



RECOVERY

GBS | CIDP
GUILLAIN BARRE SYNDROME
CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY

From the Editor

Welcome to our new and long-term members, we are excited to bring you our 1st 2015 edition!

It is already looking like a very busy year. In fact I feel I've already done a year's work in a month and a half so hope I have the stamina for what's in store over the next 10 ½ months!

Stamina is something we GBS and CIDP people have in limited supply and we need to manage and monitor it constantly. Whilst I have certainly built it up in the years since my last major CIDP attack, I do sometimes go to the well too often and then wonder why I find it dry. I am amazed at colleagues who seem to have boundless energy reserves and friends who can attend endless social engagements with no sign of under eye bags! I then think about how lucky I am to be able to go to the pump and fill up my tank with 'premium unleaded' Intragam that will then sustain me for another 6 weeks of quality life.

I also think about where I was and how important rehabilitation was to my recovery. I was privileged enough in days gone by to access a live in facility for approximately three months and then as an outpatient for at least six.

Sadly, it is not so for newly diagnosed patients. You will read further in this edition how cut backs are severely affecting the rehabilitation of patients because they are limited to only one month of live-in rehab. We all know that GBS and or a major exacerbation of CIDP can leave the patient in serious trouble and requiring many months of specialist care to recover.

This is an important issue we will be following up and lobbying for change. To help us challenge, please send your stories and tell us how important rehab was to you, all your feedback may just help us make a case and reverse this unfair policy.

We hope to hear from you and until June, good health to all.

Christine Simpson-Morgan

Treasurer, Editor, Public Officer and Website Facilitator

*Want to access the Recovery back-catalogue via the website?
Sign up as a 2015 member and we'll tell you how.*

Next Meeting: 2nd May 2015
Royal Rehabilitation Centre Sydney
235 Morrison Road, Ryde
"Susan Schardt Conference Room" L1

9:30 to 11:00 - Committee business and administration
11:00 to 12:30 - Open forum for members and family /
guest speaker

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



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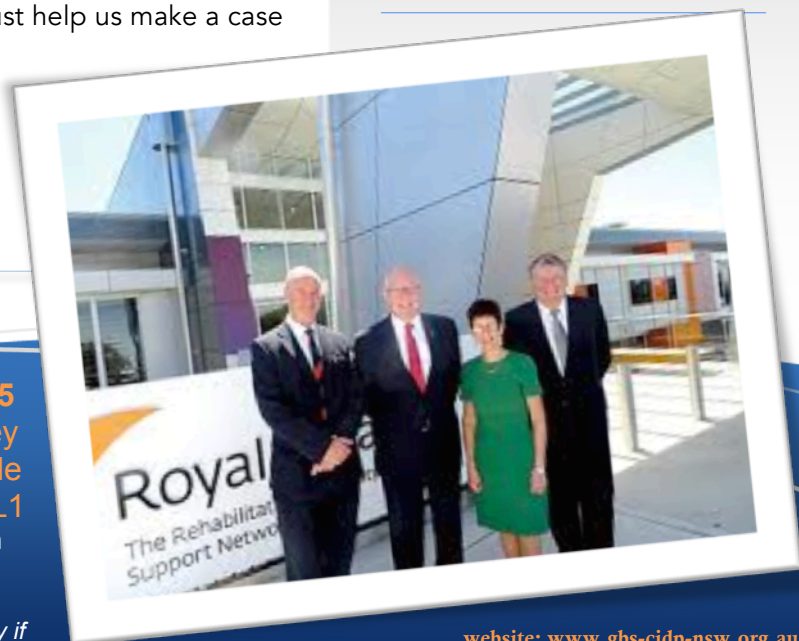
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Message from the Chair

Welcome to the first edition of Recovery for 2015. We look forward to an even better year than 2014 and I hope to see more new and current members at our meetings.

