#### GBS .....CIDP

## **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)

#### A TRIBUTE TO JAMES AND BETTY GERRAND

In 1990 James Gerrand was diagnosed with CIDP (Chronic Inflammatory Demyelinating Polyneuropathy).

On the suggestion of Professor Pollard, James formed a support group for people diagnosed with GBS (Guillain-Barre Syndrome) and CIDP. Patients with other inflammatory neuropathies also became part of what is now known as "The 'IN' Group."

James worked tirelessly giving support to patients and their families. This may have taken the form of answering queries by phone or E-mail or even arranging hospital visits by himself or other members of the group.

Always there lending a hand has been his supportive wife Betty.

Together they have made The IN Group

what it is today. They should be very proud.

James has been receiving 'Intragam' for many years and was a major influence on winning support for people with GBS and CIDP to be listed high on the priority list for this wonderful product.

All members are kept informed by our Newsletter. James has typed and printed all previous issues.

At age 87 James feels it is time to hand over the reigns.

Those who have been privileged to know James and Betty personally have been treated to time with one of nature's gentle couples.

At public meetings Betty has served numerous cups of tea and coffee. Committee meetings were always conducted professionally and finished with "supper and a cuppa". James was kept busy giving support, answering the mail, preparing the newsletters, keeping tidy financials, preparing submissions to Government, and the list goes on.

Betty organised functions like the Christmas Luncheon. Members who have attended over the years will know of the delicious food lovingly bought and prepared by Betty and her wonderful helpers.

How many chickens, hams, asparagus, sandwiches and salads have been prepared and set out over the years?

To our esteemed Director James Gerrand and his wonderful wife Betty, it is with deep respect that we say a heartfelt

"THANK YOU" from all members of The 'IN' Group.

## **CONGRATULATIONS** on a job well done!

#### **A.G.M**.

We started our Annual General Meeting with seating in a circle.

Margaret Lawrence chaired the meeting.

James Gerrand explained that he was experiencing problems with continuing to run The IN Group.

Following James, all present introduced themselves. This was very interesting and informative and gave us the opportunity to get to know something about each member and their carer.

John Burke thanked Margaret and Doug Lawrence for stepping into the breech.

**Apologies**: Ken Clarke, Barbara Clifford, Fred Hooton, Steven Cohen, John Pollard, Peter Malcolm.

The Minutes of last year's meeting were not available. The Director's Report was available.

Margaret explained how James did all things and now many people are going to do a little each.

Margaret said how grateful all members were to James for running the Group for so long. All applauded James.

Because there were no Minutes available from last year's meeting there was not Business Arising from those Minutes.

#### Treasurer's Report -

Fred Hooton has been the Treasurer for the past 12 months but because he is not well Doug Lawrence produced the Treasurer's Report.

#### **Profit & Loss Statement**

#### **Income**

Subscriptions	\$2908.00
Donations	4746.00
Sponsorship	1000.00
Bank Interest	46.53
Fund Raising	1220.54
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Total Income 9221.07

#### **Expenses**

Print/Stat/Pcopy	1004.97
Internet Costs	562.17
Postage	949.25
Donations	12000.00
Bank Fees	174.62
Office Equip.	129.00
Depreciation	774.08
Misc.Exp.	163.60
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Total Expenses 15757.69

Net Loss (\$5836.62)

Doug also gave a verbal report which was very informative.

The 'IN' Group donated \$12,000 to Medical Research in the last year thanks to our members.

As at the 30/6/06 our bank balance was \$3,117.

Since then membership payments have been banked.

Discussion took place regarding the Group.

We have a copy of Certificate of Incorporation and also the Regulations for Incorporation.

Margaret read from a letter received from Margaret Wilson in relation to a role for James and recognition of his work, taking into consideration our rules.

Amendments can be made to the rules. This is not to make the rules more complicated but to ensure they work for the group and to be what the members want.

The Group might like to think of a Life Membership for James.

