



RECOVERY

GBS / CIDP
GUILLAIN BARRE SYNDROME
CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY



From The Editor's Desk

To open this edition of Recovery I'd like to take this opportunity to wish all of our members and their families a very Merry Christmas.

In the last couple of editions members have shared their stories with us. I'd like to encourage others to share their journey through GBS or CIDP with our members. I'd also like you to share your feedback with us regarding what we include in Recovery, as well as your concerns and what you would like to see included. Remember we are here for all!

To that point, this month we introduce feedback from our members. Good or bad feedback we want to hear from you. There will be no censorship except for length or legalities of comment without removing the concept or the view expressed in the correspondence.

I was touched to receive an email from a member of our association Graham Tucker (printed in this edition), thanking me for last month's My Story. As Graham says it really is "Our Story". That is why we need to share our stories to let everybody affected by GBS and CIDP know that they are not alone.

So it is with that in mind I ask our members to share their stories. Not just GBS/ CIDP members but medical staff, who also have to deal with us. Whether it be ICU /Rehab, Wards people, people, staff in areas like A&D, or OT personnel It helps to make us all understand we are not alone and that we share a journey through this cruel affliction.

That information just may ..may... help us, come to terms with our affliction. Wouldn't it be great if someone was inspired to do more research into the cause, better treatment and eventually find a cure or prevention.

It appears contrary to the reply we received from the NSW Health Minister, there is still an inclination from hospitals to push patients aged over 65 into nursing homes rather than allow them to receive rehabilitation through the sometimes slow recovery period.

I recently had contact with a lady whose father, aged 72, is in hospital. He was diagnosed mid June but was told he would be transferred to a Nursing Home. She has won an extension until late December before this occurs.

After our conversation I met with her and her father at the hospital. Her story of the treatment her father received surprised and shocked me. How many other patients have had a similar experience, I wonder.

The good news is that the father, although still being discharged before the end of the year, is now likely to be admitted to a rehab hospital.



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Next Meeting: Saturday, 6th February 2016
'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

Message from the Chair



Welcome to the final edition of Recovery for 2015. It seems like only yesterday we were celebrating the highly successful Sydney Olympics/Paralympics. It is an interesting phenomena that a long day can feel like a lifetime but when we look back on our life it often seems so short and we wonder where did all that time go?

When I think back to those dark days when both my CIDP and Ulcerative Colitis were both highly active I wonder how did I manage? Those seemingly endless days and nights of pain and anguish. But you do, you pick yourself up dust yourself off and go on!

"... you pick yourself up dust yourself off and go on..."

Where am I going with these musings you ask? Well Mary, our wisp of a girl stalwart phone a friend, font of knowledge for all things GBS/CIDP, pioneer sufferer and mother in thought and actions to many, our steady hand on the bridge of the good ship GBS Association of NSW Inc. since she was launched, helping guide us through good and not so good times has advised that she, and Art, her husband of 60 years (how good is that!), are taking their foot off the accelerator of life. Good thing too for their neighbours. Less noisy late night parties and calls to the Police!!!

"...Mary, our wisp of a girl stalwart phone a friend..."

However, there is a double edged sword in this decision. Whilst it is fabulous news and not so very surprising, it once again highlights how much the Association has come to rely on Mary for her unwavering support (and that of Art) year in and year out for a cause that is part of her (their) very being. Who will step up to be our phone a friend? Who has the commitment to take those calls for help from sufferers and/or family and friends who are struggling to come to terms with a diagnosis of GBS/CIDP? Who has the empathy and calm demeanour to allay those fears and bring a ray of hope or help cut through the medical maize that can accompany a diagnosis and/or lack of treatment options? Who will replace Mary??? I will leave you with these thoughts for now.

"...a ray of hope or help cut through the medical maize..."

Much as transpired since Landry made some early discoveries relating to a paralytic disorder that became known as Landry's Ascending Paralysis in 1859 and then Guillain, Barre and Strohl made further discoveries in 1916 resulting in the name GBS and we have made many advances in treatments such as plasmaphereses and IVIG since then yet a cure still alludes us and there are few treatment options apart from the above. However, despite the highs and lows we carry on because new models of treatment are being developed as we speak, new medications trialled and new theories discussed, that will eventually lead to a cure.

"... new models of treatment are being developed..."

