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The IN Group takes a lead in promotion of blood donations - WE NEED YOUR FRIENDS AND FAMILY TO HELP

Newsletter No.29 - December 2000

by BRONWYN CLARKE, Treasurer

Anyone know where Intragam comes from?

It is simple really - from blood donations and lots of them! Intragam is made exclusively from voluntary blood donations and is made by CSL Limited from plasma collected from Australian donations- there are no overseas donations used in the manufacture of this all-important product. Many of the patients that battle CIDP and GBS rely

on Intragam as a key weapon to fight this condition. How many times have you heard someone say that they have had less Intragam because there is not enough available?

You can help. We need people to make more blood donations. Over 12,000 individual plasma donations are pooled together to produce each batch of Intragam One donation of whole blood makes over 13 different products ranging from red blood cells, platelets, Albumex-20, prothrombinex and of course Intragam.

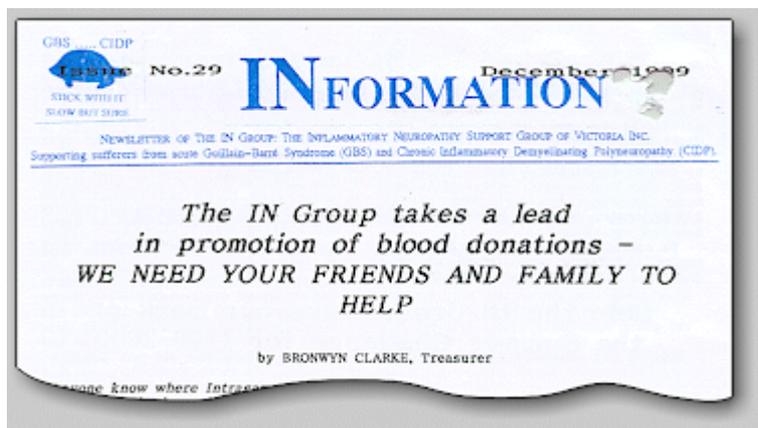
As a group that relies heavily on blood donations we want to encourage all our family members and friends to make blood donations. In support of this, The IN Group has joined the Red Cross - Summer Blood Challenge for 1999.

History of the Blood Challenge

In the summer of 1979, the Motorcycle Riders Association (MRA) issued a challenge to other organisations to give more blood than the state's motorcyclists did during the three months of summer.

The MRA recognised that summer, and particularly the Christmas holiday period, can be a difficult time for the Blood Service, with an increased demand for blood while fewer people donate.

Their challenge was met by a few groups including the Scouts and Police. These groups have maintained their support and enthusiasm for the challenge over the last 21 years, building the Summer Challenge into a well recognised annual community event. This is the first year the IN Group has participated but we recognise the reliance on blood donations for our well-being and are wanting to be active in this area.



Summer Blood Challenge 1999-2000

The 21st Summer Blood Challenge will run from 1 December 1999 until 28 February 2000. The blood bank are particularly looking for groups to donate as much blood as possible over the New Year period.

How can you be a part of the Summer Blood Challenge and help the IN Group make a mark in the Challenge?

It is easy. All you have to do is register a donation for the IN Group when you next donate or when you take the very easy step of your first donation. There are forms available at the refreshment area at all Blood Service venues. Please ask staff if you require assistance.

All our donations are collated and awards are presented to groups that have the most donors, the most new donors and an Ambassador Award. (Certificates of participation will be presented to all groups).

So are you convinced yet?

You've heard the advertisements - only 3% of Victorian are donating blood!! This is not enough blood for CIDP/GBS battlers to receive optimum levels of products such as Intragam. How many times have you heard someone say "I turned up for my fortnightly treatment of Intragam, only to find that I was getting less again as there has not been enough blood donated to make more Intragam". How can we ignore this?

We are trying to do our bit by encouraging our **family and friends** to make donations and lots of them! **Can you help us???** (*You are probably aware that present sufferers and people over 65 years old are not eligible to donate their blood. If in any doubt ring 13 14 95.*)

I have provided some general information below, but I am happy to hear from you to talk about this some more, so please give me a call on 03 9331 6548. Please also feel free to copy this article to show your family and friends. When you send your Christmas cards (The IN Group ones of course!) this year, maybe you could copy this information to be sent too?

