



NEWSLETTER OF THE GBS ASSOCIATION OF NSW INCORPORATED

RECOVERY

GBS | CIDP
Guillain Barre Syndrome
Chronic Inflammatory Demyelinating Polyradiculoneuropathy

From the Editor

An Open Letter to the Hon. John Alexander, MP

Dear Mr. Alexander,

I have recently learned the Government may be considering limiting IVIG as an outpatient treatment option for people with GBS and CIDP.

As one such patient who receives 6 weekly infusions for CIDP may I first say how sincerely grateful I am to the Government and blood donors for making this precious product available to me and other people with these debilitating neurological conditions.

With this discussion 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 can continue to work, pay taxes, and, I would like to think, make a valuable contribution to my community. I do this via donating time to work as a Committee member of 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 IVIG I am also able to assist scripture teachers each week at our local Eastwood public school and have driven and supported fund raising events for many other charities throughout the past 18 years as a CIDP sufferer. There are many more such 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 may look to the Government for more assistance, for 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 others outlined further in our publication.

Christine Simpson-Morgan

Treasurer, Editor, Public Officer and Website Facilitator



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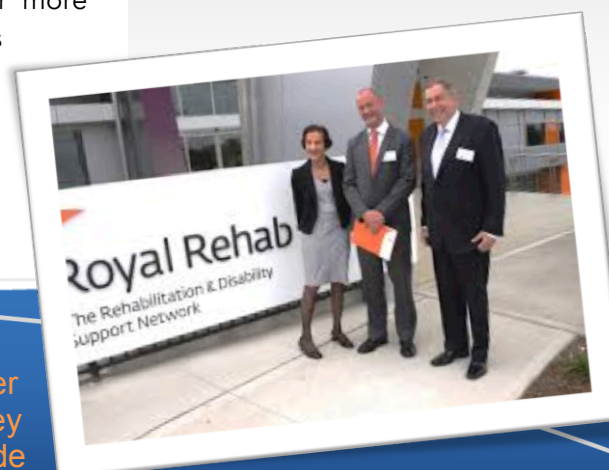
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Next Meeting: 1st November
Royal Rehabilitation Centre Sydney
235 Morrison Road, Ryde
"Susan Schardt Conference Room" L1

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.

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

Message from the Chair

Welcome all to another great edition of Recovery and I hope we find all our members and readers in good health. I, like many, struggle with the cold weather; my fingers and legs tend to become like icicle extensions, often despite my best strategies.

I read recently an article in an IVIG newsletter that espoused the thought that those living with peripheral neuropathies should concentrate on doing their best in themselves and not compare their performance to 'normal' individual performance or even making comparisons with performance before CIDP. However, look to what you can do with what you have now and yes, test the boundaries now and then, but do not become despondent, just ensure you continue to be active within your capabilities.

Sure we have seen sufferers go on to compete in bike riding marathons and some have competed in triathlons but as we know recovery is unique to the individual and moreover what you take with you along the way.

I was recently corresponding (emails as you do these days) with Christine our Editor In Chief, amongst many roles, and discussing this upcoming edition and the need for content. I mentioned that for me each day is not only about recovery but also discovery. Sure my legs become long icicles at times during winter and my fingers work slower requiring more concentration so not only are the physical demands greater but also the mental. I know when my legs begin to feel cold I go for the sports socks and knee high ugg boots and if that does not work I have even tried going to bed with the ugg boots on, sometimes all to no avail, the legs stay cold and then a day or two later they spontaneously thaw.

As with the pain I often feel, I try to compartmentalise it and concentrate on something else, usually something I really enjoy. Also, fatigue is a constant partner I have and will likely have as long as I am afflicted by CIDP and also Ulcerative Colitis.

However, we adapt and put in place strategies to get along as best we can. Sometimes they work and at other times they don't so you re-evaluate and try again.

Yesterday I went for my monthly IVIG infusion not to cure my CIDP but in the hope it will slow the progression. I know there is no current cure and it is unlikely to be found for some time to come.



"The Association is there for anyone who requires our support whether telephone, email, our great new website, hospital visits and our meeting forums which have been a huge success. The feedback has been very positive from both first timers and old hands alike."

So hanging out and just waiting for a cure is not a good strategy. But, trying new things can be; the discovery factor!

