Issue No- **June**

INFORMATION

NEWSLETTER OF THE IN GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC. Supporting sufferers from acute Guillain-Barre Syndrome (GBS) and Chronic Inflammatory Demyelinatuig Polyneuropathy (CEDP).

Recent Research into Inflammatory Neuropathies

From the address by Dr ANDREW KORNBERG, Neurologist, Royal Children's Hospital, to the May meeting of The IN Group, held 9/5/95 at 4 Alandale Avenue, Balwyn. JHG

It is very important that there are groups like The IN Group for rare conditions. As much as we doctors try to be as good as we can be and reassure patients, there is no one better than some one telling a patient "Well, I've had this and look at me. I've recovered (or I am recovering)."

I'll tell you a little about what research and other activities are happening in the inflammatory neuropathies (IN). Most IN patients have GBS or CIDP but there are many other neuropathies that are even rarer but which as a neurologist I see. What they all have in common is an auto-immune basis which in a way means for some reason a person's own body is fighting, damaging their own nerves. As a result you have problems such as weakness or tingling or numbness or breathing difficulties, etc. As time goes on this IN group may become larger and there may be other sorts of neuropathies which we may see.

Basically research into inflammatory neuropathies revolves around three areas. The first is the most important: without the answer to it - some evidence to help you to understand what causes the disease - then the other two, better tests and better treatment won't happen.

Over the last ten to fifteen years we are beginning to understand a little more about why these things happen. By understanding more we have started to develop better diagnostic tests. Most importantly the patient is given a specific treatment. As it turns out the treatments we have available do work for many patients although some have side effects. There may be better treatments found as we gain more knowledge.

The first area is one I have been involved with over a number of years in the USA and most recently I have started up a laboratory at the Children's Hospital looking into it. But some may ask "What is a child neurologist doing looking at patients who are mostly adults?" Weil as it turns out, much of my work in the United States, besides being a child neurologist, I was a neuro-muscular specialist, so I was predominantly seeing adult patients, and that fact continues to this time.

Now every IN patient obviously had a problem and that's why they went to the doctor. Some of the problems were very acute, happened very quickly; others happened very slowly - slowly progressive, slowly getting worse, or getting better.

Your doctor would have based the diagnosis on three things. Firstly, is there a clinical pattern? Doctors try to think of patterns, because many different things present to a doctor - weakness, its distribution in arms or legs, feeling, movement.

Then there are tests. If you have a neuropathy does it involve the myelin -the outer lining of the nerve or the nerve itself?

The most recent factor that I have been involved in is to measure the antibodies in the blood which we believe may have some importance in what has caused this disease. With GBS and CIDP the antibodies are high and so gives a clue.

Now the question is, why do these antibodies occur? What importance do they have in causing the disease? making it worse?

I mentioned GBS and CIDP as the most common of the inflammatory neuropathies. Another occasionally met is multifocal motor neuropathy (MMN). The important thing about it that it is treatable but may look like motor neurone disease (MND). So by using tests and other approaches such as types of antibodies we may differentiate.

One treatment is to dampen down the immune system with medicines like predisolone. But these can have unwelcome side effects. This is presently rather a "shot-gun" approach - they sometimes hit the mark but we don't know why.

Another approach is plasma exchange which involves taking antibodies out of the blood. This is often wonderfully effective for both GBS and CIDP and has been brought into use as we begin to learn a little about the disease. It is used in the moderate and severe forms of the disease - when a patient is on a ventilator or going that way or can't walk. But most patients with GBS - the mild cases - don't have plasma exchange. Many persons with GBS don't see a doctor - they feel a little weakness then get better. About 25% of IN patients admitted to hospital would receive plasma exchange.

Most recently intravenous immuno-globulin (IVIG) has been found to be beneficial to GBS and CIDP but not everybody responds. It does work for many but we don't know why. It is particularly helpful in that it can be used for those who may not be able to tolerate plasma exchange and also it is a simpler process. A problem is the gammaglobulin is very expensive and also for CIDP the effect may wear off.