As you will recall, we lost our beloved Ronald Nichols a year ago to multiple cancers. As with so many sufferers it was not GBS/CIDP but some other illness that prematurely took him from us. There are many sufferers who still speak of the great lift they received when Ronald visited them in hospital. His memory lives on and whilst no one will ever replace Ronald, Trish has stepped in as Minute Secretary and Ken has conducted quite a few hospital visits as well as taking the reins of Recovery from Christine. They have both committed to picking up those not inconsiderable batons bringing their own style and substance to the roles.

"... great lift they received when Ronald visited them..."

As an Association we have achieved much in the past few years through the hard work of the Committee. Many outside the Committee would not know of the extra meetings, frank discussions, disagreements, compromises etc. that were required to consolidate the platform and launch pad we now have for the future. A new Constitution, modern website, revamped Recovery and email contacts all help support/supplement our primary point of contact, phone a friend. We cannot afford to sit on our laurels. It is our responsibility to continue the good works of those who have come before us and build an even better and more responsive Association.

As Chair I am happy to be the face of the Association but we also need a voice, a person who can bring their own style and substance to the role of our telephone contact. It should be noted Mary is not severing all ties with the Association just yet and will be able to assist and I am sure answer any questions from those considering the role. As a member of the Committee you will never be alone providing support inward so we can project outward. Indeed, there is much to consider over the Christmas break and before the next AGM in May 2016.

In conclusion, I would like to wish everyone good health, a very Merry Christmas and a happy New Year.

Kindest Regards

Mark.

When An Infusion Is Prescribed

GBS and CIDP sufferers are often prescribed a one-off, or a continuing regime of infusion therapy. For the newly diagnosed GBS/CIDP sufferer, infusions are another of life's unplanned experiences.

Infusion therapy today is used for an increasing range of illnesses. When infusion therapy was first introduced, it was regularly administered in a hospital ward setting to carefully monitor for any adverse reactions. Protocols for the safe administration of each new infusion therapy were developed this way.



Today ambulatory patients have infusions at designated infusion centres in the public and private hospital systems. These centres are usually located within the hospital grounds and are staffed by a team of specially trained nurses.

One such centre is the Infusion Lounge at the John Hunter Hospital in Newcastle. The John Hunter is one of the largest public hospitals in NSW, with the state's busiest emergency department. Its infusion centre grew out of an outreach service for HIV patients in the 1980's.

The purpose built John Hunter Infusion Lounge opened its doors in 1991. It has 10 "lounge chair" treatment stations. Last year more than 3,800 infusions were done at this facility.

When a patient arrives for their infusion appointment at the John Hunter, observations are recorded which include temperature, blood pressure, pulse and respiration. Any abnormal results may require a review by a medical officer prior to commencing the infusion, or if the patient is deemed not well enough, the infusion may need to be rescheduled.

The most common infusion treatment for GBS and CIDP sufferers is immunoglobulin. This infusion can take up to several hours to complete. Amenities within the Infusion Lounge include restrooms and tea/coffee making facilities.

Thanks to GBS Association member Howard Morrison for his contribution and effort in obtaining this insight into the John Hunter Infusion Lounge. Also thank you to the Hunter/New England communication unit.

2016 Meetings

6th February

7th May (AGM)

6th August

5th November

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

Diagnosing and Treating CIDP

The primary function of the immune system is to differentiate between self and non-self, to keep self healthy and to destroy or neutralize non-self. When the immune system malfunctions and attacks itself, it is known as an autoimmune disease. CIDP is considered an autoimmune disease, and occurs when the myelin sheath that covers the nerves and assists with impulse transmission is attacked. This is known as demyelination. Because of the nature of the attack, there is usually inflammation. The result is an interruption in nerve signals between the peripheral nerves and the muscles they control.

CIDP presents slowly, usually over several months, unlike the acute form of demyelinating neuropathy known as GBS. GBS presents rapidly, usually over days, but sometimes even more quickly, and frequently occurs following some sort of infection or illness. Unlike GBS, CIDP is usually a chronically progressive neuropathy and is rarely associated with antecedent illnesses or respiratory failure.

Diagnosing CIDP

Usually, CIDP presents as a motor predominant neuropathy with prominent proximal weakness, meaning the muscles responsible for movement closest to the torso are affected first. The weakness is typically symmetrical, affecting both sides of the body equally. Occasionally, CIDP can present in the pattern of a mononeuropathy multiplex, large-fibre neuropathy with sensory ataxia, pure motor neuropathy, or small-fibre neuropathy.

It's not uncommon for CIDP to go undiagnosed for a while due to many factors. The symptoms may be vague and brushed off until they become more profound and/ or interfere with everyday functioning. Once an individual does go to a physician, a definite diagnosis still may not follow.

