

# 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 Demyelinating Polyneuropathy \(CIDP\).](#)

## SUPPORT -The Name of our Game

**JAJ**

*Director, The IN Group*



What better way to start the third year of publishing this newsletter than by presenting a round up of ways members are helping achieve our primary objective - to provide support to IN patients and their families. Overseas traveller stricken by GBS.

An Evelyn Woods rang me. Could we help? Her father Robert (72) was in St Vincents Hospital with his legs paralysed, having contracted GBS 9 weeks earlier while holidaying in Northern Ireland. I rang member George Wilby, who had had a similar experience whilst travelling in The Philippines in early 1993. George kindly and quickly responded and this is his report.

*I saw Robert Woods on 18/11. He said he caught flu on a trip to Ireland - later he went down with GBS and was in a provincial hospital for some time before being diagnosed over the phone by a doctor at Royal Belfast Hospital. He was immediately transferred and received treatments of plasmaphoresis and intragam. His whole system was affected but fortunately he did not require ventilation.*

*He had arrived in Australia five days before (he took ill in July) after some problems arranging a flight but as there is a reciprocal arrangement he did not incur any hospital fees.*

*He has now recovered the use of his arms and upper body but still has some drooping in the left side of his face - he was having an operation on his left eye that day. His legs are still causing problems - severe limited movement at present and he is receiving extensive physio.*

*He appeared in good spirits and I will visit him again in a few weeks. He was very grateful for your speedy contact after you heard about his pre-*

*dicament and said he was impressed with The IN Group.*

*GEORGE WILBY, East Hawthorn*

Closer to home

On 15/11 Fairfield Hospital rang me to advise there was a young man, Mark Roper from Ascot Vale, suffering from GBS in their Intensive Care Unit. I was able to visit Mark that day and then called on a member who had gone through the GBS trauma at Fairfield as a young lad. Chris very kindly responded to the request and reports: *Dear James,*

*Mark's symptoms included paralysis from the neck down and was placed in a respirator shortly after admittance.*

*By the time I of my first visit, four weeks ago, Mark was already being weaned off the respirator and was able to move his upper arms. Now he has movement all over, right down to his toes, but he still tires easily from the exertion of moving his weakened limbs.*

*Mark is now undergoing physio at the Talbot Hospital.*

*Like most of us, Mark loves receiving visitors and seems to "perk-up" when you enter. He appears to be genuinely appreciative of The IN Group's help in his mental battle against "something that could knock one around this much".*

*Although I've not heard any official reports, my limited experience suggests that Mark should be up and walking by the end of January.*

*CHRIS HAGARTY, Glen Waverley*  
Offering support *Dear James,*

*I have your name from the May'94 SA newsletter and was pleased to see there is now a group operating in Victoria. I would be pleased to join.*

*I contracted GBS in 1990 and al-*

though am now back to "normal", would like to be able to help others if at all possible. Whilst at my worst in St Vincents in Melbourne I spoke to another GBS patient who was nearly ready for discharge and return to New Zealand where she lived. This helped me enormously at that time as it seems to be such a puzzling complaint and was very frustrating to me at the time as I felt "well" even though I was paralysed.

Good luck with the group.

GAIL CANTWELL, Maryborough

### GBS Support Group of Tasmania

Dear James,

Earlier this year my wife C and I visited Chris Salmon and family at the Royal Hobart Hospital. Chris was suffering from a severe case of GBS, having been ventilated for 1/2 of his 3 months in the Intensive Care Unit. He is now making a good recovery at Rehab Tasmania's Private Hospital, All up he has been in hospital for 6 months and is now able to walk about on crutches and hopes to be an outpatient by 16/12/94.



**DRIVING FORCE:** Discussing new ideas to raise more funds for Mary Rose Gallagher following the electric wheelchair recently are (from left) Philip Gallagher, St Brendan-Shaw College principal Br Peter Smith, City of Devonport Lions Club member Ken Walton, St Brendan-Shaw College teacher Mike Reilly and Pethybridge.

