



STICK WITH IT
SLOW BUT SURE

INFORMATION

Issue 101.

February 2018.

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Glen Waverley, 3150
Victoria, Australia
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NEWSLETTER OF THE 'IN' GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC., supporting sufferers from acute Guillain-Barre Syndrome (GBS) & Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) and other Inflammatory neuropathies

**THE NEXT MEETING WILL BE HELD ON 11TH MARCH, 2018 FROM 2-4PM
AT THE ASHBURTON LIBRARY,
154 HIGH STREET, ASHBURTON. ALL WELCOME.**

GUEST SPEAKER: MALCOLM LEVY, PHARMACIST. MEDICATIONS

A small plate to share would be appreciated. Thank you.

Our meeting dates have now been confirmed. *Please note the AGM and Luncheon will be held at the refurbished Balwyn Library.

ASHBURTON LIBRARY 24 June 2018 2-4 pm. St. Johns Ambulance

Community Transport Services

***BALWYN LIBRARY 19 August 2018 2- 4 pm (Includes AGM)**

***BALWYN LIBRARY 2 December 2018 12 - 5pm Christmas Luncheon**

Notes from the Christmas Luncheon

Margaret: You will notice we have a PA system. It is a wonderful donation from Gwen. It will make a big difference when we have speakers as it is difficult for some members to hear.

Welcome everyone. There are just a couple of things. Two of our Committee Members are not here today because they have family functions, which happen at this time of the year, so apologies from them. Ken Clark, (who just last week was re-elected Mayor of Wangaratta) is also an apology as Wangaratta has enormous problems with flooding at the moment. As you know Ken usually conducts our Dutch Auction.

I want to say to the Committee, "Thank you very much for the wonderful help with our luncheon". Most of it is donated by the Committee and they work very hard, so thank you, especially from me and I'm sure once you eat the food it will be from you too.

I do have a very big “thank you” to Gwen again because Gwen has given me a lot of lovely little things and you are all going to get a gift today for Christmas. Also she’s our “doll lady”. She makes dolls with other people and gifts them to us and makes lots of money for us. We received \$216 this morning from Gwen. Applause.

Last year we had a friend of the group who gave us a \$1000 donation. They don’t want anyone to know but another donation of \$1000 has been given to us too. People are very generous to The IN Group and of course that all goes into research which is wonderful.

I am advised that Assoc. Prof. Andrew Kornberg is on long service leave but we hope he will be able to give us an update sometime next year.

Please now help yourselves to the buffet when you are ready.

Doug took on the role of Auctioneer and we raised \$930. A great result

A big “Thank You” to all who attended for bringing a gift to be auctioned and for being so generous with your bids. As always it was lots of fun, especially for the new members who were most enthusiastic.

GBS/CIDP FOUNDATION INTERNATIONAL

Center of Excellence in Australia. Our Global Medical Advisory Board has set standards for what they consider to be excellent medical centers for the diagnosis and treatment of GBS and CIDP. Based on levels of expertise, available treatments, facilities, and research capabilities, these are the medical centers that we can unequivocally recommend as “Centers of Excellence.” Additionally, the members of our Medical Advisory Board are available to consult with your doctor or neurologist if your physician would like extra support.

The COE in Australia is:

University of Sydney

4/94 Mallett St
Camperdown , 2050

Phone - [61293510730](tel:61293510730)

<http://info@sydneyneurology.com.au>

Our Committee Member Melva Behr represents The IN Group as a Liaison Officer with the GBS/CIDP Foundation International. There is a wealth of information on their sites.
info@gbs-cidp.org www.gbs-cidp.org

AIDS FOR DAILY LIVING - You may find something to assist you.
www.aidsfordailyliving.com.au. Check it out.

CIDP CAN HAVE VERY GOOD SIDE EFFECTS (Sent in by one of our Members)

In early 2017, I became aware that several times I had noticed the same man, in a mobility scooter, around our local shopping centres. I believe that the reason I particularly noticed him was, that from a distance, he looked a bit like Geoff when he is out on his mobility scooter. Both wear similar peak caps; both have grey beards. Both this man and I seemed to be aware that we had seen each other before, and had given each other a half smile, as strangers sometimes do, but we had never spoken.

