

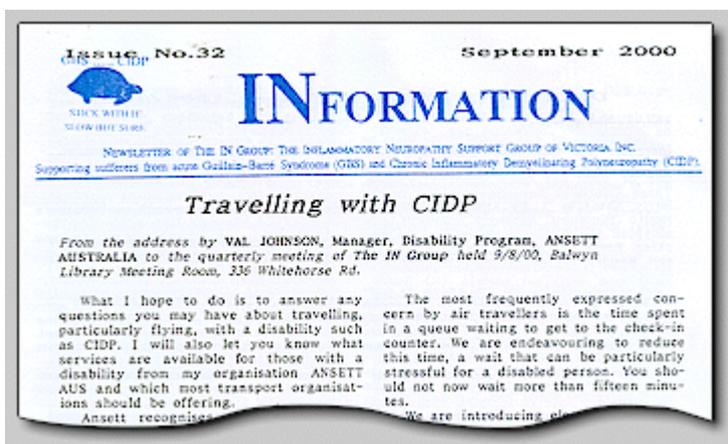
[Home](#) | [About](#) | [Newsletters](#) | [INvoice](#)

Travelling with CIDP

Newsletter No.32 - September 2000

From the address by **VAL JOHNSON**,
Manager, Disability Program,
ANSETT AUSTRALIA to the quarterly
meeting of **The IN Group** held 9/8/00,
Balwyn Library Meeting Room, 336
Whitehorse Rd.

What I hope to do is to answer any questions you may have about travelling, particularly flying, with a disability such as CIDP. I will also let you know what services are available for those with a disability from my organisation ANSETT AUS and which most transport organisations should be offering.



Ansett recognises that those with a disability are a large customer group as are now the aged. People want to fly now it is more affordable.

Services that Ansett offers

Ansett has a policy that they will not discriminate against those with disabilities in transport, employment, information and a range of other issues. Anything an able-bodied person can do should be available to a person with a disability.

In air travel there are a number of specific issues and problems. There are narrow aisles, limited leg room and toilets are not built for disabled access. We endeavour to provide what is best whilst recognising that these aircraft arrangements cannot be changed.

The most important action for a person to take when making an airline booking is to advise of any disability they may have that might need particular assistance. It is much better for the airline to know in advance rather than when the traveller arrives at the departure terminal. The booking staff should be able to help you by advising what special services can be provided to facilitate the travel.

As a major example, if you advise that you have difficulty in walking, then on the day that you travel a "golf-cart/buggy" or a wheelchair can be provided on arrival at the terminal with a Customer Assistance Officer to wheel you through Security and Customs to the aircraft entrance or even to your air-craft seat. The same facility will be provided on your return flight.

The most frequently expressed concern by air travellers is the time spent in a queue waiting to get to the check-in counter. We are endeavouring to reduce this time, a wait that can be particularly stressful for a disabled person. You should not now wait more than fifteen minutes.

We are introducing electronic check-in service where you can go straight up to the electronic check-in machine where somebody will be there to help you check yourself in.

Presently we have a staff member at a major terminal who will help a person with a disability through the check-in process.

It is helpful if a person with a disability travels with an able partner or friend. If a disabled person needs help in the toilet a flight attendant is not allowed to provide such help.

The most difficult situation for a disabled person is at a smaller airport where passengers have to walk up stairs to board the aircraft. Wev can provide a disabled passenger lift. Again it is important for a passenger to advise of a disability when making the booking so the facility can be ready at the time of boarding.

Another facility available for a passenger having difficulty in seating is to allocate the person to an aisle seat that has a removable arm.

The row of seats facing an exit door does provide more legroom but passengers with a disability cannot be seated in such a row. In the event of an emergency the exits must provide a departure for passengers and crew as possible as speedy as possible.

Ansett offers a 50% reduction on the full fare for a disabled passenger and for a carer if the person needs a carer during a flight.

