

THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC.

Supporting sufferers from acute Guillain-Barre Syndrome (GBS) and
Chronic Inflammatory Demyelinating Polyneuropathy (CDDP).

MAIN ITEMS

In this first issue of our Newsletter we publish three main items:

1. A report on the first Get-Together of The IN Group,
2. The inauguration of a system of designated IN Supporters who will visit sufferers from the IN disorders, GBS and CIDP,
3. A letter from Patron Associate Professor John Pollard, reporting on the latest research developments, based on his recent work in Germany.

Successful First Meeting

Some 25 members from near and far attended a GET-TOGETHER at 4 Alandale Avenue, Balwyn, the home of our Deputy Director RAY DAHLITZ. VILPTA CLARKE and husband KEN came from Wangaratta and JILL GRIWIOND travelled from Uodonga with her daughter and partner.

Highlight of the evening was the address on the two IN disorders of our concern - GBS and CIDP - followed by an extensive question and answer session by our consultant neurologist Dr BRUCE DAY.

Amongst the questions asked and answered was why these disorders usually started at the extremities, the feet and the hands. Dr DAY explained how the nervous system like other parts of our body is under constant repair and maintenance and the end of the lines are where such maintenance is likely to be affected first.

The evening concluded with more discussion over supper together with a warm vote of thanks to Dr BRUCE DAY for his informative talk and to RAY DAHLITZ for so kindly making available his home for the meeting. It should also be mentioned that RAY thoughtfully installed hand rails on his front and rear steps before the meeting.

(I reprint a nice letter of appreciation of the evening from VILMA CLARKE over page.)

One member, GREG GILLESPIE of Peterborough, wrote apologising for not being able to make the evening and paid great tribute to his wife and a particular nurse at the Royal Melbourne Hospital for his recovery. (A copy of GREG's letter is printed over page.)

The next meeting of The IN Group is planned for early February.

Designated IN Supporters

GREG GILLESPIE of Peterborough has started the system of Designated IN Supporters by volunteering to be the IN Supporter for the Western District. He will be available to visit any sufferer from GBS or CIDP in this area to provide support from his personal experience and understanding of these rare disorders.

VILMA CLARKE from Wangaratta has similarly volunteered to be the IN Supporter for Wangaratta and district.

I have been doing some visiting in the meantime. I had a call recently from a mother of a 15 year old lad who was in the Essendon & District Memorial Hospital suffering from GBS. She also reported there was a man in the next bed with GBS. I went to the hospital and met 26 year old JOHN WARD and his wife. JOHN was making a good recovery such that he was due to leave in a few days and he joined up on the spot.

A few days later I had a call from JOHN, now back in Beechworth, wanting some advice as he felt he was having a relapse. I advised him to see a neurologist as soon as possible. The upshot was he was put into Wangaratta Hospital under observation then flown the next day to the Royal Melbourne Hospital where he was given treatment such that he was able to return home in two days. JOHN was advised that if there had been a delay of 15 hours then his case would have been quite serious.

I would welcome all other members who think they could be of help as Designated IN Supporters to contact me:
JAMES GERRAND, 13SB Princess St KEW 3101
tel 853 6443

NEWS of members

MARGOT BROWNING kindly supplied me with a report she had written about her experience with GBS that had been published in the SA GBS Support Group newsletter (June '91). MARGOT contracted GBS in April '84. Within 24 hours she was admitted to Fairfield Hospital and remained there for the next 10 months on a respirator in Intensive Care, totally paralysed for most of the time and only able to communicate by opening and closing her eyes. Her husband GEORGE stayed with her every day during her stay at Fairfield. Today her mouth and fingers are still partially paralysed and her legs have no movement below the knees. She can walk on crutches, uses a wheelchair in their home and a battery operated scooter for moving around their retirement village and shopping complexes. Marget is full of praise for the wonderful staff at Fairfield. (GEORGE and I were colleagues in the Civil Aviation Department but I only knew of MARGOT's GBS disorder after I contracted CIDP.)

DYRANDA PREVOST was amongst those who joined The IN Group following the note in "The AGE". DYRANDA had a form of GBS in 1988 and then had a recurrence this year. Amongst her many talents DYRANDA is a professional photographer and pianist. Her disorder has left her with difficulties in walking but she still manages to drive her car with modifications to the control elements. DYRANDA helpfully supplied me with extracts from a recent book "Guillain-Barre Syndrome" by Ropper, Wijdicks and Truax, 1991, F A Davis Company USA.

Mrs LUCIE SHAKESPEARE is a sprightly 85 even though her GBS has left her with some walking difficulty. LUCIE kindly lent me her copies of THE SA GBS Support Group newsletters when I visited her at her Freemason's Hostel in Punt Road Prahran.

UPDATE on The IN Group

Our membership is now 46 including 20 past and present sufferers.

I am hopeful that The IN Group will be shortly accepted by the Australian Taxation Office as a benevolent Institution, thus allowing for tax deductible donations. The Office had mislaid my application for some 3 months.