Neuropathy has many causes, and CIDP has several variants, therefore, it is important that a thorough health history, physical, and neurological examination be performed to determine the cause of the neuropathy. CIDP is rare, but its incidence ranges greatly due to the potential of over- or under-diagnosis. An individual may be thought to have CIDP when it is actually another form of neuropathy, and the reverse can happen as well. Many physicians and patient groups have worked on a standard way to identify CIDP more quickly and accurately, but appropriate diagnosis remains a challenge.

Symptoms are first noticed as numbness, tingling, pain and weakness, which are vague and can be the initial symptoms of many conditions. This usually occurs first in the toes and feet, eventually resulting in foot drop or drag and increased difficulty in walking. The weakness and numbness are typically symmetrical—equal on both sides of the body—and sensory loss is often in a stocking and glove distribution.

A diagnosis of CIDP is based on an electrophysiologic pattern of multifocal demyelination identified through an EMG/nerve conduction study, elevated CSF (cerebral spinal fluid) protein and, when necessary, nerve biopsy. These tests, combined with a thorough health history and neurological exam, will help guide the physician to a correct diagnosis.

Treating CIDP

Once CIDP is diagnosed, treatment options are considered and discussed. The treatment of CIDP is based on immunomodulating therapies. Immunomodulation refers to suppression or alteration of the immune response so that attack on the self subsides and symptoms improve. CIDP does respond to corticosteroids; however, long-term use of high-dose steroids comes with its own set of issues. Side effects can be severe and affect multiple organ systems.

Plasmapheresis is generally reserved for refractory patients—those who have tried all the standard therapies and the condition is still not controlled. The only treatment that has received FDA approval for the management of CIDP is intravenous immunoglobulin (IVIG).

Rare, But There Is Hope

Although CIDP is rare and difficult to diagnose, once it is accurately diagnosed, there are treatment options. CIDP can be treated with a variety of immunomodulatory therapies, including FDA-approved IVIG. Fortunately, CIDP can be managed to help patients live relatively normal and healthy lives, and there are many patient-to-patient support groups that include oversight by experts in neuromuscular disorders.

By Michelle Greer, RN and Gil I. Wolfe, MD

Professor of Neurology, SUNY Buffalo School of Medicine and Biomedical Sciences; Member, GBS|CIDP Medical Advisory Board

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My Story - Mary McAlister



My onset of GBS was in 1948 aged 15 years old. My own diagnosis was described as a "sort of Polio, but not Polio" – subsequently I was treated as a Polio patient. In 1948 no medical interventions such as IVIG or Plasmapheresis treatments were then available. Treatments depended on physiotherapy, coupled with rigid support frames and plaster splints, into which my whole body was splinted and strapped. The upper frames were called "aeroplane splints" the arms being set at right angles to the body, the arms bent at the elbows, whilst my torso and legs were strapped down in a rigid frame; plaster boots held my feet at right angles, whilst my hands were also strapped into splints. I was in the body frame the whole eighteen months of my hospitalization.

Even after discharge I wore the plaster boots nightly for the next five years. My immediate hospitalization lasted 18 months. After discharge in 1949 I spent the following 5 years as an outpatient receiving physiotherapy, initially every day, later three times a week. It was a long and slow recovery. I was in my thirties when I has told what I really had was actually Guillain Barré Syndrome.

My own personal toughest challenge as a patient was to catch Scarlet Fever, one month from my initial onset. I had been admitted to a Tasmanian hospital, placed alone in an Isolation Ward in the Infectious Diseases area of the hospital, because of my 'sort of Polio' diagnosis. My initial condition had resulted by this time as being most profoundly paralysed, and now this, Scarlet Fever; it was indeed the toughest challenge at that time of my life. Overcoming it? – One had just to wait patiently for the body to heal itself, no penicillin was available, nonetheless faith and confidence that things must get better, always prevail. If this is the bottom there is only one way and that is up!!

Definitely, my life with GBS must have changed me, how I find it hard to be specific. At fifteen prior to my onset of GBS, I had no preconceived concepts about my life ahead. Hospitalization between fifteen and nearly seventeen must have shaped my life ahead but I cannot say how. After my discharge from hospital in 1949 and still greatly 'not-able', my mother gave me some good advice, *"face the world, do not hide at home, the world will not come to you at home... go to them... your life will be enriched if you do – at the end of each day go to bed reflecting on the positives of your day, and day by day the list grows longer"*. I still do this.

