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Chronic Pain Management

The wounded do not scream

Newsletter No.24 - September 1998

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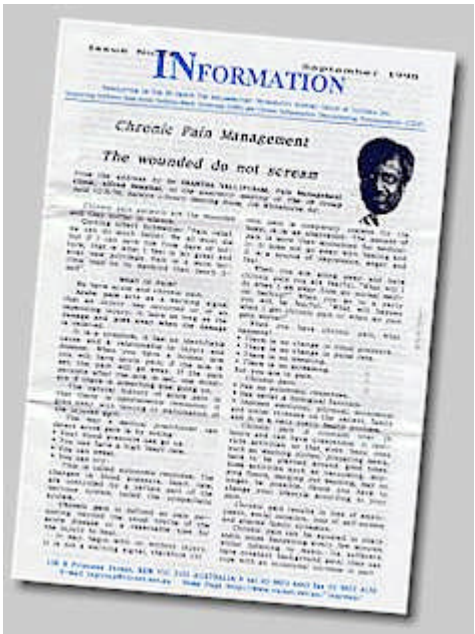
See also:

- Luncheon Party Order Form (Nov-98)



From the address by Dr SKANTHA VALLIPURAM, Pain Management Clinic, Alfred Hospital, to the quarterly meeting of The IN Group held 12/8/98, Balwyn Library Meeting Room, 336 Whitehorse Rd.

Chronic pain patients are the wounded and they suffer in silence.

Quoting Albert Schweitzer "Pain relief, we can do much better. We all must die but if I can save him from days of torture, that is what I feel is my great and ever new privilege. Pain is a more terrible load on to mankind than death itself".

WHAT IS PAIN?

We have acute and chronic pain.

Acute pain acts as a warning signal that an injury has occurred or of an impending injury. It lasts as long as the damage and goes away when the damage is relieved.

It is a symptom, it has an identifiable cause and a relationship to injury and disease. When you have a broken arm you will have acute pain; if the arm is set, the pain will go away. If the pain persists after the arm is set, one wonders if there is something else going on.

The natural history of acute pain is that there is spontaneous remission; it goes away with healing or stabilisation of the injured part.

The way a medical practitioner can detect acute pain is by noting:

- Your blood pressure can go up.
- You can have a high heart rate.
- You can sweat.
- You can cry.

This is called autonomic response. The changes in blood pressure, heart rate, are controlled by a certain part of the nervous system called the sympathetic system.

Chronic pain is defined as pain persisting beyond the usual course of the acute disease or a reasonable time for the injury to heal.

It may begin with or without injury. It is not a warning signal, therefore chronic pain is completely useless for the body, it is an aberration. The amount of pain is more than accounted for medically. It does not go away with healing and it is a source of depression, anger and fear.

When you are going away and have chronic pain you are fearful. "What will I do when I am away from my normal medical backup?" When you go to a party you will be fearful. "What will happen when I get chronic pain or when my pain gets worse?"

When you have chronic pain, what happens?

- There is no change in blood pressure.
- There is no change in pulse rate.
- There is no sweating.
- There is no screaming.

But you are in pain.

Chronic pain:

- Has no autonomic responses.
- Has never a biological function.
- Imposes emotional, physical, economical and social stresses on the patient, family and it is a very costly health problem.

Chronic pain is constant over 24 hours and can have crescendos. It restricts activities so that even basic ones such as washing dishes, preparing meals, have to be planned around good times. Some activities such as vacuuming, mopping floors, hanging out washing, may no longer be possible. Hence you have to change your lifestyle according to your pain.

Chronic pain results in loss of employment, social isolation, loss of self-esteem and altered family dynamics.

Chronic pain can be equated to sharp static noise happening every few minutes whilst listening to music. Its sufferers have constant background pain; they can cope with an occasional increase in pain but when the increases are constant, they are unable to deal with it.

Myths of Chronic Pain are:

- Low pain threshold.
- Poor coping skills.
- Drug seeking.

Chronic pain cannot be cured but can be controlled. We are unable to cure anyone one and we will never be able to cure anyone.

Health professionals' response should be to:

- Initially accept the patient's report of pain.
- Respond to prevent suffering.
- Avoid missing the diagnosis.
- To avoid adversary relationships.

Occasionally we would have patients who say they have chronic pain but there may be other problems.