In furtherance of our research project, Dr ALLEN CHRISTOPHERS and I visited Dr BRIAN SPEED of the Fairfield Hospital, following which the officer in charge of their statistics section promised ALLEN as a start their computer data on their IN patients over the past five years. Dr SPEED also sent me a copy of a report "Review of GBS Treated at Fairfield Hospital", by Dr H Newton-John, 1991.

Finally and most importantly we have received a great letter from Dr John Pollard which is published over page.

LETTERS

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the University of Sydney
Department of Medicine

SYDNEY, N.S.W. 2006
AUSTRALIA

9 December 1992

Mr James Gerrand Director The IN Group 138 Princess Street Kew VIC 3101

Dear Mr Gerrand,

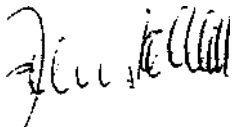
Many thanks for your letters concerning the IN Group and I would like to offer my congratulations on the superb job you have done of establishing the group and planning an exciting program for the future. I regret that I have not been able to write to you in the sufficient time for your first meeting as I have had an enormous amount of work to catch up on since returning to Australia. I am very pleased to hear that already you have started to gather material for the research project to determine the incidence and prevalence of inflammatory neuropathy in Victoria. This is a particularly important project as there are no figures from any world centre for the chronic inflammatory neuropathies.

We did have a most fruitful and enjoyable time in Germany. We worked in a small town called Wuerzburg, which is roughly in the middle of Germany, about an hours drive from Frankfurt. Wuerzburg is a university town, and the unit at which we worked is very famous. The director is Professor Klaus Toyka, and the unit he directs has a research budget of about five million dollars. Such a budget of course is many times greater than any comparable unit in Australia, consequently it is possible to do many more experiments there than it is possible to do back home. Moreover, the hospital in a small town has 100 neurology beds, whereas the largest hospital in the major cities in Australia would rarely have more than 25 - 30 beds. The Wuerzburg group focus their interest on the inflammatory demyelinating neuropathies and they produce a great deal of very high quality work. In my time in Wuerzburg, I conducted experiments on the blood-nerve barrier, examining the factors which allow antibodies and cells to pass from the vascular system into peripheral nerves. I also conducted experiments which examined the capacity for various antibodies to damage the myelin sheath. In particular, we used antibodies to various gangliosides and glycolipids, in addition to antibodies to well known glycoprotein antigens. There is increasing interest in the possible role of antibodies to gangliosides, not only in the inflammatory demyelinating neuropathies, but in various forms of lower motor neuron syndromes, and the Wuerzburg group have a wonderful reservoir of high titre antibodies with which to perform experiments. Experiments in our own laboratory and in the German laboratory have demonstrated that if small amounts of circulating antibody are present, that various vaso active amines and cytokines produced by T cells will allow these antibodies access to the nerve compartment where they may cause demyelination.

Hence, we believe that an important aspect of treatment of the inflammatory neuropathies will be to examine substances that will allow the healing of defects within the blood-nerve barrier, and thus prevent movement of these harmful substances to nerve. Whilst in Germany I visited other centres in Germany and in Italy, London and Scandinavia, and was pleased to find that throughout Europe there is a great deal of research being conducted into inflammatory demyelinating neuropathy. From all this research, we can expect exciting and important results to issue. Various groups, particularly the Dutch workers, have demonstrated that high dose immunoglobulin therapy is effective for Guillain-Barre Syndrome and for many patients with chronic inflammatory demyelinating neuropathy, and although we have been using this treatment in Australia, it is extremely difficult to get sufficient immunoglobulin to treat the large number of patients who need it. I think it will be important therefore, to lobby our politicians who control the public purse to let them know how effective this agent is so that more money may be provided for CSL to produce more of the agent for use in patients with inflammatory demyelinating neuropathy, and to provide the agent so that we can conduct controlled trials of its use.

There is no question that the research work in Australia into these disorders is of a high international standing, but we are hampered by limited funds to do this important work. There is no question that more wealthy countries, such as Germany, are able to produce a much greater research output than we can manage. It is therefore very important for members of the IN Group to take every opportunity to educate the rest of the community about IDN, for only when the community is aware of the condition will they provide funds for research. It is encouraging that there are treatments available for inflammatory neuropathy, but better treatments are needed, and they are produced only as the result of well directed research work. I believe that the formation of the IN Group is a very important step towards achieving greater awareness of inflammatory neuropathy by the community and a better understanding of the pathogenesis of the condition. I wish you well and warmly encourage you in your efforts.

With kind regards,



John Pollard

HFLP NEEDED

A number of members have already offered to help in the activities of The In Group.

One activity already mentioned above is nominating to be a Designated IN Supporter.

Other activities are contributing to this INformation Newsletter. It is your Newsletter.

This can include writing articles, letters, poems, or otherwise sending items including cartoons that you think will interest members and readers.

Then there is the more mundane but necessary work of helping with the preparation, publishing and mailing of the Newsletter.

An important area is suggesting ways we can better achieve our aims.

What I propose is that all members who would like to be actively involved contact me. I will then suggest that those who are able, come to a meeting at my residence in KE'o) some time early in January to work out what we can all do.