

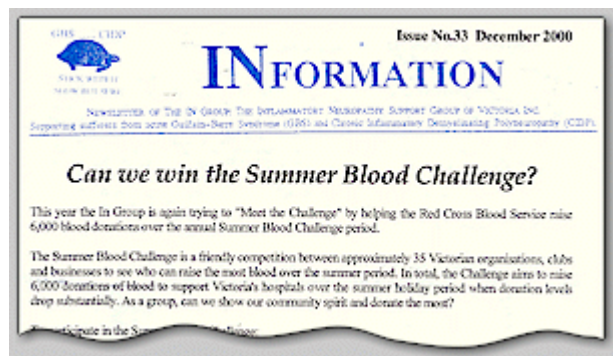
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Can we win the Summer Blood Challenge?

Newsletter No.33 - December 2000

This year the In Group is again trying to "Meet the Challenge" by helping the Red Cross Blood Service raise 6,000 blood donations over the annual Summer Blood Challenge period.

The Summer Blood Challenge is a friendly competition between approximately 35 Victorian organisations, clubs and businesses to see who can raise the most blood over the summer period. In total, the Challenge aims to raise 6,000 donations of blood to support Victoria's hospitals over the summer holiday period when donation levels drop substantially. As a group, can we show our community spirit and donate the most?



To participate in the Summer Blood Challenge:

- Give blood anytime between 1 December and 28 February
- Ask for a Summer Challenge Registration form - a simple mark against our company name is all that is needed
- These forms can be found at all blood collection centres
- Encourage your friends and family to donate, their donation can be registered for the IN Group.

Some useful facts to consider:

- Did you know that many patients with CIDP rely on Intragam for their medical treatment?
- Did you know that the plasma from approximately 10-15 whole blood donations is required to make up one 12gm bottle of Intragam?
- Did you know that the average monthly adult dosage of Intragam is 3-4 bottles (ie 36-48gm)?
- Did you know that there is no synthetic product that can replace Intragam?

The Australian Red Cross Blood Service (through CSL Ltd) issued the equivalent of 56,250 x 12 grams bottles of Intragam last financial year and is planning to issue the equivalent of 62,660 x 12 grams bottles this year. Given our reliance on Intragam, we have a vested interest in getting our friends and family to donate blood to help meet this target. For more information you can call either Bronwyn Clarke (9331 6548) or the Australian Red Cross Blood Service on 13 14 95 (the national donor information line).

Stop Press

As a means of increasing blood and plasma donations The IN Group has taken the initiative of trialling letter-boxing.

Some ten of our members and friends will each drop 100 letters to households in their area inviting them to donate blood or plasma. Each letter will contain the two pamphlets of the Australian Red Cross Blood Service - *Blood Donors - People helping people* and *Plasma - a golden gift* -plus a short note from The IN Group, thanking them for their most helpful gift and asking them to mark the Challenge Registration Form against The IN Group. Such a marking will both help our numbers in the competition and also be an indicator of success in this letter-boxing trial.

The Australian Red Cross Blood Service has provided the Blood and Plasma donation pamphlets and The IN Group is very grateful to **IAN CLARKE**, Franchise Owner of Snap Printing, Ground Floor 499 St Kilda Road Melbourne for his generous gift of the initial printed envelopes for this trial. Ian is a son of committee member **VILMA CLARKE** and brother of our Treasurer **BRONWYN WALSH** - what a wonderful helpful family to The IN Group cause!

Most Generous Support by CSL Limited

CSL Limited has donated \$6,000 (six thousand dollars) to The IN Group for our purchase of a modern copier - a **Konica 7020 Digital System**.

This issue of the newsletter has been copied by our new copier with outstanding performance.

The IN Group had been using a Konica analogue copier since its formation in 1992, belonging to another organisation. This organisation purchased a replacement a year ago and The IN Group purchased this 12 year old copier for \$100. The IN Group will be continuing to use it in a limited capacity because of its now unique facility to print in blue, red and

green as well as black.

The In Group has forwarded most grateful thanks to CSL Limited in a letter addressed to **Mr WERNER FIEDLER**, Sales & Marketing Manager. Enclosed with the letter is our **Certificate of Appreciation**, as shown below (in small scale). CSL has been a great and continuing benefactor of The IN Group, beginning in 1995 with a donation of 3,500 for our purchase of a computer and a continuing annual financial support reaching \$1,100 for our current financial year that has enabled The IN Group in particular to be on the Internet.

