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Newsletter No.51 - June 2005

Intragam P

*From the address by **PAUL BORDONARO**, President, Asia/Pacific CSL?BioPlasma, to The IN Group Public Meeting, held Wednesday 11th May 2005 at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn.*

I will begin by saying how pleased I am to be here and to have the opportunity to speak to you about CSL and Intragam P. I will also speak about how the blood and blood products system works in Australia.

CSL started life as the Commonwealth Serum Laboratories in 1915. This was at the time of the First World War where supplies of vital medicines from the United Kingdom were cut off. Australia?s founding fathers decided to establish the Commonwealth Serum Laboratories to ensure that Australia was self reliant with regards to the availability of these important medicines. CSL?s current corporate office at Parkville, Victoria was the original site where Commonwealth Serum Laboratories was first established.

CSL has a long history in the field of plasma products and in fact we have been involved in the fractionation of Australian plasma since the early 1950s. We have been New Zealand?s fractionator since the early 1960s and in the early 1990s we established similar relationships with Malaysia, Singapore and Hong Kong.

We receive plasma from these countries and the final products manufactured from this plasma are then returned to the country of origin. We use a very strict approach to separation of plasma from different origins through the entire manufacture process.

In 1994 there were two significant milestones in CSL?s development. First, the privatisation of the Commonwealth Serum Laboratories by the Federal Government which led to the establishment of CSL Limited and secondly, the commissioning of our plasma fractionation facility located at Broadmeadows, Victoria.

I think the growth and success of CSL since privatisation in many ways has endorsed the

Australian Government?s decision to privatise the company back in 1994. Through organic growth and acquisitions like Aventis Behring, CSL Limited is now one of the two largest providers of plasma therapeutic products in the world. What is often forgotten is that CSL was the first of the Government Business Enterprises to be privatised. Others that followed included Telstra, Commonwealth Bank and Qantas.

CSL?s Broadmeadows facility uses the state of the art chromatography process to manufacture a range of therapeutic plasma products (12 in all). The facility has a capacity to process 500,000 litres of plasma each year. In excess of \$350 million has been invested at Broadmeadows to create one of the most sophisticated plants in the world. CSL?s range of plasma products are used to treat several serious medical conditions including Guillain/Barre Syndrome (GBS), Chronic Inflammatory Demyelinating Poly-neuropathy (CIDP), a number of serious infections, severe blood loss and haemophilia.

The use of chromatography at Broadmeadows has significant advantages over the old Cohn technology:

- higher yields of Intragam P from each litre of plasma (5 grams per litre).
- Gentler process.
- High degree of automation which minimises risk of adventitious agents.

How does the system work?

Australia has one of the safest blood and blood products systems anywhere in the world. The success of the system is underpinned by important relationships between Governments (represented by the National Blood Authority (NBA), Australian Red Cross Blood Service (ARCBS) and CSL Limited. The most important component that makes it all possible is the Australians who donate their blood voluntarily.

From a population of 20 million, only 3% of Australians donate blood. These people do not get paid to donate their blood but rather see this as a very important contribution to Society.

The ARCBS centrifuges the donated whole blood; the cellular material such as the red blood cells, white blood cells and platelets fall to the bottom. The cellular products are used in transfusion medicine. The straw coloured fluid (supernatant), floating on the top, contains the plasma proteins, one of which is IVIG (Intragam P).

The plasma is sent to CSL in a frozen state. The frozen plasma is thawed, pooled and processed. The usual batch size for Intragam P is 7.5 tons. A single batch of Intragam P may include up to 30,000 individual donations.

The manufacturing process for Intragam P takes approximately 14 weeks from receipt of the plasma from the ARCBS. The final product is then returned to the ARCBS for distribution to medical providers, principally hospitals.

As Australians we are lucky. We are fortunate to have a high quality pool of donors. Together with the role of the Therapeutic Goods Administration (TGA), Australia's Regulator, and the Australian Quarantine Inspection Service, Australia has one of the safest blood and blood products systems in the world.

Over the past five years the ARCBS has done a tremendous job in increasing plasma volumes by about 5% each year despite rigorous donor deferral guidelines introduced by the TGA. We have also been successful in continually improving the yield of Intragam P. Total issues of Intragam P have increased approximately 8% each year over the past 5 years. Based on usage per capita of IVIG, Australia ranks very highly with countries such as the USA and Canada and well ahead of several world nations such as the UK, Germany and Japan.

Future

Through active consultation with all stakeholders, CSL is always exploring ways to enhance our product portfolio and in particular Intragam P.

Some of the enhancements currently being considered include improved convenience for users of Intragam P, different formulations, our continued goal to improve yields and safety.

I trust you have found my presentation both informative and interesting and I look forward to catching up with you all again.

Entertainment Books ? Last Chance

Five of the 2005/2006 edition have so far been sold. We need to sell at least ten to make a profit So please send in your order, set out in the wrapper, by the 15/06/05.

Our Most Successful Cake Stall Fund-Raiser

A total of \$1,270.30, including \$575 donations, was raised at the Maling Road Canterbury Cake Stall held Saturday morning 7th May. Many thanks to organisers, **MARGARET LAWRENCE** and **BETTY GER-RAND**, helpers and contributors who included **BARBARA RIVETT, DOROTHY BRENNAN, BARBARA CLIFFORD** and **LUCY TIDBURY** and donors who included **BOB MELVILLE, JOAN HEGEDUS, JOHN WIDDICOMBE, JOYCE MONTGOMERY** and **PHYL CAMERON**.