If one has chronic pain and goes into hospital, what happens?

- There should be a good support group.
- There should be a skilled and caring support team.
- There should be a person who is wil- ling to listen.
- If management is changed, if there is any change in medications, the alter- native must be as effective.

In hospital, one expects compassion, a person to speak to and able to suggest alternatives if the requirements are not meeting the needs. One wants frank honesty, as even if one is honest with bad news, one is able to deal with it. There needs to be honesty regarding the management, the plans, the feelings.

There is the saying "The advantage of telling the truth or being honest about what is said, is that you don't have to remember what you said". Frank honesty builds a relationship.

When we practitioners deal with chronic pain, we manage it not as a traditional disease model but as a bio-psychosocial model where the patient participates in the management and decision making. The management is individualised for each patient and type of pain. We choose adequate therapy and the therapy is multi-modal (a number of modes). It is not merely drugs, surgical procedures, interventions or injections. Treatments may involve drugs, occupational therapies, psychology support, group therapy, hydrotherapy, physiotherapy, activity, occupational retraining and so on. Because we are addressing multi-dimensional problems, therapy has to be used concurrently, rather than sequentially.

Although return to work for an injured person has been mooted on television recently, as an end point in treatment, it may not be appropriate. We have to look at quality of life and equip one to manage the environment. We look at management strategies that allow therapy to be directed away from cause and cure.

There is no satisfactory treatment available for many types of pain but we have to try. With osteoporosis, whiplash injuries, pain after amputation, pain after strokes and pain after nerve injury, treatment is not satisfactory but we try a management program to see what can be done.

Medications are only a small part but an important part of the management. Medications in chronic pain help to reduce the pain. Medications can either help with the pain, may not help, or, if not taken properly, can cause serious injury.

Medications commonly used are painkillers which could be simple ones bought over the counter such as Aspirin, Paracetamol or some anti-inflammatories or the controlled ones such as opiates.

We use other drugs in conjunction with chronic pain medications. We use anti-depressants, sometimes we use steroids such as Cortisone, we use antihistamines like Phenergan and associated group of drugs. We use creams and certain cardiac drugs. All these drugs help if used appropriately.

Anti-depressants can work on nerves dealing with pain, can alter moods to handle the pain and help with sleep. The problem with anti-depressants is that you have to take care under certain conditions such as certain heart conditions, high blood pressure, epileptics. They can interact with other drugs, with alcohol and can make one feel sleepy.

We use anti-convulsants, or anti-epileptic drug, for pain. It can help with conduction of pain but there are problems. They can cause skin rashes, allergies, dizziness, blurred vision and so on. You have to look at side-effects when one takes drugs.

We use narcotics such as morphine for certain types of pain when they have to be used. Narcotics can cause dependence because when they are stopped, your body will react. This does not mean you are addicted. Addiction is when you take narcotics for a psychological boost. If you are taking narcotics for pain, you definitely get dependent. It can change your appetite, alter your balance, effect breathing, cause constipation (commonest problem), confusion (common in the elderly), drowsiness and withdrawal effects.

If narcotics are stopped suddenly, you start having a runny nose, teary eyes, abdominal cramps, gooseflesh, diarrhoea and anxiety.

When one is taking narcotics for chronic pain, one has to get all the prescriptions from the one doctor and filled at one pharmacy. Otherwise you have a lot of inconvenience.

Occasionally opioids have to be stopped. The commonest reason is misuse; others are one not being compliant with the treatment, developing rapid tolerance, there is loss of effect or there are significant side-effects. Because of its side-effects, its dependence, its abuse in the community, opioid use has to be register-ed with the Department of Health.

We also use exercise programs, TENS machines (TENS is a machine that vibrates and blocks the pain by vibrating another nerve fibre), psychology (not used because you have something wrong with you but because it gives you strategies to cope with your pain), behavioural therapy, hypnosis, and other fairly sophisticated techniques.

When one takes medications related to pain therapy, one has to be careful of doing certain activities like driving. You need to get your doctor’s advice.

The chronic pain patients are good copers, they do deal with pain very well but unfortunately one has to get help when the pain gets out of hand.

DIRECTOR’S REPORT Year 1997/8

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.

Good Questionnaire Response

Seventy members returned filled-in Questionnaire forms which is a most helpful response. The Questionnaire is based on one created by the GBS Association of NSW. As mentioned below its information has already been the means of arranging matching support to a GBS sufferer.