Help the IN Group make our mark on the Summer Challenge for 1999-2000

Blood Service metropolitan static sites

Southbank Blood Centre

Cnr Kavanagh and Balston Streets, Southbank
Monday, Tuesday, Wednesday and Thursday 8.00am-7.30pm

Friday 8.00am-3.30pm

Sunday 9.00am-11.30am

Northern Donor Centre

within La Trobe University Medical Centre, cnr Plenty Road and Kingsbury Drive
(enter via Ring Rd, Carpark 9)

Monday and Friday 8.30am -4.00pm

Tuesday, Wednesday and Thursday 8.30am -7.45pm

Appointments - telephone 13 14 95

Parking available

Blood Service metropolitan mobile collection sites

A mobile blood collection unit regularly visits over 70 sites throughout metropolitan Melbourne and surrounds.

Blood Service regional collection centres

The Blood Service also has sites in more than 40 regional areas including Bendigo, Ballarat, Geelong, Horsham, Traralgon, Mildura, Shepparton, Warrnambool

RING 13 14 95 FOR FURTHER INFO ON THE LOCATION OF ANY COLLECTION POINTS

Intragam again in short supply

A number of our members have in recent weeks not received the Intragam prescribed for their GBS or CIDP treatment or else been given a reduced amount.

I contacted Dr Neil Boyce, Director of the Victorian Branch of the Australian Red Cross Blood Service who confirmed a current shortfall. He did not expect that the medical demand for Intragam would be met until the Review Of the Australian Blood Banking and Plasma Product Sector, chaired by Sir Ninian Stephen, has made its report to the Federal Government. This could be 12 to 24 months away.

Dr Boyce was not confident that there would be any major increase in the output of Intragam by mid 2000 through CSL improved production as had been suggested.

The report by the AHMAC Working Committee may be announced before the end of this year. If this happens, it is expected that the categorisation of CIDP will be raised from B priority to A which will be greatly helpful to CIDP patients.

Support is the Name of our Game

An Inexcusable Crisis

I had a call from **WAYNE CASTLEMAN** of Bald Hills, Victoria advising that his 65 year old father Phillip, living in Mildura, had been stricken with GBS such that he had been flown to Adelaide and placed in Intensive Care at the Royal Adelaide Hospital. Wayne asked if we could supply any information about GBS. I said we would do that and also try and arrange through the SA Neurological Centre somebody who had been through the GBS experience to visit his father. I also

arranged for our GBS experienced member, Keith Colwill, to speak to Wayne and his wife. The SA Centre organised a visit to his father by Pauline Major who had suffered from GBS.

Wayne and his wife showed their appreciation of this support by joining The In Group, enclosing a generous donation and sending a warm letter of thanks to me.

Some weeks later I received another call from Wayne expressing his great concern that he had heard there had been talk at the hospital of turning off the ventilator that enabled his father to breathe.

This was horrifying news and I rang the hospital and talked with their neurological registrar. I told him of our grave concern of any idea of turning off a GBS patient's ventilator and how we had a number of members who had spent many months under ventilation being treated in Intensive Care for GBS and had made recoveries. The registrar checked and advised there had been possibly some talk within Intensive Care about turning off the ventilator but there would be no further consideration of any such action.

It is pleasing to report that Phillip Castleman is making slow but good recovery. Let us hope we never hear of talk of any such action in the future at any hospital.

Helping an "AGE" journalist

(Kylie Miller is Deputy Editor of the "AGE" Green Guide. She has been diagnosed with Multifocal Motor Neuropathy (MMN). I visited her twice at the Alfred and gave her a six page article on MMN which I pulled down from the Internet - a handy source. This material indicated that the chance of recovery from MMN is good. Kylie has joined The IN Group.)

Hello James,

Thank you for your prompt response. Yes, I am going into the Alfred on Monday for 10 days, for plasmapheresis, as you described. I would welcome a visit if you happen to be there, but please don't go out of your way. I have a friend who had GBS and who is helping me through (he also told me about your group).

I would like to join the group.

As you may gather from my email address, I also work at The Age and have spoken with the Age editor, Mr Michael Gawenda, and the health editor, Ms Mary-Anne Toy, about doing a story on the shortage of Intragam. It is possible that Mary-Anne will start work on a story next week. I have also told her about your group and given her the Website address so it is possible she may approach you for comment. I hope this would not be a problem.

Regards, Kylie Miller.

Some further Thank Yous

Dear James,

Thank you for your help with providing a personal visit from a former patient - Angela was excellent in her visit to Neil and is a very positive and courageous young lady. Please forward us the booklet on GBS. Have enclosed cheque for membership.

Shirley Shields.

Neil, Shirley's husband, was in Ballarat Base Hospital in rehabilitation from severe GBS. **ANGELA**

BRAMLEY, a Ballarat member who had been through the GBS "mill" in 1998, most kindly gave the much appreciated support.