New research from Europe has shown that certain antibodies are causing the IN disorder. There is still a lot of work to be done including finding out why only 50% of GBS patients who receive plasma exchange benefit therefrom.

The research that I am involved with is measuring antibodies. What has been found is that certain antibodies appear more frequently in patients with GBS and different antibodies with different frequencies in patients with CIDP and other antibodies are seen in patients with such neuropaths as MMN.

What this means is that firstly we may be able through a blood test to identify particular inflammatory neuropathies. Secondly we may through a blood test be able to follow the response to treatment. Thirdly the antibodies may be able to tell us what is actually happening, how the nerves are being affected.

I am asked how does the IVIG treatment work? Well the theory is that we are giving gammaglobulin, not from one person, but from many and somehow by giving a patient a burst of different sorts of antibodies from a variety of sources this may block the action of the bad antibodies causing the myelin damage.

As regards the effect of stress in causing disorders always remember what the person I trained with told me. He had a GBS patient who spent 9 months on his back and on a respirator. He visited this patient each day to tell him he was improving. When the patient had recovered after this time he told the doctor how important it was to his recovery hearing these regular words of encouragement. Groups like your IN Group play a very important part in such recovery.

GBS tends to be a self-limiting illness and therefore there is likely to be a trigger to set it off. We use the term molecular mimicry which means there is something similar between the virus trigger and nerve component being affected. With CIDP there is not the same trigger effect.

Research with children diagnosed with GBS has three advantages. The first is they tend to less severely affected. Secondly they tend not to be affected by other disorders of a long-term nature. Thirdly the recovery tends to be quicker.

We should consider GBS and CIDP as two separate conditions. With recurrent CIDP for some reason the nerves stop conducting. There is probably a process going on all the time. With treatment the nerves recover and then the process returns. Some people may have a slow progression until they are treated.

DIRECTOR' REPORT Year 1994/5

The IN Group has continued to justify its existence, particularly through the personal support given to GBS and CIDP sufferers and their families and friends. Particular thanks to those who have visited sufferers in hospital which include Stuart Vincent (Taral-gon), Bryan Luscombe (Mt Waverley), George Wilby (East Hawthorn), Chris Hagarty (Glen Waverley), June Cathcart (Stawell), Graham Wright (Abbotsford), Tricia Folvig (Frankston), Pauline Whit-elaw (Brighton).

VILMA CLARKE not only greatly helps as Secretary but also arranges 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, family and friends. Membership

Over the year membership has increased from 120 to 144 which includes 100 past and present IN sufferers. Quarterly Meetings.

These meetings have continued to be popular. Quality speakers for the Tuesday evening meetings - CINDY SHAW, Social Worker Dept Social Security on "How the Disabled can be Socially Helped"; AMANDA CRANE, Podiatrist on "Care of the Feet"; Dr ANDREW KORN-BERG, Neurologist Royal Children's Hospital on "Recent Research into Inflammatory Neuropathies" - were very helpful, both through their addresses and also subsequent questions and discussion. The Sunday daytime meeting 13/11/94 was a happy get-together over shared food and drink, particularly for those who find travelling at night difficult. Newsletter "INformation"

This quarterly is a vital means of communication to and between members. The Newsletter is yours so make the most of it. Thank you, Dorothy Bren-nan, Betty Gerrand and Fred Hooton for help with the mailing. Purchase of Tape Recorder and Transcriber

Thanks to the generous donations from many members The IN Group has now a small audio tape recorder (Digit-or) and transcriber (Sony) for recording and subsequent transcribing the addresses at our quarterly meetings. Patient/Support Group Linkage

The proposal to use a hospital's computer system to advise a patient when diagnosed as to what support group may be available is on the verge of being introduced by the Alfred Group of Hospitals, notwithstanding the difficulty of starting something new during the present period of major review of Victorian hospitals.