Intragam still in short supply

The continuing shortage of Intragam (the CSL tradename for the gammaglobulin it produces for the Federal Government from the blood and plasma donations of caring Australians) is producing increasing worry and even desperation from patients not able to get their prescribed medical treatment for their CIDP, GBS and allied conditions.

Such desperation was expressed by member **KYLIE MILLER** in an Open Letter to Federal Minister for Health **Dr WOOLDRIDGE**, published in "THE AGE" newspaper 15/11/00 and

reprinted at the back of this issue's wrapper. The Minister's reply ("THE AGE" 25/11/00) is also reprinted there.

I, as Director of The IN Group, sent a letter to "THE AGE", congratulating **KYLIE** on her strong stance and stating "If the Minister still refuses to lift the ban he should at least provide the \$14 million recommended by his Working Committee to overcome the present 20% shortfall in the supply of the needed Intragam." (Letter not published.)

"THE AGE" did publish a full page article by Anne Crawford in their "TODAY" section (20/11/00) featuring our member **MICHELLE HUGHES** as one, afflicted with CIDP, who needs Intragam regularly to continue as an engineering student at the Monash University. The article then describes how the Australian Red Cross Blood Service collects the blood and plasma from the caring donors at its various collection centres.

The IN Group News

Another successful Summer Luncheon

A grand total of **\$965.33** was raised at our annual Summer Luncheon held Sunday 12th November at the Balwyn Library Meeting Room. The 35 members and friends first enjoyed the very tasty food and drink (returning **\$264.33**) and then the hilarious Dutch Auctioneering by maestro **BARBARA STEFANOWSKI** of the many gifts contributed (returning **\$500**). A new initiative, Mystery Jars, replacing the Christmas Hampers raised a further **\$24**. Finally a number of members who apologised for not being able to attend, kindly donated a total of **\$176.50**.

Our very Special thanks are due to those who prepared the luncheon - **BETTY GERRAND, MARGARET LAWRENCE, ROSEMARY MACQUALTER** and **BARBARA CLIFFORD**.

A new printer for The IN Group

The IN Group has purchased a HP Deskjet 640C black/colour printer to replace its Epson 800 Stylus printer that had deteriorated after some years of use. Its cost of \$169 (including GST) was surprisingly low but replacement cartridges at about \$60 somewhat offsets the capital saving. The present newsletter has been printed with this new deskjet.

Sad Death of JAN AYRES

It is with great sadness that we report the death of **JAN AYRES**, Secretary of the GBS Association of NSW after a sudden and short illness. **JAN**, whilst suffering from CIDP for some eight years, spent many hours as Secretary counselling and advising the families of new patients with GBS or CIDP.

She liaised with the major public hospitals, organising visitors to new patients and forwarding booklets where the families and friends had no Internet contact. She worked with the Red Cross Blood Bank to try and increase the quantity of Intragam available to GBS and CIDP patients.

Council of GBS/CIDP Support Groups of Australia

The main effort of the Council has been to co-ordinate efforts at State and Federal level to increase the supply of Intragam.

Five groups currently comprise the Council - The GBS Association of NSW, The GBS Support Group of North Queensland, The GBS Support Group of South-East Queensland, The GBS Support Group of Tasmania and The IN Group of Victoria In. Unfortunately there is no longer a support group in South Australia with the closing of the Neurological Resource Centre of South Australia following the withdrawal of government subsidy.

Quarterly meetings are held by telephone - Conferlink. An annual sponsorship by CSL Limited provides appreciated financial support.

The Council is seeking ways to initiate Support Groups in South Australia, Western Australia and Canberra ACT. Any suggestions by members as to how this can be done would be welcomed.

Support is the Name of our Game

Helping a Presentation

I had a call from **BRIAN BRENNAN**, a nurse at the ICU of the Austin Hospital if The In Group would help him in a presentation on GBS, as part of his post Graduate studies. I told him I would send him a booklet on GBS plus The IN Group brochure and latest newsletter "INformation". I also said I would see if we could provide him with one of our members who been through ICU when suffering from GBS. I approached member **KEITH COLWILL** and this was the pleasing result.

Dear James,

On 16 Nov 00, my wife and I had the pleasure of meeting a group of eleven bright young nurses at the Austin & Repatriation Medical Centre, Heidelberg. They were attending a study day at the Austin Campus of the hospital as part of their 12 months' post-graduate Intensive Care nursing course.

