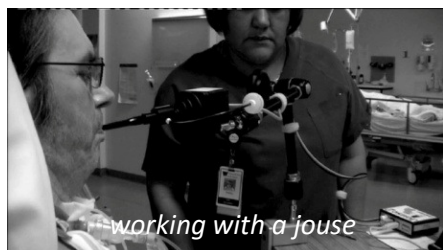
In ICU I had many good days and nearly as many bad. The worst thing was not being able to move or communicate, I wasn't brain dead...just my body wouldn't (couldn't) react or do what I wanted it to. In fact my body didn't respond to my wishes, or others, at all. So frustrating.

During this time I was hallucinating and having really bad dreams as a result of the cocktail of drugs I was receiving at the time. Added to that I couldn't completely close my eyes, so they were taped shut (pictured right) to prevent damage keeping me in perpetual darkness. This combination was really scary. Fortunately this stopped after a time.

A major part of my treatment in the early days was the use of plasmapheresis. I remember very little of this time, except it seemed to last forever (in fact it was only 2 - 3 hours each time) and feeling very, very cold and uncomfortable.



*Eyes taped shut and drugs -
a scary time.*



Actually everything seemed to last forever and felt uncomfortable, whether it was creating splints for my hands or laying me on my side and I hurt whenever I was touched.

I was always an IT freak, partly due to my occupation. My laptop was brought into ICU, mainly so I could watch dvds my friend had made of all of my favourite footy teams and the goings on of the footy club of which I was President. Eventually, the ICU team decided I needed to get more interactive. So with the purchase of a piece of equipment called a "jouse" by the ICU team, a mouth

controlled mouse, and a very good friend, who set me up with an internet connection and email account, I went live on the internet.

Talking to (or at least being talked to) and being visited by previous sufferers was so important to my recovery. That's a major reason why I am so happy to visit patients, and talk to them if requested. I am also happy to address medical students, as I have done in the past, to pass on my experience as a patient.

Eventually I was weaned off the ventilator, which created a lot of fun for me and the ICU staff. I'm not sure if it was my idea or one of the nurses'. The idea was if I had to do breathing exercises they had to do exercises too. So each day there was a line up of Doctors, Nurses, Physios and ancillary staff doing things like star jumps, burpees and push ups. If I was able to reach the target 10 times they had to do that day's designated exercise 10 times as well.



I owe so much to the ICU Nurses, ICU Doctors, my family, friends and a couple of former GBS patients. One former patient will always live in my heart. She would come and visit almost every 2 weeks and, even though rehab was moved to another location (it was being rebuilt at the hospital) she still visited. I owe her much. I was always being encouraged and told how strong I was. I didn't feel strong.

My next move was to rehab. At first I felt deflated because I still relied on a hoist to get me out of bed, I couldn't walk or even stand up. I remember my first day in the rehab gym watching a little old lady walk up and down, up and down and here I was standing on a tilt table, watching and thinking "I've got nothing".

Once again I received great support from the Rehab team, Doctors, Physios and OTs. The importance of these people should never be underestimated. Just as the ICU team got me to a level, the rehab team lifted me beyond that. ICU kept me alive, Rehab gave me a life.

It was not just hard work but a social activity as well. As a matter of fact I believe the socialising was just as important as the physio and in some cases more so. I loved the rehab work but I could also interact with other patients and I felt "normal".



I have made friends with and visit people who suffer from MS, stroke, amputees and GBS. It has become a major part of my life.

I am so lucky. I'm alive, I have my faculty (some may question that), my family and many friends. I walked my daughter down the aisle at her wedding (that was a very big thing), saw my son get married to an ICU nurse (that too was a very big thing) and have been able to spend time with my recently arrived granddaughter. My wife has played a major role in my recovery and without her I couldn't have got this far. I have also had the opportunity to meet and talk to people about GBS, a subject I think awareness needs to be raised to the general public.

WHAT THE NDIS MEANS TO YOU AND YOUR FAMILY

As the NDIS (National Disability Insurance Scheme) is rolled out over the coming years, many people rightfully ask how will that affect me and/or my family. It is our intention to keep our members up to date with the latest information. The good news is the new Prime Minister, New South Wales and Victoria Premiers have signed off on the NDIS for those states, which means it should roll out starting in July 2016. Updates as they come to hand, so watch this space.

**GBS | CIDP**GUILLAIN BARRE SYNDROME
CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY**THE GBS ASSOCIATION OF NSW INC**

Supporting people with GBS | CIDP and other related disorders

1st June, 2015

The Hon. Jillian Skinner
Minister for Health
GPO Box 5341
SYDNEY NSW 2001

Dear Minister,

Reference: Rehabilitation amongst Patients 65 and Over

We are contacting you as members of the The GBS Association of NSW (Inc). Guillain Barre Syndrome and Chronic Inflammatory Demyelinating Polyneuropathy are both conditions that often initially leave sufferers severely disabled. The disease, when it strikes (and this can happen at any age) not only affects the sufferer. It also affects their family and loved ones.

