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Issue 63. June 2008

INformation

STICK WITH IT SLOW BUT SURE

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)

ANNUAL CHRISTMAS LUNCHEON
17TH August, 2008, 2pm.
Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn
Guest Speaker: Malcolm Levy, Pharmacist
Subject: Medication Awareness
 A small plate would be appreciated

Christmas Luncheon: 12:00pm, Sunday 7th December

Notes from May Meeting

A friendly group of members attended our May meeting where we were saddened to learn that **Dr Russell Gibb** was hospitalised with pneumonia. We wish him a speedy recovery. We hope he will be able to attend another meeting for his talk on Anxiety and Depression.

We also learned that one of our dear members **Fred Hooten** was hit by a car and has a broken leg. Fred is in the Austin Hospital. Our thoughts are with you Fred.

Member **John Widdicombe** from the Geelong group is now home from hospital. We send our best wishes to both John and Margaret and our thanks for their generous donation to our luncheon.

Member **Peter Avery** from Sydney is being reassessed and perhaps re-diagnosed following skin rashes and breathing difficulties. He was originally diagnosed with CIDP, but with these complications perhaps he has POEMS which is a 1 in a million problem. Our thoughts are with you Peter and we send our best wishes.

Peter is now having chemotherapy and his breathing has slightly improved. Joe and Melva Behr hope to visit Peter when in Sydney next month.

Peter Malcolm, now out of rehab, is receiving physio at his home in Prahran with his mornings busy. Keep up your spirits Peter. We are all thinking of you.

Jan and Bernie Pettit are still overseas caring for their elderly father. They do great work visiting newly diagnosed people in Melbourne hospitals and rehabs, etc. Our thoughts are with you both during this difficult time.

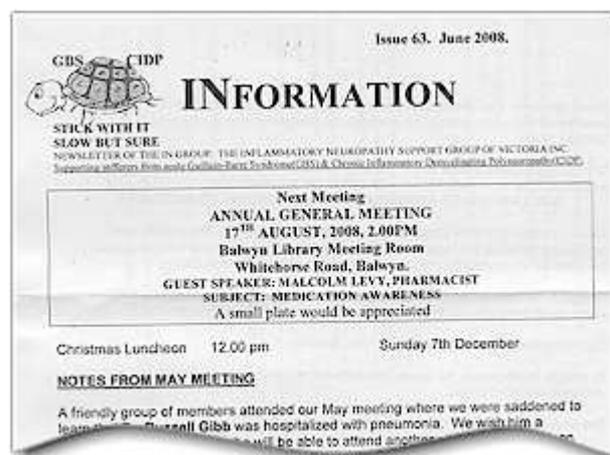
Our thanks to **Robert Avery** for allowing us to pass on his phone number to another gentleman (also named Robert) who lives in the Bendigo area.

Gewn McInnes has donated a Foot Spa which she found quite beneficial. It can be used either wet or dry and will be available for borrowing from the library. See Barbara Rivett.

Don't forget to have look in our library. There are some wonderful publications available. One is **American Academy of Neurology, Guillain-Barre Syndrome, from Diagnosis to Recovery**.

The committee of The IN Group has copies of this publication. The copies were purchased following the recommendation of a member of our group who described the book as an excellent summary of information about GBS and CIDP.

The book contains an enormous amount of clearly expressed, detailed information which could be of interest to sufferers and their families and supporters. Eight chapters are devoted to GBS. They



describe: Its effects, its diagnosis, its cause, its treatment and the advantages and disadvantages of differing available treatments.

*Thanks to **Peter McInnes** for reviewing publications for us.*

Copies may be borrowed by members for The IN Group, c/o The Secretary, **Barbara Rivett** who can be contacted on 9543 2825.

Update of Websites

CSL are helping us update our websites. Thank you CSL. More on that next issue. Thanks also to Greg Keogh for his work (all voluntary) on the site over many years.

GBS and CIDP Booklets

Have been printed and hope all those who were waiting for these publications have now received them.

