

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

9th International Congress of Neuromuscular Diseases

Newsletter No.25 - December 1998

Report by Dr BRUCE DAY, Neurologist Alfred Hospital and Consultant Neurologist to The IN Group.

I was fortunate to be able to attend this meeting at the Adelaide Convention Centre this year. The meeting was exceptional and congratulations should be extended to the organiser of the program. A great many highly regarded international experts attended and scientific presentations were state-of-the-art. The conference covered a wide range of peripheral nerve and muscle disorders. Genetic advances featured strongly in the program.

With regard to the inflammatory neuropathies, there were many interesting presentations. The struggle we all have with the accurate diagnosis, classification and categorisation of these disorders were exceptionally well aired. The grey areas of overlap between diabetic neuropathy and inflammatory neuropathies was addressed and a difficulty we have in adequately diagnosing and categorising the chronic focal inflammatory neuropathies was also a topic of much discussion.

Unfortunately, therapeutic gains in the inflammatory neuropathies have been few and far between in recent years. We are perhaps getting a better understanding of how to use the various agents in different sub-groups of inflammatory neuropathy, but novel therapeutic agents have been few and far between.

A number of patients with very unusual clinical features were described, including patients presenting with isolated weakness of the eyes, falling difficulties, loss of hearing and loss of the ability to smell. Several patients were described who had developed secondary inflammatory neuropathies on top of the previously undiagnosed hereditary neuropathy and further patients were described where the inflammation appears to attack the nerve itself instead of the lining of the nerve, which is the usual case in inflammatory demyelinating peripheral neuropathies.

In addition to the presentations on the inflammatory neuropathies, there were also many interesting presentations on inflammatory myopathies and the inflammatory disorders affecting the neuromuscular junctions. Although these disorders are clinically distinct from the inflammatory neuropathies, breakthroughs in the understanding of these conditions often provide insight into the mechanisms involved in other inflammatory disorders.

In all, the conference was an enormous success and it provided an excellent opportunity to catch up with a number of interstate and overseas colleagues and visit one of the most charming parts of Australia.

**5th International Symposium
GBS Foundation
Held Dallas, Texas USA 13-15/11/98**

An interim report from attendee JACK HOUSTON, Knoxville, Tennessee.

The symposium was generally a success. I, like many of the other participants, went thinking we would hear of a revolutionary cure for GBS/CIDP. This was not to be; however we did hear of new statistics and studies that were being conducted around the world. We heard conflicting advice on the feasibility of flu shots for those with GBS. I gleaned from the various presenters that this should be an individual's decision, based on age and past history. Neuro- logist Dr. Hahn, says that those with CIDP should not opt for a flu shot (too late for me as I've already had mine).

I was able to talk with many who had horrifying stories about the onset and subsequent problems with GBS. I consider myself lucky to just have a mediocre case of CIDP. I'm sure Ray Chidester, Pam Wrobel and Andy Leitch from Ireland will post their ideas on the symposium at a later date.

\$3,000 Donated to Research

A further **\$3,000** was given to the Royal Children's Hospital Research Foundation to aid Dr **ANDREW KORNBERG**'s research into GBS and CIDP.

In accepting the donation, Dr Kornberg expressed his gratitude to the continuing generous support being provided by The Inflammatory Neuropathy Support Group of Victoria Inc. to his research. This brings the total of our contribution to date to **\$12,050**.

Membership still growing

Our membership is now **279** which includes **20** interstate (**4** NSW, **10** Qld, **2** SA, **4** Tas, **1** WA) and **48** overseas (**33** USA, **5** NZ, **3** Canada, **2** Italy, **1** Austria, **1** UK, **1** Slovakia, **1** Philippines, **1** Japan).

Questionnaire

78 members have returned the Questionnaire which is a big help in matching support to the patient.

For those members who have not received the Questionnaire and would like to support or receive support please contact **JAMES GERRAND** tel 9853 6443.

Help in making Video

Those members who attended the Winter Luncheon at the Margaret Lawrence's home saw the video produced for the Neurological Resource Centre of South Australia "**CHALLENGES & CHOICES - Exploring the non-physical issues of GBS & CIDP**" and were much impressed by this presentation of how patients responded to their disorder.