There are many aspects to one's inspiration. It comes in many guises from many ordinary people we meet. It is a many faceted emotion. We absorb and learn and hope to emulate these positive aspects into our own lives. However quite simply and truthfully, it is my own family which inspire me, my parents now deceased, my husband, my children and my grandchildren, each adds an element of inspiration to my life and inspires me to realise and appreciate how lucky I am to be part of their lives, to love and to be loved. No one could wish for more than that.

Little confidence in NDIS revealed in latest report

Disability groups have reported an alarming lack of confidence in the rollout of the National Disability Insurance Scheme (NDIS) before the full transition to the \$22 billion scheme which will launch across the country next year. Only one-third of organisations in trial sites reported scheme administrator, the National Disability Insurance Agency (NDIA), was working well with providers and almost two-thirds said governments were not responding to their requirements.

The State of the Disability Sector report reveals wide-ranging concerns about the NDIS, including workforce shortages, financial pressures and a lack of housing and job opportunities for people with a disability once they are in the scheme.

Ken Baker, chief executive of National Disability Services, which will release the report on Monday, said while disability groups supported the scheme there was uncertainty about its implementation. "Providers feel let down ... they are not getting sufficient assistance from the government and the agency," he said.

There are 20,000 participants in NDIS trial sites, which will increase to 460,000 as the scheme is implemented. Disability groups expressed concern about the rapid expansion, but were divided on whether it should be slowed down. One organisation complained: "It seems decisions are being made on the run and the scheme is not well planned." Another provider noted: "The lack of consultation and disrespect of service providers ... has astonished the sector."

Almost 600 disability sector leaders will meet NDIA representatives in Sydney on Monday to address the issues in the report.

As reported in Sydney Morning Herald 7th December 2015 with permission of Reporter Rachel Browne

Feedback



Hi Mark,

Thank you so much for meeting with myself and the A4D team on Monday. Please also thank Ken for joining us. It was lovely to see how your donation from the GBS Association is helping the Ward.

Please find a link below to the Parramatta Sun's article on your donation – just fantastic!

<http://www.parramattasun.com.au/story/3372596/8500-donation-to-lift-quality-of-life/?cs=1497>

On behalf of the Foundation, please thank everyone at the GBS Association for their amazing support. Your donation has significantly improved patient care. If you need any assistance in the future, please contact me at any time. Thank you again.

**Melinda Ledwith Relationships Coordinator
Westmead Medical Research Foundation (WMRF)**

This is your column where you can give your views on any subject that is of importance to you. It is especially good if you can give, but is not exclusive to, comments on articles that appear in Recovery or that you would like to see in Recovery. Feel free to email or send a letter.

Thx so much for 'My Story'. It is of course 'Our Story' and it is so good to have the story told so well. Even now, 5 years since I came home from hospital after GBS, I can learn from your account. You portray so clearly the feeling of hopelessness and the determination to recover.

My GP said I'd probably had a mild stroke. When I couldn't walk my family took me to hospital. As you say, the doctors, nurses and other staff are brilliant. Thx for mentioning the spinal tap. When the doctor shoved the needle in for the fourteenth time (I was counting) I was just about ready to give in.

I realise that this was just part of the deal. It helps even now to know that other GBS patients went through this whole bloody business. At the time, I did not realise that the terrible dreams and frightening nightmares were not just specifically for me. Thx for talking about yours.

I am also a heart patient and my cardiologist very kindly visited me a couple of times in hospital. After I came out I said to him at my next regular visit: Thanks for visiting me...you were the only person who told me I would recover."His reply was delightful: "I know what a stubborn bastard you are."This was echoed by the neurologist as I walked into his room after my 'recovery'... "The only reason you are walking is your own determination."

Of course there were other reasons but I know what he meant. For me the most important factor in my recovery was Family Support. The hospital was a long way from home but my wife and other family members came every day. Love. Thank you Ken...In future when people ask me about GBS I shall show them your article. Very best wishes.

Graham Tucker

Thanks for the great links and comprehensive coverage of GBS with the updated links for articles interesting as well. I just wanted to let you know that the Neuropathy in the heading is spelt without a t. Many thanks again for the great page!

Brianna

Hullo Mary,

I viewed the Recovery Newsletter with great interest. I could identify with Ken Brookes' story which brought back many unpleasant memories whilst delirious and with recurring nightmares that I still remember.