Once a goer at the Alfred we shall be proposing its adoption at all other Victorian public hospitals. Epidemiology Study

The results of the Study will be considered at this August meeting of The IN Group, with introduction by Dr MALCOLM SIMS, epidemiologist, and discussion led by Dr BRUCE DAY, Consultant Neurologist to The IN Group. Bingo Bear Raffle

Thanks to the generosity of member TED BASARKE who donated the $100 prize Bingo Bear plus that of raffle ticket buyers, the raffle raised $519 for The IN Group.

When the winner, member MARJORIE AUSTIN (Hobart) generously returned the prize, it was given to the newly formed GBS Support Group of Tasmania where it raised some $300. The winner of this raffle, member DAVID ASHTON (Surrey Hills), also kindly returned the prize so it now awaits its use in a third raffle at an appropriate time. IN Group Poster

An eye-catching A# size colour poster to publicise the existence of The IN Group was commissioned of a professional artist. The artist's background as a nurse helped her realistic depiction of half a dozen experiences that may befall GBS and CIDP sufferers -intensive care, wheel chair, hydro-ther-apy, electrical testing, Intragam treatment and an IN Group meeting.

The laminated posters have been well received by the medical and nursing staff at the Alfred, St Vincent's and Fairfield Hospitals. It is now proposed to distribute through our Contact members to the other Victorian public hospitals. Liaison with CSL

A helpful liaison has been effected with CSL. As a user of their Intragam product, I was invited by Mr Jack Wood, General Manager Bioplasma, CSL, to address their staff.

My talk not only raised $49 from the staff but Mr Wood advised that CSL would be prepared to consider funding any project that The IN Group may propose of benefit to the community.

Mr Wood also suggested that The IN Group should consider setting up, in conjunction with allied state groups, a national body based in Canberra to lobby the Federal Government on such matters as Intra-gam supply. Great publicity by John Stanley

As featured in this issue of "INformation", (see pages 6,7), member JOHN STANLEY (Devonport) arranged with the help of member GRAHAM WRIGHT a two page spread "Kicking goals for health" in the "NEW IDEA" of 10/6/95. Well over a million readers of this magazine will have read this article and thus become aware of G
and the availability of a suppor
Thanks

Particular thanks are due t
tary, VILMA CLARKE (Wangar
her enthusiastic efforts; to T
NORM BLYTH (Coburg) for hi
plaining devotion to keeping
incomes and expenditures; to
FRED HOOTON (Templestowe)
watchful eye; and Deputy Direc
DAHLITZ for continuing to pr
delightful residence for our
meetings.

JAMES GERRAND

TREASURER'S PROVISIONAL REPORT for Year ending 30/6/95 (30/6/

INCOME and EXPENDITURE

INCOME: Membership fees for 1994-95
Membership fees for 1995-96
Donations
Proceeds of raffle Proceeds of luncheon 13/11/94 Sale of publications Bank interest (estimate for 1994-95)

Total income

$1185.00 (1190.00) 160.00
919.00 (787.00) 519.00 155
36.50 15.00 (22.50)
2989.50 (1999.50)

EXPENDITURE:
Postage
Stationery
Copying, word processing, facsimiles
Telephone
Incorporation charges
Purchase of transcriber and access.
Purchase of tape recorder, access, cartridges 87
Advertising - colour poster
Subscriptions: GBS Foundation Int, COSHG
Hospital visits &.-
Bank charges and miscellaneous

Total expenditure

$230.40 (374.0
58.00 (75.4
545.20 (349.9
35.00 (57.5
32.00 (29.0
231.95 (519.0
es 87.81 (550.4
200.00
62.25
6.00
7.94 (25.

$1496.55 ($1980.

$1492.95 ($18.
$2457.65 ($964.

Total income over expenditure Bank balance at 30/6/95 (30/6/94)

*(Fax-modem) ** (Epson printer)*

LETTERS

Dear James,

The story behind "NEW IDEA" Story

Firstly I would like to explain how the story came about and what my main goal and objective was.

