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# Help for Everyday Living

Newsletter No.27 - June 1999

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*From the address by **DEE WALDRON, Occupational Therapist, Independent Living Centre** to the quarterly meeting of **The IN Group** held 12/5/98, Balwyn Library Meeting Room, 336 Whitehorse Rd.*

The aim of The Independent Living Centre, a unit of Yooralla, is basically to provide for equipment needs for people with difficulties and disabilities, including information about what is available.

Wednesday 11th August 1999 at 7:30pm  
Balywn Libray Meeting Room  
336 Whitehore Road, Balwyn

### [An Update of Research into GBS/CIDP](#) by Dr. Andrew Kornberg

There is no age eligibility; anyone can have access to the service. You don't need a referral such as from one's doctor or an appointment - just drop in between 9am and 4.30pm. You need \$2 to get through the door, basically to cover photocopying costs. Hopefully when you come in you will see a piece of equipment of interest. We will print out a description of the equipment with a picture, price and where you can buy it. The Centre does not sell any of the items.

We are now located in a large building at 705 Geelong Road, Brooklyn. We celebrated 21 years of service last year. We have a range of 1,500 items on display and some 5,000 items in our data base.

If you choose you can have an appointment. It takes 1 1/2 hours and is usually for something like a powered wheelchair or a scooter - a piece of equipment which will be quite dangerous just to pick up and drive away. Seating is another area for appointment.

## Areas covered

**Household and Kitchen** We have a lovely kitchen display, set up with workbenches at different heights.

**Bathroom and Toilet** We have three bathrooms - two functional - and all fitted out for wheelchair access.

**Building Fixtures and Designs** We have books and ideas. We have railings and boards with different floor coverings.

**Beds** We have three beds set up for display, all electrically operated. They need to be trialled of course. We encourage people to use, sit on and move.

**Clothing and Dressing**

**Eating and Drinking**

**Wheelchairs** Manual and electric.

**Electric Scooters**

**Vocational Needs** We have an office area set up with different types of office chairs.

**Computer Area** We have an Ergo Arm which is clipped on to the side of a desk on which you can rest your forearm. There is a covering for a computer mouse that spreads your grip.

**Recreation** We don't cover this area very well; we tend to refer on to another agency called Achievable Concepts. They will tell you where to buy a fishing rod or a snooker table for a person with the use of only one arm.

**Hoist and Lifting Equipment**

**Communications** Ways of holding a pen, book rests.

**Transport** We have a car with a swivel seat. The whole seat swivels around for ease of getting in and out.

**Walking** We have mobility aids, frames, walkers.

## Items displayed by Overhead Projector

- **The Kettle Tipper** (To assist in pouring without lifting)
- **Good Grips Cutlery Range** (Larger, non-slip handle)
- **Key Holder** (To grip in palm rather than between thumb and finger)
- **Arthwriter** (Large ball shaped handle to grip pen)
- **Dycem non-slip matting** (To secure plate on a table)
- **Spinner knob for driving wheel**
- **Bell clamp** (For use with one hand for opening jars)
- **Gripmate** (To position pencils, tooth brush in large handle with velcro strap for extra stability)
- **Shower Stool** ( With padded seat and armrests)
- **Stepless Shower Base** (To access shower without lifting a foot over the lip)
- **Sirex General Knives** (With pistol grip handles)
- **Foldaway Fitting Shelf**

- **Pull Out Pantry**

## \$5,500 Donation to GBS/CIDP Research

On Tuesday 18/5/99 The IN Group donated \$5,500 to the **Royal Children's Hospital Research Fund** to support medical research into GBS/CIDP being carried out by **Dr ANDREW KORNBERG** of the Neurology Department of the Hospital.

\$2,500 of this amount was in memory of **JENNY HEFFERNAN**. Jenny sadly passed away last March and her husband **IAN** and family asked family and friends to donate to this research rather than sending flowers. Jenny's lovely presence will be missed but her memory will live on through this continuing research.



James Gerrand presenting cheque to Dr Andrew Kornberg

The donation cheque was presented to **Dr ANDREW KORNBERG** by **JAMES GERRAND** Director of The IN Group in the presence of **Dr LLOYD SHIELDS**, Director of the Neurology Department, **MARGARET LAWRENCE**, Deputy-Director of The IN Group, **IAN HEFFERNAN**, **TAMARA HEFFERNAN** (daughter of Jenny) and **Mrs VAL FREED** (sister of Jenny).

Dr Shields kindly made a short video of the presentation which will be shown at our Winter Luncheon Sunday June 6th.

This donation brings the total sum donated to this medical research by The IN Group to \$17,550.

**Dr ANDREW KORNBERG** will speak on "*An Update of Research into GBS/CIDP*" at our next quarterly meeting, Wednesday 11th August 1999, as set out in the newsletter wrapper.