In the past 18 months to 2 years the Association has moved ahead with our new look Recovery, new website, new constitution, we have been able to return to the new Royal Rehabilitation Centre, Ryde, our meeting attendance grows and our donation to Westmead Hospital is almost complete with some of the equipment funded by us currently on backorder. We also continue to benefit from some very generous donations and I would like to thank all our benefactors who help us to support others. We further benefit from some shrewd investments and our balance sheet reflects the sound decisions of the Committee and the work of our Treasurer. Our aim in 2015 is to continue to build upon this great work by the members of the Committee to help ensure we can continue to provide support to those impacted by GBS/CIDP or related disorder.

As mentioned, the GBS Association of NSW Inc. continues to grow and mature and this is attributed to the dedicated members of the Committee who sacrifice their personal time to ensure the Association is always there to answer a call for help from a distressed patient, emotionally distraught partner, family member, friend or colleague who is attempting to come to grips with a diagnosis of GBS/CIDP but it is all too complex. We often hear the cry, "What is this funny sounding condition and why haven't I heard about it before?" This help could be in the form of phone a friend, accessing our website for information, email, reading Recovery and/or attending on of our meetings/forums.

As many of you will know the Association was formed more than 20 years ago by a group of patients and doctors who saw a need for a patient support group to help fill the information/support void. Since then we have learned much about GBS/CIDP but equally there is still much we do not know about this complex condition. Whilst specialists provide as much information as they can, many newly diagnosed patients, family and friends still come away with many unanswered questions. Often over the past 20 years or so these people have found comfort in contacting the GBS Association, realising they are not alone and this facilitates their journey along their road to recovery.

Yet, despite all of the above achievements, at this time, the Association is itself in need of support! We may not be able to continue to offer the same level of services of previous years.



"despite all of the achievements, at this time, the Association is itself in need of support! We may not be able to continue to offer the same level of services of previous years."

As you are aware late last year we lost our beloved Minutes Secretary Ronald Nichols and since his ill health took him away from this role Mary, who is also our phone a friend telephone support person and a founding member, has taken it upon herself to fulfill this role as well. I would suggest the greater majority of our first contacts have been through Mary, the calming voice at the other end of the telephone for many who have been struck like a lightning bolt by a diagnosis of GBS/CIDP. We then have Christine, who is Treasurer, Recovery Editor in Chief, website officer and public officer all in one. This means we have the greater majority of the Committee roles filled by just two volunteers!

As abovementioned the GBS Association of NSW Inc. is in a sound financial and administrative condition. We have built a strong foundation to continue the work of the Association for the next 20 years. However, this can only be achieved with a Full Committee and a regular influx of new ideas, new thinking, new strategies and new people.

Our AGM is on Saturday 2nd May 2015 where all Committee positions will be declared vacant and thence persons can be nominated for various positions. Please consider nominating for a Committee position. If you have a bit of interest I am sure Christine or Mary would be more than happy to give you a run down on what is required be it Treasurer, Editor, or Minutes Secretary; or any committee position for that matter and you will be supported in your new position. You will not just be thrown in if that is a concern. Remember support is what we are good at.

If I have not already planted a seed of interest consider this. Mary, our phone a friend telephone contact was struck down with GBS as a young girl approximately 6 decades ago. I have had CIDP for just over 10 years and cannot conceive being able to endure that for 6 times as long! So not only has she endured GBS when there was no IVIG/plasmapheresis, specific treatments etc. she has worked all her life, raised a family, she is also a founding member and has been the voice of the Association for many years; and she has also stumped up to fill in after Ronald became sick and passed away so unexpectedly quickly. Whilst I know Mary will chide me for saying so, I am humbled by her industry and only wish I have the same dedication and energy to endure in the same vein. I would think many members and the multitude of person/s she has helped over the years, would similarly nod with a chorus of 'hear, hear'.

As there remains no cure for GBS/CIDP, for the vast majority of sufferers they will experience a lifetime of learning of what they can and cannot achieve living with a peripheral neuropathy all the while within an ageing body. Yet many I would suggest vividly recall the day of their diagnosis and also the relief of contacting the GBS Association and discovering they are not alone, and despite each sufferer presenting differently there are other sufferers with similar strange sensations or physical changes.