DIRECTOR'S REPORT Year 1999/2000

Shortage of Intragam

The plight of our members relying on Intragam (the CSL trade name for their gammoglobulin product) for treatment of GBS or CIDP has been slightly relieved. These disorders have been raised to priority Category 1 by AHMAC (Australian Health Ministers Advisory Council) who accepted this recommendation by its Working Party set up to review "The Use and Supply of Intravenous Immunoglobulins".

However, AHMAC did not agree to provide the \$13 million needed to overcome the current shortfall of 20% in the supply of Intragam. So, many members are only receiving say 24gm instead of 30gm for their medically prescribed treatment.

Following the Federal Government setting up a high-level committee to review the Australian Blood Banking and Plasma Product Sector, the IN Group made a strong presentation to its Chair, **SIR NINIAN STEPHENS** and members **DAME MARGARET GUILFOYLE** and **PROFESSOR ROBER BEAL**, for the extra funding. Four members affected by the Intragam shortage - **JAMES GERRAND, MICHELLE HUGHES, ROSEMARY MACQUALTER, GINA MERNONE**, all spoke to the Committee.

CSL expects, with its new production process, to increase the output of Intragam by some 10%. This should at least cover the next annual increase in dem-and.

Our thanks to **BRONWYN CLARKE** and **STEPHEN WALSH** for their initiative in arranging for 21 contributions to the Red Cross Summer Blood Challenge.

Personal Support

The IN Group has continued its main purpose of providing personal support to GBS and CIDP

sufferers and their families and friends. Visits were made to patients and contacts made to their families at the Alfred Hospital, Austin & Repatriation Medical Centre, Caulfield Rehab Hospital, Hampton Rehabilitation Hospital, Royal Melbourne Hospital, Royal Talbot Rehabilitation Centre and St Vincent's Hospital.

VILMA CLARKE continued to arrange helpful meetings of our members in the North East Victoria area.

Such help has been backed up by the continuing support of our Patrons, Consultants, Committee, members, family and friends.

Internet Support

The IN Group continues to provide support worldwide through being on the Internet. We received about 100 email messages during the year from sufferers from GBS and CIDP seeking information about the rare disorder. We airmail back usually the appropriate GBS or CIDP booklet and latest newsletter "INformation". This response is greatly appreciated and many subsequently join The IN Group. ON occasions this can lead to a correspondence between parties such as between a 22 year-old Missouri USA student, **STEPHANIE HESS** and 21 year-old Melbourne student **MICHELLE HUGHES**.

Good Questionnaire Response

Ninety-three members have now returned filled-in Questionnaire forms. The Questionnaire is used to match up a person suffering from GBS or CIDP with one who has been through a similar ordeal. This matching has been found to be most helpful in providing personal support.

Also the detailed information could possibly prove helpful to a researcher into aspects of GBS and CIDP.

Membership

Membership is 298 which includes over 250 past and present IN sufferers. Thanks mostly to being on the Internet, 35 are from interstate and 72 from overseas - mainly from the USA but also from Austria, Canada, Italy, Japan, New Zealand, Slovakia and UK.

I particularly thank the many members who donated generously to our cause. The \$10 annual subscription covers our running costs such as the newsletter "INformation". The donations, a wonderful \$5465 from members, allow us to expand our efforts, particularly in helping the research into GBS and CIDP being carried by Dr **ANDREW KORNBERG** at the Royal Childrens Hospital. We donated another \$10000 to this research, making a total of \$27,500 to date.

Quarterly Meetings

These meetings have continued to be popular. Quality speakers for the evening meetings - Dr **ANDREW KORNBERG**, Royal Children's Hospital, on "*Update on GBS and CIDP Research*" August'99; **MARK HINSON**, Physiotherapist, Austin & Repatriation Medical Centre, on "*Physiotherapy in helping recovery*" February'00; **JULIE MILLER** on "*The Care of the Feet*" May'00 - were informative and led to interesting questions and discussion. A report on each presentation was published in our quarterly newsletter "INformation".

As well, our very helpful computer mentor **GREG KEOGH** kindly adds each newsletter issue on to The IN Group web page

<http://home.vicnet.net.au/~ingroup/>

Socials

The November Sunday Luncheon Party meeting was again a happy social get-together as well as a great fund-raiser. A total of \$963 was raised, including \$382 from the delicious luncheon, \$438 from a Dutch auction, conducted with great fun by **BARBARA BURZAK-STEFANOWSKI**, \$73 from raffling two Christmas Hampers, and generous donations from members of \$70.

