

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

Treating GBS

Newsletter No.36 - September 2001

From the address by **Dr RICHARD STARK**, Neurologist, Alfred Hospital, to The IN Group meeting, held Wednesday 8th August 2001 at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn.

What is Guillain-Barré syndrome?

GBS is a syndrome, a group of clinical features that come together. It has come to mean the same as an acute inflammatory neuropathy. Most acute inflammatory neuropathies are GBS and most GBS are acute inflammatory neuropathies. There is a little overlap at the ends. For example, you can get an inflammatory polyneuropathy that is not mostly motor but sensory.

Typically GBS comes on acutely, involves mostly motor functions (sometimes sensory as well), often does start at the legs and works up. In making the diagnosis we are helped by lumbar puncture changes which give us a clearer idea of the protein levels and so tell us about the inflammatory pattern and we examine the patient. Often there is a viral illness beforehand, often it is symmetrical and usually the nerve conduction (EMG) studies will give us a clue as to what is going on. Often the studies are not revealing for a few days at least and there may be difficulties about getting accurate information from the EMG for some time.

There are a number of other acute neuropathies that don't quite fit in. There is the Miller Fisher variant (characterised particularly by double vision or problems with changing gaze from weak eye muscles) and AMAN (acute motor axonal neuropathy, frequently occurring in children in northern China).

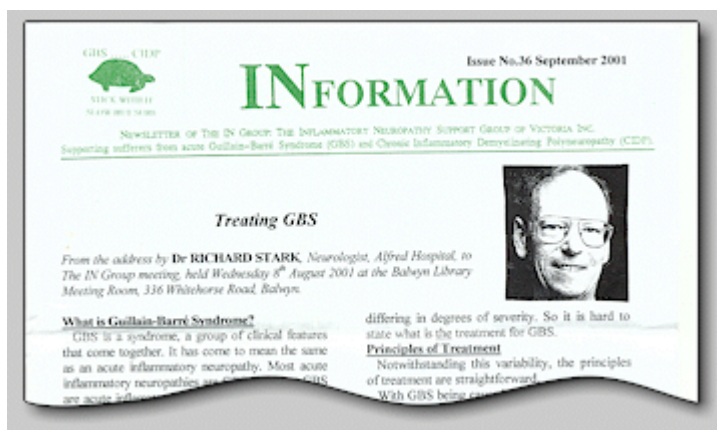
Then a patient with the relapsing form of CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) may have an acute onset such that we may think this is GBS.

We may say all cases of GBS are different, differing in degrees of severity. So it is hard to state what is the treatment for GBS.

Principles of Treatment

Notwithstanding this variability, the principles of treatment are straightforward.

With GBS being caused by a disturbance of the immune system, some of the problem relates to proteins circulating in the blood. These can include antibodies, immune complexes and inflammatory proteins. The infection that triggered the problem has usually settled by the time the neuropathy has appeared. (Perhaps the campylobacter jejuni infection can be an exception).



As GBS can cause life threatening complications, treatment should aim to minimise these risks. A particular threat is through loss of breathing from the effect on the lung muscles and so the breathing ability of the patient should be particularly watched.

GBS usually gets substantially better by itself but treatment can speed up recovery. A small proportion of patients is left with long-term problems, a few make a complete recovery and the majority are left with some disability.

Dealing with acute complications

The first action on the admittance to a hospital of a patient with GBS is an accurate assessment of the respiratory function. The bedside lung function is assessed through checking how much volume of air the patient can breath in ? Vital Capacity (VC) ? or the Peak Flow Rate (PFR). The oxygen saturation level in the bloodstream can also now be readily measured through a device which accurately measures the colour of the blood in the fingernail ? higher oxygen levels make the blood redder. If the VC or PFR falls then the patient needs to be transferred to the Intensive Care Unit (ICU) where respiratory support can be provided.

The other respiratory concern is pneumonia. Physiotherapists can help a patient to breath deeply and cough more effectively to avoid, if necessary, to treat pneumonia. Early diagnosis and the use of antibiotics when necessary are important.

DVT (Deep Vein Thrombosis, recently publicised as Economy Class Syndrome) can occur in severe cases of GBS. The main risk is immobility, lying in bed. The prescription of a low dose of heparin can reduce the risk of DVT.

Variation in the pulse and blood pressure can occur and this requires appropriate treatment.

The acute treatment of the immune process

The two main treatments are **Plasma Exchange** and **Intravenous gammaglobulin (IVIG, Intra-gam)**.