Also the detailed information could possibly prove helpful to a researcher into aspects of GBS and CIDP.

Membership

Over the year membership has increased from 220 to 265 which includes over 170 past and present IN sufferers. Thanks mostly to being on the Internet, 21 are from interstate and 46 from overseas - mainly from the USA but also from Austria, Canada, Italy, Japan, New Zealand, The Philippines, Slovakia and UK.

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 $3208 from members, allow us to expand our efforts, particularly in helping the research into GBS and CIDP being carried by Dr ANDREW KORNBERG at the Royal Children's Hospital. We donated another $3000 to this research which was much appreciated.

Quarterly Meetings

These meetings have continued to be popular. Quality speakers for the evening meetings - Dr TONY MOORE, Medical Superintendent, on "Caring for the Patient" August'97; Dr RICHARD MACDONELL on "*Inflammatory Neuropathies other than GBS and CIDP*" February '98; Sister CATHERINE HATTERSLEY on "*Hospital in the Home*" May'98 - were informative and led to interesting questions and discussion.

The November Sunday Luncheon Party meeting was again a happy social get-together as well as a great fund-raiser. A total of $578 was raised - $131 from the luncheon, $297 from a blind auction, conducted with great fun by BARBARA BURZAK-STEFANOWSKI and $150 from raffling a doona.

Other Fundraising/Social Get-to-gethers

Twenty-one members and friends enjoyed the Winter Luncheon Social Party held on 28/6/98 at the Glen Waverley home of MARGARET and DOUG LAWRENCE. Adding to the pleasure of lunching in the delightful surroundings was the sho-wing of a video "Coping with GBS/CIDP" made by the SA Neurological Resource Centre. The icing on the cake was the $198 made from the occasion.

A Film Luncheon was tried and voted a success by the twenty-five who saw "The Horse Whisperer" at the Balwyn Cinema on 17/6/98. This was organised as a social but we made $27.50.

Our Secretary MELVA BEHR raised $103 by raffling a Talking Bear at her Sunbury Supermarket on a Saturday morning.

Finally our greatest fund raiser of the year, thanks to the initiative of Committee member MARGARET LAWRENCE, plus her helpers, was the Cake Selling Stall on Maling Road, Canterbury, on 2/5/98. All cakes and biscuits were sold in 2 ? hours on the Saturday morning raising $503.

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, FRED HOOTON and MARGARET LAWRENCE for help with the mailing.

The National Council in action

Three meetings of the Council of GBS/CIDP Support Groups of Australia were held during the year, at the Alfred Hospital 21/9/97 and by telephone Conferlink 18/2/98 and 3/5/98. The President is BARBARA BURZAK-STEFANOWSKI (Vic IN Group), Vice-President HEATHER TRENORDEN (SA NRC), Secretary MELVA BEHR (Vic IN Group), delegates BETTY GERRAND and JAMES GERRAND (Vic IN Group), JOHN STANLEY (GBS Support Group of Tasmania). The GBS Association of NSW is an Associate member.

Agreement was reached on the Constitution. Action was taken by the State groups to publicise National GBS/CIDP Awareness Day 1/6/98. Letters were sent to Federal and State Ministers of Health and Shadow Ministers, seeking more funding to the Australian Red Cross so as to increase the supply of badly needed gammaglobulin. A biennial newsletter is to be produced.

CSL Ltd has kindly supported the Council by donating $600.

Action is proceeding to promote and assist the formation of GBS/CIDP support groups for Queensland and Western Australia and to establish a national data-base of members willing to support those afflicted by GBS or CIDP. NSW and Victoria has the basis of such a data base with their Questionnaires.

Sponsorship by CSL Limited

The IN Group particularly wishes to thank CSL Limited for their continuing generous support. CSL has given $900 to The IN Group for 1998/99.

Also CSL invited members of The IN Group to an Open Day inspection on Awareness Day 1/6/98 of their most impressive Broadmeadows factory where gammaglobulin in particular is prepared.

The IN Group Christmas Cards

We sold 92 of our quality IN Group Christmas Cards (12 in a packet for $10) which was all profit. this leaves 170 packets for the next one or two years for selling, again all profit. Thanks to the Kew Primary School, both for their student’s art and also their continuing help in sales.

