

THE NEWSLETTER OF THE IN GROUP

THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC.

Supporting sufferers from acute Guillain-Barre Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIBP).

INTRAGAM IN SHORT SUPPLY - AM IN DECENT- EXPOSURE

As reported (see ad-joining block) gamma-globulin became seriously short supply last September.

This was of particular concern to The IN Group as the intravenous gammaglobulin treatment (Intragam) has now become the preferred treatment for GBS and CIDP patients.

I became personally aware of the shortage when I was all set to receive the gammaglobulin at the Alfred when told there was none available. So the nurse had to disconnect the saline drip and wish me better luck next time.

After checking on the situation with various authorities at the Alfred, the Red Cross and the Commonwealth Serum Laboratories, I, as Director of The IN Group, sent off faxes to a number of the media. Helen Carter responded with her good report. (See box. There was a minor error - the cost from overseas is \$2,500 for 30g not 6g.)

Since the publicity, all IN patients seem to be getting their prescribed Intragam treatment after some initial short measure. I understand from Or Peter Schiff of CSL that better supplies should be available by next April when their new Broadmeadows establishment should be fully tested out. Need for plasma donors.

As a further development the Red

Shortage alarm for patients

A SHORTAGE of a vital reagent for a nerve disease may endanger some patients' lives and worsen their condition in quarters. It has been claimed.

But the public can help overcome the crisis by donating plasma or having it withdrawn because the treatment is

About 100 Victorians with rare neurological neuropathies such as Guillain-Barre syndrome and chronic inflammatory polyneuropathy rely on the treatment.

Mr James Gerrand, 74, of Sew. TCO, was in chronic pain. He had been treated with intravenous gamma globulin treatment for several years.

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By HELEN CARTER, medical reporter

The treatment has kept the retired engineer from a wheelchair by improving his balance and ability to walk.

Mr Gerrand was diagnosed two years ago with the disease. Toich destroys insulating sheaths around nerves and stops serving activating muscles. It can result in paralysis and pain which comes on after a time when the autoimmune system over-reacts.

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PLEA for help ... James Oerrand worried at the shortage of intravenous gammaglobulin treatment. Picture: JOE AR...

Cross advised me that it needed plasma donors. They sent me a bundle of pamphlets "For Pete's sake, give plasma", one of which you should receive with this newsletter. IN patients are not suitable donors but family and friends should give it a thought. (For the record Victorians are the most generous of Australians as regards blood and plasma donations - but we need to be told of the need.)

They are also seeking \$60,000 to run

a 3 months TV campaign to boost plasma donations. This is out of our IN Group "ball park" but I sent off letters to both our Victorian Health Minister and Australian Health minister seeking such funding.

So far, the Victorian Minister has replied with an informative letter. The Hon Marie Tehan, MP, advised that the Victorian Government has provided \$22.4m for 93/94 to the Red Cross Blood Bank, \$1m more than in 92/93. In 1992 the Blood Bank was producing 23 kilograms of Intragam per million population against a demand of 23 kilograms per million population. Demand has increased rapidly in 1993 to 26 kilograms and likely to go to 30 kilograms per million population.

The Minister also referred to the clinical guidelines for utilising Intragam published in the Medical Journal of Australia, Aug '93. The relevant sections for GBS and CIDP are: Consensus Guidelines for use

Category A - is indicated in the following diseases or indications

...

8. CIDP in children too small for plasma exchange.

Category 3 - may be used for the following potentially severe diseases or situations

...

4. Some patients with the following neurological diseases - CIDP, GBS, ... Not all patients with these diseases need treatment with Intragam. The following situations would constitute appropriate indications.

(a) Other therapy has failed or is contra-indicated.

(b) Difficulty with venous access for plasmapheresis.

(Thanks, Dr Annabel Jenkins, IN Group member, for supplying me with a copy.)

The Australian Health Minister, Hon Sen Graham Richardson, MP, has yet to reply. I am working on him through a

PROPOSED EPIDEMIOLOGY STUDY

The IN Group consultant neurologist, Dr Bruce Day, has drafted out a questionnaire to form a basis of an epidemiology study aimed at trying to discover what factors may contribute to contracting GBS or CIDP. The draft has been examined by our consultant epidemiologist Dr Allen Christophers who has also secured advice on the draft from Dr Jenny Smith who has carried out a similar study for the Anti-Cancer Council of Victoria.

The draft will also be examined by our Patrons, Professors Jim Mcleod and John Pollard of Sydney University and Drs Bernard Gilligan and Richard Stark, before being finally adopted.

On adoption it is proposed that the questionnaire will be sent to those 94 members who have signed the Permission to Entry into Registry Form. These members will be asked to advise if they

are available -- ~ "" and interviewed to willing to be the questions, obtain their answers to A being affected control group, not by the IN disorders, will need to be selected who will match suitably the IN members who agree to being part of the study.

A TRIAL OF PHYSIO FOR CIDP

The trial of physio treatment as a means of improving the condition of sufferers from CIDP, as mentioned in our September Newsletter, has been started as a private undertaking by Barbara Burzak-Stefanowski.

All four members taking part report an improvement, mostly in posture but one member also in a much improved sense of well-being.

It is early days - there will be further reports in later newsletters.

NEXT MEETING OF THE IN GROUP

When: Tues. Feb 8th at 7.30pm. Where: 4 Alandale Avenue, Balwyn.

Speaker: Ms LU CRAVEN, Occupational Therapist, Fairfield Hospital. Topic: OCCUPATIONAL THERAPY for the IN Patient.

Please let me know by Sunday 6th Feb that you will be coming, tel 853 6443. Family and friends always welcome. A small plate of food will help the supper.

friend, Sen Olive Zakharov.

