



# RECOVERY

GBS / CIDP  
GUILLAIN BARRE SYNDROME  
CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY

## From the Editor

This time of year I would usually be writing the editorial with a sense of excitement at the prospect of holidays and festivities. Not so this year.

Our GBS family is deeply saddened to share the news that our much respected Minute Secretary, Ronald Nichols left this world on 25<sup>th</sup> November.

Ronald fought a brave battle for life, which he loved and lived and has left an indelible mark on the people within our Association. Ronald worked tirelessly to support and comfort GBS patients in hospital and was the voice of calm and reason within the Committee. Ronald always had concern for others first and foremost, and in his kind, gentle and unflappable way could sooth and smooth any mood or situation. He quietly, and unaware, commanded respect and admiration. When I think of Ronald I think of a true gentleman, dignified, humble and caring.

Outside of the Association Ronald, a fellow cat lover, would speak to me of his precious cat Pushkin, of his devoted partner Stephen, his deep faith and his passion for travel. Well Ronald. Sir. We shall miss you and wish you Bon Voyage on your final journey. Thank you for your friendship and your service. May you rest in peace as you live on in our memories always.

Briefly in other news, the situation regarding Intragam is gaining more discussion. It is the main theme of this edition and if you are affected, we're sure you will find it interesting to know where this is headed. We encourage you to write to your local MP so they are aware of the looming issue and that they might rally on our behalf.

Well, as I sign off with a heavy heart I know that Ronald would want us all to keep working hard and with purpose. As we hurtle towards another year may your Christmas be filled with family, happiness, health, peace and joy. I look forward to bringing you more in 2015.

Christine Simpson-Morgan  
*Treasurer, Editor, Public Officer and Website Facilitator*



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**Next Meeting: 7<sup>th</sup> February**  
**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.*

# Message from the Chair

Welcome to the last edition for 2014.

Firstly, I am told I am good with words, yet on this occasion I struggle to articulate the loss and deep sorrow I feel at the passing of our dear friend. As the tears well in my eyes I will attempt, in some small way, to make sense of the premature departure of someone who still had so much to offer.

His loss not only impacts his partner, family and friends, the nation has lost a willing volunteer, a person who thought nothing of putting aside his own pain and disability in order to help others.

Ronald was a friend and mentor not only to me but to many. His humanity, compassion, empathy, dedication and fastidiousness for good form and doing the right thing are some of his traits that stand out for me. He was a champion for sufferers of GBS/CIDP and there are many whose speed of recovery, especially their mental acceptance of GBS/CIDP, was facilitated by his calm demeanor during hospital visits.

Whilst I am not thankful that I am afflicted by CIDP, without it I would not have met Ronald and for that I am immensely thankful. As Minute Secretary, Ronald had the job of keeping our meetings flowing according to the agenda and accurately recorded. I miss his polite interjections reminding me of the time and to wind up waffling on too much!

As Chair my role is made easier in the knowledge I have a dedicated and hard working Committee and Ronald was an integral and much loved member.

I know each and every one of them feels a deep sadness as I do that we will no longer see Ronald's smiling face and resolute countenance as he duly records our meetings. They say no one is irreplaceable and the GBS Association will eventually recover from the grief and continue to offer support to sufferers; he would not want it any other way. However, if you happen to meet another person of similar caliber to Ronald Nichols, take the time to get to know them and your life will be remarkably enriched for the experience.

We mourn the passing of a member of the GBS/CIDP family. He is no longer with us yet will forever be in our thoughts.



*"As Chair I feel privileged to be part of the Association providing the opportunity to help those impacted by GBS/CIDP to tell their story."*

As business goes on, I would like to start by acknowledging the fine ongoing work of your Committee without which we would not have a functioning and active GBS Association with telephone and email support, a first class website and Recovery our newsletter. No organisation can function without Administration and our Committee ensures inquiries are answered, bills paid, Recovery edited and printed, website kept up to date, meeting rooms and catering booked and minutes taken to name just a few of the regular duties. They get no pay and ask no reward other than to help offer support to those afflicted by GBS/CIDP or related disorder. They can all relate back to their own circumstances, the myriad of questions, the disbelief, fear, stress, trauma etc. of a diagnosis of GBS/CIDP and the sense of relief when contact was made with the GBS Association. Further, they know without the Association sufferers, family and friends would continue to face an often uncertain future without the readily available support of fellow sufferers along the road to recovery.

