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Caring for the Patient

Newsletter No.20 - September 1997

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*From the address by **Dr TONY MOORE, Medical Superintendent, Mt. Eliza Centre**, to the quarterly meeting of **The IN Group** held 13/8/97, Balwyn Library Meeting Room, 336 Whitehorse Rd.*

What interests Dr Moore most are human emotions. He doesn't know if a human emotion can be the cause of a disease but he does know that human emotions will affect its course, its consequences and its complications. It is in the region of human relations that he likes to wander most.

As a twelve year old Dr Moore was captivated by the story-telling of a famous Armenian/American writer visiting Melbourne. His advice to any of his audience wishing to be a writer was "to speak from the heart and about what you know".

Dr Moore stated he tries to follow the first precept but admits that on any subject what he doesn't know is usually more than what he does.

Dr Moore believes everything is interconnected, everything is changing, everything is unique but ultimately everything is out of reach.

Many things happen to us that cause us to ask why? Much energy can be wasted down that track. Reasons may become apparent later but they can't be forced.

About 13 years ago while Dr Moore was driving to work, a semi-trailer ran through a red light and into him. He was in Intensive Care at the Royal Melbourne Hospital for a week, in their wards for three months and then for nine months at the Hampton Rehab Hospital on the physio couch. When he was asked whether he would be Medical Director there, his reply was, he needed to get off the couch before giving it consideration. It took about 15 months for the physical things to be repaired and then another three years before he started to feel any sense of balance or harmony. His injuries included about 22 fractures, including a scapula, ribs, ruptured lung, lumbar fracture. Fortunately his head did not suffer damage.

Dr Moore learnt eight things as a human being during his recovery which he wrote about in his book *Cry of a Damaged Man*. He was surprised that his book reached not only people who had suffered accidents but those who had suffered in other physical areas, eg strokes, cancer, GBS, CIDP, in emotional areas and also relatives of sufferers.

1. Rest in Recovery

Dr Moore mentioned how a wise man named Hilton wrote a book *On Rest and Pain* last century in which the author stressed the importance to recovery of providing rest and eliminating pain. Modern medicine is not bad at providing pain relief but is often poor at providing rest. Dr Moore recounted how when he was a patient at the Royal Melbourne Hospital he was kindly placed in one of the two single wards so he would not be unduly disturbed by visitors but the room was next to the Pan room. He then understood what was meant by Heavy Metal.

What is meant by rest? There is a certain amount of energy to be spent on a day. An able person will have a greater pool of energy than one recovering from an accident or operation. Energy level 1 will be spent on common courtesies - "How are you? I'm fine." We don't want to be delved deeply. Level 2 will be spent on what has to be done - our work, getting the rent. Some are fortunate in working at what they like, many work because they have to. Level 3 is the energy devoted to what we love doing - our hobbies, our recreations.

Level 4 is on survival. This energy for one struggling to survive after, say an accident, takes the available energy away from the other levels. So you can't be bothered about pleasantries, you tend to be rude. Nor can you have the energy to do what you love. This can create a despondency. Dr Moore calls this not depression but a reasonable melancholy. Abnormal reactions can be expected to abnormal situations. This can produce a difficult choice. Will I pretend I haven't changed or do I behave as I feel and embarrass and stress others?

What such patients don't need is to come home from hospital to a household full of warring teenagers or a disputatious marriage or difficulties at work. Rest is for restoring energy.

2. Honesty

This honesty is the courage to say: "I am in trouble. This hurts. I am in pain." Most people addressed so would feel encouraged that the speaker had confidence in their confidentiality and their understanding. Yet people are reluctant to be honest to ask for help. "No, I am self sufficient. I don't want to be a bother. That's a sign of weakness." We are all frail; we all have our threshold. Dr Moore said that a person who is compulsively recovering, denying what have affected them - "I am going to make a 100% recovery, I am not going to surrender" - is in a very precarious state. They can't accommodate the fact that they need to accept the situation.