Twenty-four members and friends enjoyed the Winter Luncheon Social Party held on 18/6/00 at the Glen Waverley home of **MARGARET and DOUG LAWRENCE**. Adding to the pleasure of lunching in the delightful surroundings was the showing of a video recording of part of a TV program "Health Matters" showing our Patron Dr **RICHARD STARK** demonstrating a new medical treatment for migraine.

The icing on the cake was the \$240 made from the occasion.

Film Luncheons held on a weekday morning at the Balwyn Cinema were again an enjoyable conjunction of a good film, a pleasant light luncheon and good company. Films seen were "The Winslow Boy"; "Tea with Mussolini"; "Snow Falling on Cedars": "Angela's Ashes".

Cake Stall Fund Raiser

This now annual event, thanks to the initiative of Deputy Director **MARGARET LAWRENCE**, plus her helpers, was again very successful, being held on Maling Road, Canterbury, on 13/5/00. Within 3 1/2 hours on the Saturday morning, \$915 was raised from the sale of many cakes, jam and some produce.

Donation from the Geelong CWA

The Geelong Coastal Group of the Country Women's Association of Victoria donated a most welcome \$350 to The IN Group for medical research thanks to the initiative of member **LOYIS VOIGT**.

IN Group Frig Magnets

The result of a fine publicity initiative of our Treasurer **BRONWYN CLARKE** will become reality at our 2000 AGM. They will be presented to leading hospitals and neurologists and will be available for purchase at \$2 (\$3 inc. postage).

Newsletter "INformation"

This quarterly publication is a vital means of communication to and between members. The Newsletter is yours so make the most of it. Thank you, **MELVA BEHR, DOROTHY BRENNAN, BETTY GERRAND, FRED HOOTON, MARGARET LAWRENCE** and **ROSEMARY MACQUALTER** for help with the mailing.

The National Council in action

Two meetings of the **Council of GBS/CIDP Support Groups of Australia** were held during the year by telephone Conferlink. The GBS Support Groups of North Queensland and of South East Queensland have joined the Council, which includes the GBS Association of NSW, The IN Group of Victoria, The Neurological Resource Centre of SA and the GBS Support Group of Tasmania.

Its second bi-ennial newsletter "INvoice" was published. Our thanks go to CSL Limited for their generous financial support of \$850.

Council Secretary/Treasurer **MELVA BEHR** made a valuable presentation to the Sir **NINIAN STEPHEN** Review Committee requesting more funding from governments to overcome the shortage of Intragam.

Sponsorship by CSL Limited

The IN Group particularly wishes to thank **CSL Limited** for their continuing generous support. CSL gave \$1100 to The IN Group for 2000/01.

The IN Group Christmas Cards

We sold 28 packets of our quality IN Group Christmas Cards (12 in a packet for \$10), the return of \$296 being all profit. This leaves 100 packets for the next one or two years for selling, again all profit. Thanks to the Kew Primary School, both for their student's art and also their continuing help in sales.

Entertainment Books

Sixteen Entertainment Books at \$50 (\$55 posted) were purchased by members to give The IN Group a quick return of \$160. Both the Christmas Cards and the Entertainment Books will be available at our August and November meetings.

Sale of Booklets

We have a steady demand for the GBS booklet published by the US GBS Foundation International and the CIDP booklet published by the GBS Support Group of the UK, both of which The IN Group has reprinted.

Similarly there is a steady sale for **JUNE CATHCART**'s booklet *Road to Recovery A-Z* and **JOHN POLLARD**'s *Boy, is this Guy sick*.

Thanks

Particular thanks to our Deputy Director **MARGARET LAWRENCE** for her great support; Secretary **MELVA BEHR** for her enthusiastic efforts; to Treasurer **BRONWYN CLARKE** for her rewarding initiatives; and to Committee members **VILMA CLARKE**, **BETTY GERRAND**, **ROSEMARY MACQUALTER** and **PETER MALCOLM** for their varied talents and sterling efforts in making The In Group such a continuing success.