## Cake Stall raises \$1,006.70

In a few hours on the Saturday morning of 1st May The IN Group raised this marvellous amount in selling cakes and other goodies at Maling Road Canterbury.

Our special thanks to **MARGARET LAWRENCE** who splendidly organised this fund raiser including battling with the Council bureaucracy, as well as to those who supplied cakes etc and/or helped on the day - **BETTY GERRAND, BETTY & DAVID GERMANO & GRANDDAUGHTER, MARGARET RIVETT, MELVA & JOE BEHR, VILMA & HER NORTH-EASTERN GROUP, DOUG LAWRENCE, DOROTHY BRENNAN.**

### Good Sales of Entertainment Books

This year we have already raised \$135 through the sale of 15 of these books that cut \$25 or so from your bill at selected restaurants, less formal dining, theatres, sporting events, hotels.

**BRONWYN & STEVE WALSH** have done a great job selling many of these to their work mates.

You buy an Entertainment Book from The IN Group for \$45 (it costs us \$36) and its use is valid to 1st June 2000.

## GBS/CIDP Council News

The **Australian Council of GBS/CIDP Support Groups** held another successful meeting (by telephone hookup - Conferlink) on Sunday afternoon 11th April. The GBS Association of NSW has now joined Victoria (The IN Group), South Australia (Neurological Research Centre of SA) and Tasmania (GBS Support Group of Tas.) as members of the Council. Action is proceeding to start support groups in Queensland, Western Australia and the ACT. The next issue of the Council's newsletter "INvoice", containing details of this Conferlink meeting and other news, is scheduled to accompany the September issue of our newsletter "INformation".

## Logo for The IN Group

Your Committee has adopted as its Logo the one submitted by member **LOIS VOIGT** as printed on the "INformation" masthead. The GBS Support Group of the UK has written stating they are pleased we wanted to use their tortoise logo as our central theme.

Thank you **LOIS** for your fine design.

## Membership

Our membership is now 295. It includes 33 interstate (NSW 13, Qld 9, SA 4, Tas 5, WA 2) and 61 overseas (Austria 1, Canada 5, Italy 1, Japan 1, New Zealand 5, Philippines 1, Slovakia 1, USA 43 and UK 3).

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# We need more Intragam - An update

## The Good News

The Federal Minister for health, Dr Wooldridge, announced in a media release 10/5/99, "that he had established a **review of the Australian blood banking and plasma product sector** to ensure the highest standards of blood supply continue to be met in Australia."

The review will be headed by Sir Ninian Stephens, with other committee members being Dame Margaret Guilfoyle, Professor Robert Beal and Professor Judith Whitworth. Listed for review is to "consider ways to increase the supply of essential blood products". The Minister is "concerned that the demand for some processed blood products exceed supply to the extent that effective treatment of some products is being compromised. ... Patient advocacy groups such as Haemophilia Foundation Australia and **The Inflammatory Neuropathy Group** (*my emphasis*) are calling for a solution to these problems."

The public acknowledgment of The IN Groups efforts to overcome the Intragam shortage is one welcome reward to our many members' efforts, particularly the collecting of over 5,000 petitions presented to the Minister on the 22/3/99 and the letter to local members of parliament.

A reply was finally received from Mr Mike Mossop, Director Special Access Programs Section, on behalf of the Minister, in reply to the many letters The IN Group had sent. The most welcome of its contents was that Dr Wooldridge had "approved the formation of a national reserve of essential

plasma products to cover acute shortages that arise... due to a disaster or major threat or because of significant production delays or losses at CSL." ... "Dr Wooldridge approved the purchase of a foreign gammaglobulin (Sandoglobulin) to augment Intragam in the national reserve."

## The Disappointing News

Following receipt of the Minister's Media Release, The IN Group issued a response Release headed ***Dr Wooldridge, We need the Intragam now!***. We wondered whether the announcement of the long-term review was in the nature of a *Yes, Minister* tactic. The review "will not solve the present problem that many patients are not receiving the necessary treatment of Intragam..." "Our members' need for Intragam for their GBS and CIDP disabilities has been further substantiated by a recent statement from the Australian Association of Neurologists who 'is

gravely concerned about inadequate supply of Intragam.' The health and physical capacity of many of our members have already deteriorated and a further delay of many months will see many in wheelchairs or back in hospital."

The Shadow Minister for Health **JENNY MACKLIN** supported our case with her Media response headed ***Non-Decision on Blood Services***. "It is disappointing that the Government has failed to take urgent decisions to ensure supply of vital blood products ...". "The inquiry will ... bring little joy to those people who have been waiting months for the Minister to announce action to increase the supply of Intragam ..." "I am pleased that very eminent people have been chosen to consider the long-term issues affecting the supply of blood and blood products."

