

Issue 60. August 2007

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

SUNDAY, 11TH NOVEMBER, 2007.

Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn

1pm \$15 per head

Guest Speaker: Dr. Andrew Kornberg

Dutch Auction (A wrapped gift indicating some value for Auctioneer)
RSVP by 4/11/06 – Barbara Rivett 9543 2825 or Melva Behr 9707 3278
Come along and join in the fun!

■ **Annual General Meeting held Sunday, 8th August, 2007.**

Motion: "That the Minutes of the 2006 Annual General Meeting be accepted."

Moved: Margaret Lawrence Seconded: Doug Lawrence Passed

President's Report - Margaret Lawrence

The In Group has gone through a change in the past 12 months. James Gerrand began the support group over 15 years ago and he has stepped down to take it easy after so much hard work. Betty Gerrand was a wonderful support at all our functions.

A new committee was elected 12 months ago and as no other nominations have been received the committee will continue for the coming year. Thank you for all the loyal support and assistance I receive. The committee work hard with many jobs undertaken willingly.

2007 has seen a few changes; new format with newsletter, Melva ably helped by Joe has taken on this mammoth task. Margaret Wilson has recommended changes to our rules and this will be discussed later. Brian Boyd has looked into our website and this will be brought up to date.

CSL have confirmed their continuing support to the group.

I have spoken to the Geelong Cluster Group. They are an interested and keen group who welcome new members.

Our Christmas Luncheon last year was a wonderful success and also the Winter Luncheon. Thank you to all our members for your support.

We have also trialled daytime meetings which were a huge success so this will be part of the ongoing process.

Finally thank you to everyone for your support, enthusiasm and interest in making the group so go ahead.

■ **Treasurer's Report.**

[table not ready yet]

Therefore: Surplus = \$3,974

Assets: Bank Account as of 30/6/07 = \$9,489

Property & Equipment. \$6,000 all has now been written off through depreciation.

We have no liabilities. Therefore our current equity is \$9,489 which is the money in the bank made up of the surplus plus earnings from previous years.

Motion: "That the Finance Report be accepted".

Moved: Doug Lawrence, Seconded Barbara Clifford

Passed.

■ Election of Office Bearers

The existing committee is re-elected unopposed.

■ Special Business: Of which 21 days notice has been given.

Our Public Officer, Margaret Wilson has kindly prepared a draft set of Rules of Association for consideration for which we thank her very much as it is not an easy task.

The background is that it is more than 15 years since The IN Group was formed and the first Rules of Association adopted in 1992. Since then there have been many changes to the Association Incorporation Act and these new rules reflect the changes which we believe may be of benefit to The IN Group and its members. Copies of the Rules are available and Margaret will happily answer any questions.

As mentioned in my report the Rules were tabled and discussed at our last executive meeting and it was agreed unanimously that these rules be presented at this meeting for your approval.

Peter McInnes asked if the rules need to be reviewed every year.

Margaret Wilson replied: All regulations have a 10 year lifespan. When those regulations on which our rules are based are reviewed, it would be beneficial to check whether any changes still reflect what is required of our group.

Vicki Malcolm asked if these Rules are in line with other small incorporated organisations.

Margaret Wilson replied: "Yes our current rules were accepted under the rules at the time. Since then there has been some changes and these new rules are now up to date with what is acceptable.

These rules have been lifted exactly from the rules in the regulations. (Copies distributed to members present.) The right hand side of the page is lifted from the rules. What we propose for The IN Group are on the Left and what we have deleted from the right hand side is underlined.

Things that would benefit us in particular in relation to the setting of the membership fees is to give authority to the Executive Committee to set fees from time to time obviously taking into account our financial position and our ability to cover costs through membership.

Re: Clause 25a To update our ability to have executive meetings by teleconference, email, etc. It means that particularly people who are unable to get out can still join the meeting by sitting in by phone and that business discussed will be valid.

Re: Clause 30a is a new clause. As you know, friends, relatives and carers have been invited to all our meetings, including both committee and general meetings. Strictly speaking it's difficult when people come unless they are provided for within these rules. This just provides for anyone to come as an observer, which means that members that have to have a person who is not necessarily a member accompany them, can come to meetings.

Re: Life Membership I understand there have been some life members, and this will enable the group to honour and recognise members who have given outstanding service.