In view of my age at the time, 81 years (erroneously mentioned earlier as 80 due to my daughter's influence) and slow recovery progress, the nursing staff mentioned a nursing home frequently. As far as I was concerned this was not an option. However, the prospect of this solution in the future is unacceptable for GBS patients and I trust that this procedure does not occur.

As you know, in time I was able to return to my home and independent lifestyle which I am still pursuing at 86 years of age. Had I been transferred to a nursing home and programmed into a sedentary lifestyle it is highly unlikely that I would have attained my present age. Trust that you, like me, are still in reasonable health although the years pile up. Best Wishes,

Dulcie Hartley



Dear Mr Kunach

I read in this week's edition of the *Parramatta Sun* an article about your experiences at Westmead Hospital and Guillain-Barre Syndrome.

I was delighted to read that you made a \$8500 donation to Westmead Hospital on behalf of the Guillain-Barre Syndrome Association of NSW to replace outdated equipment such as a dressing trolley, two saddle seats and two portable machines with advanced vital sign technology.

I'm sure all patients who use this equipment will appreciate your generosity and that of the Guillain-Barre Syndrome Association of NSW.

Furthermore, the Westmead Medical Research Foundation has said that the equipment benefitted patients and staff. If there is anything I can do to help on State Government matters, please do not hesitate to contact me.

Julia Finn MP, State Member for Granville.

Hi Mark,

It was great meeting you in person today. Thank you again for your continued effort. As discussed, if you can email me the newsletter we will pass it on to patients. See you in clinic :)

Linda Mechael, ICPMR, Westmead Hospital.

Article from the Parramatta Holroyd Sun

\$8500 donation to lift quality of life

By Kylie Stevens
Sept. 23, 2015, 1:25 p.m.

WESTMEAD Hospital is almost a second home for Mark Kunach.

The Westmead resident has been a regular at the hospital since he was diagnosed 12 years ago with chronic inflammatory demyelinating polyneuropathy, a form of Guillain-Barre Syndrome, an autoimmune disorder. The rare illness affects the peripheral nerves, causing weakness, paralysis and abnormal sensations.

Mr Kunach has monthly blood infusions at Westmead's immunology ambulatory care ward. Each treatment involves 1000 blood products and costs \$5000, covered by the federal government. Inspired to improve the treatment and conditions of other patients, he donated \$8500 to the ward on behalf of the Guillain-Barre Syndrome (GBS) Association of NSW.

"There is no cure on the horizon so I was looking to improve the quality of life for patients," Mr Kunach said. "I wanted to do as much as I could to help people. There was one surgical trolley between three registered nurses." The donation replaced outdated equipment, including a dressing trolley, two saddle seats and two portable machines with advanced vital sign technology.

Westmead Medical Research Foundation relationships co-ordinator Melinda Ledwith said the equipment benefitted patients and staff.

"In the past, staff had felt compelled to get on their hands and knees to give proper treatment. Mark wanted to ensure staff's safety and comfort," she said.

Mr Kunach is chairman of the GBS Association of NSW, a volunteer support group for patients. Many donations received come from the estates of people who had the condition.

"It can attack anyone at any time, where they can go from a normal functioning person to paralysed in intensive care within 24 hours," Mr Kunach said. "They get the disease through no fault of their own. They're doing the best they can and just need extra help."

Mr Kunach still works full-time. "You become more aware of your body, not only its limitations but also its capabilities. You never know what life will throw at you," Mr Kunach said.

Back Page Bits 'n' Pieces

GBS Association of NSW

A NON-PROFIT VOLUNTEER ORGANISATION

Registered ABN: 59 166 877

537 Incorporation No. Y13693-

COMMITTEE

PATRON:

Ursula Carlile

CHAIRMAN:

Mark Kunach

DEPUTY CHAIR:

Atila De Szoeke

TREASURER & PUBLIC OFFICER:

Christine Simpson-Morgan

SECRETARY:

Glenda Ford

MINUTE SECRETARY:

Trish Brice

GENERAL:

Mary McAlister

Jane Rothman

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ANNUAL SUBSCRIPTION / DONATIONS

Financial Year 1st January 2016 to 31st December 2016

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

Bank Account: St George 161403610 BSB: 112-879

Cheques payable to: **The GBS Association of NSW Inc**

PO Box 572, EPPING NSW 2121

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

Donation

Total

\$ 20.00

\$

\$

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.

2016 Meeting Dates

6th February	7th May AGM	6th August	5th November
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Financial Year 2016

Members are reminded the Association's financial year is

1st January 2016 to 31st December 2016

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