Because of our small population in Tasmania our Group, thankfully, has little to do, with only 2-3 cases of GBS reported this year so far (none severe). So I envisaged a promotional exercise for the national effort.

I wrote to "NEW IDEA" with the story in early November '94 and received a response in late December. Yes, they would do a story on Graham Wright, myself and GBS. Major objects were to raise public awareness and to promote the very important existence of the Vic and NSW Groups. However I was informed that only one contact address and phone number could be published. A national story in a magazine like "NEW IDEA" has many advantages over newspapers. A circulation of 800,000 was quoted and the issue stays in circulation for many months.

I stayed in regular contact with Bill Ayres, the journalist who was to handle our story and who, I might add, is an avid Collingwood follower.

In late May I flew to Melbourne to have photos taken with Graham Wright at Victoria Park and we were both interviewed by Bill Ayres. A point to mention is that both Graham and I were both recovering from surgery and brief hospital stays.

Then it was only a short wait to June 5th for the story to be published. I'm sure you will agree that the wait was well worth the final result.

Response to the story was very encouraging - to date around 40, either phoning or writing to me. At present I am receiving on average one phone call a night at home and two letters daily.

The people contacting me had varied reasons - information on GBS, on their nearest support group, wanting to exchange information or just have a talk on their own experiences.

Letters and phone calls come from all over Australia with the majority from Queensland where unfortunately there is no support group.

Information was sent to everyone who asked. Both "The IN Group" and "NSW GBS" support booklets, phone numbers, addresses, were also sent to most, detailing regular newsletters and other varied and important functions of both groups. The SA Group's phone number with information was also sent.

I'm positive the "NEW IDEA" story has been a very successful vehicle to convey to people wanting information on GBS and CIDP, also raising much needed public awareness.

JOHN STANLEY
GBS Tasmanian Support Group

Dear James

Family man with GBS *I saw MICHAEL HERBERT on 21/4 at Mellor Ward, Royal Talbot Rehabilitation Centre. He was transferred from Fair field Hospital on 20/4. As advised in our telephone conversation prior to Easter I thought it better to see him at Talbot.*

Michael lives at Merimbula NSW and had been getting weaker for some time before being hospitalised. Fortunately when he did go to hospital the examining doctor had had previous experience with GBS and diagnosed it immediately. He was airlifted that day to Fair field. He was in Ward 1 for one week but as his condition continued to deteriorate he went to Intensive Care Unit where he was intubated and received plasma-phoresis treatment. He remained in ICU for five weeks - returned to Ward 1 and thence to Talbot.

He appears to have recovered full bodily movements and has no problems with speech and eating. However he is still very weak in all limbs but the prognosis appears good.

He was thankful for the support of The IN Group, having been seen by two members and yourself prior to my visit. I will see him again in approximately two weeks.

GEORGE WILBY East Hawthorn

Dear James,

Fighting GBS

I am writing to keep you posted about Joanne and her progress in the fight against GBS.

I have been keeping in touch with Joanne's mother, Jackie, and have been able to answer a lot of her questions thereby giving her and her family some support.

Recently Joanne was transferred from St Vincent's to Fair field and I had a call from her physiotherapist asking me to visit her. This was on 3/5 and she was on the respirator full time and feeling very depressed. She was not

(continued page 8)

Kicking goa fo r health

When champion Coilingwood footballer Graham Wright feit a virus coming on. he thought a few days rest at home in Tasmania would help him overcome the illness.

Little did he know that ihe pain and numbness he began to :eei were the first signs of a iittle-known. debilitating ilness that attacks the nervous system.

The next rew months became tougher than any on-rield conflict in the Australian Football League as Granam -ought a desperate battle against the disease that has the potential to Xiil.

He had to iearn ail over again how to walk and talk as he struggled against guiilain-barre syndrome, a disease that has had doctors battled for 300 years. n its most severe form it can iead to iong-term paralysis and even death.