JAMES GERRAND,

Director.

Council of GBS/CIDP Support Groups

A meeting of the Council was held 21/5/00. Members reported on their submissions to the National Review Committee, particularly stressing the need for increased government funding of \$14 million to overcome Intragam shortfall.

IN Group News

Annual General Meeting

The AGM was held at the Balwyn Library Meeting Room on 11/8/00 in the half-hour before the public meeting. The

Director **JAMES GERRAND** welcomed some 30 members. Following the confirmation of the minutes for the year 1998/1998, the Director presented his Report for the past financial year 1999/2000 (pp 2,3 of this issue), particularly thanking the Committee and the many members for their help and generosity that had made for another outstanding successful year for The IN Group. Following the acceptance of the Director's Report, Treasurer **BRONWYN WALSH** then presented her Report for the financial year 1999/2000 (p 4 of this issue), setting out The In Group's income and expenditure as well as assets and liabilities. Generous donations and fine fundraising allowed The In Group to donate \$10,000 to Dr Kornberg's medical research into GBS/CIDP. The Treasurer's Report was endorsed.

Election of Committee

Secretary **MELVA BEHR** advised that she was not standing for position of Secretary due to family reasons but offered continuing help. **JAMES** and **BETTY GERRAND** each thanked her for all the work and time she had given to the Group and expressed sympathy for her mother's situation. The following were then elected unopposed:

Director: JAMES GERRAND

Deputy Director: MARGARET LAWRENCE

Secretary: BETTY GERRAND

Treasurer: BRONWYN WALSH

Committee: VILMA CLARKE, ROSEMARY MACQUALTER, PETER MALCOLM, BARBARA RIVETT.

Director **JAMES GERRAND** asked the meeting for any suggestions for speakers/subjects for the next year's program. The following was suggested: A nurse to speak on the care of GBS/CIDP patients, a speaker on homeopathy, a doctor to speak on the role of prednisone in treatment of GBS/CIDP, a speaker on reflexology. These suggestions will be considered at the next In Group Committee meeting.

Amongst the items on sale were the new Frig Magnets devised by Treasurer **BRONWYN** and **STEPHEN WALSH** to publicise. As well as selling to members and friends, we will donate them to hospitals and neurologists who would welcome them. We ask members who would be prepared to be on a distribution list for this purpose to contact our secretary 9853 6443.

VILMA CLARKE was busy arranging loans of books and videos from The In Group Library she brought to the meeting. The current Library List is published on page 7.

Donations still tax-deductible

The IN Group has retained its status of having donations to The In Group income tax deductible. We had to apply under the new GST taxation system for endorsement as a deductible gift recipient as the

previous tax-deductible status lapsed on 30/6/00. This endorsement came into force from 1/7/00 so all our generous donors will be pleased to know this renewal has been granted by the Australian Taxation Office.

The IN Group has also been endorsed as an income tax exempt charity, something I believe is a formality as we are a non-profit organisation.

The In Group is awaiting GST registration. We are giving the GST a trial to check whether the 10% on our goods we sell, mainly our membership fees, are outweighed by the 10% levied on our expenditures, mainly Telstra internet charges, postage and stationery etc purchases for our newsletters.

As you will note we have placed our ABN (Australian Business Number) 77 954 503 188 on our newsletter, letterhead, membership application form and donation receipt form.

JAMES GERRAND, Director.

Dr Kornberg's research

Dr ANDREW KORNBERG, whose research at the Royal Children's Hospital into GBS/CIDP is being financially supported by The IN Group, has been invited to attend the December meeting of the European Neuro Muscular Centre (ENMC) to deliver a paper on research into CIDP, mainly in regard to children but also adults.

We hope to receive a report from Dr Kornberg on his return to be featured in our March 2001 newsletter "INformation".

E-mail addresses

As those fortunate to have access to the Internet know, e-mail is a quick means of communication between correspondents world wide.

The following are the e-mail addresses of a number of our members.