Why is this so important for not only the individual sufferer but for other sufferers? Well not only are you helping yourself but you may also help fellow sufferers. We are interested in hearing your strategies of how you get along living with GBS/CIDP. I sometimes have balance issues and feel more comfortable walking close to the wall in a corridor. I take more time and care walking down stairs or when I see a wet or loose surface that I may have to walk along.



If you have developed strategies to help with your quality of life then please consider sharing them with fellow sufferers and write to our Editor to include your useful tips in future editions of Recovery. Further, researchers investigating GBS/CIDP are also interested to learn not only about how GBS/CIDP has impacted upon your capabilities but also how you work around them and turn them into abilities. I know there are many clinicians and allied health professionals who read Recovery and I know when I drop in copies at Westmead Hospital the copies do the rounds of the immunology/ambulatory care clinic and the neurological ward. Plus, newly diagnosed patients are keen to learn about what happens post a diagnosis of GBS/CIDP.

Reading about strategies put in place by those living with GBS/CIDP is a good news story and helps those new to GBS/CIDP understand there is a future and you can go on to do many things.

You will often hear me speak about improving the quality of life of sufferers. As previously mentioned a cure is a distant aspiration and current treatments may work for some and not for others and we do not know why. I currently receive treatment with IVIG, a very expensive treatment but, one with few of the side effects of other treatments such as immunosuppressant medication that I am also taking. I do not know the future of my CIDP and how slow my progression will be. Currently I am self-ambulatory and work full time but I sometimes wonder how long my strategies will work and whether at some stage I will require external help with day to day living. IVIG is part of a suite of strategies, albeit currently a very important part, I have to help me improve the quality of my life.

It has recently come to my attention that the Federal Government may be reviewing the use of IVIG which may mean they are concerned about the cost and looking at ways to reduce the cost. We know IVIG is expensive to make and uses a lot of blood products in the process. I am sure those specialists who prescribe IVIG do so taking the health of the patient plus the above into careful consideration. I will be expressing my concerns about any proposed reduction in the availability of IVIG to my Federal Member as the treatment options for GBS/CIDP patients are few indeed.

Until next time, cheers
Mark.



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

How to clean with alcohol-based hand rubs*

Alcohol-based hand rubs significantly reduce the number of germs on the skin, are fast acting and can cause less skin irritation than frequent use of soap and water.

Alcohol-based hand rubs don't work well when skin is visibly unclean because they don't release and rinse away dirt the way soap and water do.

- Alcohol-based hand rubs clean hands without water.
- They evaporate cleanly away, and also contain moisturising agents to preserve your skin's good conditions.

The key steps to good hand hygiene with an alcohol-based hand rub are:

1. Apply the product to the palm of one hand and rub hands together, covering all surfaces of the hands and fingers, until hands are dry.
2. Long fingernails or artificial nails make hand hygiene difficult to achieve. For these people extra attention to scrubbing underneath fingernails is required to remove dirt and germs.

** International Muslim Imam scholars allow the use of alcoholic hand rub for hygiene purposes*

How to clean hands with soap and water

Soap and running water remove dirt and grease from hands. This is the best way to clean your hands when they are visibly dirty.

The six key steps to good hand washing with soap and water are:

1. Turn on water and let it run over hands.
2. Apply soap.
3. Rub hands together in order to work up a lather
4. Cover and rub all surfaces of the hands. Lather and rub for at least 10 to 15 seconds. Rinse hands thoroughly.
5. Pat hands dry with a clean paper towel.
6. Dispose of towel in a waste bin.

In one eight hour shift the average nurse can spend close to one hour ensuring good hand hygiene with soap and water.*

Based on a total time of 56 minutes reached through seven (60 second) hand washing episodes an hour.

** Source: Voss A. and Widmer AF, Infect Control Hospital Epidemiology 1997.*

The role of gloves

Gloves can be a helpful and important supplement to good hand hygiene. However, gloves don't eliminate the need for hand washing.

The campaign posters you'll see in this building are there to keep reminding everyone how important clean hands are in the fight to prevent infections.

Like to know more?

Please speak to any of the staff caring for you. They can also refer you to our infection control practitioners if you require more detailed information.

Remember, it's OK to ask.



Exercise and GBS

by Dr Thomas Hedge

As a generality, exercise is good for people of all ages, and specific training produces improvements in muscle strength and endurance, no matter what the age of the individual. Exercise also benefits agility, balance, cardiovascular conditioning, metabolism, work capacity, and weight control, and often fosters a greater sense of well-being.

