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Newsletter No.41 - December 2002

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Another Great Summer Luncheon

Some 32 members, family and friends had a great get-together at The IN Group Summer Luncheon Party held on Sunday 17th November at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn, from 1pm to 4pm.

After a delicious luncheon of cold meats and salads, pavlovas and fruit, the party was entertained by a Dutch Auction, performed in her consummate *Barbara Burzak-Stefanowski* 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 **\$848.28**, comprising \$295.28 from the lunch, \$376.95 from the Dutch Auction \$101.05 from the raffles and \$75 from donations by two non-attendees.

Great credit and thanks go **MARGARET LAWRENCE** who shouldered the major responsibility for the function and to her many assistants, including **DOUG LAWRENCE, BARBARA RIVETT, ROSEMARY MACQUALTER, 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 gammaglobulin product) is still in short supply, at least in Victoria, with most of our patients receiving only 80% of their medically prescribed amount. One of our members recently drove with his wife to Brisbane on a holiday. He was surprised and pleased to receive his full supply in Brisbane. His wife suggested that they drive each month to Brisbane to attain the prescribed amount!!

Opening of new CSL Laboratory

James Gerrand, as Director of The In Group, attended the official opening by the Victorian Treasurer, John Brumby, of the CSL Limited new laboratory, the Nucleic Acid Testing Amplification Laboratory, at Broadmeadows, costing \$10 million. This laboratory reduces the incubation period for possible HIV/AIDS incubation before detection from 60 days to 20 days. CSL Manager, Mr Paul Bordonaro, stated that this provision further improves the safety of their product, already a world leader in gammaglobulin safety.

Value of Australian Red Cross Blood Service

The Australian Red Cross Blood Service (ARCBS) recently conducted a study involving a questionnaire to assess "stakeholder" needs and interests. (The IN Group is one as a user of blood product Intragam.)

Nine key characteristics were identified as adding value for the stakeholder, namely Safe product, Product sufficiency, Research and Development, External management, Internal management, People management, Working with stakeholders, Donor and volunteer management and Public confidence.

Patient Groups, one of the eleven Stakeholders listed, valued Safety as No 1 priority, Sufficient Supply as No 2 and Public Confidence as No 3. Safety was listed No 1 also by 5 other Stakeholders including ARC, State/Territory Governments, and Sufficient Supply as No 1 by 5 other Stakeholders including Federal Government, Unions, and Health Sector.

Let us hope this study will improve the chances of the safe supply of Intragam being increased to meet the medical needs.

Personal Support

Following a request from Selana Nivele, Social Worker at the St Vincent's Hospital, information about GBS was sent and resulted in my paying a visit to Phil Fleming, a patient being treated there for GBS. Phil appreciated my visit and I learnt that he, now 65, had been a lecturer in Philosophy at Latrobe University until he retired some 10 years ago.

I also visited 22 year old Graham Bradley recovering from GBS at the Monash Medical Centre following an email from his father. Both most appreciative.

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 12 people relating to CIDP, 5 to GBS and 5 to MMN. The seekers included an occupational therapist, a social worker and a third year nursing student. Seven communications came from Victoria, 2 from the ACT, 2 from WA, and 1 from each of SA, NSW, Tas and the USA.

The In Group has now five more members.

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 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.

Film Luncheon

Seventeen members and friends enjoyed the movie "My Big Fat Greek Wedding" held at the Balwyn Cinema on 19th November. Unfortunately there was a contractor breakdown so we didn't have the basket lunch but the Cinema management gave us each a complimentary movie pass.

GBS Conference in New Zealand

The In Group wrote to Qantas requesting a return airfare for a representative, **VILMA CLARKE**, President of the Council of GBS/CIDP Support Groups of Australia and also Committee Member of The In Group, to attend the GBS Conference in Wellington, New Zealand on April 25-27 th April 2003.

Qantas advised that while a full return airfare was not available due to many such requests they are offering a concession airfare to Vilma.

A Pleasing and Valued Tribute

Dear James,

I thank you for sending me information about Polyneuropathy (GBS booklet sent). I have found the Booklet most interesting as I was diagnosed in 1960, then being Polyneuritis (Charcot-Marie-Tooth) and have learnt a lot more since reading the material.

Thank you again. Please find enclosed Money order for \$50 - \$5 Joining Fee, \$10 Subscription, \$3 Booklet ? leaving \$32 Donation.

Mrs Pat Kenny, Lalor Park NSWt

Hospitals need Mozart background music

*Dear Dr Bruce Day,
The IN Group Consultant Neurologist,
The Alfred Hospital.*

Some time ago I read a report that Mozart music (and only Mozart music) was great for calming hyperactive kids.

Now I am a great lover of Mozart's music (I hope you are too) and I find when I attend the Alfred each fortnight for my Intragam hit that the back ground music - usually some radio station? - is rather irritating.

I would like the Alfred to adopt Mozart music for the background ambience to soothe the "savage breasts" of patients and staff. I think this would be an excellent experiment for the Alfred to try out.

So what do you think?

James Gerrand

Quiet Achiever Life Skills

Member **VICKI BROUS**, Residential Aged Care Placement & Life Coach, BA, BSW, MAASW, has set up a consulting practice. To contact, her address is PO Box 3017, Prahran East 3181 tel

0407547184 email vickib2@ozemail.com.au.

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