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We Donate \$3,000 for Medical Research into GBS/CIDP

Newsletter No.17 - December 1996



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Dr ANDREW KORNBERG, Neurologist, receives \$3,000 to help his medical research into GBS/CIDP at the Royal Children's Hospital from Mr JAMES GERRAND, Director of The IN Group, in the presence of Dr LLOYD SHIELDS, Head of Neurology, and Mrs BETTY GERRAND and Mrs MELVA BEHR, committee members of The IN Group.

This initial donation by The IN Group was particularly due to most generous donations of \$1,000 each by members Mrs GWENNETH MANN and Mr ALLAN GOYEN, supported by donations of \$100 by member Mrs HELEN MAHON and \$25 by Mrs BETTY FAYNTUCH, plus the proceeds \$740 of our very successful November luncheon.

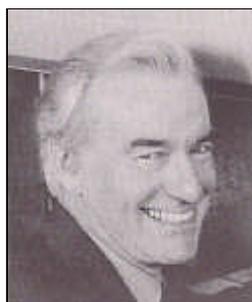
The donation is an expression of the importance The IN Group places into medical research into these inflammatory disorders and of the confidence The IN Group holds in Dr Kornberg's ability to further the medical understanding of GBS and CIDP.

Dr Kornberg is the Director of the Neuromuscular Laboratory at the Royal Children's Hospital. The laboratory is studying serum antibodies against a variety of neural antigens in autoimmune neuromuscular disorders including neuropathies and myopathies. The research involves potential pathogenic antibodies and understanding how these antibodies cause disease. An understanding of the pathophysiological processes involved can be used to formulate treatment options.

Immune neuropathies are conditions where the body's immune system "fights itself" and damages peripheral nerves. Antibodies may be formed as part of an immune response, and can be measured. Understanding how these antibodies cause disease may allow development of blood tests useful for diagnosis and development of treatments. The study of these antibodies and how they cause disease will be the basis of the research.

News of Two IN Group Patrons.

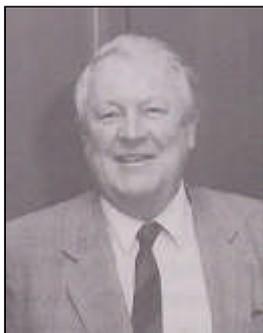
A Personal Chair



JOHN POLLARD

has been awarded the title **Professor of Clinical Neurosciences** in recognition of his excellence in research in the field of neurology. Professor Pollard holds positions of Academic Head, Institute of Clinical Neurosciences, and Director of the Neuromuscular Laboratory at the University of Sydney - the leading Australian centre for research into nerve disease, particularly GBS and CIDP.

Long serving Head retires



Dr **BERNARD GILLIGAN**

has retired as Head of Neurology Unit, Alfred Hospital, a post he had held for 20 years. His retirement coincides with the establishment of the Van Clef/Roet Centre for Nervous Disorders. Dr Gilligan spent many years endeavouring to establish this centre which will advance neurological research and development at the Alfred. The Centre's Foundation Director, Professor **ELSDON STOREY**, will co-ordinate the research and clinical work conducted at the centre.

Dr Gilligan earlier this year retired as President of the Australian Brain Foundation. He will continue as honorary neurologist to the Alfred and in his well established private practice.

I would like to take this opportunity to thank both Patrons for their help - Professor Pollard suggested I start The IN Group some five years ago and Dr Gilligan has provided continued sound advice and effective support over these years.

James Gerrand, Director.

Successful November Luncheon

Forty two members, family and friends enjoyed a very happy get-together Luncheon Party on Saturday 16th November, held at the Balwyn Library Meeting Room, 336 Whitehorse Rd, Balwyn.

Betty Gerrand with the generous help from Dorothy Brennan, Barbara Clifford, Melva Behr, Margaret Lawren-ce and Vilma Clarke, provided a delicious lunch which raised \$161.65.

Much fun was generated by Barbara Burzak-Stefanowski who conducted a blind auction of wrapped gifts donated by members. This brought us \$283.75 and the raffle of a wonderful hamper made up of individual donations yielded \$295.00. This brought up a total of \$740.40 raised on the day.