Entertainment Books

Four Entertainment Books at $40 ($45 posted) were purchased by members to give The IN Group a quick return of $24. Both the Christmas Cards and the Entertainment Books will be available at our August and November meetings.

GBS/CIDP Awareness Day - June 1st

Our Secretary MELVA BEHR promoted the Day to the media. Our Life Member CLAIRE BROOKS was "profiled" in Terry Laidler's drive time ABC Radio 3LO program which resulted in six enquiries to The IN Group for information about GBS.

Committee Changes

Deputy-Director BARBARA BURZAK-STEFANOWSKI and Committee member TED BASARKE resigned from the Committee following a transfer to Traralgon. However BARBARA has promised to conduct her celebrated Dutch Auction at our November Social Luncheon. Thanks BARBARA and TED, for your great support of The IN Group.

Treasurer PHYL CAMERON resigned at the end of May for personal reasons. Thanks PHYL for filling the breach so capably. Fortunately former Treasurer NORM BLYTH agreed to return until at least the AGM.

Thanks

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

JAMES GERRAND, Director.

1998 Annual General Meeting

At the AGM held 12/8/98 before the address by Dr VALLIPURAM on Pain Management the following were elected to the 1998/99 Committee:

Director JAMES GERRAND
Deputy Director MARGARET LAWRENCE
Secretary MELVA BEHR
Treasurer NORM BLYTH
Members JOE BEHR
VILMA CLARKE
BETTY GERRAND
ROSEMARY MACQUALTER

The reports of the Director and the Treasurer for the financial year 1997/98 (see above and below) were endorsed.

TREASURER's REPORT for Year ending 30/6/98 (30/6/97)

INCOME and EXPENDITURE

INCOME:	Membership fees	$2618.74	(1970.00)
	Donations	3208.24	(3409.37)
	CSL sponsorship	2400.00	(1196.00)
	Sale of Christmas Cards	939.50	(1471.00)

Sale of Entertainment Books	160.00	(135.00)
Proceeds of raffles	541.50	(160.00)
Other fund raising (Luncheons, Film Social, Auction)	1307.78	(1162.82)
Bank interest	5.72	(59.75)
Total income	11981.48	(10599.59)

EXPENDITURE:			
	Newsletter "INformation"	$1021.05	
	Printing inc. GBS, CIDP booklets	234.00	
	Internet costs	535.55	
	Cost of Entertainment Books	128.00	
	Incorporation charge	32.00	
	Donation to RCH Research Foundation for Dr Kornberg's research	3000.00	(3000.00)
	Purchase of Term Deposit	3000.00	
	Australian Council of GBS/CIDP Societies	166.90	
	Postage Stamps	366.50	
	Misc. expenses (Running Costs)	1592.14	(2535.79)
	State Govt. Duty and tax	20.64	(11.64)
	Total expenditure	$10096.78	($8875.99)
	Total income over expenditure	$1884.70	($1724.60)

ASSETS and LIABILITIES

ASSETS:			
	Bank balance 30/6/98 (30/6/97) $7183.08 (5298.38)		
	Term Deposit 3000.00		
	Computer 486, cost $2600, depreciation $1600	1000.00	(1800.00)
	Epson Printer, cost $520, depreciation $400	120.00	(150.00)
	Fax-Modem, cost $444, depreciation $394	50.00	(70.00)
	Tape Recorder, cost $46, depreciation $26	20.00	(24.00)
	Sony Audiotape Transcriber, cost $300. dep. $250	50.00	(100.00)
	FM Public Address System, cost $119, dep. S69	50.00	(70.00)
	170 Packets of Christmas Cards	1700.00	(2860.00)
	Total assets	$13173.08	($10406.56)

LIABILITIES: Nil.

P.Cameron/J.Gerrand,
Treasurer.

The IN Group Christmas Cards

These quality Christmas Cards are again available at $10 a packet of 12 ($12.50 inc. postage). Sales last year raised $934; your buying this year of a similar or greater number will bring in a similar amount 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 15th November.

1998/99 Entertainment Books

Members who purchase these books at $45 each ($50 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 $9 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.

THANKS for $3,050 DONATION

Dear James,

I write to again express my sincere thank you to you and The IN Group for your kind donation for research into immune mediated neuropathy such as GBS and CIDP.