The usual method for **plasma exchange** is 5 exchanges over two weeks. Venous access can be a problem for some patients ? large veins are needed. The facility is not available at some hospitals. It works best if started within 2 weeks of the onset of GBS. 10-20% of patients may relapse and need a second course. Low blood pressure and faintness can occur, especially in the frail and elderly.

IVIG supplies gammaglobulin pooled from many blood donations with the concept of supplying many antibodies that could bind and inactivate the proteins of the patient that may be the cause of the GBS. The usual dose is 0.4g/kg of weight of patient for each of 5 treatments over 7-14 days. Overall, IVIG is probably equivalent to or marginally better than plasma exchange in effectiveness. Some patients may relapse and need a second course, probably more often than with plasma exchange.

The choice between IVIG and plasma exchange will usually depend on the availability locally and globally at the time, local experience and the speed with which each can be started.

Corticosteroids (cortisone, prednisolone) have been tried but oral steroids are not helpful. Rec-ently there have been claims that huge doses of intravenous methylprednisolone have been helpful but this is not proven.

Rehabilitation

The need for rehabilitation and the type chosen are mainly matters of commonsense and will depend on individual factors including the severity of the neuropathy, the speed of recovery, the availability of services and social factors.

Options include inpatient intensive rehabilitation, outpatient physiotherapy and a simple exercise program.

Management of residual symptoms

About 10% of GBS patients have significant residual functional deficits. A further number have minor ones of "nuisance value". Some deficits such as "footdrop" can be helped by splints and other orthoses.

Pain usually responds better to specific treatments for neuropathic pain than to strong pain killers. Types of medication include anticonvulsants such as Tegretol (carbamazepine), Epilim (valproate) or Neurontin (gabapentin) and antidepressants such as amitriptyline.

Questions & Answers

Q. Does all gammaglobulin used here come from Australian donors or is any imported?

R. By and large we rely almost entirely on blood which is collected in Australia from volunteers. There is an imported gammaglobulin ? Sando-globulin ? which is available in Australia but it is expensive. We have a problem that there is not enough Australian gammaglobulin ? Intragam. Overseas donors are usually paid which can be a problem. The people who give blood for free tend to be good citizens who will truthfully state on the forms that they are not at risk for hepatitis C, Aids etc, whereas paid donors may include people who need money for the worst of reasons. So the quality of blood collected overseas from paid donors is not as good as that collected from volunteers. All of the Australian blood products are screened carefully from infections. Also gammaglobulin can be made in such a way that it is possible to treat the blood to destroy viruses etc that doesn't destroy the effectiveness of Intragam.

Q. I get treated every fortnight with Intragam to control my CIDP. Although naturally healthy I seem to be even healthier since this treatment. Could Intragam help against infection?

R. Yes, because Intragam contains such a mixture of antibodies whose purpose is to resist bodily invasions such as viruses it may well help a person to avoid colds and flu.

DIRECTOR'S REPORT Year 2000/2001

Continued shortage of Intragam

The shortage of Intragam has continued with many patients receiving only 80% of prescribed amount. The IN Group has continued to press the Federal and Victorian Governments to provide the \$15 million recommended by the Blood Product Working Group as needed to overcome this shortfall.

The IN Group experiment of letterboxing 1,000 Melbourne residents only produced 3 extra blood donors for the Australian Red Cross Summer Challenge. However the trial would have had some

publicity value.

Member **KYLIE MILLER** expressed her desperation from the shortage in an Open letter to Federal Minister of Health **Dr WOOLDRIDGE** which was published in "THE AGE" newspaper. "THE AGE" later published a full page article featuring our member **MICHELLE HUGHES** as one, affected by CIDP, who needs Intragam regularly to continue her engineering course.

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 by **KEITH COLWILL, JAMES GERRAND, ROSEMARY MACQUALTER, GINA MERNONE** and **JOHN POLLARD** to patients and contacts made to their families at the Austin & Repatriation Medical Centre, Brighton Rehab Centre, Hampton Rehabilitation Hospital, Royal Talbot Rehabilitation Centre and St Vincent's Hospital. **KEITH COLWILL** also helped a nurse make his postgraduate presentation on "GBS and GBS patient nursing" to a class of nurses attending an Intensive Care course at the Austin Hospital ICU by personally describing his experience in coping with the Syndrome.

