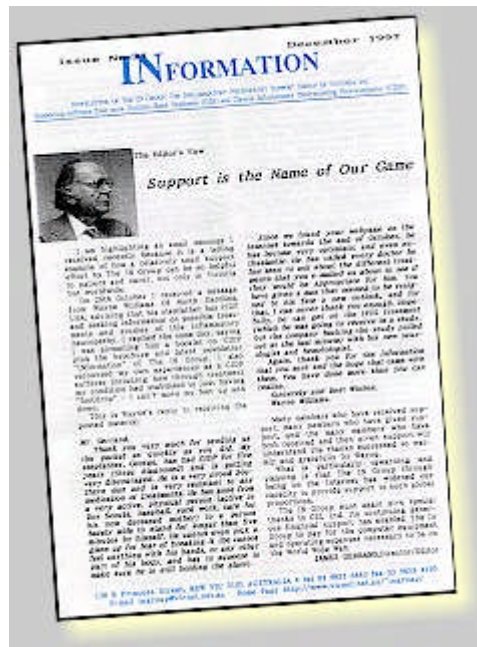


Support is the Name of Our Game

Newsletter No.21 - December 1997

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The Editor's View

I am highlighting an email message I received recently because it is a telling example of how a relatively small support effort by The IN Group can be so helpful to patient and carer, not only in Victoria but worldwide.

On 26th October I received a message from Wayne Williams Of North Carolina, USA, advising that his stepfather has CIDP and seeking information on possible treatments and studies of this inflammatory neuropathy. I replied the same day, saying I was airmailing him a booklet on CIDP plus the brochure and latest newsletter "INformation" of The IN Group. I also recounted my own experiences as a CIDP sufferer including how through treatment my condition had stabilised to just having "footdrop" - I can't move my feet up and down.

This is Wayne's reply to receiving the posted material.

Mr. Gerrand,

Thank you very much for sending us the packet as quickly as you did. My stepfather, George, has had CIDP for five years (three diagnosed) and is getting very discouraged. He is a very proud Southern man and is very resistant to any medication or treatments. He has gone from a very active, physical person (active in Boy Scouts, baseball, yard work, care for his now deceased mother) to a person barely able to stand for longer than five minutes by himself. He cannot even pick a glass up for fear of breaking it (he cannot feel anything with his hands, or any other part of his body, and has to squeeze to make sure he is still holding the glass).

Since we found your webpage on the Internet towards the end of October, he has become very optimistic and even enthusiastic. He has called every doctor he has seen to ask about the different treatments that you e-mailed us about to see if they would be appropriate for him. You have given a man that seemed to be resigned to his fate a new outlook, and for that, I can never thank you enough. Hopefully, he can get on the IVIG treatment (which he was going to receive in a study, but the company backing the study pulled out at the last minute) with his new neurologist and hemotologist.

Again, thank you for the information that you sent and the hope that came with them. You have done more than you can realize.

Sincerely and Best Wishes,

Wayne Williams.

Many members who have received sup-port, many members who have given sup-port, and the many members who have both received and then given support will understand the thanks expressed so warmly and gratefully by Wayne.

What is particularly rewarding and pleasing is that The IN Group through being on the Internet has widened our capacity to provide support to such global proportions.

The IN Group must again give special thanks to CSL Ltd. Its continuing generous financial support has enabled The In Group to pay for the computer equipment and operating expenses necessary to be on the World Wide Web.

JAMES GERRAND, Director/Editor

Successful November Luncheon

Now for news back home. Thirty-six members, family and friends, enjoyed a very happy get-together luncheon on Sunday 16th November, held at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn.

BETTY GERRAND, with generous help from **MARGARET LAWRENCE**, **MELVA BEHR** and **DOROTHY BRENNAN**, provided a delicious lunch which raised **\$131.20**.

Much fun was again generated by **BARBARA BURZAK-STEFANOWSKI** who conducted a blind auction of wrapped gifts donated by members. This brought us **\$297.05** and the raffle of a doona yielded **\$150**. This brought up a grand total of **\$578.25** for the day.

National Council Meeting

The second meeting of the Australian Council of GBS/CIDP Support Groups, held on Sunday 21st September at the Alfred Hospital, was attended by President **BARBARA BURZAK-STEFANOWSKI** (Victoria), Vice-President **HEATHER TRENORDEN** (South Australia), Secretary **MELVA BEHR** (Victoria, delegates **JOHN STANLEY** (Tasmania), **BETTY GERRAND** (Victoria) and **JAMES GERRAND** (Victoria). Also in attendance were **CATHRYN HOPE** (CSL Pty Ltd) and **KEITH COLWILL** (Victoria). **DUNCAN MACPHERSON** (New South Wales) sent a late apology.

