



NEWSLETTER OF THE GBS ASSOCIATION OF NSW INCORPORATED

RECOVERY

Dear Members,

Well things have quieted down somewhat since last I wrote when we had launched the new website and newsletter (phew!). Generally we feel the whole new look has been well received and we certainly hope that you the members are happy with what we have achieved.

Since then we also re-worked our Constitution (Step 1) that we shared with you (Step 2). I can report that has now been registered with the Fair Trading department (Step 3) so next stop is the Taxation Department (Step 4 and last step). So you can see that whilst it may be a little quieter there is always something to do and that is a good thing, it means we are moving forward!

Our AGM held in May was a time for reflection but also for us to see what is next in our quest for giving help and support to our members and new GBS I CIDP patients.

As Treasurer it's my job to ensure that your wonderfully generous and kind-hearted donations are put where they can give maximum benefit and make a difference to someone who is in need.

Whilst this is a function of the Committee in the broader sense, it is really important that you should have a voice in where we might choose to invest. We have had discussions, and in fact have set up a 'sub-committee' to explore where we may best assist the health services Community. Anything we do should have a focus on people receiving treatment or having suffered GBS, CIDP or indeed any other related disorder but for whom life may not have yet returned to normal.

Over page you will find a form that we would like to you complete and return to us if you have any ideas about where you see a gap in the current system we could fill. Was there, or is there, something you needed as a patient or observed as a family member that would've helped to make your recovery easier, or helped you a little more.

If so we want to hear about it. PLEASE. It could just be the idea we can actually make happen and it could happen because YOU made it happen!



Inside

Page 2 Community Support Project

Page 3 Chairman's Message

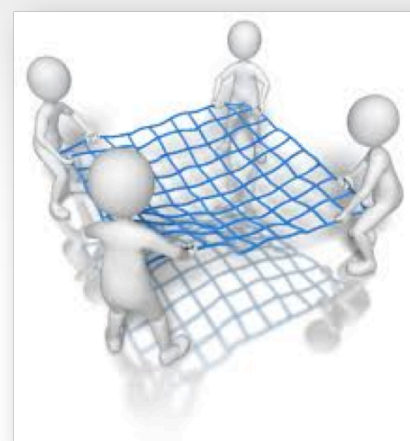
Page 4 NSW Health – Hand Hygiene

Page 5 Update on Guillain-Barre Syndrome (cont'd)

Page 7 Call-a-Friend

Member to Member
Dulcie Hartley update

Page 8 Back Page Bits n Pieces



GBS | CIDP AND RELATED DISORDERS

Community

Support
Project



Name:



My idea is:

Before signing off from this edition I would like to ask our membership to spare a thought for a number of our Committee who have fallen on ill health in recent times. We have had some ups and downs with Mary's husband Arthur now doing really well after not being at his best and this is wonderful news for Mary and Arthur. Others are not doing so well and it is for them we take the time to reflect and appreciate their tireless efforts for the Association and pray for a full and speedy recovery.

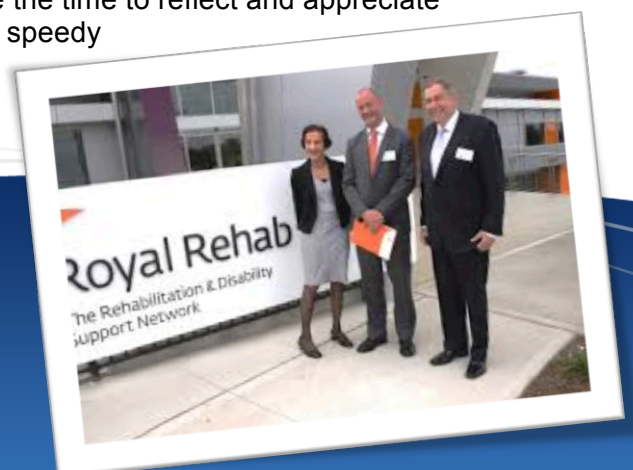
Until September - **Christine S-M**

5th July

Royal Rehabilitation Centre Sydney

235 Morrison Road, Ryde

"Susan Schardt Conference Room" L1



09:30 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 another edition of Recovery and with the weather turning decidedly cooler it is time to rug up, sit back and read on.

However, have you ever wondered what goes into publishing our newsletter Recovery? Well for one a lot of effort and time by our intrepid Editor Christine, who is also Treasurer, Website Manager and Public Officer. At our recent AGM there was some discussion about committee positions and the reality that in the absence of more volunteers, some existing committee members such as Christine must wear several hats if the GBS Association is to continue to provide the current level of support for sufferers, family and friends. We are always seeking content. If we haven't heard from you in a while, updates on how you are going are always of interest or perhaps a partner may have an interesting perspective. Perhaps you have some useful tips about how you manage your GBS/CIDP that might help someone else.