## Rallying to help friends in need

PHILIP Gallagher, of Spreyton, has had more than his share of bad luck over the years but still manages to keep positive.

"People have asked me how I keep going and if I believe in Goa ... he doesn't blame me when things go wrong so I don't blame him."

infection which attacks the nervous system causing the victim to lose all motor control. It is a rare condition and effects one in 100,000 people.

Mary Rose was stricken with the disease two years ago. She now needs constant care.

Students and staff at St Brendan-Shaw College were

to mobilise and soon had the 55800 necessary to buy Mary Rose's chair.

"Ken Walton and Mike Reilly were driving forces behind the fundraising campaign — it was a magnificent effort by all those involved and only took two months." Mr Smith said.

"I was a little up against it financially and had to be

Mary Rose at the University of Launceston science before Mr Gallagher decided to return to his career.

"There's a lot of people who can fully recover from the side effects of GBS but it can become too

*Our major undertaking has been the proposed epidemiology study of GBS in Tasmania. This study has been gratefully taken over by Mary Rose Gallagher who has the medical background and knowledge to head the study. Thank you for the survey from the IN Group study. (See newspaper article on helping Mary Rose, opposite).*

*There seems to be fewer reported cases of GBS this year in Tasmania - to my knowledge 3, 1 North and 2 South, 3 less than average.*

*Other plans for 1995 are to incorporate our group thus helping to raise funds. I will look at telephone listings for White and Yellow Pages. I have registered our group with the local council and also with TICO (Tas Index of Community Organisations).*

***Do any other members suffer from:  
Watery eyes and runny nose  
when I eat or drink? Bright sunlight  
affecting eyes?***

*I have suffered from the above ever since contracting GBS. I would be interested to hear from anyone who may be able to help. (Please write or phone.) My initial paralysis extended to my face and part of it is still paralysed.*

*JOHN STANLEY, Devon port,  
Tas*

Thirty members enjoyed a get-together at our quarterly meeting held Sunday 13th November.

As well we made \$150 for T Group from the \$10 lunch prepared by Betty Gerrand with the help of Clark, Dorothy Brennan and B Clifford.

### **Bin so Bear Raffle**

This raffle raised \$529 for T Group. It was drawn at the luncheon by a member, Mrs Marjorie Aus Hobart. When I rang her to tell her success, Marjorie said she was thrilled but her youngest grandchild was now 15 and she was happy to turn it to raise further funding. Marjorie was very nice of you, Marjorie. (Marjorie joined when her 20 year old son Tom O'Hara contracted GBS some months ago.)

Our thanks to the many members who supported this raffle and particularly to Ted Basarke for donating a beautiful talking bear.

We have now donated the Bing to newly-formed GBS Support Group Tasmania. Our speaker at our meeting, Cindy Shaw of the Department of Social Security, has been especially

# Support oftped to **suffe** rare virus

***Congratulations, GREG,  
You are really spreading  
the message in Western  
Victoria.***

A RETIRED  
man and  
inflamm  
has offe  
Western  
who ha  
rare dise  
Greg  
inflamm  
was' a  
affect t  
system.  
"It is a

## Newsletter of The IN Group

he  
was  
irushe  
d to a  
Melbo  
rne  
hospita  
l  
where  
;  
h  
e  
  
w  
e  
n  
t  
  
i  
n  
t  
o  
  
a  
  
c  
o  
m  
a  
  
f  
o  
r  
  
a  
  
w  
e  
e  
k  
  
.

I It  
was  
18  
months  
before  
he  
•recov  
ered  
from  
the  
virus.  
"As a  
lucky  
.surviv  
or of  
GBS,  
having  
the  
diseas  
e  
IS-yea  
rs-ago  
when  
little  
was  
known  
of  
cause  
and

contracted, tijis^are-disease."

The- "Inflammatory Neuropathy  
group^was 'a 'support group for the  
families; arid; .sufferers of- Guillian  
JBaCTe.-'SjmdBJmei.; poiyneuritis or  
' c^bm^rijflainmatory demyelinating  
poiyneurbpatKy, "h'e said.

