

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.

**ANNUAL CHRISTMAS LUNCHEON
BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN
12.30PM ON SUNDAY, 21ST NOVEMBER, 2010.**

\$15 per head. RSVP to Margaret 9802 5319 douglawrence26@optusnet.com.au
or Melva 9707 3278 behrsdn@optusnet.com.au by 15th Nov.

A wrapped gift for our Dutch auction (indicating approximate value for our auctioneer) would be very much appreciated. Come along and enjoy the fun, food and friendship. New members will be very welcome.

Minutes of the Annual General Meeting, held Sunday, August, 15th 2010.

Apologies: Noel and Jan Petheridge, June Cathcart.

President's Report – Margaret Lawrence

It is with pleasure I present my report for the year ending 2010. The IN Group is a great support to many people especially now the website is up and running so well. We receive many enquiries and these are all dealt with by committee members. Melva makes many phone calls to people who ask for verbal help. We also arrange for visits, if needed.

The Geelong Group is working well and helping many people in that area and we also have contact with the Sydney President.

Our newsletter is very well received by everyone and a big thank you to Melva and Joe for many hours of hard work.

Our Christmas Luncheon in 2009 was a great success and Peter Males did a marvellous job as auctioneer.

A cheque for \$12,000 was presented to Associate Professor Dr. Andrew Kornberg on the day, for the research programme. Andrew also gave us an update on his work.

Throughout 2009/10 we have enjoyed our get togethers, speakers, the fun night at McDonalds and the Winter Luncheon.

A special thank you to everyone who supplies the food for our functions, the greater part of which is donated.

The Committee remains the same for another year and my thanks go to all these special people. Also, a thank you to Dorothy Brennan who collects the library key to allow us into this room and to Barbara Clifford who supplies the tea and coffee.

On a sad note, we lost our long term member, Fred Hooten, a true gentleman who will be sadly missed.

This year we look forward to enjoying each others company and support.

A special thank you to the wonderful members who are so generous with their donations. We are well on the way to presenting a large cheque for the research programme.

I look forward to another good year for us all.

Treasurer's Report – Doug Lawrence

Rather than looking at the individual values, I am looking at the movements against the previous year. Would you believe our subscriptions were within \$10 of the past year, which is fairly consistent, however our donations from members for medical research have gone up by \$1,415 against the previous year. Our donations this year total \$4,945. Our other income was down a little, but overall our income for the year was \$634 higher than the previous year at \$9,652. Our bank balance as at 30th June stands at \$10,656. As subscriptions have been coming in over the past month I have done some sizeable banking so it is a very good start to the financial year.

I too would like to say **thank you firstly, to all members who have given these great donations** which are really well worth a mention as **it is a great effort and I'm sure it will be very much appreciated by Andrew for his research work.**

Secondly, to **Gwen McInness** for all her tremendous work on her jewellery, coat hanger sales and craft work. **She has made a huge contribution financially, thank you.**

Thirdly, to **the Geelong group for their produce sales.** They have their get togethers and they sell produce, jams, etc. that members make.

To **Margaret** and all the committee, especially **Jan & Bernie Pettit, Barbara & Tom Rivett, Gwen & Peter McInness and Melva and Joe Behr** for the mid-year luncheon which is our second largest individual fund raiser. For many years now, **not only have they prepared the foods, but they donate them as well**

Finally to the **committee and all members who have given so generously to our Christmas Luncheon**, and when I say "given freely" **not only the gifts for our auction but also the donation of the foods.** So as Treasurer I say **THANK YOU to all concerned.**

Moved: Doug Lawrence. Seconded: Peter McInness. Carried.

The Annual General Meeting closed at 2.03 p.m.

General Business

It is quite difficult getting Guest Speakers and we ask for input from members who can't attend meetings as to what guest speakers they would like to hear. The talk is noted in the newsletter for the information of our members. If you have a suggestion for a guest speaker, please return the form on the coloured sheet. Thank you.

February Meeting

We are delighted neurologist Dr. Valerie Tay will be our Guest Speaker for the February meeting. (Date to be announced.) Dr. Tay treats the largest number of our Melbourne based members. If you have a question you would like to ask Dr. Tay, please complete the form enclosed and mail it to Melva Behr, 44 Mavis Avenue, Beaconsfield, 3807 by the 15th January, 2011. One question per member only please. We will do our best to have your question answered.