We need people who want to help run the Association, not for monetary gain but because they know whilst a cure remains elusive there will be a need for the Association. One of my greatest joys as Chair is to see the concerned countenance of new visitors as they enter our meetings and the change that comes over them as they recall their story and realise they have found kindred spirits. I leave these meetings feeling I am part of a team that really makes a difference.

Priceless!!!

Cheers

Mark.





ECULIZMAB appears to be one of those drugs which has been widely used to treat several conditions (PHN) & (aHUS) already listed on the Australian PBS, whether in the future it will be used in treatment of GBS will depend on the outcome of Trials in the US and in Scotland...

ECULIZMAB or SOLIRIS?

pronounced = " ek-u-liz-oo-mab"

(Generic Name: Trade Name: **Soliris®**)

Eculizumab is the generic name for the trade chemotherapy drug Soliris. In some cases, health care professionals may use the trade name Soliris when referring to the generic drug name Eculizumab.

Drug Type: Eculizumab is a "monoclonal antibody" that binds or attaches to a protein present in the blood. **What Eculizumab Is Used For:**

Eculizumab is used for the treatment of the blood disorders:

- paroxysmal nocturnal hemoglobinuria (PNH)
- atypical Hemolytic Uremic Syndrome (aHUS)

**Note: If a drug has been approved for one use, physicians may elect to use this same drug for other problems if they believe it may be helpful. [GBS?]*

How Eculizumab Is Given:

- Eculizumab is given through an infusion into a vein (intravenous, IV).

The amount of eculizumab that you will receive depends on many factors, including your height and weight, your general health or other health problems, and the type of cancer/ condition you have. Your doctor will determine your exact Eculizumab dosage and schedule.

Eculizumab Side Effects:

Important things to remember about the side effects of eculizumab:

- Most people will not experience all of the Eculizumab side effects listed.
- Eculizumab side effects are often predictable in terms of their onset, duration, and severity.
- Eculizumab side effects are almost always reversible and will go away after therapy is complete.
- Eculizumab side effects may be quite manageable. There are many options to minimize or prevent the side effects of Eculizumab.

The following Eculizumab side effects are common (occurring in greater than 30%) for patients taking Eculizumab:

- High blood pressure
- Diarrhea
- Headache

These are less common side effects for patients receiving Eculizumab: This list includes common and less common side effects for those taking Eculizumab. Eculizumab side effects that are very rare -- occurring in less than about 10 percent of patients -- are not listed here. Always inform your health care provider if you experience any unusual symptoms.

- Anemia
- Nausea, vomiting
- Nasal congestion
- Back pain
- Urinary tract infection
- Upper respiratory tract infection
- Low white blood cell count
- Difficulty sleeping
- Sore throat
- Cough
- Fatigue
- Fever
- Dizziness
- Abdominal pain

How Eculizumab works:

Eculizumab is classified as a monoclonal antibody. Monoclonal antibodies are a relatively new type of "targeted" cancer or biologic therapy. Antibodies are an integral part of the body's immune system. Normally, the body creates antibodies in response to an antigen (such as a protein in a germ) that has entered the body. The antibodies attach to the antigen in order to mark it for destruction by the immune system.

In the laboratory, scientists analyse specific antigens on the surface of cancer cells (target) to determine a protein to match the antigen. Then, using protein from animals and humans, scientists work to create a special antibody that will attach to the target antigen. An antibody will attach to a matching antigen like a key fits a lock. This technology allows treatment to target specific cells, causing less toxicity to healthy cells. Monoclonal antibody therapy can be done only for cancers or diseases in which antigens (and the respective antibodies) have been identified.