MELVA BEHR melva@onthe.net.au

VILMA CLARKE k.clarke@netc.net.au

BETTY and JAMES GERRAND and The IN Group ingroup@vicnet.au

ROSEMARY MACQUALTER mackew@netspace.net.au

BRONWYN WALSH Bronwyn.Clarke@nre.vic.gov.au

Other member who wish their e-mail addresses listed please e-mail The In Group.

An Important Publication

REVIEW OF THE USE AND SUPPLY OF INTRAVENOUS IMMUNOGLOBULINS IN AUSTRALIA. A report by the Blood and Blood Products Committee of the Australian Health Ministers Advisory Council (AHMAC). June 2000. 112pp. Available from AusInfo - shops in capital cities, mail order GPO Box 84, Canberra ACT 2600.

This publication is a must for all our Australian support groups. It gives a great round-up of the current situation with regard to the use and supply of IVIG, particularly our Australian Intragam.

It gives the details on which this Committee made its recommendations to AHMAC. As stated in our June "INformation" AHMAC agreed to the raising of CIDP and GBS to priority 1 - there is now convincing evidence of benefit. AHMAC did not agree to provide the \$14million needed to overcome the current 20% shortfall (239kg) in the supply of IVIG. Our Council of GBS/CIDP Support Groups of Australia in conjunction with the State Groups need to organise a campaign to obtain this funding to ensure prescribed medical treatment is available.

Some of the interesting factual details:

- Australian IVIG (Intragam) is currently supplemented by imported Sanoglobulin (at twice the cost), mainly to provide a 25% reserve.
- It takes about 300kg of plasma to make 1kg of Intragam.
- Cost of 30gm Intragam is \$1,713.
- About 10kg of plasma collected per 1000 population per annum.
- CSL has a contract, 1994-2004, with the Commonwealth government for supply of Intragam, produced from plasma collected from volunteers by the Australian Red Cross Blood Service. Intragam is provided by the Commonwealth free of charge.
- Less plasma is collected in winter due to higher sickness amongst donors. (Currently patients are getting a further 20% cut!)
- Plasma donations can be made more frequently than whole blood donation but requires expensive plasmapheresis equipment.

Support is the Name of our Game

Visiting

JAMES GERRAND was surprised and pleased to find the patient he visited at the Royal Talbot Rehabilitation Centre was **PHILIP CASTLEMAINE** who was the GBS patient in Intensive Care at the Adelaide Hospital in some danger of having his life support turned off ("INformation"Dec'99). Philip was recovering well. Other visits James made were to Hampton Rehabilitation Hospital visiting **NATHAN MITTELMAN**, now a member, and to the Austin Medical Centre.

ROSEMARY MACQUALTER and **MICHELLE HUGHES** have also been busy making contact with patients.

Internet Contact

Many inquiries continue to come in world wide and interstate seeking support. We send back information which is appreciated leading in many cases to becoming members. Amongst the latter are **MARLYN WEBB** (Ohio USA), **EDWARD FERGUSN** (California USA), **LARRY CASSADAY** (Indiana USA), **PAMELA GENNARI** (Arkansas USA), **MARGURITA JANATA**

(Cooma NSW). **DEBORAH NELL** (Indiana USA), **ANDREW PAGE** (Virginia USA), **LISA TRACEY** (Kogarah NSW), **RON WELDON** (Sawtell NSW).

We were able to lay to rest a fear from a correspondent from Michigan USA. A relative had died from CIDP and she was concerned that it might be hereditary. Not so.

Then we have had enquiries from Auckland, New Zealand about a nephew in Bangladesh suffering from GBS, from Oslo Norway about a 11 year old son with GBS, from Riyadh Saudi Arabia about a father-in-law with CIDP wanting information about treatment centres in Europe and Australia.

What a nice letter to receive!

Good Morning:

Just a note to comment on how much I appreciate the receipt of the newsletter. About three years ago, at the age of 64, I was diagnosed with CIDP.

The neurologists have me on steroids and antidepressants. They had commented to me "be careful not to break any bones ", and that's exactly what I managed to do in January - I broke my leg. The leg is almost healed at this writing.