Mr Brian Brennan, a male nurse of the group, had chosen as his special study project "Guillain-Barre Syndrome and GBS Patient Nursing." I was invited to supplement the presentation he made to the class by speaking about my experience as a GBS patient who had spent four months in intensive care and was totally paralysed for five months.

I was well impressed by Mr Brennan's knowledge of the subject and pleased to note the interest shown by other members of the group in his excellent presentation. The IN Group, and the valuable information service it provides for GBS patients' relatives, were highlighted throughout the session.

*Kind regards,
Keith Colwill*

and thanks from **BRIAN BRENNAN**

Dear James,

Thank you for your assistance and valuable information about The In Group and about the Guillain-Barre Syndrome.

*I must say when I started all this I knew nothing. But with your help and resources, I met **KEITH COLWILL** and his wife **MARJORIE**. They were wonderful and gladly gave me their time.*

As a result of your help, my presentation and assignments were completed successfully and the post graduate Intensive Care students have learned a great deal.

BRIAN BRENNAN

Helping in Auckland

On 1/12/00 I received this E-mail:

Hi,

My name is Michelle Beach and I am writing to ask if you would have a contact I could phone in Auckland, NZ with regard to CIDP.

My father-in-law has been recently diagnosed with this condition and I am keen to speak to someone to find out more.

Kind regards,

Michelle Beach

and I replied

Dear Michelle Beach,

If you send me your address and telephone number I will firstly airmail you a CIDP booklet published by the GBS Support Group of the UK which The IN Group has reprinted plus our brochure and latest quarterly newsletter "INformation".

Secondly I will send our two members in Auckland who have had CIDP your address and telephone number, asking each if they would contact you to give what support you would like as regards your father-in-law diagnosed with CIDP.

Best wishes to your father-in-law and regards,

James Gerrand,

Director.

And closer to home

Dear James,

I am a 62 years old male having been diagnosed with CIDP under the care of Medical Centre.

On October this year I received treatment of Intragam over a 5 day period as an out patient which was of no benefit to me. It made no difference to my condition.

As a result Dr ... has discharged me from the clinic. Enclosed is a copy of a letter stating this.

Could you send me any information on

treatment other than Intragam that may have helped others with this condition.

I heard about The IN Group from a patient receiving treatment from the clinic.

JOHN ALBAN, Endeavour Hills VIC

I telephoned John and told him I would post him a CIDP booklet published by the GBS Support Group of the UK which The IN Group has reprinted plus our brochure and latest quarterly newsletter "INformation".

I also said in my own case, diagnosed with Progressive CIDP some 9 years ago, my neurologist stated he would try up to six different treatments to see which might be effective. After trying five I have been treated with the fifth, Intragam every fortnight (when it is available) for the past 7 years which has stopped it progressing beyond giving me "footdrop" - I can't move my feet up and down.

I gave John the names of two neurologists I would recommend if he felt like getting a second opinion and asked him to let me know how he gets on.

People seeking information

The Internet is a wonderful means of quick communication world-wide. THE following is a list of persons seeking information from The In Group during the past 3 months and to whom I sent appropriate material.

Valeria de Araujo Ferreira da Silva (Rio de Janeiro, Brazil); Roy White (CIDP - Minyama Qld); Len Lddelow (CIDP - Bentley WA); Heidi R Austin (Mother CIDP - Philadelphia Pennsylvania USA); James H Molenda (Greenfield Wisconsin USA);

Dr Robert Moffat (CIDP - South Morang VIC); Claude Pilon (wife CIDP - Brossard Quebec Canada); Tammy Sparks (CIDP - West Blocton Alabama USA); Gwendoline Treble (CIDP - Doncaster Heights VIC); Bryan Goulstone (CIDP - Christchurch NZ); Ron Harmsen (CIDP - Richmond Tas);

Becky Swan (4 year old niece CIDP - Hamburg Arizona); Tom Bertram (GBS - Warnambool VIC, advised by Greg Gillespie); Helen Tabrah (CIDP - Clifton Hill VIC); Katherine Maurakis (CIDP - Winston Salem North Carolina USA); Clyde Michael (CIDP - Parsons Kansas USA); Betsy Lancaster (CIDP - Little Rock Arkansa USA); Carol Harvey (husband Wayne CIDP - Broadmeadows VIC); Wendy Husker (CIDP - Salisbury SA); Margery Hibbs (GBS - East Ringwood VIC); Diane Smithers - Bensalem Pennsylvania USA); Gladys Brown (CIDP - Pittsburg Kentucky USA).

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