'At that stage, playing football again was the iast thing on my mind. Graham. *26.* says. "\ had to iearn how to walk again. "The disease attacks the sheath surrounding the nerves messages as simple as moving in rront of the other don't get from the brain."

Graham, well known for his dasnes out of the Coilingwood is back on the fie;d and has the high-profile ceienrity drawi attention to :he Jisease tha about 240 Australians eacn yea

Determined to recover

Despite doctors predictions. from Devonport. was determ recover in time ror :he start of season, in that quest he 'oun in an equally determined Tasman-ian John Staniev. 3 Devonport.

'Now jonn is one guy who hard." Graham says. '\ was iuck to have a mild dose of the synd jonn was very, very ill for a <o

John, who estaoiishe Guillain-Sarre Syndrome Grouo in Tasmania, says the struck inim with lightning speed been to a business seminar n August. 1992. wnen ie exp muscie soreness.

"I didn't thinK Tiuch about *35.* says. "I got :iome on the and the pain 301 .vorse. I had needles in my nands and feet.

He saw a pnysiotrierapis

9 John Stanley had to iearn how to waik again after aeing struck by the paralysing guiilain-barre syndrome.

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on a ventilator. His heart and brain were the only organs functioning on their own. ~he rest of his body had shut down and an intravenous drip supplied morphine for the excruciating pain.

"! couldn't close my eyes or eat. .Vly weight dropped from *55* to 50kg," Jonn says. He even became addicted to the morphine, hardly surprising considering that in a two-month oenod *20* litres of the drug were pumped into his :ody!

'3y that first night in hospital : was very close to dying," he says.

John spent two months in the intensive care unit. He was in isolation for three months because, wnile he was so ill. he picked up a common hospital virus. He had 'our total blood exchanges in an effort to remove the bad protein that attacks the nerves.

Secause of the drugs he had to take, John also had blood toxicity, anemia, oneumonia. the racial paralysis beii's daisy, an altered mental state and coi-iapsed veins in the arms and legs.

During his renaoiiitation ne was con--ined to a /vneeicriair.

Knowing there is a supportive -amiiy and a group or rriends sticking by you heips with the -ecovery,' Jonn savs.

There 's a iot of confusion. Science has not come up with a reason as to .vny people contract the condition.'

Numbness in feet

Graham recalls he was in Tasmania wnen he first felt numbness in his feet, and he gradually got weaker.

"After four or *'ive days i started to get pretty worried," he says. "! rang one ot the ciub doctors and he suggested i see a specialist immediately."

The club flew Graham to Melbourne. He was admitted to hospital and a ium-bar puncture confirmed what doctors already feared.

'I was very scared," Granam says. "3y this time one side of my race had dropped and my speech was badly affected, i Jidn t want anyone to see me iike this.'

After several weens in nosoitai in

Coilinewood speedster Graham Wright needea ail his API toughness tc battle <3 :he agony OT a fiwsierv disease

Reporters' Network

Vle!bourne, :he sic:<ness naa :eveilea DUI enough -or Granam ;o recover with ils -amiiy *n "asmania.

". lost :2kg, so. as rar as -ootbail was loncernea. naa :o start ail ove' again.' Granam says. "No one .vas sure low ong t vcuid :aKe Tie :o 'ecover.

"t :urnea DUX i 'naa ^us: a niia acse ^f :he synarome. 3ut '.vnen you -irst get t. "our priority s on lathing :nore :han "ecovenna.

I3ilina'.vcoa stooa :v 'ts ::ayer. ana ".e "esurnea oiayins "Or :he ::UD s :OD :aam n viarcn. "99^. But -irst Graham 3iso iaa :c overcome 3 lean jrooiem ;aiiea virai oericaraitis. .vhicn arfects the ;ac surrounaing -he neart.

"t '.vas not as jeoiiitating as :he 5111!-am-oarre syndrome ana :he :wo are not connected, out : am '00 oer cent :it now ana certain :his s ail oehina me.' Granam savs. "onn s joing great worK ^taDiishmg grouos ail over Australia. 'm nappy :o leio cut \vnere . can.