Discussion on sharing the load and responsibilities took place. The following people offered to accept responsibility for a particular area.

#### Barbara Rivett as

Secretary will receive all mail. The new address will be advised in the newsletter.

**Barbara Clifford** -Tea and Coffee for all public meetings.

**Melva Behr** – Type/Print Newsletter.

Newsletter mailing will be from **Betty and James'** home.

## **Dorothy Brennan** - Key to the Library meeting room.

#### Peter McInness bookings at the library for the year and for making the payment.

#### Daytime Meetings.

It was suggested perhaps the Winter meeting could be in the daytime.

We decided we will have a short meeting before each Guest speaker.

John Burke will maintain the website and be responsible for all electronic mail.

Our Home Page is: http://home.vicnet.net.au/ ~ingroup/ E-mail: ingroup@vicnet.net.au

John Burke spoke of the membership lists.

A New Subscription form will enable people to add their email address and update their information.

Some members may like their Newsletter by email.

The Newsletter will also be on our website. John will look at this. We now have an email mailing list for members.

# Bernie and Janet Pettit will be the contact for people diagnosed with GBS, CIDP and other neuropathies. They will visit patients in hospital where possible.

**Peter Male** will visit newly diagnosed patients at Box Hill Hospital.

Margaret Wilson will be the telephone contact to support family members and friends. She will also send out the GBS and CIDP information booklets as required.

Discussion took place regarding Tax Deduction for donations. We are approved for donations for taxation purposes.

Membership.
All members are entitled to inspect the membership list at any time.

Privacy legislation both Federal and State was explained to us by Margaret Wilson.

James thanked everyone for their appreciation saying "I have found it very rewarding over the years. It has kept me occupied after I retired and I had good members

on the committees, especially Margaret and I am very pleased with how The IN Group has continued over time. It started 15 yrs ago after I met Prof. Pollard who was researching GBS and CIDP. He told me the best thing I could do would be to start a support group in Victoria.

There was one in NSW which had been very successful. There have been groups in all States but because they are all voluntary groups some have wound down over recent years.

In groups like ours people come and go. I have found it very rewarding and now with other people doing quite a bit of work to carry it on, (especially here tonight) The 'IN' Group should continue into the future. Thank you very much."

#### The new Committee is:

Pres. Margaret Lawrence V.P. John Burke Sec. Barbara Rivett Treas. Melva Behr Public Officer Margaret Wilson.

#### **Committee Members:**

James Gerrand Brian Boyd Peter Male Janet Pettit

Moved: Doug. Lawrence, Seconded: Joe Behr that the committee members be elected. Carried. John Burke reminded us that committee meetings are open meetings. All members are welcome.

James and Betty would like Committee meetings to be held at their home.

Next committee meeting 18<sup>th</sup> October at James and Betty's house, 138b Princess St., Kew.

Motion: "That a Life Membership be granted to James Gerrand." Moved: Margaret Wilson Seconded: Margaret Lawrence. Carried.

Motion: "That James be Honorary Director." Moved: Margaret Wilson Seconded: Margaret Lawrence. Carried. It was decided that our public meetings should continue at the Library.

At the next committee meeting we will pick the date of the Winter meeting to be held in the daytime.

Peter will see if we can use the library room.

Discussion took place regarding obtaining guest speakers for meetings.

Dr.Andrew Kornberg will speak at a meeting next year.

3 public meetings next year we should fill. We need a pool of ideas and someone we can call on if speaker unable to attend. Ideas for speakers:

CSL – update on dosages for 'Intragam'. Also new product you inject.

Rep. from Octagram.

Motivational speakers – Footballers, Blind Dogs Australia, etc.

It was decided to put out a Return questionnaire asking for names of speakers; could you visit people; would you like a day meeting; would you like to know people near you who are members.

The luncheon and Dutch Auction shouldn't change.Ken Clarke is an outstanding auctioneer. End AGM