Many of our members had become totally paralysed with days of the onset of the disease, and fortunately most are now fully functioning and productive members of society. This recovery was not an accident or due to 'good luck'. It happened as a result of hard work, usually over many months, on the part of the affected individuals, their families and their rehabilitation team of physiotherapists, occupational therapists, and speech therapists, etc. This recovery was not only a significant benefit to the patients and their families. It also had major benefits for the wider community and delivered cost-effective solutions to government – reducing the need for further economic support of these individuals.

It is within this context that our members are deeply troubled and concerned to learn that it is now government policy that afflicted persons such as ourselves can be severely limited in the amount of rehabilitation they will be able to receive. We understand that, rather than assessing potential capacity and providing access to appropriate rehab services to restore this capacity, those aged 65 and over will be treated as separately as 'aged care' patients and denied the access to the same level of rehab services as would be provided to comparable patients aged under 65.

This policy is not only cruel; it is arbitrary and economically unsound – especially within the context of encouraging people to remain in the work force into their 70's.

We would be happy to meet with you and ask that your government seriously reconsiders this inappropriate response to an individual and community need.

Thank you in anticipation.

Yours sincerely

Mark Kunach
Chairman

**Editor's note: A copy of this letter was
also sent to the Federal Health
Minister Sussan Ley.**

The GBS Association of NSW – PO Box 572 EPPING NSW 1710 – tel. (02) 9617 0883 mob.0487 843 723

email: info@gbs-cidp-nsw.org.au web: www.gbs-cidp-nsw.org.au



The Hon Sarah Mitchell MLC
Parliamentary Secretary for Regional and Rural
Health and Western NSW

M15/3047

27 JUL 2015

Mr Mark Kunach
Chairman
The GBS Association of NSW Inc
PO Box 572
EPPING NSW 1710

Dear Mr Kunach

Thank you for your correspondence to Jillian Skinner MP, Minister for Health, regarding the availability of rehabilitation services for people over the age of 65 years suffering from Guillain Barre Syndrome and Chronic Inflammatory Demyelinating Polyneuropathy. Mrs Skinner has asked me to respond.

As you have noted, Guillain Barre and Chronic Inflammatory Demyelinating Polyneuropathy are conditions that have significant effects on the patient, as well as their families and carers. Rehabilitation is a key component of the recovery journey that in many cases occurs over an extended period of time. I am advised that there are no NSW Health policies that restrict access to rehabilitation for this group of patients.

Rehabilitation services in NSW are guided by a model of care that was developed by clinicians, consumers and managers and endorsed by NSW Health in 2011. The Agency for Clinical Innovation's (ACI) Rehabilitation Network has been working to support the implementation of the NSW Rehabilitation Model of Care which supports the provision of rehabilitation care based on functional need. Through the provision of multidisciplinary, patient-centred, goal oriented and coordinated care, patients are enabled to achieve their maximal potential. Rehabilitation services are provided following individual assessment by local providers and in accordance with local policies. Access to, and provision of, rehabilitation services is based on the patient's clinical need.

Rehabilitation can occur in general rehabilitation units or rehabilitation units catering specifically to the older population. The average age of patients admitted to rehabilitation units in NSW in 2014 was 75.1 years, while for those with neurological conditions which would include the conditions you are enquiring about, the average age was 66.4 years. Fortunately, almost 90% of patients admitted to these rehabilitation units in NSW are discharged to private residences, with around 10% discharged to residential care facilities.

Thank you again for bringing this matter to the Minister's attention. The work of your organisation in supporting and advocating for patients with these disorders is valued. Should you have further concerns in relation to patients being refused access to services, or wish to discuss this matter further, please contact Mr Chris Shipway, Director of Primary Care and Chronic Services, ACI on 9464 4666 or chris.shipway@health.nsw.gov.au

Yours sincerely


Sarah Mitchell MLC

OUR DONATIONS AT WORK

By Ken Brooke

I was lucky enough to accompany our Chairman Mark Kunach to Westmead Hospital for the official donation ceremony of equipment to Immunology Ward A4D. The equipment donated was 2 x vitals monitors, 3 x saddle seats and 1 x surgical trolley.

To meet the nurses involved at the patient level along with those involved in research and to see their enthusiasm and gratitude for the donation was rewarding.

RNs Paula Cook and Marjorie Bennett said the equipment not only made a difference to the day to day duties it also improved quality of patient care.

The GBS Association Chair said of the presentation "A great occasion all round and the staff could not be happier with the additional equipment that has already resulted in improved treatment times and overall ward functionality".

He added "now look forward to working with a number of other hospital and rehab centres with a view to improving models of treatment and quality of life for those impacted by GBS/CIDP and related disorders through similar donations and further developing working relationships".

I've got to say the reward was not just meeting and talking to the fabulous people. It was knowing that the Association is not only a contact point for family and friends who are looking for information and to understand what their loved ones are going

through, the value of which should not be underestimated. We are also able to make a difference to sufferers by providing equipment to, as in this case, help speed up treatment but hopefully help with recovery.



Paula Cook RN, Ken Brooke Editor Recovery newsletter, Marjorie Bennett RN, Mark Kunach Chair GBS Association, Kylie Chaplin RN and Melinda Ledwith, Westmead Medical Research Foundation.