VILMA CLARKE continued to arrange helpful meetings of our members in the North East Victoria area. **JILL GRIMMOND** visited two patients at the Albury Base Hospital and one at Myrtleford.

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 usually airmail back the appropriate GBS or CIDP booklet and latest newsletter "INformation". This response is greatly appreciated and many subsequently join The IN Group.

Sponsorship by CSL LIMITED

The IN Group is most grateful for the continuing financial support of CSL (makers of the gamma-globulin product Intragam). This support has covered the cost of being on the Internet since 1955, by their initial donation of \$3,500 to cover the cost of a computer/printer and annual donations now \$1,100.

Then in November 2000 CSL was outstandingly supportive in donating \$6,000 to cover the cost of a modern photocopier. A very hearty thankyou to **CSL LIMITED** from The IN Group for such generous sponsorship.

The Helpful Questionnaire

Ninety-eight 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.

If you have not received a Questionnaire and would like one contact the Secretary.

Membership

Membership is 282 which includes over 250 past and present IN sufferers. Thanks mostly to being on the Internet, 27 are from interstate and 58 from overseas - mainly from the USA but also from Canada, Japan, New Zealand, Slovakia and the 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 out by Dr **ANDREW KORNBERG** at the Royal Children's and St Vincent's Hospitals. We donated another \$3,500 to this research, making a total of \$31,000 to date.

Quarterly Meetings

These meetings have continued to be popular. Quality speakers for the evening meetings - **VAL JOHNSON**, Manager, Disability Program, ANS-ETT AUSTRALIA, on "*Travelling with CIDP*" August'00; Dr **BRUCE TAYLOR**, Neurologist, St Vincent's Hospital (Melbourne) and MBF Clinic (Hobart) on "*Treating CIDP*" February'01; **JEN-NY COTTRELL**, Reflexologist, on "*How Reflexology may help*" May'01 - were informative and led to interesting questions and discussion. Each presentation was published in our newsletter "INformation".

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

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

Socials

The November Sunday Luncheon Party was again a happy social get-together as well as a great fund-raiser. A total of \$965 was raised, including \$264 from the delicious luncheon and \$500 from a Dutch auction, conducted with great fun by **BARBARA BURZAK-STEFANOWSKI**. A new initiative, Mystery Jars, raised \$24 and \$177 was kindly donated from members apologising for non-attendance.

Twenty members and friends enjoyed the Winter Luncheon Social Party held on 17/6/01 at the Glen Waverley home of **MARGARET and DOUG LAWRENCE**. Adding to the pleasure of lunching in the delightful surroundings and providing helpful information was a presentation on "Hypnotherapy" by member **JULIE LONCAR**. Her talk will be featured in the December "Information". The icing on the cake was the \$300 made from the occasion.

Cake Stall Fund Raiser

This now annual event, held at Maling Road Canterbury, thanks to the initiative of Deputy Director **MARGARET LAWRENCE**, plus her helpers, was again very successful on Saturday morning 12/5/01. \$917 (including direct donations of \$165) was raised from the sale of many cakes, jam and some produce.

Fundraising from a 50th Birthday

Our member **MOLLY GUNTARIK-CAMP-BELL** raised \$496 as a donation to The In Group for medical research through inviting her family and friends to consider a donation as a present for her 50th birthday celebration. A wonderful idea leading to a great success. Many thanks, Molly.

IN Group Fridge Magnets

A number of the 500 Frig Magnets purchased through the initiative of our Treasurer **BRONWYN CLARKE** have been presented to leading hospitals and neurologists and are 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

Four 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, and the GBS Support Group of Tasmania. Unfortunately there is no SA support group now that government funding has ceased to the SA Neurological Resource Centre. The GBS Association of NSW is having difficulty in finding a Secretary following the sad death of Jan Ayres.

VILMA CLARKE of Wangaratta was elected President at the February 2001 AGM following **BARBARA BURZAK-STEFANOWSKI** advising she was not seeking re-election. Barbara was warmly thanked for leading the Council since its inception so successfully.

CSL LIMITED was a most generous sponsor with a donation to the Council of \$1,000.

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

Eleven Entertainment Books at \$50 (\$55 posted) were purchased by members to give The IN Group a quick return of \$110.

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.

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*.

The IN Group thanks **IAN CLARKE** of Snap Printing, St Kilda Rd Melbourne for his generous donation of reprinting 100 copies of June's booklet following the sell-out of the initial production.

Thanks

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

JAMES GERRAND,
Director.