INformation

IN GROUP NEWS

Pur Social a happy get-together

The thirty one who attended our final quarterly meeting of the year on Sunday 14th November all reported enjoying meeting each other over shared food and drink in the very pleasant and convenient home of our Deputy Director, Ray Dahlitz, at 4 Alandale Ave, Balwyn.

Some of our members find travelling at night difficult, so having the meeting in the daytime enabled them to attend. Membership

Membership is now 108, a steady if small increase over the past three months. Amongst new members is the Occupational Therapy Department of Fairfield Hospital. A similar type of membership is that of the Social Work Department of the Children's Hospital.

Some members have still to renew. A form is included with this issue for those who may have overlooked renewing The IN Contact Network

The Network continues to be the means of providing ready personal support to patients stricken "out of the blue" with GBS or CIDP.

Twenty-one year old member Chris Haggerty again rose to the occasion by visiting Collingwood football star Graham Wright suffering from GBS. Graham's doctor contacted The In Group requesting a visit from somebody of about Graham's age who had recovered from GBS.

We are pleased to accept Mrs Ualma Wood's offer to be the IN Contact Person for the Caulfield General Medical Centre.

The IN Group is grateful to those members who have offered their services to visit patients as desired. To provide the best service we have to have a large list of such members to match appropriately the visitor with the patient.

There has been a lull in GBS and CIDP cases reported to The IN Group and I shall check to see whether there have been in fact less cases or our system is not working as well as it should.

Because GBS and CIDP are rare, we need to continually make our presence felt to avoid being swamped by the multitude of other complaints.

IN Contact Report Re:

Mr Rewie Ellis.

At the request of Dr Natalie Kitchens (28/10), Neurology Registrar, Mon-ash Medical Centre, I went to see Mr Ellis, a GBS sufferer, the next day.

Rewie is 62 years of age, a retired SEC employee, living in Mildura. He noticed the first symptoms early in October and within a matter of days his arms and legs were paralysed and he needed to be transferred to Fairfield. He did not need a respirator but was given plasmaphoresis over five days.

He has very restricted movement in legs and left arm but is slowly improving, particularly in the movement of his right arm. He believes he will shortly be transferred to Hampton Rehabilitation Hospital. I was able to inform him of my time there. He seemed to be pleased to discuss the problems of GBS and was interested in our support group.

ERN KEARLEY

(Rewie has continued to progress and now attends Rehab as an outpatient. He has joined The IN Group. Ed)

We have a Fax/Modem/Printer

Thanks to the generosity of donors The IN Group now has a Fax/Modem and associated InkJet Printer.

Through this resource the media release concerning the Intragam shortage was quickly faxed to many newspapers and other media.

Faxes can also be sent to The IN Group using the common tel/fax number of 853 6443.

Technical details are Fax/Modem Type Banksia Blitzer XM124S/RFAX (\$299) with associated software Hot Fax (\$195) and Printer Stylus-800 (\$520). The facility works in conjunction with an IBM compatible computer.

LETTERS

To the Support- Qioup,

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I have, vejuj little. balance. and use. a walking stick to help me.. I have, had so many fall* Hut am still alive, to tell tke. tale.. Bering of. old age. do&s not help.

7 hank. you. for. tke. article.,

cLVA mpIN

PS . Uhen I was in the. Austin Hospital they made. me. le.g Hr.acej> to see. if it u>ould help my walking Hut oJL counsise. they make, my sho&s hurt.

(I contacted Elva and she now has purchased larger shoes so her feet don't hurt so much when walking with the braces. JHG)

De-or. flr. (jejuiond,

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ne. is an orthopaedic. Surye-on and sie.-qu&sted that I forward the. enclosed amount (\$30) to you as a donation.

BARBARA CLITTOKD

(Many thanks for the donation. I have passed on your thanks for the "finale" to my wife Betty who was mainly responsible for it. James)

a Ahont note. o£ thank* JLon. tending Ian K&l&j in to B/iyan. He. koA Hnsn a gieat Aupposit to him..

He. WOA aLf>o delighted to m&et you. and vejuj g/iateJLuJt f.ost the. time. you. have. i.otk given him,

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Thanking you. again and J hope. Bryan can He. o-l tome, help to someone, in the.

LLSCOKBt

(Wendy advises me that Bryan has now recovered to the extent that he is now back at work on a half day basis. JHG)

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7hank you vesiy much for. your, informative. newAletteJiA. 7 hey have, really helped me. undeju>tand thL>> drje.adfjjJL

Bc77t/ cLLIS

(Betty tells me Rewie is making slow progress at the Talbot Rehab Centre recovering strength in his arms and legs. He has high hopes of being home in n Mildura by Easter. JHG)

7o Whom It flay

I am writing on behalf, o-f. my daughter. Skannyn Flahon. She. contracted QBS in 1987 when the. wo* eleven yeasIA oM. She. wa/> admitted to the. Children -4 Hospital on 18/11/87. During heji *tay in hospital ^ke. &je.came. inc/ieaAing£y we.ak Auch that the. wa6 una&le. to u.Ae. kesi hands or. to walk. Skannyn spent one. wejek in intensive. ca/ie. unit having p£asmaphosi&sis, She. was discharged home, on the. 10/12 still in a wkejzlchaiM. and regained some. strength in h&r. hands Hut still una&le. to walk. At potent she. has only a residual foodr.op.

Skannyn has coped extremely well dueling the. past jLive. yea/is pkysically Hut is veMy self.- conscious \$Le.ccuisse. o-f. keji d/iopped -fjnet.

I have. QLe.en thinking aJLout a self.-help gr.oup and I am v&ry pleased and excited about -finding out aJLout this gr.oup. 3-ust to exchange, views and ska/ie. •feelings and ex.pejLience^> with others will He. wondejjjLul,

HILEN MHDN