You may be aware we held our last meeting for 2014 at the Royal Rehabilitation Centre at Ryde on Saturday 1<sup>st</sup> November 2014. It was a great meeting on a number of levels.

Our donation of equipment to Ward A4D, Ambulatory/Immunology clinic, at Westmead Hospital was approved. I am advised this clinic has the highest throughput of patients receiving IVIG in NSW and possibly Australia, including myself. It was decided we could support GBS/CIDP patients directly by providing the hardworking staff with additional equipment they need to help them provide even better treatment/support to patients such as saddle seats, vitals monitors and a surgical trolley to the value of \$8514.00. We will have more about this donation and the process in future editions.

We continue to have very beneficial forums during our meetings where either new sufferers, their partners, family and friends plus some old acquaintances drop in to talk about their experiences and share their knowledge. These forums are often very cathartic and I encourage both new and older sufferers to come to our meetings to experience the highs and lows of these often emotional journeys to recovery. Yes, there are often tears of sadness but also tears of joy of an experience shared. I always take something personal and positive away from these forums and learn so much.

Also at the last meeting Ken and his wife returned with Ken recalling a recent visit to a GBS patient in Nepean Hospital where he also spent many many months in ICU and recovering from GBS. We continue to hear of the immense value such hospital visits are to both the patient, family and friends who are thrust from an erstwhile healthy existence into the intense and complicated world of GBS/CIDP. Just having a fellow sufferer already on the road to recovery visit helps brighten that dim light at the end of the seemingly endless GBS/CIDP tunnel. If you hear of anyone in hospital suffering from GBS/CIDP and you think they might benefit from a visit please refer them or their family to the GBS Association website.

Further, we had a very welcome visitor in the form of Trish Brice, wife of David Brice who recently passed away in 2012. David was a past president of the GBS Association and suffered 5 GBS attacks in his lifetime, an extremely rare occurrence. David was a huge inspiration to many with his commitment to those living with disability receiving accolades from many including the Governor-General. We hope to continue to see both Trish and Ken at future meetings.



*In a special mention to those in the Association who have been unwell, we wish them, their family and friends, and indeed all our members, the best for the coming festive season and a Happy New Year.*

*Kindest Regards  
Mark.*

## An Important Issue of Concern

We, as sufferers ourselves or as those closely related to sufferers of GBS and CIDP, are very concerned about the Government's possible introduction of a policy to restrict access to IVIG treatment in the future.

We need **you**, if you hopefully share our concern, to write to your local MP expressing your position. **Even better**, encourage friends and family to do the same. **The more the merrier!**

Below please find a form letter, which you can modify as you wish, and send to your local member.



Dear (Local Member),

I have recently learned that the Government may be considering limiting IVIG as an outpatient treatment option for people with GBS and CIDP. As one such patient who / as a close associate of someone who receives these infusions may I first say how sincerely grateful I am to the Government and blood donors for making this precious product available to those with these debilitating neurological conditions.

I feel it is important to raise awareness, and for decision makers and change leaders to understand, how crucial this treatment is to maintaining and stabilizing the condition and how it assists individuals manage daily living. It is because of this treatment I/my friend/relative can continue to work, pay taxes, and make a valuable contribution to the community.

This is done via donating time to the GBS and CIDP Association NSW, a support group focused on providing information and emotional support to newly diagnosed and long term patients and their families. Because of this on-going IVIG treatment, I /my friend/family member is also able to assist in .....(any community activities that are relevant)

There are many more similarly affected people who are able to give back in the same way. We can ONLY function in this capacity because we are fortunate enough to receive IVIG. Without it we are likely to need to look to the Government for more assistance. I fear a life without IVIG is not a life, and work, taxes and charity will be the casualties. I sincerely appreciate your time in considering my concerns and those of many other 'fellow travelers'.

Yours sincerely

(Name)

(Address)

(Date)





Mr Mark Kunach

Chairman

Guillain-Barre Syndrome Association of NSW

Dear Mr Kunach,

I am writing to advise the membership of the Guillain Barre Syndrome Association of NSW about the publication of the national policy for access to government funded immunoglobulin products in Australia, effective 5 November 2014 (in all states and territories except Western Australia).

The National Policy clarifies the roles, responsibilities, authority and accountability of those involved in authorizing, supplying, managing and using immunoglobulin products throughout the supply chain and within health services. It is one of a number of measures being developed and implemented under the immunoglobulin Governance Program, endorsed by all governments, to improve the governance and management of government funded immunoglobulin products. These measures are being implemented to ensure sustainability of immunoglobulin products into the future.

