

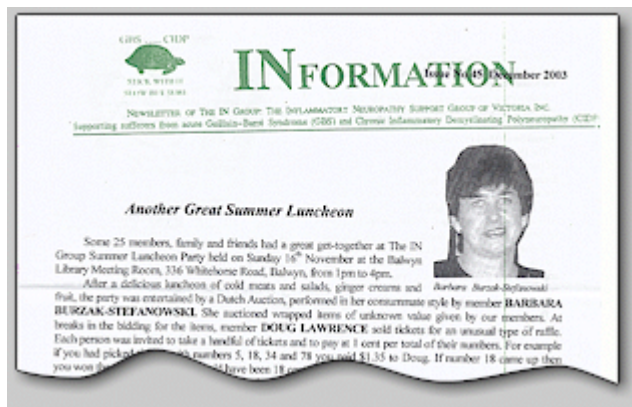
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## Newsletter No.45 - December 2003

### Another Great Summer Luncheon

Some 25 members, family and friends had a great get-together at The IN Group Summer Luncheon Party held on Sunday 16<sup>th</sup> November at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn, from 1pm to 4pm.

After a delicious luncheon of cold meats and salads, ginger creams and fruit, the party was entertained by a Dutch Auction, performed in her consummate style by member **BARBARA BURZAK-STEFANOWSKI**. She auctioned wrapped items of unknown value given by our members. At breaks in the bidding for the items, member **DOUG LAWRENCE** sold tickets for an unusual type of raffle. Each person was invited to take a handful of tickets and to pay at 1 cent per total of their numbers. For example if you had picked tickets with numbers 5, 18, 34 and 78 you paid \$1.35 to Doug. If number 18 came up then you won the raffle gift for what could have been 18 cents!



Not only was the party delightful but it was also most bountiful for raising money for medical research. The total profit for the day was **\$779**, comprising \$182.10 from the lunch, \$405 from the Dutch Auction \$71.90 from the raffles and \$120 from donations by two members who were unable to attend.

Great credit and thanks go **MARGARET LAWRENCE, BETTY GERRAND** and **BARBARA RIVETT** who shouldered the major responsibility for the function and to the many assistants, including **DOUG LAWRENCE, DOROTHY BRENNAN, BARBARA CLIFFORD** and **KEN CLARKE**. A big thank you to **BARBARA BURZAK-STEFANOSKI** who came from Traralgon to ensure the success of the Dutch Auction. And many thanks to all who bid and gave so generously to make our annual summer social again such an outstanding success.

## The IN Group News

### Continuing Shortage of Intragam

Intragam (CSL's trade name for their gamma-globulin product) is still in short supply, at least in Victoria, with most of our patients receiving only 80% of their medically prescribed amount. Some of our members have recently received their full prescribed amount for two sessions but then have been disappointed to have it reduced to 80% for later sessions.

### Donation to Medical Research

In September The IN Group donated a further \$7,500 to the

### Red Cross Summer Blood Challenge

The IN Group have again shown support for the Red Cross Blood Bank by entering the annual Summer Blood Challenge. All members are challenged to get family and friends to donate blood over the next three months. All donations need to be recorded against our Groups entry. Lets make a contribution to help our members that rely on blood products and others who

research being carried out by A/Professor Andrew Kornberg, Director, Department of Neurology, at the Royal Children's Hospital. Since the initial donation to this research in December 1997 The In Group's donations now total \$51,050,

In thanking the IN Group, Dr Kornberg stated this latest donation "will go towards the employment of a neuromuscular fellow who is currently looking at Intragam and inflammatory neuropathies.

desperately need blood.

Further information on venues for mobile blood bank sites can be found on the IN Group web page by calling the Red Cross 13 14 95.

## Personal Support

Following a family request I visited Mr Valentino Pravlic, a patient at St Vincent's Hospital, recovering through rehab from GBS. - James Gerrand

## Email/SnailMail/Phone Support

The IN Group provides support to a great number of people over a wide distance through the above forms of communication. In the past three months we sent material - usually a GBS or CIDP booklet , The IN Group brochure and latest quarterly newsletter - to 6 people relating to CIDP, 9 to GBS and 2 to MMN. The seekers included an occupational therapist and a social worker. Twelve communications came from Victoria, 1 each from SA, Qld and PNG and 2 from the USA. The In Group has now five more members.

Some pleasing tributes:

*Thanks for the info sent to my partner here in New York named Richard Byrne. I enjoyed and learnt a lot from it.*

*Brad Lohrenz, NYC, NY.*

*Dear James,*

*Thank you so much for your assistance. I appreciate all the work you have done for this disease.*

*Pat Caviness, Oklahoma USA.*

And a helping hand;

*Dear James,*

*Have been contracted by a friend who had medium GBS a couple of years ago who now wishes to join The IN Group, receive Newsletter and other material. Could you please help by sending her the necessary papers. Address follows.*

*Greg Gillespie, Peterborough.*

As a result we have a new member - Mrs Jane Neville of Bannockburn. Welcome, Jane, and thanks, Greg.

## Film Luncheon

Eight members and friends enjoyed the movie ?Japanese Story? and the following luncheon held at the Balwyn Cinema on 6<sup>th</sup> October.

## Relation between Diabetes and CIDP?

*Dear Dr Bruce Day (The In Group Consultant Neurologist),*

*Someone asked whether there is a connection between diabetes and CIDP. A couple of our members have both. Is somebody with diabetes more likely to get CIDP? Or if one has CIDP is he/she more likely to get diabetes? Probably these queries are a bit way out.*

*James Gerrand.*

*Dear James Gerrand,*

*On the contrary, this is a very good question and very timely as we (peripheral neurologists worldwide) are currently struggling with this very issue. In short, if we see patients with diabetes whose electrophysiological studies satisfy the criteria of CIDP we will treat them as if they have CIDP and most will respond satisfactorily.*

*Based on these criteria quite a few (one figure I've come across is 6%) patients with so called diabetic neuropathy probably have an immune mediated neuropathy*

*There is some suggestion that diabetes is a risk factor for CIDP; I think this is still very unclear. In addition there are some diabetic neuropathies such as so called "diabetic amyotrophy" which are now well documented to be due to a microvasculitis and are currently being studied in large randomised placebo controlled trials using IVIG and high dose IV methylpredisolone. Case reports suggest these are likely to be very effective interventions.*

*This type of diabetic neuropathy is usually quite easy to distinguish from focal CIDP but this is not always the case. Furthermore some patients have typical diabetic amyotrophy but don't have diabetes by accepted criteria and it is a moot point as to whether they should be called focal CIDP or one of the many acronyms now attached to "atypical CIDP".*

*In any event it is clear there is a complex interaction between diabetes and immune mediated neuropathies. At this stage I would say that if one has diabetes there is perhaps an increased risk of CIDP but if you have long standing CIDP you probably don't have an increased risk of developing diabetes apart from the added risk due to steroid usage.*

*Dr Bruce Day.*

## Smallpox Vaccination and GBS

An article by Dr Joel Steinberg in the Fall 2003 "The Communicator", newsletter of the GBS Foundation International, concludes that the neurologic complications from smallpox vaccination, such as a GBS-like picture, tend to be extremely rare. And the rare patients who develop such complications apparently recover relatively rapidly. It appears that, with respect to effects on the nervous system, smallpox vaccinations for children are rather safe.

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