Your Committee is considering making a video that would help inform the public about GBS and CIDP, perhaps by interviews of a selected neurologist, general practitioner, nurse, physiotherapist, occupational therapist plus patients.

Members who would be interested in helping this project, particularly anyone with some experience of producing videos, are asked to contact our Secretary **MELVA BEHR** tel **97408983**.

Workshop - Involving consumers in improving hospital services

The Health Issues Centre advised that the Victorian Department of Human Services in collaboration with the Commonwealth Department of Health and Family Services is running a series of workshops to promote the research done by Mary Draper on the above subject. The Department sought 3-5 rural consumers to participate in a workshop to be held at Bendigo on Thursday 3rd December.

Our North-Eastern Representative, **VILMA CLARKE** of Wangaratta, has kindly agreed to participate.

Most Successful Summer Luncheon

Not only was our Summer Social Luncheon, held Sunday 15th November at the Balwyn Library Meeting Room, the most financially successful yet but the forty one members, family and friends, who attended voted it the most fun.

\$1017.90 was the magnificent proceeds. Of this total **BARBARA BURZAK-STEFANONOWSKI** collected **\$409.90** by her marvellous and amusing Dutch auctioneering of mysterious gifts from those present. The profit from the delectable luncheon of cold roast and smoked chicken with many salads, chocolate rolls and fruit salad, fruit punch and wine was \$323. Thanks **MARGARET LAWRENCE, BETTY GERRAND, MELVA BEHR, DOROTHY BRENNAN** and **ROSEMARY MACQUALTER** for the choice menu and its preparation. The raffle of the Christmas Hamper, made up again from gifts, raised **\$110** and some generous members donated a further **\$115**.

The Luncheon could have been a "schmozzle" as, due to a mixup with the Library, we didn't get access to the Meeting Room until some fifteen minutes after the luncheon was scheduled to start. But such was the competence and ready commitment of our committee and fellow members, that tables were laid and the spread assembled in record time.

Here are two tributes:

Dear Mr & Mrs Gerrand,

Just a quick note to say thank you for your kind invitation to the luncheon at Balwyn Library, giving me a wonderful opportunity to meet some of the Committee and people with GBS and CIDP and their friends and family. I sincerely look forward to the next IN Group function.

Regards,

SUSAN PERKINS.

and

Dear James,

Enclosed is a supplementary donation for our IN Group worthy cause. Please use whatever is needed to "top up" the 15 Nov function proceeds to a rounded result of \$1,000.

Congratulations on the success of Sunday's luncheon and Barbara's fun auction.

Please thank the Committee ladies for the wonderful job they did. It was a very happy day.

Season's greetings,

KEITH CALWELL.

Submitting with Hope for more Intragam

26/11/98

Professor Ron Penny
Chairman, AHMAC Blood & Blood Products Sub-Committee Working Party
C/- NSW Health Department
73 Miller Street
NORTH SYDNEY NSW 2060

Dear Professor Penny,

National Review of the Use and Supply of Intravenous Immunoglobulins

Thank you for your invitation to make a submission to the Working Party.

The IN Group offers support both to patients suffering from GBS and CIDP and to their families and friends.

The IN Group understands both from the medical literature and the experiences of our 250 plus Group members that gammaglobulin is an almost essential treatment for both the acute Guillain-Barre Syndrome (GBS) and the Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) disorders.

It is understood that for GBS patients the intravenous gammaglobulin treatment is the treatment most likely to succeed (sometimes with plasmapheresis), if carried out at the early stages of the disorder. It is a simpler and less disturbing treatment for the patient than plasmapheresis and is less likely to incur adverse side effects.

For most CIDP patients, intravenous gammaglobulin treatment is necessary both for the Progressive and the Recurrent versions. As to date there has not been any treatment that cures CIDP. Intravenous gammaglobulin is needed for many CIDP patients indefinitely. I was diagnosed with Progressive CIDP seven years ago and have been on a fortnightly gammaglobulin drip (30gm) for the past five years. Due to this continuing treatment the CIDP has not progressed beyond giving me "foot-drop" - I can't move my feet up and down but with this treatment my condition is slowly improving. A number of our members report the almost magical restoration of the use of muscles when they receive the gammaglobulin treatment. It can restore mobility and independence and so avoid the need for carer assistance.

