

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)
26 Belmont Road, Glen Waverley, 3150. Victoria, Australia. www.ingroup.org.au email: info@ingroup.org.au.

NEXT MEETING

12.30PM SUNDAY, 20TH NOVEMBER, 2011 AT THE BALWYN LIBRARY
WHITEHORSE ROAD, BALWYN

ANNUAL CHRISTMAS LUNCHEON AND DUTCH AUCTION
\$15 per person. Please bring a wrapped gift for the Dutch Auction.
RSVP Margared (03) 9802 5319 or Melva (03) 9707 3278

NOTES FROM THE ANNUAL GENERAL MEETING

Welcome. Thank you for coming.

Apologies: Ken Clarke, Margaret and Russell Wilson, June Cathcart and Barbara Clifford.

Minutes of the previous A.G.M were moved by Margaret Lawrence. Seconded: Joe Behr Carried

President's Report – Margaret Lawrence.

Once again I am very happy to report another enjoyable year as President. My thanks to all the members for their wonderful donations, which enable us to pass on a sizeable cheque each year for research.

We have all enjoyed the speakers and friendship at the meetings. Our Christmas and mid year activities are enjoyed by many, raising funds while having a fun time.

My special thanks go to the Committee, a great bunch of very willing friends who not only give time but supply delicious food at their cost.

A big “thank you” to Janet and Bernard Pettit for their participation on the Committee. They are retiring after a job well done! A warm welcome to Rebecca and Len our new Committee members.

The Geelong group enjoy their meetings at the Widdicombe home. Sadly John passed away a few months ago. Margaret has very kindly offered to continue holding the meetings at her house.

Margaret and Dee are stepping down after a number of years running the group. Thank you to you both.

Jim and Sadie Coates have kindly offered to take over.

To everyone my thanks for your support. Many people help in small ways making this such an enjoyable support group. Thank you everyone.

Margaret Lawrence
President.

The President's Report was moved by Melva Behr, Seconded by Gwen McInnes. Carried

Treasurer's Report – Doug Lawrence

The Treasurer's Report was distributed. \$2700 less than at 30th June last year. Our members are very generous and donations almost double subscriptions. Fundraising \$1930 being Christmas Luncheon, Winter Luncheon and I would make special mention of the Coat Hangers which Gwen has been doing. \$413 That's a lot of coat hangers. We donated \$10,000 to medical research. We rely heavily on all our members. It is a fine effort.

Balance as at 30th June, 2011. \$7900.

Doug Lawrence: "I propose that the accounts to June 30 be accepted."
Seconded by Tom Rivett. Carried

Election of Office Bearers

Our new committee members are Rebecca Engsmyr and Len Walker. Len has been an active member for many years and now wants to contribute even further. Welcome aboard Len. Rebecca (who is rehabilitating following GBS approximately 10 months ago) is a young nurse who will bring her personal experience, enthusiasm and innovating thinking to the committee. We are delighted Rebecca has joined us.

General Business:

There was no general business items with 21 days notice.

The Annual General Meeting closed.

Members then asked questions:

How many financial members do we have? We have 74 members who have not paid their subs for 3 years. We decided we have to do something about it so some will be removed. We have a natural wastage for various reasons and then we have new ones coming along.

We have members from America, UK, Canada and China with the rest from across Australia the bulk being from Victoria. We have quite a few from NSW and few from Queensland, only a couple from SA and WA. At this moment if I said how many had paid I would say there were only 100 but I get money coming in every month for the whole year. If anyone paid in March/April/May, and they don't pay until the next May, we don't care. Our donations are generally about 2-1/2 times our subs. There are some that just pay their subs and that's fine, but we get some very good donations. Margaret writes personally to everyone who donates \$50 or more and she writes about 5 per banking.

We send the newsletter to some people who don't pay subs., but visit patients in hospital for us and people who do other things. It is quite an intricate thing and we also have honorary members; those who work in ICU's, hospitals, neurologists, physiotherapists who love to get the newsletter but we don't charge because they are passing on the information to other people.

It is not like an ordinary association. Our idea of not putting up our subs and not charging more for the Winter and Christmas Luncheon is because people are very generous. If you come along for a lovely luncheon for \$15 you are quite happy to bid at our Auction of donated gifts, etc.

New committee member Rebecca asked, “Do we have a Facebook page?” I know people who can help me with this. It would be ideal for members to keep in touch and to hand on information.” An excellent idea which we hope to implement a.s.a.p.

Doug spoke regarding **ICE** – **IN CASE OF AN EMERGENCY**.

In the event of accidents, Police, Ambulance Officers, etc. now go to a person’s mobile phone and look for ICE meaning In Case of Emergency. You can have 4 numbers under ICE. ICE 1, ICE 2, ICE 3, ICE 4 and you put the number next to it of a person you would like contacted in an emergency.

We then watched a DVD on CPR which was most interesting and with this knowledge those present could save a life.

CPR is changing. **They now say to do chest compressions of 120 per minute and keep that up until the ambulance arrives, but any CPR is better than no CPR. So just do your best if ever you are in this situation.**

If you are at home your front door should be unlocked so the ambulance service has access and if possible the patient should be near the door. Another thing one of our members advised was to have a list of all medications you take attached to the back of your front door.

