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Newsletter No.49 - December 2004

Number 49 - Another Great Summer Luncheon

Some 27 members, family and friends had a great get-together at The IN Group Summer Luncheon Party held on Sunday 14th 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 an Auction, performed in consummate style by our member **KEN CLARKE**. (Our usual auctioneer **BARBARA BURZAK-STFANOWSKI** was

unfortunately not able to attend. We missed you, Barbara.) Ken 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 **\$865.55**, comprising **\$259.45** from the lunch, **\$481.10** from the Auction and the raffles and **\$125** from donations by two members who were unable to attend.

Great credit and thanks go to **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**, and **KEN CLARKE**. 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 P (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 November The IN Group donated a further \$7,500 to the 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 **\$64,000**,

In thanking the IN Group, Dr Kornberg stated

Red Cross Summer Blood Challenge



this latest donation will again "go towards employment of a Neuromuscular Fellow who is currently undertaking projects looking at Intragam and the inflammatory neuropathies and the benefit from the therapy. We have had a couple of studies in press."

Dr Kornberg will be our speaker at our August 2005 public meeting, giving an update on his research.

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 news-etter - to 6 people relating to CIDP and 5 to GBS. The seekers included a nurse; 9 communications came from Victoria, 2 each from NSW and Qld and 2 from the USA. The In Group has now five more members.

A pleasing tribute:

I am grateful for all the work that you do for The IN Group, thanks.

Bernard Pettit, Narre Warren.

Reply

Thanks. I am one of many who endeavour to help. I think we all find it very worthwhile.

James Gerrand.

This email says it all ? *My mum*

Hello, my name is Bronwyn, I am a registered nurse working in Victoria. I remember quite vividly looking after a young man with GBS 15 years ago in an intensive care unit in my home town of Burnie Tas. This young man was ventilated for ages and as a young nurse I believed I looked after his physical needs to the best of my ability. I helped to wash him, clean his teeth, give him pressure care, observe his vital signs, suction his et tube etc. But I now realise that there was one component of his care that I, as a young nurse, neglected ? his emotional and psychological care. I realise that now, because my mum has been diagnosed in Burnie with GBS. Mum has had a very quick progression of the syndrome, stating to me one Saturday that she had a "numb bum" and "weakness in the legs" and then being ventilated on the Monday. I flew home to be with her and dad last week. I can handle all the equipment as I understand their uses. I can?t however come to terms with what she must be going through. How can anybody who has never been there begin to comprehend. I have come back to Melbourne as I need to be mum to my ten year old, but I am distressed as to how I can help, other than give my dear dad emotional support over the phone. I am emailing letters to be read out to her and I will send a cassette over, taped with our weekly events. I would be grateful if anyone has advice they can share with me and my loving family in Tas.

Bronwyn.

Contact wanted with parents of young children

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 and by calling the Red Cross 13 14 95.

Hello, my name is Nancy Inches and my 6 year old daughter has GBS. She was in the Royal Children's Hospital for 2 weeks and in our local hospital for 1 week prior to that. Now she has been home from hospital for 3 weeks. She is walking again now and even running a little bit. She has physio every day and we are trying to reintroduce her to school. I am looking for information on GBS and came upon your support group and thought I would email you. I would be interested in joining the Group and receiving the newsletter. We live in rural eastern Victoria. I would be interested in being in contact with other parents of young children who have had this syndrome to discuss the return to school etc.

Having obtained Nancy's address I posted her the GBS booklet published by the GBS Foundation International (USA based) plus The IN Group brochure and latest newsletter. If any member wishes to contact Nancy, contact me first and I will supply contact details.

James Gerrand, Director.

Rapid progress with CIDP

My father was diagnosed with CIDP about 9 months ago but has just started a rapid decline in the last 2 weeks despite continued Intragam infusions and commencing prednisolone 10 days ago. He can notice a daily decline and, from being able to walk unaided a week ago, is only just managing to walk with a frame. His hands and arms are also affected and he sometimes is unable to hold a knife or fork. He can notice the weakness increasing in his arms daily.

Is there anything that can be done to stop this rapid progress?