Why is it important to maintain not only our current level of support but to seek out new ways to provide support? Well in short things change, technology is ever changing and the expectations of people change. When the GBS Association started more than 20 years ago the internet was an idea, mobile phones were so large they were not truly mobile and Recovery was a simple black and white newsletter.

Today the GBS Association has a new contemporary website, inquiries to the Association can come in via letter, email or telephone and today's Recovery is in colour and professionally published. The Constitution has had to be updated to reflect changes in technology vis-à-vis online donations. During our meetings there is a time set aside for a forum where sufferers, family and friends can talk about their journey to recovery. Also, on meetings we are back at the Ryde Rehabilitation Centre and I must say the new centre is truly impressive. Anyone who attended earlier meetings in the old Charles Blunt Room will marvel at the changes.

However, there is always more to be done and your committee cannot work in a vacuum. We need input from members, carers, sufferers, health professionals etc. What areas of support need more work? Is it in providing funding for research, providing funds to up and coming students interested in GBS/CIDP research or equipment to assist/support GBS/CIDP patients in hospital or some other area we haven't yet considered?

The GBS Association is not just the committee. The committee represents the membership. If you have an idea give us a ring, write a letter, send an email or come to a meeting. You do not have to drive any subsequent project yourself, just provide the acorn and we will see if we can grow a tree.

Kindest regards,

Mark



If you have an idea give us a ring, write a letter, send an email or come to a meeting.

There are now more ways to contact the GBS Association and more ways to obtain information and support.

Your committee has worked very hard over the past 12 months to ensure the GBS Association is keeping pace with change.



Our Committee member Jane Rothman is a patient advocate whose GBS experience has made her passionate about the health system, especially the lack of understanding and support for the role of rehabilitation services. She provides input to health professionals about how the patient is affected and offers insight as to how to help improve patient health and wellbeing. Here we share one of her collaborations with NSW Health.



English March 2006 CEC8285/06 [DOH-7680]



Why is hand hygiene important?

Hospital patients are generally unwell, re-covering from an operation or may have decreased immunity leaving them at increased risk of infection from germs. We want to help stop patients from getting these infections because often causes lengthy and serious infection in people who are already unwell. One of the easiest and most effective ways to reduce infection is for all staff, patients and visitors to practice good hand hygiene.

What is good hand hygiene?

Good hand hygiene means washing using either alcohol-based hand rubs or soap- and-water to help stop the spread of germs. By stopping the spread of germs we can reduce infections among patients.

Our commitment to you

All staff in this hospital treat hand hygiene seriously because we know this is one of the easiest ways to help keep patients as safe and healthy as possible.

Our staff should clean their hands 'at each contact' or, put more simply, before and after touching each patient.

During your stay as a patient or visitor at this hospital we invite you to join us in the fight against infection by achieving the best hand hygiene possible.

Hand hygiene is everyone's business

Patients and visitors have an important role to play in ensuring hand hygiene throughout the hospital.

- **Visitors** should clean their hands each time they enter or leave a patient's room.
- **Patients** and visitors should never touch wounds, dressings, intravenous lines or other tools being used to treat a patient
- **Patients** should have good personal hygiene, especially while in hospital. This includes cleaning their hands after going to the toilet and before meals.



It's OK to ask

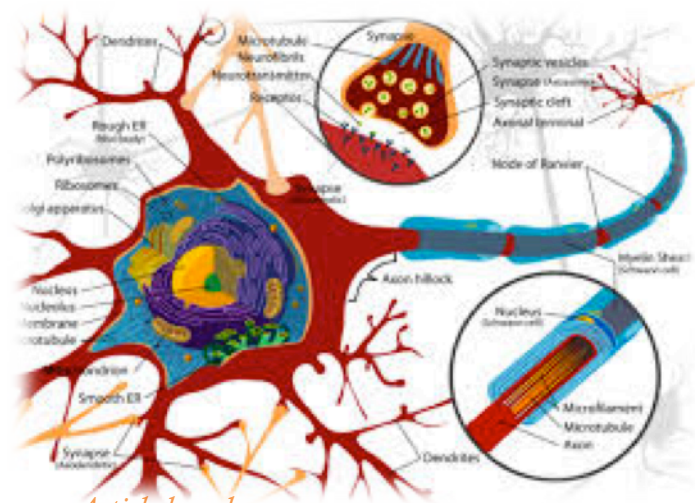
From time to time our staff can become very busy, and patients may wonder if their doctor, nurse or other healthcare provider cleaned their hands before and after touching them.

As part of your role in the fight against infection we hope you will remember that 'it's OK to ask'. If you are in any doubt, don't hesitate to remind hospital staff about this important practice.