GEELONG GROUP

The Geelong Support Group Christmas Get Together will be held on **Saturday 27th November 2010, 2pm** at Margaret & Johns Home. Please bring a plate of afternoon tea to share. New members most welcome
Further details ph: **Margaret 52445311 or Dee 52443382**

GBS/CIDP FOUNDATION INTERNATIONAL are holding their Eleventh International Symposium to be held from 5-7th November at Dolce Hotel, Valley Forge, 301 West Dekalb Pike, King of Prussia, Pennsylvania 19406. Information and registration forms at www.gbs-cidp.org/symposium2010

The Foundation is Celebrating 30 Year of Support, Education, Research & Advocacy and we wish them every success with this event.

GBS Association of NSW news

Recently **Patricia Bryant the Executive Office of the GBS/CIDP Foundation International** in America visited Sydney and had an informal lunch meeting with committee members of the GBS Association of NSW.

Dr. Stephen Vucic, Head of the Clinic specifically for CIDP patients at Westmead Hospital, will be their **guest speaker**. The meeting, to be held in the **Charles Brunt Room** (at the end of the corridor), **Ryde Rehab. Centre**, Ryde (enter via Morrison Road), will commence at **10.30 a.m. sharp on Sunday, 23rd October**.

Support

Millie phoned saying her husband was in hospital, newly diagnosed with GBS and he was very concerned because he had lost the expression muscles in his face and couldn't smile at his 12 month old baby. Jan Lane visited him and also Jim Sadler. **“Thank you” to Jan and Jim for your willing assistance**. Terry came out of ICU after having IVIG treatment and he's walking again and doing well.

We had a phone call from **Kathy Dale, of Monash University** who is working on contaminations in drinking water. This is part of the desalination discussions and she said that GBS can be contracted through water contamination. “The people drink the contaminated water, this gives them the gastro and that triggers the GBS.” **She wanted to know if any of our people had GBS from contaminated water**. I told her that we hadn't seen this on any of our member questionnaires.

Dorothy told us that Barbara Clifford wondered about that because she had a house in the same area as did I and so did the man who was in the next bed to me at Fairfield hospital. **The water was coming from a dam there and Barbara just wondered if it would have been the water**. (Dorothy and Barbara had GBS many years ago and are valued members of The IN Group.)

I did phone her Cathy back as I realized we have our greatest number of members in a particular suburb of Geelong. She was going to make enquiries through the Geelong hospital regarding the incidences of gastro from that region.

Tom told how he had seen a program on television regarding desalinated water, where they said they take out the salt, but are testing for what bacteria remain.

Gwen told how Andrew Kornberg said they have discovered in children a trigger for GBS was a common childhood bacteria.

A lady from Queensland who was going to be out of a job through her ill health (CIDP) and company changes was advised to go to Centrelink and see a FIS officer who would be able to explain things like the Disability Support Pension. They can also look at your personal financial situation and make suggestions that perhaps you wouldn't know about.

If, for example you are working 3 days a week and you can't travel on public transport due to your disability (balance is a factor here) there may be an allowance you can get which also gives you a Health Care Card. This may not be means tested and can help with medication expenses.

There is usually a payment through your superannuation for disability. She was going to look into these things.

If you are on a Disability Support Pension and you need to buy a new car, it may be free of GST. A certificate may be required. Spare parts for the car may also be GST free.

There is a **Care Plan for people with two chronic diseases or disorders** which can cover things like dental, physio, podiatry, etc. **This plan begins with your GP.** If you are in this category, e.g. you may have CIDP and diabetes, **please speak to your doctor.** If you don't ask about it, you won't be told about it. This may be able to assist with payment for orthotics.

Two Neurological Physiotherapists from Sunshine Rehab. introduced two new members. From the conversations it seems physiotherapy for GBS/CIDP patients has changed over the years. More on that in the New Year.

Question for Dr. Valerie Tay, Neurologist, Guest Speaker, February meeting.

My question is: ...

.....
.....
.....
.....

Your name:

Guest Speaker Form

I would like to hear a guest speaker onand/or

I know of someone who would be a worthy guest speakerand their contact information is

.....
(If possible you could contact the person you nominate to see if they are willing to be a speaker.)

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

Subscriptions due on the 1st July of each year.

1st July 2010 – 30th June, 2011.

I am happy to help The 'IN' Group by my membership.

Initial Joining Fee	\$10	\$
Annual Subscription		\$ 15.00
Other Items		
Booklets- The Road to Recovery A-Z	\$6	\$
- Boy, Is This Guy Sick	\$2	\$
- CIDP	\$2	\$
- GBS	\$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