3. Acceptance

Why do we get upset? Level 1 is when my ego or pride has been trampled on. This is easy to get rid of; don't let the trampers occupy your mind. Level 2 is when something you would like to happen, can't or won't. An example would be control over your children. This is a losing battle. All parental power is based on bluff. We can spend a lot of energy on trying to make things happen that can't happen. In recovery from illness Dr Moore is all for striving but also for commonsense adoption and acceptance of those activity levels which one is capable of, and acceptance of those which we are not. Dr Moore related how silly he was in not accepting the weakness in his ankles when he tried to run around Albert Park Lake.

4. Humour

It is not funny to lie in bed with tubes in your orifices, you can't move, every time you breathe it hurts, you are living in a cell, your career has been arbitrarily arrested. It took Dr Moore to see a humorous side. It brought him back to earth.

5. Emotional Recovery

Whilst one can predict with reasonable accuracy the time it takes to recover from physical injuries - a collarbone break should mend in 6-8 weeks - there is no time frame for the healing of the human spirit, for the human emotions to repair. It depends on the individual. For this reason it is not possible for one person to fully understand what another person has gone through even if the injury has been similar. A doctor needs to know about a patient before getting anywhere close to assisting in his recovery. A patient may have recovered physically but the emotional recovery may not have started. Such a person may feel very alienated; he is at home, possibly at work, and without any professional support. A family may be puzzled at this remoteness of a loved one who is said to have recovered. What is needed is sympathy and time.

6. Friendship

Darwin in his *Origin of the Species* does not report any instance where one member of a species attacks another of that species except symbolically. The species that have been most successful over the millennia of evolution are those that practise mutual support. In the insects it is bees and ants, in the bird kingdom it is parents, in the mammals it is primates. Dr Moore remarked that The IN Group was an example of mutual support. However, unless humankind stop their tribal slaughters, they will fail their evolutionary future.

Many sufferers of traumatic experiences have reported that what helped them most was the sharing of experiences with like sufferers. One of the most appalling aspects of affliction is the feeling of alienation, that we are alone. In his book *Echoes of the Early Times* Dr Moore tried to make patients feel comfortable about the mystery of what was happening, know that they were not alone in what they had been through and offer some options that might be helpful.

To give definite prescriptions can be harmful if the patient finds the prescription doesn't work.

Mutual support groups are very helpful in providing knowledge.

7. One's Uniqueness

Dr Moore found the most important factor in his self-esteem was his, and everybody else's, uniqueness. This can never be taken away. One can not be replaced.

8. Partner Your Sorrow

Sorrow is the loss of some one or something emotionally dear to you. That sorrow will never go away nor should it; it represents the love you feel for what has been lost. Such losses could be the death of a partner, one's health through illness or accident, one's dignity through humiliation, trust through betrayal, of innocence through abuse, security through displacement, safety through being damaged, faith through injustice. Doing away with sorrow is a mi-directed industry. Doing away with the sorrow is to do away with the love of the lost.

Dr Moore gave as an example of partnering a sorrow that of a mother who lost a child through a car accident and then set up a self-help group to help parents suffering a similar sorrow. The mother feels her memory of her child is given a caress every time a new member joins the group. Her sorrow has been partnered, it is not a burden.

Annual General Meeting

At the AGM of The IN Group, held on Wednesday 13th August at the Balwyn Library Meeting Room, 336 Whitehorse Road, Balwyn, the following Committee was elected:

Director: **JAMES GERRAND**

Deputy-Director: **BARBARA BURZAK-STEF- ANOWSKI**

Secretary: **MELVA BEHR**

Treasurer: **PHYL CAMERON**

TED BASARKE

VILMA CLARKE

BETTY GERRAND

MARGARET LAWRENCE

The reports for the financial year 1996/97 by the Director and the Treasurer (see pages 4 and 5) were endorsed.

Winter Luncheon - Sunday 29th June

A very enjoyable and most reasonable, winter luncheon (soup and muffins for \$5) at the Balwyn Library Meeting Room on Sunday 29th June provided a happy social meeting. **JOE** and **MELVA BEHR** made the fine soup and daughter **AMY BEHR** baked the delicious blueberry muffins.