Main business was agreeing on the revised Constitution.

It was decided the next meeting would be by telephone conferencing towards the end of January 1998.

Shortage of Intragam

Many Victorian GBS and CIDP patients relying on intravenous gammaglobulin treatment found they were only able to be given a reduced amount of Intragam, the CSL trade name for their manufactured gammaglobulin, in October. For example I received 21 grams instead of my usual 30grams.

I faxed the following letter to the Victorian Minister of Health, seeking his action to improve supplies of Intragam.

23/10/97

Mr Robert Knowles

Minister for Health and The Aged

Dear Minister,

Shortage of Gammaglobulin

The IN Group was made aware last week that gammaglobulin is in such short supply in Victoria that many patients are not able to be given their needed treatments. This affects many members of The IN Group, suffering from Guillain-Barre Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), where intravenous gammaglobulin is often a required treatment.

Not having this treatment can mean a patient ending up in a wheelchair in a nursing home instead of making a recovery.

It is understood that the shortage has arisen from an increasing medical demand for gammaglobulin (supplied by CSL Limited under their trade name Intragam) not matched by an increasing number of plasma donations to the Australian Red Cross Blood Supply Service.

What is now needed is a major publicity campaign by the Australian Red Cross to attract more volunteer plasma donors.

The IN Group asks you to urgently examine this need for more gammaglobulin and provide the necessary funds to the Australian Red Cross for them to advertise widely in Victoria for volunteer plasma donors.

Yours, in need,
James Gerrand, Director.

There is currently an even more serious shortage of Intragam in New South Wales, mainly due to there being less plasma donors in that State. The Australian Red Cross Blood Service allocates

Intragam to a State in proportion to the number of blood plasma donations in that State.

The President, **BARBARA BURZAK-STEFANOWSKI**, of the Council of GBS/CIDP Support Groups of Australia, has written to the NSW Minister of Health, Dr Andrew Refshauge, urgently requesting his government to make available the necessary funds to the NSW Branch of the Red Cross Blood Service for a publicity campaign for more blood plasma donors.

As every contribution helps, family and friends are asked to consider being blood plasma donors. It is understood those who are, or have been, sufferers from GBS or CIDP are not considered acceptable blood plasma donors.

Support is the Name of our Game

Cluster Group (North-East)

*Just a little note about our Group. We have had a couple of lunch time chats with those who can get there and three of us will be having lunch in Wodonga and catching up with news of the others, of medical and of IN Group advances. One of our members (**JILL GRIMMOND** see below) has visited a man with GBS at the Albury Base Hospital. The area of the cluster stretches from Leeton in NSW down to Taggerty.*

One of our members has had a lot of pain in his feet and has been in touch with another with the same for advice. As well we have fun together even if we don't win at the pokies. It is nice to know that someone is not far away - and that we are not alone even tho' we are rare.

Have you thought of forming a cluster in your area?

VILMA CLARKE, Wangaratta

From one of the cluster

Dear Editor,

I have been to Albury Base Hospital to visit Christopher Grover. He was situated in ReHab but was not feeling very well as he had pneumonia for the second time.

We had a talk and he related his story to me. He does not seem to be a typical GBS. It took a long time for him to be diagnosed as they kept telling him he had arthritis.

Have rung the hospital again and will visit him again tomorrow, perhaps he will have more news on his condition. Even though he is 82 he was a very fit and active man and is of course finding this sudden change difficult.

JILL GRIMMOND, Wodonga

Saved from a Nursing Home

Mr Keith Gaff has suffered badly from GBS. After some months in Intensive Care at the Austin Hospital he has since spent some six months at the Royal Talbot Reha-bilitation Centre. When visiting him recent-ly he and his wife Agnes expressed their concern that the Centre was wanting to transfer him to a nursing home notwithstanding that he was making progress, if slow, under their

rehab program.

I suggested he get a second neurolog-ical opinion which they did. The advice was that Keith should stay at the Talbot

until he was sufficiently recovered to be looked after at home by his wife and attend regularly rehab programs to continue his recovery over the next twelve months - a much better prospect.