Membership

We have now topped the two hundred mark (206 in fact) in our membership, including again a number from overseas who have found our support group through the Internet.

So a special welcome to our new overseas members; Lena & Nikita Arnold (Linz, Austria), Pamela Barry (Montreal, Canada), William Boyea (Green Bay WI USA), Robert Lunardon (Rutherford NJ USA). Also of note are new members Mr Philip Webb of Balwyn, President of the Real Estate Institute of Victoria (contacted through the local press reporting him as a sufferer from GBS), and two members from CSL P/L: Mr Peter Turner, new General Manager, Bioplasma Division, and Ms Cathryn Hope, new Product Manager, Bioplasma Division.

Continued Support from CSL

Mr Peter Turner, General Manager, Bioplasma Division, CSL P/L, quickly granted our request for continued funding of our Internet operating expenses, sending The In Group a cheque for \$570 to cover our expenses for 1997. Such expenses include an annual fee of \$200 to our Internet Server, Vicnet (run by the State Library of Victoria) which allows The IN Group 20 hours of working each month, with the rest being Telstra charges (\$140 for service and equipment plus the local calls to Vicnet).

Many members will know that CSL P/L (previously Commonwealth Serum Laboratories) make the gammaglobulin that is one of the particularly favoured treatments for GBS and CIDP. A year ago CSL P/L generously donated to The IN Group \$3,500 to enable The IN Group to be on the Internet - \$3,000 for purchase of the computer equipment and \$500 for annual running expenses.

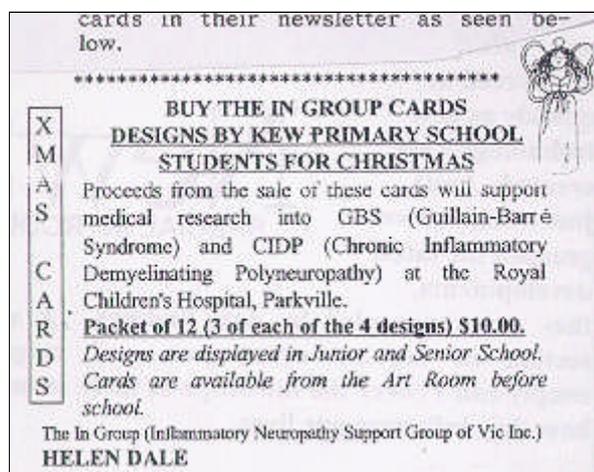
Have You Bought Our Xmas Cards?

Our Xmas Cards, with appealing designs by children of the Kew Primary School, have been well received by those who have purchased them.

Members and friends have so far bought some 60 packets and Kew Primary parents have purchased 55 and expect to sell another 50. All we have to do now is sell another 100 for it to be all profit for Dr Kornberg's medical research into GBS and CIDP.

So please send in your orders - the form is on the wrapper.

Kew Primary School advertised the cards in their newsletter as seen below.



Member helpful on the Internet

Brian Wynn, whose father died following the onset of GBS some years ago, recently joined The In Group, after learning of our existence through our Home Page on the Internet.

Brian, having experienced the benefits GBS/CIDP Group members are getting from the Internet, is offering to help connect people to the Internet. Brian's telephone no. is 9762 9014 and address PO Box 27, THE BASIN 3154.

Brian has already shown his Internet ability by firstly, through his email messages to the Hilton Hotel management, having them refund hotel charges to a USA citizen attending the GBS Foundation International Symposium held in Miami who was badly treated by the local Hilton management. Brian triumphed where more local efforts had failed.

Secondly he has edited a medical document on GBS which Brian had obtained from the neurological Internet server at Johns Hopkins University and then made it available on the Internet. I have downloaded it and printed it as a nine page document. Copies are available to those technically interested at \$3.00 from The IN Group.

Awards to two members

Allan Goyen recently won the Department of Veteran Affairs prize for writing the best "True War Experience". Allan joined the AIF at the start of WW2 and was one of those captured by the German Army in Greece. He escaped three times from European prisoner-of-war camps.

Claire Brooks rowed for the Abbotsford YWCA Rowing Club back in 1927. She is now the Patron of the Club and was presented with a Gold Medallion for her efforts at the World Masters Games held in Melbourne this year.