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• Partners in pain . . . John Stanley left) and j ran am Wright.

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This story came via the New idea Reoorters Network. We gay 5500 for -eariers irue stories aublisnea 'n Mew iaea. Send details of your story to New Idea Reoorters NetworK. 3PO Sox 1292K. Melbourne 3001. .nciuae /our name, aadress ana a phone lumoer on wnich you can oe reacnea curing orfica nours.

NEW DEA '0.6,?5 13

able to move a muscle. I spent some time with her and her mother, hoping to boost their spirits - also telling Joanne to hang in there as she had youth on her side as well as a very supportive family.

I rang Jackie during the week after my visit and Joanne had progressed to being off the respirator for four hours that day and expecting to be off for eight hours the next day.

I rang again this morning (27/5) to hear that Joanne is off the respirator completely and is now in a ward and hoping to be moved to the rehabilitation ward next week.

After about three months this is great news and I know the family are delighted. They realise Joanne has a lot of physio work to do yet with plenty of ups and downs but they will be backing her all the way.

PAULINE WHITELAW (Brighton) Pauline helps again Dear James,

/ am enclosing a "thank you" card (see below) *from Joan West who was in Cabrini.*

I have been keeping in touch by phone. She was not getting on very well and I suggested hydrotherapy to her as I knew from my own experience how helpful it is - I still go once a week.

PAULINE WHITELAW (Brighton) Card *Dear Pauline,*

Just a note to say thank you for your support since I was diagnosed with CBS.

I am really starting to improve healthwise. I started hydrotherapy yesterday and felt wonderful after it. I am going again tomorrow. Thank you once again.

JOAN WEST

Director's notes.

As well as thanks to all the above members who so ably provided support to IN sufferers I also wish to commend member TRICIA FOLVIG (Frankston) who, notwithstanding being just two weeks short of delivering her baby son, visited the above Joanne, a young woman of 22 years, who was feeling very depressed as having to postpone her wedding. TRICIA was able to demonstrate that a woman could suffer from GBS and recover to lead a normal life including motherhood.

Also I hope other members watched an ABC TV episode of the life of Franklin Delano Rooseveldt (6/7) dealing with how he coped with an attack of polio that left him paralysed in both legs. For some time he was most depressed as it seemed the paralysis would end any political career. But the telecast revealed how he fought back over a period of seven years with the help of his wife Eleanor and family. This included working out how to appear in public without using crutches -a no no for voting support - by instead using a cane in one hand and the shoulder of a son or bodyguard in the other. He also tried out many treatments and found the best was the natural Warm Springs of Georgia. He became an apostle of hydrotherapy! If it is repeated don't miss it.

JAMES GERRAND

And a "cheerio"

Dear James and "IN Group" friends,

Just a card to say hello from America. We're staying near this area (Deception Pass State Park, Washington) *at the moment. I've been fishing out in the Sounds and it is as nice as it looks. Hope you are all well. Best wishes.*

DOT & BILL MILLER
(usually Tootgarook)

ANNUAL GENERAL MEETING The Annual General Meeting of The IN Group is to be held on Tuesday 8th August at 7.30pm at 4 Alandale Ave, Balwyn, the home of our Deputy Director, RAY DAHLITZ. The Director's and Treasurer's Reports are published in this issue. Details of the agenda, etc, are set out in the enclosing leaflet.

Following this business, hopefully by 8pm, we will discuss the Epidemiology Study, led by Drs MALCOLM SIMS and BRUCE DAY. Again see details in the leaflet.

Renewal of Annual Subscriptions

The annual membership subscription is due on 1/795. The earliest renewal is appreciated as it saves clerical effort of reminders. Also adding a donation if you consider The IN Group is worth such further support would be most welcome. Donations more than $2 are tax deductible.

A number of our members have already prepaid for 1995/6. Those early birds will have their subscription forms so notated.

See you at the Meeting
Tuesday 8th August 7.30pm