JAMES GERRAND, Kew

Dear James,

I am still progressing - it is a long process but sure is better than those early days of GBS. I still have "tingles and numbness" in my fingertips and toes and the end of my nose - they really tingle when I exert myself too much. A sign that I am not completely cured but sure is better than being paralysed and entirely dependent on others for survival. I go to exercises conducted by a physiotherapist, making me do things that I don't do whilst housekeeping and gardening. I have been able to get back to most of my previous activities, except my volunteer work at Cancer Clinic at Geelong Hospital. In my estimation that will come up soon.

I enjoy the newsletter - please keep it up. It serves me as a reminder - how lucky I was to have an early diagnosis and also how fortunate I was that I could have treatment so early and so near.

LOYIS VOIGHT, Whittington Vic

Flag and Lamp Man

Keith Colwill, my father is a remarkable man in the world of Signals (Army). He claims to be a "flag and lamp" man and has always been an advocate for the value of learning Morse Code. But grandchildren in the 70s and beyond were of a different era and only one of his six persevered and stored the Morse Code knowledge away.

In October 1995 Ben was 25 and his grandfather was seriously ill with Guillain Barre Syndrome - completely paralysed apart from slight movement in one eyelid!

Things looked pretty grim - our loved One's body lying rigid and still in Int- ensive Care, hooked up to tubes, beepers, computers, saline solutions, check sheets and a dedicated nurse overseeing every minute of the day. All bodily functions had shut down, machines had taken over his life; nothing moved except his left eyelid, just a slight flicker - its range was half

a flutter. That was all we had. We wonder- ed if he could hear us, see us, understand us; we wondered if he would ever come out of it. How would we ever know?

We'd all visited - peered into that left eye as the little lid flickered softly - and we'd wondered and worried. Then Grand-son NO. 2 arrived - all 6'7" of him - bent his body over the bed - and said to his grandfather "Hi, Grandy, I love you". The eyelid flickered intensely. Ben watched it

closely, then turned and told us "Grandy blinked H- I- in Morse Code". Ben watched again, concentrating on that small flicker of life. He repeated it. "Hi". We were elat-ed. He was still there and communicating. Only Ben could have read it! What a man! What a miracle!

JAN HOOKER, daughter and member

(from the newsletter of the Royal Australian Signals Association (Victoria))

Press helps public understanding of GBS

Below is a feature article published in the "Sunday Herald Sun" 30/11/97 of how Warnambool dairy farmer Barry Steel has courageously battled with GBS for 14 months. Our Western Representative **GREG GILLESPIE** has visited Barry a number of times over this period and reports 16/11:

Dear James,

Barry is making steady progress and getting out and about more often in wheelchair and taxi. He has been home on day visits, out to dinner and spent 5 hours at sprint car races last Saturday.

He has enough strength in his arms to get from wheelchair to ordinary chair but legs are not good yet - some movement but little strength.

He has been visited by two other past GBS patients in Warnambool for which he

is most grateful. He is also very enthu-siastic of the treatment from staff all through the Warnambool Base Hospital.

His positive attitude has not changed. This, as we know, is the basis of recovery.

GREG GILLESPIE, Peterborough

One immediate result from the press item was a letter from Greg & Bev Millar of Carnegie, seeking further information about GBS as they have a 23 year old son recently diagnosed with GBS.

On the opposite page is a feature art-icle published in the Brisbane "Courier-Mail" 10/6/97, kindly supplied by member **KEITH COLWILL**.

These two cases are a reminder that GBS and CIDP can attack anybody at any time.

Thank you, ANZ

It is very pleasing to report the following reply from the ANZ Bank:

...

Your request for an exemption from the current fee charged (\$15) when depositing foreign cheques (made out to The IN Group) has been considered and we are pleased to confirm your previous fee exemption will continue.

...

Judith Swan,

National Manager, Customer Liaison

The In Group will acknowledge this favourable support by an appropriate statement on The IN

Group Home Page. This statement will also serve to advise our foreign present and prospective members that their foreign cheques will be paid into The IN Group without conversion charge.

Membership

Our membership totals now 242 which includes 33 overseas (23 USA, 3 NZ, 2 Canada, 1 Austria, 1 Japan, 1 Philippines, 1 Slovakia, 1 UK) and 21 interstate (5 NSW, 9 Qld, 1 SA, 2 WA and 4 Tas).

CIDP Penfriends

As a lot of you are aware James has been receiving many calls for help, information etc on the Internet - sending them an appropriate booklet (CIDP or GBS). Many have become financial members and receive our newsletter "INformation" on a regular basis.

Well, a while ago, I decided that I would write to those who had my disorder - CIDP. Finally I wrote 13 letters thinking maybe I would get 3 or 4 replies - so far I have received 7!!! This was a very interesting exercise and means now I have returned to a pastime that I had as a teenager - having pen-pals in another country.