We understand from the Red Cross Blood Service that there is an increasing use of gammaglobulin for more disorders, Victoria reporting an increase last year of 17%. This clearly indicates a need for more government funding, both Federal and State, to publicise the need for more donors of blood plasma.

Also more plasma donors would be forthcoming if more public hospitals were requested by State Departments of Health to arrange for the collection of blood plasma.

The need for more blood donors has been personally demonstrated to me today as there was no gammaglobulin available for my appointed fortnightly treatment.

The IN Group strongly implores the Working Group to find ways and means to ensure that there are adequate supplies of gammaglobulin for the foreseeable future

Yours sincerely,

James Gerrand,
Director.
The Inflammatory Neuropathy Support Group of Victoria Inc.

It is understood the Council of GBS/CIDP Support Groups of Australia, the GBS Association of NSW, the Neurological Resource Centre of South Australia and the Tasmanian GBS and CIDP Support Group are all making similar submissions.

"The time frame for the review is six months and the review is the direct outcome of concerns expressed by clinicians and community groups that the amount of IVIG produced in Australia is insufficient for its current uses." (from Prof Penny's letter.

Surmounting all difficulties

Reprinted from "The Standard" Warrnambool 15/10/98

I visited Barry Steel a couple of times when he was in Intensive Care at the Royal Melbourne Hospital and I found it incredible - both Barry's determination to get back on his feet from his paralysed situation and Linda's capability, pregnant with twins and two young boys, to continue managing a family and a dairy farm.

Our Western Representative, GREG GILLESPIE, of Peterborough, has paid Barry a number of visits whilst Barry has been slowly recovering in the Warrnambool Hospital and been equally impressed.

Suggested Logos

< IMAGES NOT AVAILABLE YET >

The above five logos have been submitted to represent The IN Group.

If you consider one of them would be suitable please fill in its number on the tear away slip on the newsletter wrapper and post or fax.

Thanks.

Support is the Name of our Game

Good work from Wodonga

Dear James,

On Thursday 3/9/98 my daughter Jenny accompanied me to Mt Beauty to give a talk to staff at the Mt Beauty Hospital. The talk was on behalf of The IN Group and I covered both GBS and CIDP.

There were six nurses in attendance which I now realise is good. I did have to prompt four staff members from a staff meeting. As there were about twenty-five people at the staff meeting I was hoping to entice more to my talk but it was not to be.

I gave a quick run-down on my story, then covered GBS and CIDP and finished by telling everyone about our wonderful Support Group. We finished up with question time with a few questions being asked. Everyone said it was most informative.

On the way to the meeting my daughter and I called in to see Ray and Janet Pearson. Ray had GBS and had been out of hospital for one week and was doing very well. After talking to Ray I realised once again how early diagnosis is so important. So by putting these illnesses out there for all to see we are heading in the right direction.

Ray and Janet seemed more than pleased at the help they had received from The IN Group so many thanks James and crew.

JILL GRIMMOND,

Wodonga.

How the Questionnaire Helps

email 5/11/98

Dear James,

*You will remember **BROOKE** (daughter) and your visits to her in hospital (GBS, St Vincent's). She is still having lots of treatment including Imuran and monthly infusions of Intragam. She had to be taken off the Cyclosporin after contracting several infections which could not be traced but were always present in the blood and her position was considered too risky to continue.*

Thankfully she is now better than she has been for about four years although by the time the infusion comes around she does begin to weaken.

Now that she is physically able to do more than she has for those four years, she is very frustrated that she is unable to do so due to her lack of confidence and the fact that she does not drive.

These things, coupled with the fact

that she and husband Steve only moved to Melbourne during her illness and know very few people, means she spends many long days alone in a small flat.

Is it possible that someone, perhaps about Brooke's age (25) could visit, maybe on a fairly regular basis. This may be asking too much but I feel so helpless being so far away ...