Group.-members were previous sufferers of  
•-inflammatory neuropathy, ., who were  
prepared to travel to ^support any  
patients or families requiring assistance,  
Mr Gillespie "said.

He said those visits could be very important to  
the mental attitude of -those concerned at all  
stages of recovery..

IN Group Victoria was controlled by the  
director James Gerrand in Kew with members  
scattered throughout the state.. . ,

Research for the virus was under the  
control of: Dr Bruce "Day, a neurologist at the  
Alfred Hospital.

Mr Gillespie 'can be contacted at 5  
Robertson Street, Peterborough, 98 5271.

kind and supportive in already selling \$32 of raffle tickets amongst her fellow workers for this new raffle. It will be drawn at our February meeting.

### **fatie « t:/ S u. ip**

A proposal has been put to the Alfred Hospital to use their computer system to advise a patient when diagnosed as to what support group may be available for the diagnosed disease.

Preliminary discussions have been held with Dr Laurie Osborne, Assistant Director of Medical Services, and Mr David Cook, Manager of Information Technology Services.

Such a system would overcome the problem of how to be sure that patients, particularly those diagnosed with relatively rare disorders such as GBS and CIDP, can know of an available support group. Once established successfully at the Alfred, I can see it being introduced at all other major hospitals.

To assist this venture we have joined the Collective of Self Help Groups (\$25 per year) and now have a copy of their Directory of Self Help Groups. The IN Group will be listed in the next edition.

### **Epiclemiolsy Study**

Letters have been sent out to 32 volunteers for the main part of this study, following the successful interviews of the 23 who took part in the initial trial. Interviews, either personal or over the telephone depending on convenience, are proceeding as the members contact their assigned interviewer, being either Betty Gerrand, Graham Blanck or James Gerrand.

### **S Foundation Int**

The IN Group is now a member of this US body (subscription \$US25) as both a means of being known internationally and also to be sure of receiving their often informative newsletter "Communicator".

### **Listing**

We have made arrangements for The IN Group to be listed in both the White and the Yellow Pages Directories.

## **LETTERS**

*Dear James,*

*I contracted CIDP six years ago. It started with tingling on the tip of my nose. It progressively got worse over a period of about three months. It then spread across my face, then hands and feet. The inside of my mouth went numb. My protein level was very high which made it very hard to diagnose the problem. Each 3 monthly visit to the specialist found me greatly deteriorated.*

*After about 8 months I could hardly walk. I was sure I was going to die. I had so many tests done; bowel biopsy, lumbar puncture, bone marrow test, all my bones x-rayed, a nerve removed from my leg and hundreds of blood tests. I still didn't know what I was suffering from. I was put on prednis-olone and a chemotherapy drug Melpha-lan for a period of 36 weeks. The disease completely disappeared for about 18 months. I still had 3 monthly blood tests which always came up clear.*

*Then the tingling started again as before on my nose. I knew what I was in for; like before it progressively got worse - numbness inside my body and mouth, loss of reflexes, muscle wastage, double vision, weakness, constant stinging everywhere, chest pains. I was so ill I ended up in intensive care at the Albury Base Hospital.*

*When I was well enough to travel I was taken to the Austin Hospital where I was diagnosed as a CIDP sufferer. At long last I had a name for my illness. I was put on a high dose of prednisolone which I responded to. I got better each day. I have been off the drugs now for a year and I've never been better - all back to normal. I'm going overseas for 2 months soon.*

*I am very grateful to the Albury Hospital and all the specialists and staff there, not forgetting The Austin and their specialists and staff, particularly Dr Macdonell. Thank you for The IN Group information.*

*GLADYS DEMPSTER, Lavington, NSW*

**Next IN Meeting** Tuesday 14th  
February 8pm 4 Alandale Ave  
Balwyn

A podiatrist will talk about the care of the feet, often a problem area for IN disorders. There is also the opportunity to discuss other matters. See you there *For details see insert.*