Key changes that will affect health service staff and their patients, following implementation of the National policy, include the following:

- New Authorisation Request Forms will be implemented from 5 November 2014. The new forms will be available for download from the National Blood Authority (NBA) website at [www.blood.gov.au/immunoglobulin-ig-governance-program](http://www.blood.gov.au/immunoglobulin-ig-governance-program)
- Current forms will not be accepted from 5 November 2014 as they are not compliant with recent legislative and regulatory changes
- The Authorisation Request Forms will have two pages with a Prescriber acknowledgement and confirmation that the patient (or parent/carer/guardian) has provided their explicit written or oral consent to;
  - Treatment with immunoglobulin products, in accordance with National Safety and Quality Health Service (NSQH) Standard 7, and

➢ The collection, retention and use of their personal sensitive data for the purpose of authorization for access to government funded immunoglobulin products, in accordance with the changes to the Australian Privacy Principles.

- A standardized national patient treatment review process with new Patient Treatment Review Outcome Notification Forms. The provision of information from the prescriber confirming clinical benefit of treatment is required within one month of the patient review date for authorization for continuing access and supply of immunoglobulin products. In principle, immunoglobulin product use should only be continued where there is demonstrated clinical benefit. Prescribers will also need to confirm that patients (or their parent/carer/guardian) have provided their explicit consent to the collection, user and retention of their personal sensitive data, if this has not been provided in the last 12 months
- Patient weight will be required to support the requested dosage
- Access to continuing supply of product may be ceased if the patient treatment review outcomes notification is not received by the Authoriser within one month of the patient review date
- In hospital product ordering and management should be co-ordinated centrally by the dispenser role with responsibility for product inventory management to ensure transparency and maintain traceability of product use. Product ordering should be through BloodNet (where available), the NBA online blood and blood product ordering system. Product orders should be relative to clinical demand and stock on hand.
- Prescribers and Nurses should not order product directly from the Australian Red Cross Blood Service. Products should be ordered and managed by the health service central dispenser as described above.

We would be grateful if you could assist with communicating the changes with the membership of your organisation.

**Leigh McJames**

**General Manager, National Blood Authority**

Further information can be obtained from the NBA website at [www.blood.gov.au/immunoglobulin-ig-governance-program](http://www.blood.gov.au/immunoglobulin-ig-governance-program). Please address questions NBA Immunoglobulin Governance Team on 13 000 IG GOV (13 000 44 468) or email [support@blood.gov.au](mailto:support@blood.gov.au).



## *Vale Ronald Nichols*

### *1940 - 2014*

Dear Friends,

On behalf of each member of the Committee of the GBS Association, and with my own deep and personal sadness and regrets, that we announce the death of our dear friend and colleague Ronald Nichols on the 25<sup>th</sup> November 2014. Ronald passed on to a gentle peace with his loved ones with him, after ten months of the most courageous and determined confrontation with cancer. His passing will be grieved by us all.

Ronald was born in Western Australia in March 1940, the son of Walter N.J. "Jack" and Doris Nichols. Ronald had three brothers Haydn, Trevor, Kevin, and one sister Joyce "Joy". To each member of Ronald's family we extended to all, our sincerest sympathy and condolences in the passing of such a remarkable brother.

Ronald was a truly remarkable individual. Often in these sad times we feel the inadequacy and a loss of word-ability to effectively and correctly describe people such as Ronald. In his presence I felt his calmness, and a certain sense of being in the presence of safe harmony. All who met

Ronald would meet an articulate, reserved but strong, yet also gentle, humble, chivalrous, knowledgeable, smiling, charming, concerned, meticulous, compassionate, focused, and attentive to even the smallest of people's concerns. I'm not sure if I have captured even the smallest aspect of such a person. I admired Ronald very deeply and in my own life try to emulate something of his nature.

It was not for some years after I had known Ronald that I knew more about his work life, although I knew he had a deep dedication and strong religious affiliations. It was typical of Ronald that he should not speak of his achievements however the following excerpt are in Ronald's own words, a transcript from a radio interview broadcast in Singapore, soon after Ronald retired in 1998.