Physical exercise requires muscle work. Each muscle in the body is controlled or driven by a specific motor nerve (or nerves), and each motor nerve is ultimately derived from spinal roots coming out of the spinal cord.

To produce weakness, Guillain-Barré Syndrome attacks the motor nerves at the root level and along the course of the specific nerves heading to their respective muscles. Once the acute illness phase of GBS subsides, strength redevelops only according to the extent of the recovery of each motor nerve. Physicians and therapists measure the strength of muscles at the bedside, or in their offices, by manual tests which check the strength of a muscle contraction across a joint, such as the biceps.

The patient exerts as much force as possible to bend the elbow while the examiner tries to pull the elbow straight. If the examiner finds the strength of the patient's muscle to be too great to overcome, the strength is graded as normal or 5/5. If the examiner overcomes the patient's muscle pull, the strength is graded as good, or 4/5. If the patient is just strong enough to bend the elbow against gravity, without any resistance by the examiner, the strength is graded as fair, or 3/5. If the patient is not able to move the joint against gravity, but is able to move the joint fully with gravity eliminated, strength is graded as poor, or 2/5. If even in a gravity-eliminated position, the joint can only barely move, or the muscle can only feebly tighten, the strength is graded as trace, or 1/5. A paralysed muscle unable to move the joint or even be perceived by the examiner is graded as zero, or 0/5.

As a very gross over-simplification, muscle strength can be derived from the percentage of functioning axons of motor nerves. Normal strength (5/5) can be achieved with 50 to 100 per cent of functioning axons. Good strength (4/5) is achieved with around 40 per cent of functioning axons.

Fair strength (3/5) indicates about 30 per cent, poor strength (2/5) about 20 per cent, and trace strength (1/5) about 10 per cent of functioning axons of the motor nerve.

For the post-GBS patient with normal strength (5/5) throughout, the muscular response to exercise can return to normal, like before the GBS.

Progressive resistive exercises can produce the same degree of effort and muscular response like before

the GBS. There may be a more perceptible limit in strength and endurance to specific exercise, but through training and diligence, improvements may be forthcoming.

For the post-GBS patient with good strength (4/5) the muscular response to progressive resistive exercises may either be an

improvement towards normal, if the recovery of the motor nerves is substantial; or, if there is not a substantial recovery, there may still be some degree of improvement without the ability to re-achieve the previous levels of maximal muscle performance like before the GBS.

Exercise can produce less of a muscle-burn sensation before fatigue occurs. At times, if overworked, the muscle may temporarily fail to achieve the power demanded until rested. For the post GBS patient with fair strength (3/5), muscular response to exercise may be either a limited improvement in strength, or muscle fatigue and performance failure, depending on the workload.

Patients must be cautioned they may experience abrupt fatigue or performance failure in this strength range. Physician and therapist direction is mandatory in order to provide specific direction for optimising the types of exercise and to avoid doing harm. The post GBS patient with poor strength (2/5) or trace strength (1/5) should exercise in gravity eliminated positions or in a pool or spa. Exercise must be designed to maintain and possibly improve strength and function while maintaining range and preventing complications. Just performing activities of daily living may be quite enough of an exercise. Again, physician and therapist direction is mandatory in order to provide specific directions, the types of exercises, and avoiding harm. Unfortunately, if a sufficient number of functioning axons of the motor nerves do not recover or regenerate to the next higher level of potential muscle strength (such as from a 2/5 to a 3/5, or a 3/5 to a 4/5, or from a 4/5 to a 5/5), strengthening efforts will not be rewarded with an improvement in strength.

Muscle atrophy becomes prominent when motor nerve axons are irreversibly lost, such as with 0/5 and prolonged 1/5 grades of strength. No type or amount of exercise has ever been shown to regenerate lost motor nerve axons.

In summary, each post-GBS patient should consult with their neurologist, rehabilitation physician and/or therapist about what types of exercise regimens are best suited to their own personal medical needs.



Call - a - Friend

Firstly I would like to say how much I appreciated the letters and phone calls received wishing Arthur my husband and myself good wishes for our return to better health. We both hope the remainder of the year will be more positive for us both.

Thank you all, for your kind thoughts and wishes, I'm sure such kindness helped Art and myself.