Eculizumab is a targeted therapy that targets and binds to the complement protein C5; this in turn prevents the splitting of this protein interfering with the formation of membrane attack complex (MAC). This interference prevents the destruction of red blood cells (hemolysis) and therefore results in stabilization of hemoglobins and a decrease in the need for blood transfusions in persons with paroxysmal nocturnal hemoglobinuria (PNH).

Note: We strongly encourage you to talk with your health care professional about your specific medical condition and treatments. The information contained in this website is meant to be helpful and educational, but is not a substitute for medical advice.

Our Association would like to give a big thank you to Royal Rehab, a wonderful rehabilitation facility. Anyone who has been a patient at Royal Rehab has experienced the excellence of their rehab program and outstanding support of their talented staff. Royal Rehab had been our 'home' for many years, allowing us free access to meeting facilities - as well as providing us with a very generous morning tea. An important side benefit of this arrangement was that in-patients with GBS (of which I was one) or CIPD could attend Association meetings, meet other sufferers and share their stories. This can be so important and beneficial in the early stages of diagnosis and treatment.

Our arrangement with Royal Rehab was put 'on hold' for several years while the organisation undertook a major rebuilding program.

The building program is happily now complete. We were able to return 'home' last year to much more glamorous surrounds. We've even had an in-patient from the hospital attending our recent February meeting....so we've come full circle.

We would like to especially thank Stephen Lowndes (CEO, Royal Rehab) and Lynette Mason (his Executive Assistant) for their kind support. Lynette, our day-to-day contact, has always been incredibly helpful in organising the many details that enable our smooth access to this wonderful facility. Thank you!

Jane Rothman



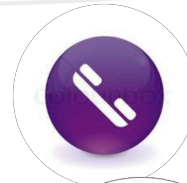
thank
you!

Call - a - Friend

How kind of the GBS/CIDP members who sent Christmas and New Year Greetings to the Association during the Festive Season, we do appreciate your support, so a warm Thank You to you all.

However for some families the season was far from festive. GBS, as we all know, has no boundaries, of place, time, age or gender. The Call-a-friend, line has been busy during this time receiving multiple calls from the families of recently diagnosed GBS persons. Each of these calls shows the families own emotional trauma during this time. GBS not only affects the patient, but also the whole family. These calls reflecting for their loved one, their fear, their misery, their uncertainty, what is going to be the future for their parent, brother /sister, child? What can be done to improve and enhance their loved ones recovery? My role is to support, inform, and to listen. The one thing I cannot do, is predict how complete, how long, or the future of any GBS patient in attaining their optimum stage of recovery. Probably the answer might be in fact, recovery may take longer than anyone is prepared to hear at this stage. The one positive fact is the majority of GBS patients will make some degree of improvement, how quickly and how completely, is the unknown factor.

The situation regarding Rehabilitation Centres has been brought into sharp focus in the last month. During this time three different patients, all male, in their senior years, two with full hospital and medical cover, the other without. All are recent GBS patients being treated in either large Sydney or regional hospitals. The families of these patients were advised by the hospital authorities their parent would be moved to the Geriatric Wards within the hospitals concerned. These arbitrary decisions by the hospital were strongly resisted by family members as being totally unsuitable for adequate recovery and rehab. requirements for their parent/s. Each case was hotly defended by the families concerned, however difficulty then arose for the family to find a Rehabilitation Centre who might be willing to admit the patient for longer than a month. None of the private Health Funded Rehab. Centres concerned would agree to any extension of the prevailing allotted time, a month, remembering these patients had private cover and these were private health funded Rehab. Centres, not Public ones.



*"the phone number is
0487 843 723 and we
hope to hear you
'calling-a-friend' "*

After the month has elapsed the future rehabilitation assistance continuing in these Centres is uncertain for both patients. (These patients are in two different Rehab. Centres). Obviously one month is not long enough for most GBS patients to be sufficiently recovered to return home, even to be moderately recovered. These calls were NSW based, so these comments relate more directly to Sydney and a regional area of NSW. I cannot comment about other states or districts whether this is a common situation.