Kind Words from the Internet

An extracts from one of many messages of appreciation I have been sent via the Internet.

Hi Mr Gerrand,

Thank you so much for the valuable information I received by Air Mail. The little Book (CIDP) was perfect.

I am taking it to my Doctor when I go for my checkup. (He cannot keep my booklet though). In my opinion all CIDP should have a copy...

After reading your booklet, I am at peace with myself for the first time in three years. I also know Dr Wood did all the tests needed to diagnose CIDP. I have sent a copy to my mom who every day worries about me, this will give her peace of mind, and for the people at my work especially my boss who really thought I should be exercising more...

... Sad it took a wonderful gentleman from Australia (of course she means The IN Group and the Internet) to help out someone in Montreal, Canada, eh?

Forever grateful,

A friend, Pamela Barry.

Support the Name of our Game

In Intensive (and kind) Care

A recent example of supporting a patient stricken with GBS. On Tuesday afternoon 3/12 a **Heather Saunders** rang me to tell me the husband, **Barry**, of a friend, **Linda Steel**, was in Intensive Care at the Royal Melbourne Hospital, paralysed "to the eye-brows", and could The IN Group help? She had found our Group through the Internet. I said I would endeavour to arrange for a member who had gone through the same GBS trauma and recovered to visit Barry Steel and that I would endeavour to see Barry personally the next day (after making the \$3,000 donation at the Royal Children's). I then rang Linda Steel at their dairy farm at Cobrico some 60km east of Warnambool to tell her of the plans, including sending her a booklet on GBS, our IN Group brochure and latest newsletter. Linda was most appreciative; she is having to look after the farm of some 3,200 cows as well as looking after two young children, aged 7 and 2, and expecting two more in February. The couple are in their 40s.

I then made contact with member **Bryan Luscombe**, about the same age as Barry who had been similarly afflicted with GBS and made a good recovery, who agreed to visit him in hospital.

On visiting Barry at about 1pm on the Wednesday at the Royal Melbourne, I was most impressed by the friendly help and warm care of the staff at the ICU, particularly **Katie Schlicht**, Clinical Nurse Consultant and **Beverley Kane**, Ward Clerk. Katie was pleased to receive the information I had brought - GBS booklet, IN Group brochure and newsletter - and said she would arrange for them to be read to Barry. She also bought a packet of our Xmas cards and said she would write and send some on behalf of Barry.

On visiting Barry, he expressed his pleasure at my visit and the prospect of a visit from Bryan Luscombe by expressive winkings of his eyes. He is already making some recovery, although very slow.

That afternoon I rang Linda about my visit to her husband and she again was most pleased with the support.

Helping at Rehab

Dear James,

*I was advised yesterday of another patient ...at Caulfield General Medical Centre ... **Jeffrey McGinty** of Mildura.*

I visited him this Friday ... and told him of The IN Group. He would be interested to receive some of your literature (sent JHG) ...

His GBS seems to be a fairly mild case as in the last week he has begun moving his hands and arms. He can feed himself now and at no time did he require ventilation, so his speech was not affected. His legs are still paralysed.

His own "target" for discharge ... is 3 weeks hence. At his present rate of recovery he might achieve that aim!

Jeffrey told me that his doctor in Mildura diagnosed his GBS very quickly because the doctor's receptionist had GBS a couple of years ago. The doctor wasted no time to get McGinty flown to Melbourne for urgent treatment by the Alfred and then Caulfield Hospitals.

Mr McGinty and his Mildura doctor will be interested to learn of the IN Group.

*Member **Bill Eades** ... is still making progress, albeit slowly. I have been keeping in touch by visiting him ... last week ...*

Keith Colwill

Latest Support

On Friday 6/12/96 Julie Doig phoned to tell me to that her mother Edna Laidlaw (in her 60s) was in the Monash Medical Centre, stricken with GBS, and could The In Group help?

I said we could arrange for one of our members who had been through it and recovered to visit her and we would also send both Julie and her mother our brochure and latest newsletter.

Member Claire Brooks was good enough to visit Edna on Saturday and reported how pleased Edna was to see her. Another member Pauline Whitelaw is to visit Edna on Tuesday following Edna's transfer to Cedar Court Rehab Centre, Glen Iris.

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