About twelve months ago I walked to the shops, and this man was in his scooter, outside the little supermarket, and for some unknown reason, I started chatting to him. I explained that he looks somewhat like my own husband, particularly from a distance, and that my husband uses a mobility scooter too.

With that his wife came out from the supermarket, and the three of us started to chat. She asked about my husband's disability, and because so few people have heard of CIDP, I just said that Geoff had a chronic neurological illness. She answered by saying that her husband had CIDP. With that statement the flood gates just opened up! We three chatted for about 20 minutes and at the end of that time I asked if she would agree to giving me her phone number as I would love to keep in touch. Her reply to me was: "I would love to have a friend who understands". We ended up exchanging names, addresses and phone numbers and discovered that we live in the same suburb, and within walking distance of each other.

As Geoff was not with me at the time, we arranged to meet for coffee a few days later. The meeting was very successful and all four of us got on very well. Both of the men are rather reserved, but they have CIDP in common. Keith* (not his real name) is a few years older than Geoff, and his condition is a little more advanced.

Since then the four of us have met for coffee several times, and last winter when it was too cold to meet in outside cafes (we need the space for two mobility scooters) we started to visit each other's homes instead.

Nancy* (not her real name) and I have become very friendly in a short time and often phone or email each other. We even went to see a movie together one Monday morning, leaving our husbands alone for two hours. We did not even have coffee after the movie as we were both anxious to return home to our husbands. No hard feelings, as each of us fully understood the need to get home. Nancy and I are now exchanging books and recipes and I think we both value our unexpected friendship very much. Keith and Geoff are both comfortable in each other's company too, and this is a blessing for each of them as they can discuss CIDP if they choose to do so.

I have mentioned that we are members of The IN Group. Keith and Nancy do not wish to join, but I do forward the Newsletters on to them which they find extremely interesting.

While having CIDP is a curse and has changed our way of life, we are thrilled that it also enabled us to meet a lovely couple; become good friends and support each other – our husbands who are the CIDP sufferers and us, their wives and their carers.

Yes, CIDP can really have good side effects and we have the proof!
Pat Cashmore. January 2018.

Reprinted from the latest Newsletter of the GBS Support Group of New Zealand.

NEW WAY TO RECEIVE AN ESTABLISHED TREATMENT.

By Dr. David Gow

Intravenous immunoglobulin (IVIG) is a well established treatment for immune mediated neuropathy. In the case of GBS, one course is usually all that is required and most patients probably forget about receiving it, as it is just a small part of a long inpatient journey. This is in contrast to CIDP and multi focal motor neuropathy (MMN) where patients need to receive regular infusions. The impact of coming backwards and forwards to hospital on a regular basis, anywhere between 3 and 6 weeks in most cases can't be underestimated.

Around 5 years ago in Manchester UK, we started to explore using sub cutaneous immunoglobulin preparations. They had been used in immunodeficiency patients for some time in our hospitals. This is another group of patients who require regular infusions. Because of the burden of these repeated hospital visits attempts were made to treat these patients at home. Initially with home IVIG but as this required intravenous access it was still problematic and required significant community nursing resources.

Subcutaneous immunoglobulin (SCIG) can be totally patient delivered with the right training and upper limb function and as such this quickly replaced home IVIG in our area as the alternative to hospital based IVIG for the immunodeficiency patients.

We were keen to try this in our MMN and CIDP patients and built up a cohort of patients that we studied carefully including assessing quality of life as well as monitoring neuromuscular function.

The patients used a clockwork pump and infused on a weekly basis. They would hook up the pump and then get on with their daily life. A delivery and community support network was required and the patients were trained by a specialist neuromuscular nurse.

The SCIG was effective and quality of life measures improved in our small cohort.

To make significant changes in health care we need large well designed studies to provide evidence that treatments are equivalent or better to current practice. This means that despite experience from centres like Manchester clinical trials were required to prove that SCIG was effective.

The PATH study, a trial of high and low dose SCIG versus placebo (1) has recently reported in Lancet Neurology. This trial confirmed that when SCIG was used in a group of CIDP patients who had previously responded to IVIG that it was effective at reducing relapses in comparison to placebo.