*Of interest is the fact that these people **do not** belong to a Group and have not met anyone in the flesh and blood to talk to; so they are very happy to write. On top of this I write to a lady in the UK and a man in NZ with CIDP - we are indeed very fortunate to have our very own group and people we can meet or telephone. I will keep you posted (pun on words).*

VILMA CLARKE, Wangaratta

Donations gratefully received

The In Group thanks the many members who add a donation when joining or re-newing their membership. Such gifts extend our ways of helping, in particular the research into GBS and CIDP being carried by Dr **ANDREW KORNBERG** at the Royal Children's Hospital.

Particular thanks firstly to Drs D & M Happold, ACT, for their gift of \$100 when told by cousin, member and herself very generous supporter **GWEN MANN** about The IN Group; and secondly to new member Mrs Valentina Cavaliolo of Flinders Park SA for adding \$35 donation to her joining fee.

How the word spreads

October 24th

Dear Mr Gerrand,

I am writing in reference to your article on The IN Group.

My employer, Larry Cassaday, recently discovered that he had CIDP and his daughter found this information on the Internet. He is interested in receiving your organisation's newsletter. He is working hard to overcome this rare disorder by taking steroids and doing his physical therapy faithfully. They told him it could take as long as two years or more to recover.

I am enclosing a check for \$15 for joining.

LUANN PINS,

Independence, IOWA USA

and again

11th November

Dear Mr Gerrand,

My employer was very impressed with the booklet on CIDP and would like 4 or more copies.

*He also has a friend that has GBS and would like to enrol him in your support group: **DON HOEGER.***

I am enclosing \$20 to cover membership and the booklets.

LUANN PINS

I sent the booklets and both **LUANN PINS** and **DON HOEGER** are now members of The IN Group.

Other recent inquiries have come from Mrs **MURIEL STACK**, Rochester Vic (is joining); **MARILYN PAYNE**, Aldaville Via Kempsey NSW; **MELANIE VAN DE WAAL**, Merano ITALY; **ELIZABETH MARSHALL**, New York USA and **VIVEK JINDAL**, New Delhi INDIA.

A Patient Guide to Intravenous Immunoglobulin (IVIG)

*The following interesting article from Harvard Children's Hospital Medical Dept (found on the Internet) has been commented on, or adapted for Australian conditions, by Dr **PETER SCHIFF**, Medical Director, CSL Limited.*

This brief section is intended to inform patients about IVIG and to answer frequently asked questions about IVIG therapy. Please read through this material carefully. If you have any further questions concerning IVIG therapy, you should discuss them with your immunologist.

Who needs IVIG, and Why?

In several forms of immunodeficiency, patients have a problem making antibodies. Antibodies, or immunoglobulins, are molecules made by special immune cells known as B-lymphocytes. These antibodies help fight infections and protect people from infections such as pneumonia, sinusitis and ear infections. Immunoglobulins is another word for antibodies. Humans make several different types of immunoglobulins, but problems in making Immunoglobulin G (abbreviated as IgG) are most commonly responsible for causing an immunodeficiency. For these patients who have

problems making IgG, intravenous immunoglobulin (IVIG) is a very important part of their therapy. Other names for IVIG include immune globulin-intravenous (IGIV) or intravenous gammaglobulin (IVGG). By giving patients IVIG, we can replace the IgG that they are missing.

Dr Peter Schiff. IVIG also plays a useful role in the treatment of certain autoimmune disorders. It is believed that the body makes unwanted antibodies against its own tissues and that giving IVIG neutralises their effects. Thus IVIG has been used successfully to manage such disorders as GBS (Guillain-Barre syndrome) and CIDP (chronic inflammatory demyelinating polyneuropathy).

What is IVIG, and How is it made?

IVIG is a concentrated solution of anti-bodies. It is made by taking the blood of many different patients (usually around a thousand for each lot that is prepared) and removing the antibodies. After the antibodies are removed, they are treated to remove any impurities and contaminants, freeze-dried and divided into sterile bottles. Just before using the freeze-dried

IVIG, sterile salt solution is added to make a solution that can be given intravenously. *Dr PETER SCHIFF: Some products such as*

Intragam, are supplied as a sterile solution and do not have to be reconstituted before administration.

Are there different kinds of IVIG?

There are several companies in the United States and around the world that process and produce IVIG. Although there are slight differences in the way each company its product, all IVIG products function the same way.

How do patients receive IVIG?