Update on Guillain-Barre Syndrome *(continued from March 2014 edition)*

Simon Rinaldi

Nuffield Department of Clinical Neurosciences, University of Oxford, Oxford, UK



Article based on a plenary lecture given at the 2012 Peripheral Nerve Society (PNS) meeting

reduces respiratory tract infection, thromboprophylaxis has reduced the risk of venous thromboembolism, and there is increasing awareness of the benefit of high-intensity rehabilitation. This article highlights some of the interesting and thought-provoking developments of the last 3 years.

Abstract Understanding of Guillain-Barre syndrome (GBS) has progressed substantially since the seminal 1916 report by Guillain et al. Although Guillain, Barre', and Strohl summarised the syndrome based on observations of two French infantrymen, 2012 saw the beginning of an ambitious collaborative study designed to collect detailed data from at least 1,000 patients worldwide (IGOS, www.gbsstudies.org/about-igos). Progress has been made in many areas even since GBS was last reviewed in this journal in 2009. GBS subsequently received prominent attention in light of concerns regarding H1N1 influenza vaccinations, and several large-scale surveillance studies resulted. Despite these developments, and promising pre-clinical studies, disease-modifying therapies for GBS have not substantially altered since intravenous immunoglobulin was introduced over 20 years ago. In other

areas, management has improved. Antibiotic prophylaxis in ventilated patients

Disease induction

More generally, the primary importance of either the cellular or humoral immune system in initiating the disease process has long been debated. As long ago as 1949, attempts were made to clarify this using autopsy data, which suggested a humoral response preceding cellular infiltration (Haymaker and Kernohan, 1949). The frequent detection of anti-ganglioside antibodies in axonal variants, only sporadic antibody detection in demyelinating disease, along with evidence of early cellular infiltration in modern pathological AIDP specimens, has led to more recent speculation that AMAN is an antibody-driven disease, whereas in AIDP the cellular immune system is primarily involved (Hughes and Cornblath, 2005). With the realisation of increasingly diverse functions for T cells, B cells, and other immune effectors, it seems intuitive that both disease processes result from interactions between these different immunological components (Fig. 3).

There is also increasing evidence that subtle differences in the infecting organism profoundly influence the subsequent immune response. *C. jejuni* lipo-oligosaccharide (LOS) containing sialic acid significantly increases the activation of

dendritic cells compared with non-sialylated LOS, a process dependent on TLR4 (Kuijff et al., 2010). This activation may also influence the subsequent antibody response, which in GBS patients is often cross-reactive with sialylated *C. jejuni* LOS and self-ganglioside molecules (Goodyear et al., 1999). Sialylation modulates the phagocytosis and tissue destination of *C. jejuni* (Huizinga et al., 2012). It increases the production of the IL-6 and IL-10 cytokines by macrophages and dendritic cells in vitro, and the production of IFN- α and IFN- β in vivo, which might be expected to lead to polarisation of the immune response, as well as an enhancement of B-cell receptor activation, immunoglobulin production, and isotype switching (Huizinga et al., 2012).

Indeed, whether monosialylated or disialylated LOS is encountered can in itself profoundly influence the subsequent immune response. It is established that infection by *C. jejuni* with $\alpha 2,3$ mono- sialyltransferase activity is more likely to result in the production of antibodies directed against GM1 and GD1a and thus induce AMAN. In contrast, *C. jejuni* with $\alpha 2,8$ bifunctional sialyltransferase activity induces anti-disialylosyl antibodies such as GQ1b and gives rise to MFS (Koga et al., 2005; Koga and Yuki, 2007).

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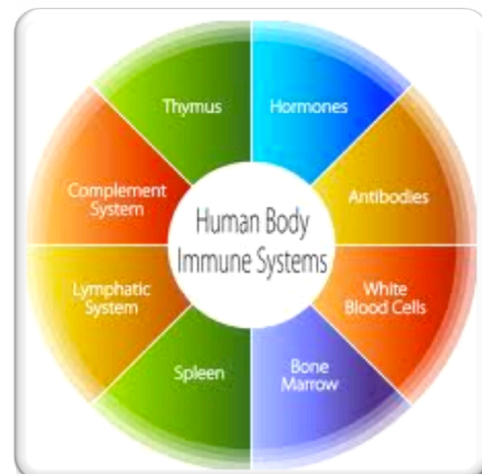
It is now additionally apparent that monosialylated LOS preferentially interacts with sialoadhesin (Heikema et al., 2010), a member of the Siglec family of immunomodulatory receptors displayed by antigen-presenting cells. This interaction favours a Th2-type response, with increased production of IL-4 and related cytokines, promoting B-cell/humoral activity. In contrast, disialylated LOS favourably binds Siglec-7, results in greatly increased production of IFN- γ , driving a Th1 (macrophage/cellular) response (Bax et al., 2011).