Many thanks,

JAN LITCHFIELD,

Ballarat.

I contacted **GINA MERNONE** as a match with the result by email 6/11/98;

Dear James,

*Thank you so much for your prompt and positive response to my problem! Brooke phoned last night and was thrilled that **GINA** had already made contact and arranged a visit for Monday. She is looking at long-term solutions to her problem such as applying to do voluntary work with some welfare and care groups but volunteering is only the beginning - there is so much red tape and, of course, she can only work for short periods of time and work is not always available to pick and choose from. Hopefully things will work out. ...*

*She has been put in touch with a young girl in Perth through Eileen Evers and the UK support group. This 17 year old has experienced an almost identical course of the disease to **BROOKE** over the last eighteen months or so and they communicate frequently.*

Once again many thanks ...

JAN LITCHFIELD

Latest support by PAULINE

Dear James.

... Kathie and Andy Van Der Zypp, ... Langwarrin, ... would be interested in joining the Group to keep in touch through the newsletters but would not be able to come to the meetings as they live so far away.

I have kept in touch by phone. Kathie is now at home and is walking with a stick but like us all she tires very quickly.

PAULINE WHITELAW

Wonderful support from the young

Dear Mr Gerrand,

*My name is **MELISA** and I am writing this letter for my mum **SUSAN**. I am 11 years old and I have a sister who is 5 years old, her name is **MONICA**.*

The doctors have told my mum that she has GBS. My mum has spent a lot of time in hospital. My mum is now home and only goes to the Royal Talbot as an outpatient. My mum has asked me to tell you she often feels alone and would like to receive further information and support from The IN

Group and if any way she can help to please let her know.

My mum has enclosed a cheque for

\$50, \$20 of the cheque are money that me and my sister saved up and would like to donate to The IN Group, the rest is from mum.

She hopes to write the next letter as at the moment her grip and strength in her hands is not good enough.

Best wishes to you all.

MELISA PERKINS

Betty and I paid an enjoyable visit to "mum" **SUSAN** at her Bundoora home. Unfortunately we missed meeting her generous daughters who were visiting their father. **SUSAN** so enjoyed the Summer Luncheon that she wrote about the "wonderful opportunity" (see p.2).

Internet's World-Wide Help

Here are a few examples of the help The IN Group is able to provide through being on the Internet. Thank you **CSL** for your continuing generous support that pays the Internet costs. It provides the facility to communicate almost instantly with anyone anywhere.

A thank you from Canada

To: James Gerrand 22/09/98

Dave is 57 and was diagnosed in Dec 97 by Dr Judith Toutar of St Catherines. He has had IVIG treatments in Jan & Mar, 4 days each treatment. He was referred to Dr Angelica HAHN at the University of

Western Hospital in London Ontario where on June through July a Plasmapheresis was done(I believe this means a complete blood change). He is presently on APO prednisone 50mg/day. He has numbness in both legs, finger tips to wrists. He has shown a considerable muscle loss in the affected areas and a loss of balance which forces him to walk with the aid of a cane. Dave had worked as an automotive body repairman and was therefore in constant proximity to paints and solvents for many years. This is as much as I can tell you at this time. If you wish to call him collect I am sure he would love to hear from you. His number in Canada is 905-934 8806. Regards

*Edward Findlater
edfind@niagara.com*

Following contact via phone with **DAVID REEVES** of St Catherines, Ontario, Canada I airmailed IN Group material to him. His wife **ROSE** sent me this letter.

Hi Mr Gerrand,

Thank you so much for sending me the little book on CIDP. Both my husband and I were very

grateful to receive it. It was very helpful to me, being the spouse of a person with this disease. It's made it easier for me to understand why some treatments work for one patient and yet the same treatment does not work for another.

DAVE (my husband) spoke to you on the phone in late September of this year. You are the first person who has been able to relate to his problem personally. It really has lifted his spirits. I thank you for that.

We would like to join The IN Group and have enclosed \$50 for membership. the fee for the little book and would like to order 1 packet of Xmas Cards. Whatever is left over is a donation to The IN Group.