Thanks to the Behr voluntary efforts, plus those of **BETTY GERRAND** and **MAR-GARET LAWRENCE**, \$149 was raised including \$55 from a raffle run by **BARBARA STEFANWSKI**.

Sponsorship by CSL Limited

CSL Limited has kindly agreed to further sponsorship through a grant of \$1,500 for 1997/98, comprising \$700 for Internet expenses, \$600 for expenses of the Council of GBS/CIDP Support Groups of Australia and \$200 miscellaneous.

The IN group thanks CSL Limited for their generous and ready granting of this amount and continuing support.

\$3,000 Donated to GBS/CIDP Research

The IN Group donated another \$3,000 to the Royal Children's Hospital Research Foundation to support the research being carried out by Dr **ANDREW KORNBERG** into GBS and CIDP. The following is Dr Kornberg's acknowledgment.

*Mr James Gerrand,
Director, The IN Group*

I would like to express my sincere gratitude to yourself and The IN Group for the kind donation of \$3,000 for GBS and CIDP research in my laboratory. As you are well aware, research budgets are quite tight and are becoming tighter. The money donated by The IN Group gives my laboratory the opportunity to pursue further important projects which may lead to the better understanding of these important conditions.

Thank you once again for your kind support.

*Dr Andrew J. Kornberg
Director of Neuromuscular Laboratory*

The IN Group Christmas Cards

These quality Christmas Cards are again available at \$10 a packet of 12 (\$12.50 inc. postage). We had good sales last year at short notice to members; your buying this year of a similar or greater number will bring in more than \$1,000 to donate to GBS and CIDP research.

Use the Order Form on the back of the posting wrapper or purchase direct at our November Social Luncheon Party Sunday 16th November.

1997/98 Entertainment Books

Members who purchase these books at \$40 each (\$45 inc. postage) can not only save themselves 50% on the cost of their entertainment at the many venues - restaurants; arts, leisure and sports centres; out of town highlights and hotel accommodation - now available but also put \$8 directly into The IN Group funds without any cost to our Group.

Details are set out in the flier enclosed. You can either use the Order Form on the wrapper or purchase direct at our Sunday Luncheon.

\$200 Doona Raffle

The Doona Coverlet and Tablecloth, value over \$200, purchased from the proceeds of **VILMA CLARKE's** Linen & Basket Party will be raffled at our Sunday Luncheon 16th November. Tickets are \$5 for a book of five; use the Order Form on the wrapper or else pay at the Sunday Luncheon.

DIRECTOR'S REPORT Year 1996/7

Personal Support

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. Visits were made to patients and contacts made to their families at the Alfred Hospital, Caulfield Rehab Hospital, Cedar Court Private Hospital, Essendon & District Hospital, Royal Melbourne Hospital, Royal Talbot Rehabilitation Centre, St Vincent's Hospital and Warnambool Base Hospital.

VILMA CLARKE continued to arrange helpful 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.

We are pleased to welcome Sister **KATY FIELDING** as Consultant Nurse to The IN Group.

Membership

Over the year membership has increased from 176 to 220 which includes over 165 past and present IN sufferers. Thanks mostly to being on the Internet, 14 are from interstate and 33 from overseas - mainly from the USA but also from Austria, Canada, England, Japan, New Zealand, The Philippines and Slovakia.

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 \$4525 from members, including \$1000 each from **GWEN MANNE** and **ALLAN GOYEN**) allow us to expand our efforts, particularly in helping the research into GBS and CIDP being carried by Dr **ANDREW KORNBERG** at the Royal Childrens Hospital. We donated \$3000 to this research which was much appreciated.

Quarterly Meetings

These meetings have continued to be popular. Quality speakers for the evening meetings - Drs **GRACE WARREN** Orthopedic Surgeon, on "*Salvaging the Nerve-Damaged Limb*" August '96 and **ANDREW KORNBERG** on "*Update on GBS and CIDP Research*" May '97. The February '97 meeting was devoted to a discussion amongst the members of the ways The Independent Living Centre could help handicapped people.