### Delay in Working Committee Report

The report of the Working Committee set up by the Australian Health Ministers Advisory Council (AHMAC) was due to be announced in May. The IN Group made a submission to this Committee on 26/11/99 (p3 Dec'99 "INformation".)



**Without blood**  
I wouldn't be active.  
Michelle Hughes helps the Red Cross

It is understood that there has been a delay due to a request for substantiation for the need for Intragam to treat some disorders listed. Intragam for GBS and CIDP is not disputed; in fact it is understood that the Report recommends the upgrading from Category B to A for Intragam for CIDP.

## Support is the Name of our Game

### Petition to Minister

On Monday morning 22nd March The IN Group presented to the Federal Minister for Health's Office at Oakleigh, Petitions signed by over 5,000 people asking Dr Wooldridge to ensure an adequate supply of Intragam.

Those attending the presentation were **JAMES GERRAND**, Director of The IN Group, **MICHELLE HUGHES** and friend, **BETTY GERRAND**, **ROSEMARY MACQUALTER**, **GEOFF WALKER** and **MR & MRS JOHANNESAN** (grandparents of Michelle). A reporter and photographer from the "Herald-Sun" interviewed the Director and Michelle and took pictures but

unfortunately were not published. We had more success with the suburban "Progress Press". It ran a good article *Group in plea for wonder-drug funds* with a picture of our Director in their edition of 29/3/99. (See back of newsletter wrapper.)

Our thanks to the many members who collected signatures. Outstanding numerically were **GEOFF WALKER, MICHELLE HUGHES, PHYLLIS CRAWFORD, Mr/s JOHANNESAN, SUSAN PERKINS, NANCY LITCHFIELD.**

In particular **GEOFF WALKER** did a wonderful job in this campaign, getting exposure in the "SUN-Herald", being interviewed by Jon Faine (ABC 3LO), collecting over 1500 signatures and getting support from the RSL (President Bruce Ruxton). Many thanks, Geoff.

## Support at Geelong

A typical example of quick and appreciated support. I had a call from a **RON SPLATT** of Highton, near Geelong, who said his 51 year old wife had been diagnosed with GBS and asked what help The IN Group could provide. I said I would send literature and asked whether his wife would appreciate a visit from a fellow sufferer. When Ron said that would be great I contacted our member **BARBARA**, of South Geelong and a sufferer from CIDP. Barbara paid a call on Marjorie that day which was very helpful.

## A tribute from New Jersey USA

How nice to receive an unexpected greeting card featuring a Matisse painting. Even more pleasing to read inside such a tribute to The IN Group as follows:

*Please forgive my tardiness in renewing!*

*Your group was the first one I found concerning CIDP (I have had it for 18 years, before "it" had a name").*

*Thank you for the wonderful work. You inspired me to start a support group as a Chapter to the Neuropathy Association*

*in New York. We meet monthly in Northern New Jersey.*

*There are 50 members, eight of us have CIDP and the others are PN sufferers.*

*Best Wishes, Lynda Icochea.*

## Sales of Booklets

We have a steady demand for the GBS booklet published by the US Foundation International and the CIDP booklet, both of which we have reprinted.

Similarly there is a demand, including from overseas, for **JUNE CATHCART's** booklet *Road to Recovery A-Z* and **JOHN POLLARD's** *Boy, is this Guy sick*. A member Alan Quibell of British Columbia Canada recently purchased two of each.

## A Veterinary Science tale

A distraught fellow rushes into a vet's premises carrying an inert dog in his arms. "Please tell me, is my poor little doggie dead?"

The vet examined the pooch, shook his head and confirmed the demise.

"No, no! It can't be! I want a second opinion."

So the vet went outside and brought in a cat. He put the cat alongside the departed pooch. The cat sniffed its way up to the little dog's head, then back along its body to its tale. The cat then stuck its own head and tail up in the air with disdain and headed out to the back of the premises. "There", said the vet, "I think you can take it your dog's dead".

"Oh, no! No! I can't bear the thought. My little doggie means so much to me. I want to be absolutely sure its dead."

So the vet went out the back again and brought in a huge Labrador which went and touched noses with the little dog. The Labrador stopped wagging its tail and went along and stuck its nose under the little dog's tail. After a few sniffs the Labrador shook itself violently and walked dejectedly from the room.

"That was pretty solid," said the vet, "my Labrador never makes mistakes."

"Oh, dear," moaned the man, 'that's terribly sad. I guess there's nothing more I can do."

"Fraid so," said the vet.

"How much do I owe you?" said the man.

"Six hundred and fifty dollars." said the vet.

"What?? How can you possibly charge that much?"

"Well, said the vet, " my initial diagnosis was fifty dollars. But the cat-scan you insisted on was three hundred dollars and the same for the lab tests."

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**Last Updated: 15 Oct 2007 17:49**