Nomination Forms for Committee 2008/2009

Enclosed is a nomination form to be on the committee. Please give this your consideration. It is very rewarding volunteering as many of you know. New people bring new ideas.

Also please note that 21 days notice is required to bring up matters at the AGM. Members must be current financial members of the Support Group to hold Committee positions and be able to vote on any business arising in the course of the meeting.

We look forward to seeing as many members as possible on August 17th.

Membership Renewal

As our membership year goes from 1st July to 30th June, the new renewal notices are also enclosed in this issue. If you have just paid prior to 1st July please disregard the notice. Thank you.

Red Cross Blood Challenge

Our thanks to all those who donated blood during the Summer Challenge. Bronwyn Clarke has received a certificate on behalf of The IN Group. Bronwyn has motivated many of her friends to donate. Thank you so much Bronwyn for your ongoing support of The IN Group.

The Winter Challenge is now on. Ask your friends and family to donate blood or plasma. Their donation can be added to others who donate under The Inflammatory Neuropathy Support Group of Victoria.

Being a blood donor is an ideal way to keep a check on your own health as only healthy people can donate. They check blood pressure and haemoglobin and if there are any problems with your donation they contact you. For "first time donors" they advise you of your blood group which is valuable information to carry with you at all times.

Years ago I challenged their decision to not let me donate because my husband received Intagam which as you know is a blood product. It took some time but they checked it all out and I was allowed to continue to donate.

It was great knowing I was helping. So, if you haven't been a donor, give it a go. It doesn't hurt and sometimes it's nice to take some time to sit and chat with strangers over a cuppa, biscuits and maybe a lolly! I found it also helpful in speaking to other donors about GBS and CIDP and they were always interested to know how their donations may have been used.

News from The USA

Reproduced from "Recovery" the newsletter of the GBS Association of NSW, with thanks to "In The Know" a newsletter from the UK group.

All of us are aware of the usual method of infusing immunoglobulin: the long hours of waiting as the Ig drips into our veins, the veins that collapse. That may be in for a change.

In January 2008 the US Food and Drug Administration approved the subcutaneous injection of immunoglobulin for human use. Subcutaneous (SC) means under the skin and these infusions are given in the fatty tissue under the skin, often in the abdomen, thigh or upper arm, rather than in a vein. The Patient can give the infusions her/himself at home. Since the Ig is more concentrated, s/he has smaller doses more often, and with the portability of the pumps s/he isn't restricted to a chair or bed

during infusion.

Thus far, SCIg has been used primarily for primary immunodeficiencies. However, studies are underway in the USA using SCIg in CIDP patients and a brief German study indicated that SCIg is just as effective at about half the price of IVIg.

Email Mailing List

If you would like to be included on the IN Group email mailing list, please send an email to John Burke at the following email address: jburke@contracts.com.au.

If you use *hotmail* or have junk mail filtering software running you will have to include the above email address in your "safe list" otherwise *hotmail* or your junk mail software is very likely to delete our emails.

Winter Luncheon

17 members enjoyed the Winter Luncheon at the lovely Lawrence home. Chicken and Sweet corn soup, vegetable soup and yummy gourmet pies plus a variety of delicious scones were the fare of the day. How long is it since you enjoyed a scone with lemon curd spread? hmmm

It was lovely to meet member **Marian Presland** who attended her first gathering of the group. Our numbers were depleted due to illness, tests and travel. We hope our members sunning it in Queensland are enjoying the break from the bleak weather.

We raised \$240 from both attendance and donations. Thank you all so much for your wonderful support, high special mention to Russell Wilson who sells his home-made pickled onions, the proceeds going to the group.

Disclaimer

Information presented in "INFormation" the Newsletter of the Inflammatory Neuropathy Support Group of Victoria Inc, is intended for information only and should not be considered as advising or diagnosing or treatment of Guillain-Barre Syndrome, CIDP or any other medical conditions.

Views expressed in articles are those of the authors and do not necessarily reflect the opinions or Policy of The IN Group.

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