The November Sunday Luncheon Party meeting was again a happy social get-together as well as a great fund-raiser. A total of \$740 was raised - \$161 from the luncheon, \$284 from a blind auction, conducted with great fun by **BARBARA BURZAK-STEFANOWSKI** and \$295 from raffling a wonderful hamper.

A Winter Luncheon Social Party (soup and muffins for \$5) held on 29/6/97 was another enjoyable function and raised \$191.

Our Secretary **VILMA CLARKE** held a successful Linen & Basket Party at the Sunbury home of committee member **MELVA** and husband **JOE BEHR** to raise \$175.

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, **MELVA BEHR**, **NORM BLYTH**, **DOROTHY BRENNAN**, **BETTY GERRAND** and **FRED HOOTON** for help with the mailing.

A National Council formed

The first meeting of a **Council of GBS/CIDP Support Groups of Australia** was held on 29/4/97 in Melbourne with representatives from South Australia, Tasmania and Victoria. The three main aims of the Council are (1) to present the views of affiliated Support Groups at the national level, particularly to the Australian Government, (2) to promote and assist the formation of further GBS/CIDP support groups, ie those for Queensland and Western Australia and (3) to establish a national data-base of members willing to support those afflicted by GBS or CIDP. The last item will enable an appropriate person to be contacted quickly so that a GBS or CIDP patient may readily receive support.

CSL Limited gave \$500 to The IN Group to sponsor the creation of this national body. \$221 was used to pay the ML-AD airfare of **HEATHER TRENORDEN** (SA Neurological Resource Centre) for her attendance. Amongst others attending were **WERNER FIEDLER** (CSL) and **BETTY GERRAND** (Proxy Tasmania).

Office bearers elected were President **BARBARA BURZAK-STEFANOWSKI** (Vic), Vice-President **HEATHER TRENORDEN** (SA) and Secretary/Treasurer **MELVA BEHR** (Vic).

A second meeting is scheduled to be held on Sunday 21st September 2pm at the Alfred Hospital Melbourne when a representative from the NSW support group is expected to attend.

Sponsorship by CSL Limited

The IN Group particularly wishes to thank **CSL Limited** for their continuing generous support. During the year CSL gave \$570 for the operating Internet costs, \$126 to pay for an anti-virus program VET and \$500 towards the cost of establishing the Council of GBS/CIDP Support Groups of Australia, a total of \$1196.

CSL make the gammaglobulin product Intragam which is a favoured treatment both for GBS and CIDP.

The IN Group Christmas Cards

We managed to sell 185 of the 500 packets of our quality IN Group Christmas Cards (12 in a packet for \$10) which was a good start for a new enterprise. This year we should be well on the way to selling the lot through continued support by members, friends and the Kew Primary School and so make The IN Group some \$2,500 profit. **Entertainment Books**

Six Entertainment Books at \$40 (\$45 posted) were purchased by members to give The IN Group a quick return of \$48. Already three of this year's edition, lasting to 30/6/98, have been sold. So here's a good way of both cutting your entertainment costs and helping The IN Group.

Both the Christmas Cards and the Entertainment Books will be available at our August and November meetings.

GBS/CIDP Awareness Day - May 1st

Following our media release three of our members were featured in their local press - **MARGARET BREW** "Pakenham Gazette", **CLAIRE BROOKS** "Malvern Progress Press", **JUNE CANTWELL** "Stawell Times-News". As a result of reading about the Awareness Day, **JIM SADLER** joined to assist.

Your Committee has decided to make Awareness Day **JUNE 1st** next year, following the UK approach rather than the US.

Thanks

Particular thanks to secretary **VILMA CLARKE** for her enthusiastic efforts; to Treasurer **TED BASARKE** for keeping track of incomes and expenditures; to auditor **FRED HOOTON** for his watchful eye and to **BETTY GERRAND**, **MELVA BEHR**, and **MARGARET LAWRENCE** for their sterling efforts in making our social activities such a success.

JAMES GERRAND, Director.