Rehabilitation Centres fall into four categories Public (Government Funded), Private (Health Fund); at the far end of the rehab. scale, Geriatric Wards, and Nursing Homes which for the purposes of a recovering GBS is somewhat unsuitable. It appears from this outsider's view point the Health Funds have tightened their funding of Re.hab. Centre benefits to the degree of almost farcical expectations of potential recovery for most GBS patients, who **do** hold and are so-called covered by private health cover; this practice seems short-sighted and totally inadvisable. The Public Rehab Centres may also have a similar time frame, but a little more elastic for a GBS patient. I cannot comment on the situation in the Public system.

Still another new GBS patient with a limited intellectual disability also currently in a Rehab Centre was thought by his family to being discriminated against because of his limitations. This family were very defensive of their family member, and rightly so if this is/was the case. Once again this patient's family acted as his guardian, his advocate to support their brother in the family's perception rightly or wrongly, of an injustice to their brother to speak out to aright the position. The role of the family in both cases is/was paramount to changing an untenable situation for their loved one. I'm not sure I can add more to recognise how important our families are to support us in these times of trying need.

Not the slightest suggestion or implication is intended of any inadequacy or indeed the quality of the attention given to patients in Rehab. Centres is in anyway implied. In fact it is the very reverse the quality of the procedures in the Rehab. Centres and the results achieved whilst in their charge, which makes the wish from both patient/s and their families to have the best possible care available to them – at least to stay until a reasonable degree of recovery has occurred before being discharged is the prime focus of all associated with patient recovery and the rehabilitation of all patients whatever the situation might prevail, but from this Association's focus, we hope in particular for all GBS patients whether they have Private Health cover or not.till next time thanks again for your on-going support, bye ... **Mary**



The Hon Jillian Skinner MP
Minister for Health
Minister for Medical Research

M14/6415

18 DEC 2014

Mr Mark Kunach
Chair
GBS Association of NSW Inc.
Email: Mark.Kunach@def.nsw.edu.au

Dear Mr Kunach

Thank you for your correspondence advising of the passing of Mr Ronald Nichols and of his lengthy volunteer service for The Guillain-Barré Syndrome Association of NSW.

Please extend my condolences on his passing and my recognition of his valued contribution and compassion in helping others who have been diagnosed with Guillain-Barré syndrome.

It is clear from your letter that Mr Nichols' work has had considerable impact upon others and provided great benefit to fellow sufferers, their families and those who care for them in our health services. His ability to put his own suffering aside to help others is truly admirable and demonstrates the immense value that volunteers can bring to patients and whole communities. Mr Nichols' work has, no doubt, made a difference to many people's lives.

In NSW, the work of volunteers is recognised as a very valuable component of health service provision. NSW Health greatly values the work done every day by hundreds of volunteers who offer their time to help patients and health service staff in a wide variety of ways.

I recognise that groups, such as the GBS Association of NSW, provide critical support for patients experiencing ongoing or long term illness, who can benefit immensely from interacting with others who have had similar experiences. Please convey my thanks to all the members of The GBS Association of NSW for their contributions.

Thank you again for bringing Mr Nichols' contribution to my attention and the important role he has played in providing support for patients and families.

Yours sincerely

Jillian Skinner MP

The GBS Association of NSW is honored as the State Minister for Health recognises not only Ronald's invaluable service, but that of the members.

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:**

Attila de Szoeko

TREASURER & PUBLIC OFFICER: Christine Simpson-Morgan**SECRETARY:**

Glenda Ford

MINUTE SECRETARY:

Ronald Nichols

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Financial Year 1st January 2015 to 31st December 2015

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CIDP

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RELATIVE

Annual Subscription Renewal

\$ 20.00

Donation

\$

Total

\$

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

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: (if would you like your Newsletter via email)

☐ 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 2014

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 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 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 Christine Simpson-Morgan:-

Mail: 8 / 36 Mobbs Lane EPPING NSW 2121

Email: smorgan8@bigpond.net.au