The above observations highlight the way in which the initial encounter with the innate immune system can modulate the subsequent adaptive response. Further support for the role of the innate immune system in GBS has come from studies showing upregulation of TLR mRNA in the acute phase of the disease. Nevertheless, the upregulation of TLR2, 4, and 6 mRNA negatively correlated with disease severity in one study (Gries et al., 2012), whereas in another higher levels of TLR2, 4, and 9 expression were positively associated with disability score (Wang et al., 2012). The reason for this difference is unclear. Both studies involved patients early in the disease course, employed identical severity scales, and used similar methodology to assess expression levels, although RNA was extracted from whole blood in one study and from peripheral blood mononuclear cells in the other. It may be that geographical differences in the proportion of patients with different GBS subtypes are responsible for the apparent discrepancy, rather than subtle differences in methodology, although the latter cannot be completely discounted.

Suppressing one aspect of the immune response does not necessarily result in improved outcomes. Mice lacking IFN- γ , and hence having a much attenuated Th1 response, develop more severe EAN than controls (Zhang et al., 2012). This result is difficult to resolve with previous observations of EAN in rats, which was augmented by recombinant IFN- γ and attenuated by IFN- γ - neutralising antibodies (Hartung et al., 1990). Of course, certain immunological responses may be reparative, suppressing one facet of immunity may enhance another (particularly Th2 and Th17 when Th1 is suppressed), and there is a long history confirming the difficulty in transferring results across species and from models to diseases.

In keeping with the typical disease course of GBS, inflammatory cytokines TNF- α , IL-1 β , and the matrix metalloproteinase 9 (MMP-9) are raised in the active phase of the disease, but fall back to below control levels in recovery (Nyati et al., 2010). The way in which these molecules fit into the overall disease process and the mechanisms by which they are subsequently down regulated are yet to be established.

The MMPs might either act as myelinolytic agents, be involved in the disruption on the blood-nerve barrier, or both. *(to be continued)*



Immune System

In summary, following infection, the nature of the immune response is governed by both host and pathogen factors.

There is evidence of early activation of innate immunity which then guides the adaptive response.

On one side a predominantly cellular response results, and on the other B cells are activated without T-cell help, but synergistic action is also possible.

Call - a - Friend

This edition we are without Mary's regular 'call-a-friend' as she recovers from a recent cataract operation. I have spoken with Mary, and whilst there have been some complications; she is in good spirits and on the mend. Of course she has still been on the telephone supporting other people throughout and she reports a spike of enquiries resulting from the publicity surrounding the high profile and public GBS diagnosis of the AFL Hawthorn coach Alastair Clarkson, who we understand is still under treatment in hospital.



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

Member to Member

In September 2010 we introduced you to Dulcie Hartley who was struck down with GBS in February of that year. In this edition Dulcie updates us on her journey from then until now.

It is now 2 ½ years since my last report when I had recently returned to my home from hospital and in which I documented my battle with GBS. I wondered at the time whether 'this is as good as it gets'.

Well, despite my best efforts at rehab, it was 'as good as'. I have been a walker all my life and active in other sports, and I was determined to get back into this pass time. I found that I have to concentrate on walking and if my mind wanders, I stagger. My daughter told me that I walked with 'an unusual gait' which was a bit of a worry. I persevered and have now settled on half hour walks, up hills with some bush tracks which is probably not a bad effort for an 85 ear old.

My balance did not improve and walking down steps is difficult, but walking up is quite ok. My manual dexterity is still impaired, with keyboard skills affected.

Ever hopeful, I consulted my Neuro Surgeon who confirmed, after tests, that I have nerve damage. However he more or less said that I had nothing much to complain of as last time he saw me I could not move at all. So just get on with it.

Unfortunately last year I developed a degree of incontinence of both bladder and bowel causing social problems. I consulted a colo rectal surgeon who, after a colonoscopy, found I had nerve damage to both bladder (from childbirth) and bowel (from old haemorrhoidectomy). He thought it likely that the GBS would have had a deleterious effect on these problems. After tests I was fitted with a sacral nerve stimulator and a good result to date.

I am still living independently in the family home, doing my own housework and shopping and still have my license. The gardening is getting a bit of an effort, but my daughter helps and continues to come from work one evening a week, and spends some time with me the following day. I continue with U3A courses and have other social interests.

Best wishes

Dulcie Hartley.

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

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\$ 20.00

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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.

2014 Meeting Dates

5 th April	3 rd May AGM	5 th July	1 st November
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Financial Year 2014

Members are reminded the Association's financial year is

1st January 2014 to 31st December 2014

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