TREASURER's REPORT for Year ending 30/6/97 (30/6/96)

INCOME and EXPENDITURE

INCOME:

Membership fees for 1995-96	\$1970.00	(1340.00)
Donations (inc. \$1196 from CSL P/1 Ltd)	5941.02	(4605.37)
Sale of Christmas Cards	1471.00	

Proceeds of raffle	160.00	
Sale of Entertainment Books	135.00	
Other items, including proceeds of luncheon	1162.82	(218.13)
Bank interest	59.75	(83.13)
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Total income (from 1/7/96 to 30/6/97	\$10599.59	(\$6246.50)
	=====	=====

EXPENDITURE:

Running costs, including postage, newsletter, internet, etc	\$2535.62	(2335.79)
Purchase of computer		(2600.00)
Cost of Christmas Cards	2554.00	
Donation to R.C.H Research Foundation for Dr Kornberg's research	3000.00	
Fare for Adelaide rep to National Council meeting	221.00	
State Govt Duty and tax	11.64	(18.23)
	-----	-----
Total expenditure	\$8875.99	(\$4954.02)
	=====	=====
Total income over expenditure	\$1724.60	(\$1292.48)

E.R.H.BASARKE, Treasurer

ASSETS:

Bank balance at 30/6/97 (30/6/96)	\$5282.56	(\$3376.15)
Computer 486	1800.00	(2600.00)
Epson Printer, cost \$520	100.00	(150.00)}
Fax Modem, cost \$444	70.00	(100.00)}
Tape Recorder, cost \$46	24.00	(36.00)
Sony Audio Transcriber, cost \$300	100.00	(150.00)
FM Public Address System	70.00	(119.00)
286 Packets of Christmas Cards	2860.00	
	-----	-----
Total value assets	\$10406.56	(\$6861.15)
	=====	=====

CLAIRE BROOKS becomes first Life Member

At The IN Group committee meeting of 9/7/97, member **CLAIRE BROOKS** was awarded the first Life Membership of The IN Group in recognition of her outstanding support and promotion of The IN Group. Included in these efforts are having The IN Group featured in the suburban newspaper *The Leader* of 30/4/97" (see below) and organising together with our Secretary **MELVA BEHR** to have a National GBS/CIDP Awareness Day of 1st June. At 86 years old Claire is an inspiration to us all.

Support is the Name of our Game

KEITH COLWILL has been a regular visitor to fellow member **BILL EADES**. Here are two of Keith's reports:

18/6/97

Dear James,

As you know, I still visit Mr Bill Eades regularly at Caulfield General Medical Centre where he is a GBS patient in Ward 6.

He is still severely paralysed and so far has minimal hand movement only. This enables him to control a battery-powered wheel chair which he now has and he is enjoying the mobility it gives him in and around the hospital ward.

Bill has his name on a couple of waiting lists for nursing home accommodation.

Three weeks ago he happily celebrated his 80th birthday with members of his family.

KEITH COLWILL

22/7/97

Dear James,

Further to my note of 18/6, BILL EADES was moved to a nursing home on 28/6. He is now at Ripplebrook Private Nursing Home, 21 Inverness St, CLARINDA 3169.

I visited him on 10/7 and he was settling in quite well. There is no change in his general condition but he is managing his battery wheel chair very effectively. In fact he took me on a guided tour of the nursing home.

KEITH COLWILL

DOUG CARTER has been having a difficult time keeping CIDP at bay whilst working at a fairly arduous job. His wife **ALISON**, in between managing a shop, gives some details:

Dear Mr Gerrand,

...

Doug is not on Intragam now, he is undergoing plasmapheresis once a fortnight. Earlier this year he actually went six weeks without any symptoms and we both started to get quite hopeful. He now seems to be able to just make it through until the next treatment. I know he gets very tired trying to cope with a full-time job that is a manual one and the treatment seems to knock him about.

I am wondering if you know of someone else in the Group whom he could talk to and/or if you could put us in touch with someone in the Group suffering from CIDP who may be in the same age bracket as Douglas (he is 41 this year). I honestly believe it would help Doug to talk to someone who is experiencing what he is. There are questions we both have that maybe someone can answer.

...