Winter Social Luncheon

MARGARET LAWRENCE will again be our hostess for The IN Group **Winter Social Luncheon** to be held from noon on **Sunday 19th June** at her home 26 Belmont Street Glen Waverley. \$15 will provide a lovely luncheon as well as raising funds for medical research. Our young member **ANNA MELVILLE** will again provide a most pleasing piano recital.

Book with Margaret 9802 5319 by 12th June

Donation to Medical Research

In May The IN Group donated a further \$5,000 to the research being carried out by A/Professor **ANDREW KORNBERG**, Director, Department of Neurology, Royal Children's Hospital. Since the initial donation to this research in December 1997 The IN Group's donations now total \$69,000.

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

Payment by Credit Card

Your Committee has decided to introduce credit card payments for financial transactions of The IN Group on a trial basis. If we find many members use the credit card for their payments such as annual sub-scription, donation, joining fee then we will continue its use on the basis that its cost justifies its use.

We need your Email address

Using email is a very quick and handy means of communication, so we ask all members who have an email address to list this on their annual subscription or membership application form.

We have a Geelong Group

Dear James,

We had our first afternoon here on Saturday 5th March and I am delighted to tell you we had 8 people here with either GBS or CIDP. Another person who initially was hoping to come, rang with an apology. Together with friends and partners there were 13 of us who enjoyed hearing about each others stories and were enthusiastic about having a group here in Geelong.

We had some suggestions that you may put in a notice in your next newsletter in case there are some who live nearby who would also like to join us in our next meeting. We have agreed to have a network of phone numbers amongst us who would be able to ask questions and answer questions for others. As there are a good number of us, it was suggested that we might be able to get an occasional guest speaker.

Another suggestion was for us to notify the local neurologists and GPs that a group like us does exist and is willing to be in touch with new patients. One member also said that you might have some posters to place in waiting rooms.

Altogether we felt the day had been most successful and we are planning another meeting later in the year. I hope this will further the advancement of The IN Group and we may get some more members who, as yet, do not know of this great support group.

Thank you for all the work you have done to get this established.

Margaret Widdicombe.

Response.

Thanks for your great work in forming this group. Please keep me posted.

James

Typical Email correspondence

To ingroup@vicnet.net.au

I have just found out I have this disease CIDP and would like to know more about it.

Jill Baker

To Jill and Keith Baker

Dear Jill, If you send me your address I will post you a CIDP booklet published by the GBS Support Group (of the UK) plus The IN Group brochure (contains also a membership application form (\$5 joining fee and \$10 annual subscription) and our latest quarterly newsletter "Information".

How has the CIDP affected you and what treatment are you receiving?

Best Wishes, James Gerrand, Director

To James Gerrand

Thank you for the booklet just received. We live at 96 Bridgewater Drive, Kallaroo WA 6025.

My legs have been getting progressively worse since at least last November; losing balance, falling over etc, till now walking with a stick. I have been doing exercises at the hospital for last 10 weeks and now started on Intragam P two weeks ago. No change yet.

Yours, Jill Baker.

Jill has now joined The IN Group. A warm welcome!

International Support

To James Gerrard

My husband Gary was diagnosed in Dec 2004. He went into hospital for a blockage in his carotid artery, completely independent, and came out dependent except for feeding himself. We had a neurologist already as he had had peripheral neuropathy for several years. Gary had been falling for several months prior to this which was our only symptom but we and the doctor thought it was his neuropathy getting worse.

The doctor put him on IVIG ? 25 gms daily for 5 days then once a month. He recovered some of his mobility but still had to have some help. He was improving slowly when he had another bout with his irregular heart beat and he lost a lot of ground. They increased the IVIG to every 3 weeks because he was having a real let down in his energy level after 3 weeks.

We are very grateful that he did not get this when people usually do ? in their 20s ? 30s. He was 70 when he got it. We are thankful to have been able to work and raise our family without this problem.

Thanks again for your help.

Carol Floyd, Utah USA.

PS. Are the books "A Road to Recovery" and "Boy, is this Guy Sick?" on CIDP or GBS. If GBS and they would be beneficial to us as well, I want to order them. Thanks for the CIDP booklet you sent, it was very informative. C.F.

I advised Carol that both booklets were from sufferers from GBS. Carol ordered the books and also has joined The IN Group.

Change of Name

The USA support group has changed its name to

GBS/CIDP Foundation International

adding CIDP to its title.

It has done this from noting more and more CIDP patients have been identified within its membership.

**Research Update into GBS/CIDP
A/Prof ANDREW KORNBERG**

**Neurologist, Neuroscience Centre
Royal Children's Hospital**

Wednesday 10th August 2005 at 8pm
Balwyn Library Meeting Room 336 Whitehorse Road Balwyn

Dear Member,

Our next GET TOGETHER of The IN Group will feature Dr Andrew Kornberg who has been conducting research now for some years into the inflammatory peripheral neuropathies of Guillain/Barre Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). His research is warmly and financially supported by the IN Group. We look forward to further medical understanding of our rare disorders.

Prior to Dr Kornberg's talk the Annual General Meeting of The IN Group will be held beginning at 7.30pm sharp. It is suggested that members bring a small plate of food for the following supper.

RSVP 6th August tel 9853 6443.

Looking forward to seeing you on the 10th August.

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