The IVIG and plasma exchange didn't seem to help DAVE very much. He is now on Predisolone (50gm per day). The dose isn't as high as his doctor would like but she was concerned about his blood pressure; it's rather high. So far he seems to be doing OK. He's gaining weight but he looks better because he was so thin and frail before. We're handling it one day at a time. It makes it easier for everyone like that.

Thanks again for caring and sharing. It's good to know you are not alone. Stay well!!

ROSE REEVES,

St. Catherines, Ontario, Canada.

Stan from California USA

Dear James,

Thank you for your quick reply.

I am 67 years old and up to now quite healthy and physically fit - last winter took two trips of intense skiing, was active hiking and running.

Last June I started experiencing numbness in my legs and toes. My doctor diagnosed it as a TIA episode. But the numbness continued to get worse and it was 2-1/2 weeks before I finally saw a neurologist. He diagnosed it as GBS and started plasmapheresis (7 of them) during which I was hospitalised. The treatments did not help but ... my condition did not deteriorate too much. ... My neurologist ... prescribed Predisone (late July) - 3 large IV infusions plus gradually decreasing pill doses over 3 weeks. This produced marked improvement ...

Late in August my leg numbness started getting worse again. ... I saw another neurologist ... He recommended 5 IVIGs ... late September. They had no effect. He then recommended going back to Prednisone. ... in the last few days ... I think the treatment is beginning to work. ...

I look forward to joining The IN Group.

STAN HANUSIAK

Lafayette, CA

STAN joined with a US\$50 cheque contributing some AUS\$78.64 to the cause. (Our other sponsor ANZ Bank kindly converts our foreign cheques without charge.)

Marie-Odile from France

James,

Thank you for your help and kindness.

My sister is 45 and her case is old (1990 first manifestation of the syndrome) after a paralysis while GBS appear (as far as the waist) she has recovered her mobility after one month. Only after-effects are remaining: at legs, hypertrophy of the muscles and painful sensations; and especially headaches very strong, and very often for six months to one year.

Our family dread for her a relapse of the disease. I wonder if the two treatment which are known (parapheresis and immunoglobuline) are efficient at this stage of the disease. As far as my know is concern, the treatment of my sister consist only in powerful analgesiques.

Thank's again for your concern.

MARIE-ODILE LORET

Toulouse, France

My reply

Dear Marie-Odile,

With GBS, the acute form of the disorder, recurrence is rather rare (5%?) whereas with the chronic form CIDP (which I have got) it is either Progressive or Recurrent it seems. My Progressive form has been

kept under control particularly with Immunoglobulin such that It has only given me "footdrop" - I can't move my feet up and down but this is slowly improving.

Does your sister have a good neurologist. I am only a lay person but my understanding is that a lumbar puncture to determine whether there is an increase in the protein level of the spinal fluid would be an indicator of any recurrence.

Plamapheresis is often given as a first treatment to reduce the protein level in the spinal fluid.

Have you managed to make contact with any of the possible 3 contacts (UK &USA Groups) I listed? And if so has any past or present French sufferer been suggested?

If it would help I could airmail you if you send me your address a GBS booklet published by the GBS Foundation International which The IN Group has reprinted, plus our brochure and latest newsletter "INformation".

Regards,

JAMES

Further medical definitions

As supplied by **JACQUELINE TRAPP** of the GBS/CIDP Internet "Chat Club".

Dilate...*To live long.*

Enema...*Not a friend.*

Fester...*Quicker than someone else.*

Fibula...*A small lie.*

Genital...*Non-Jewish person.*

Hangnail...*What you hang your coat on.*

Impotent...*tinguished, well known.*

Labour pain...*Getting hurt at work.*

Medical Staff...*A doctor's cane.*

Morbid...*A higher offer than I bid.*

Nitrates...*Cheaper than day rates.*

Node...*I knew it.*

Outpatient...*A person who has fainted.*

Pap Smear...*A fatherhood test.*

Pelvis...*Second cousin to Elvis.*

Post Operative...*A letter carrier.*

Recovery Room...*Place to do upholstery*

Rectum...*Damn near killed him.*

Secretion...*iding something*

Seizure...*Roman Emperor*

Last Updated: 15 Oct 2007 17:49