IN Group News

Annual General Meeting

The AGM was held at the Balwyn Library Meeting Room on 8/08/01 in the half-hour before the public meeting. Director **JAMES GERRAND** welcomed some 20 members. Following the confirmation of the minutes for the year 2000 AGM, the Director presented his Report for the past financial year 2000/2001 (pp 3,4 of this issue), particularly thanking the Committee and the many members for their help and generosity that had made for another outstandingly successful year for The IN Group. Following the acceptance of the Director's Report, Treasurer **BRONWYN CLARKE**'s Report was presented (pp 5,6), setting out The IN Group's Profit & Loss as well as Assets & Liabilities. The financial statement is based on the Accrual rather than the Cash method of accounting. Generous donations and fine fundraising allowed the IN Group to donate a further \$3,500 to Dr Kornberg's medical research into GBS/CIDP. The IN Group was particularly grateful to CSL Limited for their most generous sponsorship donation of \$6,000 enabling the buying of a modern photo-copier. The Treasurer's Report was endorsed.

Election of Committee

The following were elected unopposed:

Director: **JAMES GERRAND**

Deputy Director: **MARGARET LAWRENCE**

Secretary: **ROSEMARY MACQUALTER**

Treasurer: **BRONWYN CLARKE**

Committee: **VILMA CLARKE, MOLLY GUNTARIK-CAMPBELL, PETER MALCOLM, BARBARA RIVETT.**

Further Donation for Medical Research

A further \$5,000 was donated in July to the medical research being carried out by Dr Andrew Kornberg, bringing the total donated by The In Group to \$36,500 to this research into GBS/CIDP. Dr Kornberg, in gratefully acknowledging this donation, stated it would help in his recruitment of a neuromuscular fellow.

ANZ's helpful support

The ANZ Bank has for some years now been very helpful to The IN Group by not charging their fee (\$15) for changing foreign currency. In the last financial year ANZ changed 26 cheques, usually

over-seas subscriptions and donations, without charge, thus saving The IN Group a total impost for the year of \$390. Thank you, ANZ.

Breakthrough in understanding CIDP

The Nerve Research Foundation, University of Sydney, reports that in work largely performed by Dr Weixing Yan, CIDP has been proven to be an autoimmune disorder by the identification of antibodies which target a major protein of peripheral nerve, the P zero protein. This protein is known to be the major factor responsible for the binding together of Schwann cell membranes in the formation of the myelin sheath. It is therefore of considerable interest that an antibody which targets this molecule should cause myelin to unravel, ie demyelination.

IN Group supplying information

Some more examples of how marvellous the Internet is as a ready, quick means of intercommunication. When Lilyana Santoso of Kingsford NSW e-mailed us that her aunt in Indonesia had been diagnosed with GBS we sent the aunt a GBS booklet published by the GBS Foundation International (the Foundation kindly sends us a batch of copies on request) plus our brochure and latest newsletter "INformation". Similar support to Debra Talley (Missouri USA ? husband CIDP); Adam Felton (Townsville Qld ? CIDP); Cindy Branch (Alabama USA ? CIDP); Ron Coleman (Tamworth NSW ? CIDP); Lori Metz (California ? father CIDP?); Katie Wood (Illinois USA ? CIDP?).

Then we have what is now called "snail" mail. Kylie Fryer, a nurse at Monash Medical Centre studying a Graduate Diploma in Advanced Clinical Nursing specialising in Neuroscience, wrote asking for an information package for a resource folder of Neurological Support Groups she is compiling for use by patients and relatives.

OAM for member

Congratulations to Associate Professor and IN Group member **DAVID ASHTON** was awarded the Medal of the Order of Australia in the May Australian Federation Awards for his leading the post-war development of the study of plant ecology in Victoria. David has studied the 300-year-old Mountain Ash Forest north of Whittlesea for 50 years.



IN Group in "Health Issues"

The In Group was featured in a two page spread in "Health Issues", a glossy magazine of the Health Issues Centre Inc. This Centre is a non-government, health policy/research organisation which recommends improvements to the system from the perspective of consumers. It is based at La Trobe University.,

On a lighter note

He used to be an all-round athlete, now he?s

Just all-round.

* * * * *

Doctor: "Do you suffer from stress?"

Patient: "No. but I think I?m a carrier".

* * * *

Patient: "Well, doc, how do I stand?"

Doctor: "I don?t know, it?s a damned miracle".

Last Updated: 15 Oct 2007 17:49