Because antibodies work in the blood, IVIG must be put into the body through an intravenous catheter (an IV). It cannot get into the blood if taken by mouth, since the acids and enzymes in the stomach and intestines would break it up. Once in the blood, IVIG lasts for about three weeks. Therefore, most patients need to get IV infusions every three weeks. In some cases, patients may need infusions more frequently, such as every one or two weeks. The exact frequency and dosage of IVIG needs to be tailored to the individual patient after consultation with his or her immunologist. *Dr PETER SCHIFF: Infusions are usually administered in a hospital day/care centre setting.* Regardless of where patients ultimately receive their IVIG, the first infusion must be given in the hospital. On the day of the infusion, a nurse starts the IV, and the IVIG is administered. Infusions usually take 3 to 6 hours, after which the IV is removed.

Are there any side effects associated with getting an IVIG infusion?

The vast majority of patients experience no side effects from IVIG. In rare instances, patients can have fevers, chills or rash while getting an IVIG infusion. Headaches, muscle aches or abdominal pain occur occasionally. Usually, patients who have had such reactions will be pre-treated with aspirin or PanadolTM, along with BenadrylTM before their next infusion. This usually prevents reactions in the future. Slowing the rate of infusion will also help prevent reactions. Because IVIG needs to be given intravenously, there is also the slight risk that fluid from the IV will leak out (this is called an infiltration) or the very rare chance that the IV site will get infected; both these complications are extremely uncommon.

Is there any danger of getting AIDS or other blood viruses from IVIG?

Because each lot of IVIG is made from the blood of several hundred donors, there is naturally concern about passing on dis-ease from viruses in the blood.

One blood virus that causes a great deal of concern is the human immunodeficiency virus (HIV). HIV is the virus that causes AIDS (Acquired immunodeficiency syndrome). All potential blood donors for IVIG are screened for HIV, and they are rejected if they test positive. Extensive tests have shown that the purification process that is used to make IVIG from blood completely destroys any HIV in the blood; this is true for all of the different preparations of IVIG. Furthermore, in studies where HIV has been intentionally added to blood before processing into IVIG, the virus was completely destroyed after the processing procedure was completed. Those studies were done as a test of IVIG preparation, and none of those preparations were used in patients. Finally, in over fifteen years of use and hundreds of thousands of infusions, there has never been a single reported case of AIDS due to IVIG therapy.

The other viruses of concern are hepa-titis viruses, which cause inflammation of the liver. Once again, donors are screened for hepatitis viruses, and they are not used if they are positive. Many of these viruses are destroyed in the purification process. In recent years, hepatitis from IVIG therapy has been rare. However, several cases of hepatitis C occurred in 1994 with one brand of IVIG - Gammagard. All manufacturers now include a step to kill viruses such as the solvent detergent step in Gammagard SD.

What sort of follow-up and monitoring do I need while on IVIG?

The exact follow-up required for pati-ents on IVIG varies somewhat according to the specific problems being treated. In general, blood levels of antibodies are

obtained to insure that we are providing adequate amounts of IVIG. Although some patients have improved health after the first infusion of IVIG, it usually takes 2 to 6 months to have an effect. After starting IVIG, patients are usually seen after 3-6 months to see how they are doing on IVIG therapy. Thereafter, patients should be seen on a regular basis at least every 6 months. Follow-up is very important for keeping track of how patients are doing on the IVIG infusions. In addition, new developments and improvements are const-antly occurring, and we want to be sure to implement these for our patients as soon as possible.

Department of Medicine
Children's Hospital
Boston, Massachusetts USA

Editor's Notes

Christmas Cards - A Reminder

The IN Group quality Christmas Cards are a good buy at \$12.50 (inc. postage) and your money directly supports The IN Group as it is all profit now. The order form is on the wrapper.

Entertainment Books - A Christmas gift

An Entertainment Book at \$45 (inc. postage) makes a good Christmas gift - you only pay 50% at many restaurants, theatres, sports venues etc - and you are also helping as \$8 goes direct to The IN

Group. The order form is on the wrapper.

Possible Change of Meeting Venue

Your Committee would like to know members' views on whether they are happy with the Balwyn Library Meeting Room as the venue for our quarterly evening meetings.

Have you found parking a problem? Do you know of a better meeting place, at a reasonable charge. The hire for the Balwyn Meeting Room is \$17 for the evening, a good price.

Mail, telephone or email us (see address etc on front page) your views.

JAMES GERRAND, Director

Last Updated: 15 Oct 2007 17:49