Dear James,

I'm Steve, Molly's husband. ...let me congratulate you on the marvellous job you are doing for those suffering from the effects of inflammatory neuropathies. Your words of encouragement and advice to Molly have really helped her to shoulder the burden she is under. As for the newsletter it is superb. Certainly we intend to attend as many functions as we can and spread the word about The IN Group and associated matters. ...It certainly helps to make contact with others and just yesterday Molly was speaking with the contact you supplied her with in Maryborough. It just happens the lady (Nur Sissons) is Balinese so she and Molly were able to converse in Indonesian.

STEVE CAMPBELL.

MOLLY GUNTARIK-CAMPBELL, living at Kangaroo Flat with her husband **STEVE**, was diagnosed with CIDP some months ago and sought information about the disabling disorder. Various treatments are being tried whilst Molly endeavours to carry on with her art gallery business. We were all pleased to meet Molly and Steve and also Nur Sisson and her husband at the November Social Luncheon.

Where is Broken Hill?

I received a letter from **ESTELLE BENSON**, Executive Director, GBS Foundation International who, in forwarding on a letter from Mrs **JANIS GLASSON** seeking information on GBS, asked "Where is Broken Hill?"

I was able to satisfy both Janis and Estelle. Janis expressed her appreciation by joining The IN Group.

Some activities of The IN Group

A Most Successful Summer Luncheon

Not only was our Summer Social Luncheon, held Sunday 14th November at the Balwyn Library Meeting Room, a great financial success but the thirty-nine members, family and friends who attended found it great fun.

\$963.35 was the magnificent proceeds. Of this total **BARBARA BURZAK-STEFANOWSKI** collected **\$438.50** by her marvellous and amusing Dutch Auctioneering of mysterious gifts from those present. The profit from the delectable luncheon of cold roast and smoked chicken with many salads, chocolate rolls and fruit salad, fruit punch and wine was **\$381.85**. Thanks to **MARGARET LAWRENCE, BETTY GERRAND and ROSEMARY McQUALTER** for the choice menu and its hours of preparation. The raffle of two Christmas Hampers and a beautiful hand-made bag containing gardening tools, raised **\$73.00** and two generous members who were unable to be present donated a further **\$70**. The bag was made by Bronwyn's mother-in-law and was much appreciated by the winner's wife who commandeered it for her sewing needs.

February Film & Luncheon

Put this in your diary - I must see "*Snow Falling on Cedars*" on **Tuesday 8th February at 11am** to

be followed by a nice lunch, all for **\$10** (\$1 goes to The IN Group).

Judging from overseas reviews this is a delightful film. What better way to see it than amongst the congenial IN Group.

Ring **BETTY GERRAND** tel **9853 6443** to book yourself, family and/or friends by **1st February**.

The IN Group Christmas Cards

By buying The IN Group Christmas Cards (\$12.50 for packet of 12 inc. pst) you not only receive a quality product but also your payment is a full profit to The IN Group as the cards' expenses have already been covered. Use the order form on the newsletter wrapper.

Entertainment Book at \$45

If you like going to restaurants, the theatre, sports etc. then buying an Entertainment Book at \$45 is good value. It offers 2 for 1, 25% or 50% off the cost over the period to June 1st 2000. You also support The In Group as \$9 of the \$45 goes to us.

Policy & Procedures Manual

The GBS Foundation International is compiling a Policy and Procedures Manual for Liaisons (not what you think - these Liaisons are the American term for representatives.) As the Melbourne Liaison I have supplied information as to how we arrange our meetings, support visits, patient lists etc. I mentioned particularly how our Questionnaire was most helpful in providing support by matching visitor with patient.

From the Internet

A wonderful global service

Almost each day we receive via the internet requests for information on either GBS or CIDP (more often for CIDP as unlike other support groups The In Group features CIDP equally with GBS).

Here are examples:

ALMEDA STITES, Oklahoma USA - CIDP
ANISH VARGHESE, Wakad India - GBS
BARB PERK, South Dakota USA - CIDP
TEME KERNEMAN, Ontario Canada - CIDP
PAMELA GENNARI, Alaska USA - CIDP
ROBERT SHANNON, Texas USA - CIDP
RHONDA LANCIOS, Texas USA - CIDP
CHERYL JONES, Texas USA - CIDP

Ending on a lighter note

The History of Medicine

2000 B.C. - Here, eat this root

1000 A.D. - That root is heathen. Here, say this prayer.

1850 A.D. - That prayer is superstition. Here, drink this potion.

1940 A.D. - That potion is snake oil. Here, swallow this pill.

1985 A.D. - That pill is ineffective. Here, take this antibiotic.

2000 A.D. - That antibiotic doesn't work anymore. Here, eat this root.

(Thanks, Kathy, New York)

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