Member Tom told of how his neighbour arrived at their front door totally out of breath and they called the ambulance. By the time they arrived the lady had recovered and he apologized for calling them on what seemed like a false alarm. The ambulance driver said “when that happens that makes our day. If we are called out and it is resolved successfully its not a wasted call.” So **if there is any doubt, ring the ambulance.**

GEELONG GROUP

Jim and Sadie Coates (jimsade@bigpond.net.au – (03) 5243 4277 or 0407 434 275) have kindly offered to take over the Geelong Group. We would like to thank them and also thank both Margaret Widdicombe and Dee Cooper for all they have done for so many years for this wonderful group. Meetings will still be held at the Widdicombe home.

The next meeting of the Geelong Group will be held on the 22nd October at 2pm.

KERRIE KNOTT

It is with great sadness that The IN Group acknowledge the passing of our esteemed member Kerrie Knott after a long battle with ovarian cancer. Kerrie who also had CIDP was active among the Victorian members and was truly a brave and gracious lady.

Membership Renewal. Thank you to those who have sent in their membership renewal. For those who have yet to do so, please use the form enclosed. As discussed earlier in this newsletter, we are vetting our lists and those who have not paid for some time will be deleted. **If you have paid for this financial year, please disregard the form.**

SOME OF THE EMAILS RECEIVED

Thank you for your emails, the last one was about Intravenous immunoglobulin.

I did go ahead with Intragam your email helped me to make that decision. I had the 5 days in February, then once a month since, due to have another treatment on the 25th May, so far I have had only positive results, I would like to feel better, maybe that will happen in the future.

I have not been charged, Queensland seems to do the same as Victoria.

The INFormation news letter arrived yesterday.

Do you know of any one in South East Qld that I could get in contact with?

Thank you for getting back to me, I am still having the Intragam 27g every 4 weeks, I had a power port put in 2 weeks ago, I put it off for a while but a working vein was getting hard to find, so now I have a power port, it was used last week with no problems.

I think the Intragam is helping, I feel more like doing the work I have to do, I work in the clothing industry making and grading patterns, I feeling more like working but my right leg is weak and I have trouble walking very far.

Because I was told I had MS I joined the MS Society in QLD, I am still going to the MS exercise group once a week, and this seems to help, the CIDP Exercise reprint from August - September 2010 by Matthew David Hansen is very helpful and explains the Exercises.

Would you know of any physical therapist that has experience with CIDP in South East QLD, it would be good to be shown the best way to exercise for CIDP if there is any difference between MS and CIDP for exercise.

Ed. If you live in South East Queensland and could chat with this new member, please email me at behrsden@optusnet.com.au. **I did send emails to members in Queensland but they bounced back. If you have changed your email address, please let me know as support in Queensland for newly diagnosed patients with either GBS or CIDP is very limited.)** If anyone can help this new member with a physical therapist, please contact Melva at behrsden@optusnet.com.au and I will pass on the information.

The exercises mentioned were in the Summer 2010 edition of The Communicator which is the newsletter of the GBS/CIDP Foundation International at www.gbs-cidp.org We recommend this site to our members.

I am not sure if you are aware, but Barbara (my wife) passed away on 6th January 2011 after battling "Breast Cancer" for over 2 years.

Barbara who suffered from CIDP had been a member of your IN Group for many years and was very supportive of the great work that your organization does.

I would like to thank you all for the assistance you provided to Barbara over the years.

Hello, I was at the last meeting and I didn't write down any details of recommended doses for Coenzyme Q10 that the neurologist spoke about. I am wanting to try this, however, I don't want to take too little or too much. I am just wondering if anyone could help me with this query? I am recovering from GBS, it's been 7 months since it's onset and I think that it is worth a try.

We sent a copy of the newsletter with the wonderful talk given by Dr. Valerie Tay in it for Rebecca and she joined us and is now a member of the committee.

E-mail 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.

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 condition. 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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Newsletter of THE 'IN' GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC. Supporting those with acute Guillain-Barre` Syndrome(GBS), Chronic Inflammatory Demyelinating Polyneuropathy(CIDP) **Postal Address for Newsletter only: 44 Mavis Avenue, Beaconsfield, 3807. Telephone 03 9707 3278.**

THE 'IN' GROUP

The Inflammatory Neuropathy Support Group of Victoria Inc.
Supporting sufferers from acute Guillain-Barre` Syndrome (GBS and
Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
Registered No: A0025170R

Annual Subscription

Subscriptions are due on the 1st July of each year.

I am happy to continue helping The 'IN' Group by renewing my membership from 1/7/11 – 30/6/12.

Annual Subscription		\$ 15.00
Other Items		
Booklets- The Road to Recovery A-Z	\$6	\$
- Boy, Is This Guy Sick	\$2	\$
GBS	\$2	\$
CIDP	\$2	\$
Donation to support medical research (Donations of \$2 or more are tax deductible) (Tick if receipt required)		\$ _____
Total Payable:		\$ _____

Enclosed is a cheque/money order (payable to The IN Group)

Membership Details

Name: _____

Address: _____

_____ Postcode _____

Telephone: (Home) _____ (Work) _____

Email Address: _____

Signed: _____ Date: _____

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