Trish Boyd, Aireys Inlet

A CIDP booklet plus The IN Group brochure and latest newsletter, were posted and we are now hoping for better news.

WANTED: HAPPY OUTCOME CIDP STORIES

Our member PETER SIMPSON would like to talk to people who have made good recoveries from CIDP and are now living reasonably normal lives.

Peter's wife Valerie has been in hospital for most of the last two years, with about half that time in the Intensive Care Unit at the Royal Melbourne Hospital. Before that they were living and working in the Northern Territory for the past 20 years. They now plan to settle in Melbourne.

Despite many relapses and difficulties, Valerie is determined to get back to a happy existence away from hospitals, even though she will almost certainly have residual disabilities. Learning from the experience of others could be a big help.

Peter can be contacted on 0419 826 798 or by email at pandvsimmo@yahoo.com.au

Blood Donor Awareness Month

Our member BRONWYN CLARKE kindly sent this article that appeared in an internal Departmental newsletter ??how surprising to see CIDP mentioned! Hopefully this will remind readers of the need for blood and plasma donations.

Did you know it can take up to 225 plasma donations per year to keep a CIDP sufferer alive?

CIDP is a rare disease which attacks the per-ipheral nervous system, weakening muscles mainly in the arms and legs. Plasma donor and DSE Senior Analyst Chris Egan knows only too well the quantities of plasma needed to help patients on their road to recovery. After four years of fortnightly visits to the Southbank Blood Centre, Chris has made 110 donations or 70 litres of plasma that is used to make a range of products including Intragam to treat CIDP. *"The Blood Bank wanted to collect 74 tonnes of plasma in the last financial year"* he said. *"A plasma donor can give a maximum of 25 donations a year so it needs at least eight donors to support each person with this disease."*

About 600 Australians suffer from the disease in any one year and there are several hundred sufferers in Victoria alone. The uses for blood donations are many and varied and, with demand increasing, there are even more reasons to become a donor in this Blood Donor Awareness Month. A whole blood donor of 28 years, Chris says plasma can be donated every fortnight because it is replaced by the body more easily than whole blood. *"Whole blood can be donated four times a year. There are some people who are not allowed to give blood through illness or having lived in England (because of mad cow disease) ? bit I would encourage everyone to give it a go."*

DSE Manager of Integration Projects John McDougall has made 132 donations over the past 33 years. *"The biggest challenge for new donors is to make donating a regular habit"* he said. But with donors being tested for iron content, haemoglobin, weight and blood pressure, the benefits to donors can outweigh the costs, he added. *"It's like getting a free mini health check every quarter,"* he said. *"And snacks, coffee, newspapers and magazines are all part of the perks donors receive."*

For more information or to make an appointment via the Australian Red Cross Blood Service call 13 14 95.

Leading a relatively normal life

CSL featured IN Group Director James Gerrand in their latest staff magazine "Pulse" 5/7/04 with this title as a result of Intragam (the CSL product) treatment. The IN Group has expressed their gratitude to CSL's continuing generous sponsorship which has provided necessary office equipment and enables maintenance of their website.

A very generous donation

Thank you letters were sent to family members of the late Gwenda Johnson for her generous donation of \$2,000 to The IN Group as a bequest in her will. Gwenda will be remembered for her long support of The In Group.

Member's to list Email address

Your committee asks members to list any email address when they fill out their joining or renewal form as a means of extending means of communication.

Ending on a Lighter Note

Flower Show

Two old ladies were sitting on a park bench outside the local town hall where a flower show was in progress. One leaned over and said, "Life is so damned boring. We never have any fun any more. For \$5, I'd take my clothes off and streak through that stupid flower show."

"You're on" said the other old lady, holding up a \$5 note.

As fast as she could, the first little old lady fumbled her way out of her clothes and, completely

naked, streaked through the front door of the flower show. Waiting outside, her friend heard a huge commotion inside the hall, followed by loud applause. The naked lady burst through the door surrounded by a cheering crowd.

"What happened?" asked her waiting friend.

"I won first prize for "Best Dried Arrangement."

(Thanks, Jeff Richard.)

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