If anyone should break a bone and is on steroids, which diminishes the calcium in your body, eat and drink items that are loaded with calcium. Also, be sure to take calcium supplements.

One last item, I happen to be in a stressful business and stress is very hard to deal with when you have CIDP. Stressful days make you very tired in hours instead of your normal day.

Keep the news letters coming,

LARRY CASSADAY, Iowa USA

Exercise & GBS

Extracts from an article by Dr Thomas Hedge published in "The Communicator" (Winter2000), newsletter of the GBS Foundation International. These should also apply to CIDP.

"Once the acute illness phase of GBS subsides, strength (of muscles) only re-develops according to the extent of the recovery of each motor nerve."

"For the post GBS patient with normal strength (5/5) throughout, the muscular response to exercise can return to normal, like before the GBS."

" For the post GBS patient with good strength (4/5), the muscular response to progressive resistive exercises may either be an improvement in strength towards normal if the recovery of the motor nerves is substantial; or, if there is not a substantial recovery, there may still be some degree of improvement without the ability to reach the previous levels of maximal muscle performance ..."

"For the post GBS patient with fair strength (3/5), the muscular response to exercise may either be a limited improvement in strength, or muscle fatigue and performance failure depending on the workload. ... Physician and therapist direction is mandatory in order to provide specific direction for optimising the types of exercise and avoiding harm."

"The post GBS patient with poor strength (2/5) or trace strength (1/5) should exercise in a pool or spa. Exercise must be designed to maintain and possibly improve strength and function while maintaining range and preventing complications. Just performing activities of daily living may be quite enough of an exercise. Again physician and therapist direction is mandatory ..."

"Unfortunately, if a sufficient number of functioning axons of the motor nerves do not recover or regenerate to the next higher level of potential muscle strength, (like from a 2/5 to a 3/5 etc), strengthening efforts will not be rewarded with an improvement in strength. Muscle atrophy becomes prominent when motor nerve axons are irreversibly lost, such as with 0/5 and prolonged 1/5 grades of strength.

List of Library Books and other Material

Librarian **VILMA CLARKE** has supplied the following list. She brings them to our meetings where members can borrow for return at the next meeting.

Journey to Wholeness - Barbara Brewster
Echoes of the Tides - Tony Moore
It Could Be You - Dave Borshik
Let Your Spirit Run Free - Andrew J. Belotti
No Time for Tears - Dorris R. Wilcox
Numb Toes and Aching Soles - Coping With Peripheral Neuropathies - John A. Senneff
Dancing with Ms Black Patent Shoes - Eva Marsh
Achievable Concepts
Reaching Out Magazine Nos 33,34, 35 37
Life Can Be Hard Sometimes
GBS - An overview for the Layperson - GBS Foundation International
CIDP - A short guide for the patient, relative and friend - GBS Support Group of the UK
GBS - Caring For A Child with GBS - GBS Foundation International
Childhood GBS - A guide for parents and carers - GBS Support Group of the UK
Outings for People Who Have Trouble Getting Out - Bernadette Byrne
A Road to Recover A-Z - June Cathcart
Boy, is this Guy Sick - John M Pollard
CIDP Snippets - Lever Arch File
IN Group newsletters - Lever Arch File
Nutritional Research from Sam Grundfast
Review of the Use and Supply of Intravenous Immunoglobulins in Australia - A Report by the Blood and Blood Products Committee June 2000
New Zealand Newsletters 40

Videos:

Striving to Recover - UK GBS Support Group
GBS & Cidp Challenges and Choices - SA Neurological Centre

Ending on a light note

Some more answers given by UK secondary students.

What is the correct use of a semi-colon?

Only to be used as a last resort, a semi-colon is a partial removal of the colon.

What is a turbine?

Something an Arab wears on his head.

How is dew formed?

The sun shines down on the leaves and makes them perspire.

What is a fossil?

A fossil is an extinct animal. The older it is, the more extinct it is.

Name the four seasons.

Salt, pepper, mustard and vinegar.

Last Updated: 15 Oct 2007 17:49