Re: Clause 35 You will see that it is in fact the same as the current one. The winding up clause is not a rule in legislation as it allows for the assets to be divided between all members. When The IN Group was formed it was decided that the assets should only be transferred to a recognised organisation which was exempt under the income tax such as a charity or, as with this group, making the whole a donation to Andrew Kornberg's research. The Committee has agreed that this clause should again be inserted.

I think they are the main items and anything else is really cosmetic."

Vicki Malcolm asked, "If there was a change of name of the Group would these rules still apply."

Margaret Wilson answered "A change of name would be passed at something like an Annual Meeting and then we would advise the registrar of the change of name and that would be sufficient."

Re: Statement of Purposes After a discussion it was decided that a sentence at the bottom indicating that the list was in no particular order should be added.

We will put our Statement of Purpose on the Website. There was no statement of purposes provided with the original rules of Association. We will add the Statement of Purposes to our Rules of Association with our submission.

Motion: "That these new Rules of Association as accepted by the meeting be adopted."

Moved: Margaret Wilson Seconded: Margaret Lawrence. Passed.

Thank you Margaret Wilson for taking on such a task.

Meeting closed.

Vicki went on to say: We all know about GBS and CIDP and although it is good to support people who are coming down with it and helping fund Dr. Kornberg's work, GBS and CIDP have to be pushed more publicly.

If we want more funding and we want more people to know about it and we want the condition understood by the community and by the blood bank we have to be more involved. People have no idea and it doesn't matter how many times I say in my workplace give blood (and I work in a hospital), it doesn't mean anything to people. I'm married to someone with CIDP. They are not married to someone with the condition so they don't understand.

Vicki continued saying, "What is the purpose of The IN Group? I guess I am seeing changes since James has gone. People are doing a fantastic job but where is this group going? What is the focus? Is it toward support or is it looking at ways in which new treatments can be found to treat people with this condition because the times I have come with Peter there are less young people even though it is affecting young people. I find that a difficulty. I think that is a problem as this group is not reaching a large number of people and people are not turning up."

GBS and CIDP Day/Week were discussed. We have organised it previously. It has previously been shown on Medicare refund cheques too.

Margaret Lawrence said with young people once they start getting better they don't want to come to meetings. Such as on Sunday afternoons; young people have other things to do. They might come initially but then it's hard to get them to continue to come.

Still the purpose of this group is support. That is our main focus. Through the research hopefully new treatments can be found.

Peter Males said "I think the best way to give support is through the hospitals." Margaret said, "And this is what we are doing. This is one of the things we are doing as a committee. We have put out a laminated flyer which has been distributed to all the hospitals where we know the treatment is being given. Jan and Bernie are doing that." (Barbara Clifford said "My doctors have it up.") It is going in doctors' surgeries and we are spreading the word of The IN Group. We are trying to hit into the areas where patients go – the neurologists, the hospitals, etc.

We are having our web site rearranged so that we can have people having direct access rather than through links. If we can do it we can have links through other areas."

One of the members said "When you say about the name The IN Group not meaning anything to people I find that very much so. I have been saying "my neuropathy group" – it's got to mean something. You have to explain that The IN Group is The Inflammatory Neuropathy support group and as long as you keep saying both then people understand.

That's where the name change is coming about as The In Group doesn't mean anything to a lot of people. CSL's advertising agency is looking into some suggestions which would be more meaningful. These are things which are afoot at the moment. We are getting there. It all takes time but we are working on it.

Guest Speakers - John Burke told how he had three speakers keen to come – Andrew Kornberg who is in Hong Kong, Russell Gibbs on Depression and Chronic Illness, who was unable to come due to illness and Leanne Deltoso, one of our members who is pushing for selection in the Australian Wheelchair Basketball for the Beijing Paralympics. Leanne is willing to come and talk about what she has managed to do despite her CIDP but unfortunately was in Sydney tonight.

Editors Note: Leanne Deltoso has been selected to train with the Australian squad of 14. 12 will be selected to go to Beijing. We wish her every success. She speaks about CIDP whenever possible to get awareness across.

She is a very personable young lady, working part-time for Basketball Australia on a program encouraging young people to take up basketball and showing that a disability doesn't prevent people from playing sport.

The Victorian team will be playing at the Knox Community Centre at 11am on Saturday, 8th September and later in the day if they are successful. All welcome!

We are all behind you Leanne. Good luck!

[subscription section not ready yet]