ALISON CARTER

I passed on the request to **MELVA BEHR** whose husband **JOE** matches up pretty well - has CIDP, is about Doug's age and has a demanding job. After some difficulty of communication because of both working and one with shiftwork, contact has been made. I myself managed to speak to Doug and appreciated Doug's determination to cope with his CIDP.

DEE COOPER seeks membership.

To whom it may concern,

Having just had an "INformation" newsletter forwarded to me from one of your members I am interested in receiving them myself.

Four years ago I was diagnosed with GBS and felt I was somewhat of a rarity in Geelong. Having no-one who had had it to talk to in hospital, I'm sure to have known about your Group would have hel-ped. I'd like to be a support to anyone else finding themselves in the situation I was in.

Now a mum, living and working in Geelong, unfortunately it would be difficult to make it to meetings but I would appreciate any latest research as I found very little information was ever given to me.

DEE COOPER

Welcome to The IN Group, Dee, and thanks for your offer to be a support to other sufferers.

Other News

A Data Base for Supporters

As seen above, the matching of a patient with a member who has been through a similar experience and background, is often most important in providing needed support.

We hope over the next few months to develop a database so that this matching can be done initially by computer. When we have the database to suit, we shall send out an optional questionnaire to all our members seeking the relevant details for feeding into the computer, including whether they would like to provide support.

This approach will also be discussed at the meeting of the Council of GBS/CIDP Associations of Australia to be held on 21/9 with a view of ending up with a national database.

Communicating on the Internet

The Internet continues to provide ready communication anywhere in the world. It enables The IN Group to provide information and support at the touch of a typing finger.

Through this global connection The IN Group now has 34 overseas members - Austria, Canada (3), Japan, New Zealand (3), The Philippines, Slovakia, United Kingdom (4), United States (16) - and 12 interstate members - Queensland (6), Western Australia (2) and Tasmania (2).

Here are two examples how The IN Group can supply needed information to people globally (in these cases resident in the USA). **DIANE** and **AL** sent their letters after initial seeking help of The IN Group through Internet contact.

Dear James,

Thank you so much for the information that you sent to me (CIDP booklet, IN Group brochure and news-letter). I hadn't been able to find anything relating to CIDP until I contacted you. Unfortunately I do not own a computer and I am rarely able to use my friends.

I am 48, married and have 3 sons. I guess it is about three years that I have had this disease but I was only recently diagnosed. The numbness started in my feet and fingers and has now progressed to just below my knees and to my wrists and arms. The recommended treatment is daily azathioprine with immunoglobulin for 3 days and then every 6 weeks. I have not made any decisions regarding treatment. Right now I am trying to keep a positive attitude and continue to research any available information.

Do you feel that the gammaglobulin drip is helping you? Are there any serious side effects? How wonderful it is to have a support group such as the IN Group. It is reassuring to know that there is ongoing research and emotional support.

I thank you once again for your quick response and very informative guide. You can still contact me at lindaa@grove.net until I purchase my own computer. Or write to me at the above address if you have time.

DIANE CALVANO
North Carolina USA

In my reply I said "*The treatment proposed seems pretty good ...*" and "*There are usually no side effects with gammaglobulin.*" and "*Let me know how you get on*".

Dear James,

I first want to thank you for sending material on CIDP. My son Bob, through the Internet, has been giving me the information you send.

Two years ago I began to experience numbness in my feet. I was told by my family doctor that I may have Lou Gehrig's Disease. After two months and a great deal of pain I was finally sent to a neurologist.

I was then told as a result of many tests that I have CIDP. In discussing the options and cost I went the steroid route. Everything that could happen did happen while taking steroids (prednisone). I have now been taking Nortriptyline, 50gm per day, had been 100gm. The process of getting better has been very slow. Most of the pain is now in the front half of my feet. I walk each day, take all the B vitamins, watch what I eat and try to maintain a positive attitude.

Your booklet has been most helpful. Big thanks.

AL REZENDES
California USA

Welcome **DIANE** and **AL**. (Both have joined The IN group.)

And now back to Victoria

We managed to get useful publicity (free) in the suburban "Progress Press" of 12/8/97.

Last Updated: 15 Oct 2007 17:49