Do You Have a Story to Share?

We are always looking to spread the word. Looking to help those sufferers who think they are alone. Your story of recovery, the setbacks, achievements, the good times and the bad.

GBS and CIDP can be scary as we all know, your story just might make a difference to a sufferer. If it only helps one person it's worth it.

NSW Government Media Release:**Delivering the NDIS to more than half of eligible Australians**

16th September 2015

The Commonwealth, New South Wales and Victorian governments today signed the first agreements for the full rollout of the National Disability Insurance Scheme (NDIS).

Today's historic signings confirm the joint commitment of the Commonwealth, New South Wales and Victorian Governments to people with disability, their families and carers.

The agreements give certainty to around 140,000 people with disability in New South Wales and around 105,000 people with disability in Victoria. They also give certainty to their families and carers.

Together, the signed agreements with New South Wales and Victoria cover more than half of around 460,000 Australians and their families who are expected to be eligible for support from the NDIS when it is fully rolled out.

The NDIS is one of the largest social policy reforms in Australia's history. Working together, our governments are building a sustainable scheme that will stand the test of time.

Transition will begin in July 2016, with a geographical roll out moving from region to region, covering all eligible people under 65.

The region-by-region roll outs will ensure service providers have time to grow, to meet the needs of their clients and to meet demand.

In New South Wales, the rollout will start with the Central Coast, Hunter-New England, Nepean-Blue Mountains, Northern Sydney, South-Western Sydney, Western Sydney, and Southern New South Wales regions.

The Illawarra-Shoalhaven, Mid North Coast, Murrumbidgee, Northern New South Wales, South-Eastern Sydney, Sydney, Western New South Wales, and the Far West regions will start entering the scheme from July 2017.

In Victoria, the Northern East Melbourne, Central Highlands and Loddon regions will join the scheme from 1 July 2016. The regions of Inner Gippsland, Ovens-Murray, Western District, Inner Eastern Melbourne, Outer Eastern Melbourne, Hume-Moreland and the Bayside Peninsula will commence from July 2017, followed by Southern Melbourne, Western Melbourne, Brimbank-Melton, Goulburn, Mallee and Outer Gippsland from July 2018.

Victorian children on the Early Childhood Intervention Services waitlist will enter the scheme during the first two years of transition and ahead of the scheduled transition of each region.



Response To Letter to Minister Ley

This is an extract from the letter received from Kerrie Westcott, Acting Branch Manager, Ageing and Aged Care Services on behalf of Senator the Hon Mitch Fifield, Assistant Minister for Social Services after referral by Minister Ley. Unfortunately space limits prevents us from printing the full document which will be tabled at the next meeting, 7th November 2015.

People with Guillain Barre Syndrome or Chronic Inflammatory Demyelinating Polyneuropathy can get an indication of whether they may be able to access the NDIS through *My Access Checker*. My Access Checker is a tool to help people understand whether they may meet the access requirements for the NDIS. Anyone can complete the My Access Checker. Even if a person does not live in an NDIS trial site, they can still complete the My Access Checker to find out whether you could meet access requirements. My Access Checker is available on the NDIS website at myaccesschecker.ndis.gov.au. Printed copies can also be requested by calling the NDIS information line on freecall 1800 800 110 (calls made from a mobile phone may incur additional costs).

Back Page Bits 'n' Pieces

GBS Association of NSW

A NON-PROFIT VOLUNTEER ORGANISATION

Registered ABN: 59 166 877 537

Incorporation No. Y13693---18

COMMITTEE

PATRON:

Ursula Carlile

CHAIRMAN:

Mark Kunach

DEPUTY CHAIR:

Atilla De Szoeki

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Christine Simpson-Morgan

SECRETARY:

Glenda Ford

MINUTE SECRETARY:

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ANNUAL SUBSCRIPTION / DONATIONS

Financial Year 1st January 2015 to 31st December 2015

Name:

Address:

Address:

Phone / Mobile:

☐ Please send my *Recovery Newsletter* via email.

☐ email address:

Please indicate your interest

☐

GBS

☐

CIDP

☐

Doctor/Medical

☐

Relative

Direct Deposit: Guillain Barre Association Inc

Annual Subscription Renewal

\$ 20.00

Bank Account: St George 161403610 BSB: 112-879

Donation

\$

Cheques payable to: The GBS Association of NSW Inc

Total

\$

PO Box 572, EPPING NSW 2121

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

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

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

Name:

Address:

Address:

Phone / Mobile:

email address:

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

☐

Preferred area:

☐

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

Preferred contact number:

Committee Meetings

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

2015 Meeting Dates

7 th February	2 nd May AGM	1 st August	7 th November
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Financial Year 2015

Members are reminded the Association's financial year is

1st January 2015 to 31st December 2015

GBS NSW would appreciate your continued support.

Disclaimer

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

Public Risk

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

Contact the Editor

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

Mail: 16 Corio Drive ST CLAIR NSW 2759

Email: kbrooke53@gmail.com