*"Ronald leaves us a wonderful personal and real legacy of his being part of our lives and the differences for the better he made because he was there and who he was..."*

*I joined the ABC on 21 December 1955 as the office boy in Perth, but I joined the religious department on 14 February 1966. I was transferred from Perth to Melbourne, where I joined the religious department as a Grade One Religious Broadcast Officer. "Perhaps just to tell my own story, I was always interested in religious broadcasting and in the ABC, and started that work in 1966, in Melbourne in Australia, because I had a passion, a strong urge to work in this field, to see how I could make fine programs on the churches and theologians and this has been my life's work. And I've produced documentaries; I've produced music programs, liturgies, theological talks, literature, music, because I believe that the finest quality of work is what should stand up, and that if it's not good quality that it shouldn't be recognized. And so I've tried to use the best possible broadcasting principles in doing that... and it happens to be religion. And in my own work I've travelled to other countries, and won an award in some of that work: on the Anglican Bishops in England, the Lambeth Conference of all the bishops around the world; the World Council of Churches Assembly in Vancouver in 1983, and in Canberra in 1991. And I've also spent 2 years in Papua New Guinea in the early 70s,..... I was able to train a number of new broadcasters who had come in fresh, with no experience, to arrange programs for the ABC at that time, but also to work with others on what the new national broadcasting commission should be like"*  
**Ronald was Executive Producer of the ABC [Radio] from 1994-1998 when he retired.**

Ronald's first on set of GBS was in March 2001 he also suffered a relapse some weeks later, nevertheless Ronald still very weak and debilitated came to his first GBS meeting in the May of the same year. In 2005 Ronald was elected to the Committee, and from 2008 to the present was Minute-Secretary of the Association. During those ensuring thirteen years his contributions to debate and considerations, were approached with reasoned good commonsense, practicability, focus and responsibility to his fellow man. It was always in his mind to achieve more and do more for GBS or CIDP, he often said we work as a "team" for the betterment of others, principally of course it was for GBS and CIDP. In all those years I never witnessed Ronald ruffled somehow he managed to convey his strengths in a manner which appeared to have reason and rational. It is hard to imagine how we will fare without his presence, but we will ... because this was also his 'passion' to serve, therefore it beholds us all to take up his challenge and do what we can in the future to uphold his beliefs.

Ronald's last months of his tremendous battle with his cancer was nurtured, supported and loved by Stephen. There was not a moment in all those months that Stephen was not there at his side, to listen, to encourage, to rescue, to support, to just be there whether it was in the early hours of the morning, day or night, and above all to love Ronald... I cannot express just how much Stephen played a role in the life of Ronald, it makes me proud to even know of such a person, and doubly was there tirelessly for Ronald helping him through such a perilous journey as Ronald was on... I salute Stephen, and know we too grieve with him at Ronald's passing from our lives physically but always in our hearts and minds... **all my love Mary**

## 01 Vitals Machine

*reads pulse, temperature and blood pressure*



## 02 Surgical Trolley

*mobile unit stores swabs, syringes, bandages*



## 03 Saddle Seat

*nurses can sit steadily and comfortably to administer treatment*



**Our donation to Westmead Hospital, on behalf of members, goes to much needed equipment**

# Photo

**It's all in a Saturday morning's work for our Committee**



Meeting 7<sup>th</sup> November 2014. Mark Kunach and Glenda Ford (head table) and left Ursula Carlile, Max Trachsler, Mary McAlister. Jane Rothman and Max Humphries (forefront)



**The topic of Intragam generates a lot of debate and discussion**

Meeting 7<sup>th</sup> November 2014. Trish Brice and Jane Rothman (far end head of table). Left: Attila and Helen De Szoeki, Max Humphries. Right: Ken and Rita Brooke with Mary McAlister



# Back Page Bits 'n' Piece *Thank you!* SMARTPRINT for donating printing and labelling of our Newsletter

## 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 Szoeki

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

**SECRETARY:**

Glenda Ford

**MINUTE SECRETARY:**

Ronald Nichols

**GENERAL**

Mary McAlister

Jane Rothman

Wendy Burge

Max Humphreys

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**WEBSITE:**

www.gbs-cidp-nsw.org.au

## ANNUAL SUBSCRIPTION / DONATIONS

Financial Year 1<sup>st</sup> January 2015 to 31<sup>st</sup> December 2015

Name:

Address:

Address:

Phone / Mobile:

email address: (if would you like your Newsletter via email)

*Please indicate your interest*

☐

GBS

☐

CIDP

☐

DOCTOR / MEDICAL

☐

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 <sup>th</sup> February	2 <sup>nd</sup> May AGM	1 <sup>st</sup> August	7 <sup>th</sup> November
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### Financial Year 2014

Members are reminded the Association's financial year is

1<sup>st</sup> January 2015 to 31<sup>st</sup> 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