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

Since my last update the Assoc. has received calls regarding a high profile identity who suffered an onset of GBS, highlighting the fact that no one, young, middle-aged, senior, male or female, no one can claim to have an immunity to GBS or CIDP. Each and every call the Assoc. receives reflects the shock and devastation and utter disbelief of the family concerned that their loved one has developed GBS or CIDP. One cannot be other than sincerely effected from recognising the desperate tone of a father of a toddler of 3½ years paralysed with GBS to the wife of a senior of 84 years in a small country hospital, who feels that not enough is being done for her husband because of his senior years.

On behalf of the Assoc. as an individual I can only help by listening, suggesting, informing. The Association cannot alter or influence any Medical treatments or procedures prescribed for patients. As an Association we can however appropriately pressure the authorities / government instrumentalities to make absolutely certain that the appropriate treatments are available and given to both new GBS cases, as well as the regular requirements of CIDP and its variants to patients.

Lately the Assoc. has been made aware that a review by Departments in Canberra are to be undertaken in the uses of IVIG (immunoglobulin)

throughout Australia, one would imagine in an effort to rationalize the uses of this form of treatment.

Only three delegates are invited to plead the case on behalf of GBS and CIDP patients. The InGroup of Victoria will be sending a worthy delegate (Mrs Melva Behr); to plead the case for the continued availability of IVIG;- that is, freely available to those who require it where and whenever it is needed. Mrs Behr has generously invited GBS-CIDP-NSW to suggest additional points for inclusion in her case. Perhaps we as individuals who are recipients of IVIG should spend a moment or two to write or contact their local member to reinforce the dependence GBS and CIDP persons both current and future, place on this treatment for their continuing good health. Without receiving such treatment it would eventually have devastating consequences.

In reflecting on how patients feel about their treatments I know each one who depends on regular "top-ups" and the benefits of being able to be well and actually productive in the work place, is valued very highly.

I recently read a letter from a patient who has MMN, a CIDP variant. I think it worthwhile to include her comments, reflecting I suspect all those who receive IVIG regularly.

AFTER SIX YEARS of getting immune globulin (IG) infusions, you'd think I'd have a more casual attitude about seeing the bottles of IG that arrive every month. It should be old hat by now; I shouldn't even blink an eyelash anymore. And, yet the arrival of the magic liquid still utterly fascinates me.

Written by Stacey
Oliver who was
diagnosed in 2008
with MMN for the
magazine IVLiving
July 2014

The concept that I receive healing from a product that is made from thousands of donor contributions still blows my mind. When infusion time rolls around. I'm like a flower that's wilting. I need that special nutrient to perk my petals up. As far as I know, IG has yet to be recreated as a synthesized product. So, it's as organic as it gets. I like to think of it as a garden of humanity.



Have you ever really looked at a bottle? of IG? It says that it's a human product. Right next to the words 'Immune Globulin' is the word 'HUMAN.' I guess I should feel kind of like a vampire sucking on the life force of others to survive, but it's not that grim of a picture in my mind. Picturing the thousands of people giving their blood to extract the miracle IG makes me feel closer to humanity. Their life gives me life, and maybe in some mystical way, I also get their good wishes, positive feelings, strength and courage to face my autoimmune challenges. I don't have fairy dust in my eyes. I know that IG donors don't get paid for their service.

My husband checked to see if blood banks are located in our area, and there were none close by. He and I wanted to visit one of the donation centres and also ask our friends to give blood to ensure the supply doesn't deplete. I know that sometimes there are IG shortages. It hasn't affected me yet, but what a terrifying thought. In fact the blood centres we found were far away, and most were near college campuses. I'll never know the true intentions of the people who take the time and give blood to make IG for me. or maybe they know how lifesaving their donation is. I'm sure there are people? in labs working on creating an artificial substance to mimic what the natural form of IG can do. It would ensure there are no shortages.

Perhaps in the future, there will be better ways to administer IG besides infusions. Instead of getting two nine-hour doses each month. I'm hoping for administration innovations. Wouldn't it be great if there were IG lotion to slather on and get absorbed into your skin? Or IG nail polish? I'd like to think there is a scientist with a Willy Wonka spirit at heart who would invent IG bubblegum one day. Chew it all day, and the IG is released into your body via your tongue. Hey, a girl can dream. If our society can put a man on the moon, anything should be possible. Until that day comes, I am grateful to my fellow human beings for helping me, quite frankly, live. We are all in the garden of life together— a wondrous variety — and we can all help each other bloom and grow.

Thank You!

SMARTPRINT for donating printing and labelling of our Newsletter

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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:-

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