Although the study showed that SCIG was effective at controlling CIDP 30% of the high dose SCIG group and 39% of the low dose group either had a relapse or stopped the treatment for other reasons. This suggests that it is not going to suit every patient but may be the answer for some.

Over all this is an encouraging piece of work and it will provide some much needed evidence when we look to expand treatment options for patients with chronic immune neuropathy. Clearly there will be a need to develop a community infrastructure to facilitate after care also.

Reference

1. Subcutaneous immunoglobulin for maintenance treatment in chronic inflammatory demyelinating polyneuropathy (PATH): a randomised, double-blind, placebo-controlled, phase 3 trial. van Schaik et al. PATH study group. Lancet Neurol. 2017 Nov 6. pii: S1474- 4422(17)30378-2. doi: 10.1016/S1474-4422(17)30378-2. [Epub ahead of print]

The easy to read and enlightening book **GUILLIAN-BARRE` SYNDROME** written by **Dr. Gareth Parry and Dr. Joel S. Steinberg** is now available. \$30 including postage. If you would like to purchase one contact: **Tony Pearson: tonypearson@xtra.co.nz**

RESEARCH

Research into GBS and CIDP is being conducted throughout the world. The following research projects relating to GBS/CIDP were presented at the 2017 Peripheral Nerve Society Meeting in Sitges, Spain.

INCBASE Towards an affordable treatment of GBS for patients in low-income countries

IMAGiNe A new treatment with compliment inhibition improves motor function in Guillain-Barre` Syndrome: Japanese eculizumab trial for Guillain-Barre` Syndrome (JETGBS)

A dose response trial of IV immunoglobulin in Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)/DRIP study.

Milla living life to the full

REBECCA and Jamie Marciano received the shock of their life when their middle child, Milla, was diagnosed with Guillain-Barre syndrome (GBS) last year.

Little Milla was just four-years-old when she was forced to spend time at the Royal Children's Hospital to receive treatment for something very uncommon in children.

GBS is a disorder in which the body's immune system attacks part of the peripheral nervous system.

The first symptoms of this disorder include varying degrees of weakness or tingling sensations in the legs.

It reached the point where Milla was unable to walk, and was struggling to even swallow.

It was at this time that the Lucas Foundation lent their support to the Marciano family.

Jamie and Rebecca were often forced to spend time apart, with one in Melbourne with Milla, and the other at home with their other children - Indiana, 9, and Jaeger, 2.

"The Lucas Foundation were incredibly supportive," Rebecca said. "The funds we received helped with travel costs, physiotherapy and even with a wheelchair when she was unable to walk.

"At that point in time, they were able to help when nobody else could. Being such a rare condition for a child meant there weren't many options for us in terms of support.


"We cannot thank them enough for the support we received"

Rebecca said the added support from the Royal Children's Hospital, family and friends was "nothing short of amazing."

"That community support is what living in Mildura is all about," she said.

While GBS is not yet curable, most patients make close to a full recovery.


Milla, now 6, started Grade Prep at Nichols Point Primary School this year, and has regained her lust and energy for life.



NEW MEMBERSHIP AND ANNUAL SUBSCRIPTION

Item	Each	Payable
Joining Fee	\$10	
Annual Subscription (Due 1 July each year)	\$15	
GBS Booklet	\$3	
CIDP Booklet	\$3	
After GBS Booklet	\$3	
The Road to Recovery Booklet	\$6	
Boy, Is this Guy Sick Booklet	\$2	
Recipe Book	\$16	
Donation to support Medical Research (Donations of \$2 or more are tax deductible)		
Tick if a receipt is required		
TOTAL Enclosed		
a cheque/money order (payable to The IN Group)		

Thank you. Please forward this form along with your payment to:
The 'IN' Group, 26 Belmont Rd., GLEN WAVERLEY 3150

	BSB / Account: 063142 / 10006285
	Account Name: The IN Group (Include Your Name in "Description / Reference")

MEMBERSHIP DETAILS (please Print)

Name:	
Address:	
Suburb:	
Postcode:	
Mobile:	
email	

To receive your Newsletter by email sent an email to John@bal.net.au

INFORMATION

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Supporting sufferers from acute Guillain-Barre` Syndrome(GBS) , Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

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