Your last kind donation went towards the purchase of a computer system which allows us to process and analyse the data collected, as well as set up the data base for the Fairfield GBS cases. I enclose a photograph of the computer with The IN Group dedication.

This money will be used towards a salary for a visiting scholar who is currently involved in a review of the Guillain-Barre patients at the Children's Hospital over the last 20 years with analysis of clinical data, serum data to provide prognostic indications.

Once again I just want to thank The IN Group for their kind support of my research and hope that this short note provides you with information as to the great help your donations have been.

Kindest regards,
Dr A J KORNBERG
Pediatric Neurologist
Dept of Neurology
Royal Children's Hospital

Two booklets to help senior citizens

Member FRED HOOTON has kindly made The IN Group aware of two excellent publications that provide helpful information to the older generation.

Aged Care - make the choices that are right for you", published by the Aged and Community Care Division, Department of Health and Family Services, Commonwealth of Australia, details what this Commonwealth Department makes available to older Australians through its aged care system. The "system is designed to ensure that older Australians will receive support and care when they need it most - with services that help them stay in their homes or, if they need it, to move into residential Care". "There are also short care options - again either in a person's own home or in residential care. This short-term care is called respite care." "For younger people with disabilities some information in this booklet will be relevant."

A Guide to Services for Older Victorians is published by the Aged Care Branch, Victorian Department of Human Services, "to ensure that older Victorians are aware of the range of services, benefits and opportunities which are available to them".

Both booklets are available from the respective Departments.

Film Luncheon

Our next Film Luncheon will be on Thursday 17th September 11am at the Balwyn Cinema 231 Whitehorse Rd. The cost for viewing the "Washington Square" followed by a nice sandwich lunch is $10.

Please book with BETTY 9853 6443 by Monday 14th. The theatre holds us liable for the number we advise two days before the luncheon.

BOOKLET REVIEW

A Road to Recovery A-Z by member JUNE CATHCART. 1998 ppbk 36pp. Privately published. $6 (inc. postage) from The IN Group.

Review by James Gerrand

June has written an excellent, most readable summation on how to cope with, and recover from, GBS based on her personal involvement with the syndrome.

Ten years ago she contracted GBS. During her recovery she has had many experiences which she feels could be helpful to other patients. This inspired her to write this informative booklet.

I am surprised and pleased how well June’s crafty idea works, of conveying her knowledge under headings in alphabetical order.

I recommend this booklet to all past and present sufferers from GBS and CIDP, their carers, family and friends.

June arranged the publication at her own expense and has expressed her wish that all proceeds from the sale of the booklet be used by The IN Group for research into GBS/CIDP.

Booklets are available at our meetings or by mail from The IN Group - use the Mail order on the "INformation" newsletter wrapper.

Thanks June, I believe your product should be a best seller. PS. JOHN POLLARD’s booklet, Boy, is this Guy Sick, a "truthful if not totally serious account of his GBS experience" is also available by the Mail Order.

Support is the Name of our Game

This is a good example of how useful the new Questionnaire is in helping support. I received an application for membership for COLLEEN TAINTON from her friend KATHERINE LEE who advised me that Colleen, a young woman in her 20s, was recovering from GBS at the Royal Talbot

Rehabilitation Centre, Kew. I consulted the Questionnaire file and contacted member GINA MERNONE, of a similar age group to Colleen, who had GBS similarly and recovered well. Gina kindly visited Colleen to give her much valued support. Colleen has now recovered sufficiently to be back home.

Subsequently I met Gina when we both happened to visit member JOHN POLLARD at the Peter MacCallum Cancer Institute where John was being treated for a recurrence of a cancer. Gina and John had met when both were undergoing rehab at the Caulfield Rehab Centre following their GBS affliction. The pleasing news from John is that he is making a good recovery.

Another helpful support was given by member PAULINE WHITELAW who kindly visited Kathy van der Zypp at the Monash Medical Centre. Her husband ANDY had contacted me seeking help for Kathy following her being stricken by GBS. Kathy is shortly to transfer to the Mt Eliza Rehab Centre so I will be consulting the Questionnaire to see if there is a lady in her sixties or so and convenient to Mt Eliza who has had a similar experience and prepared to provide a support visit.

A report from Wodonga

Dear James,

Last Friday I visited Ray ... at the Albury Base Hospital. As you know he has GBS. He was pleased to see me and also pleased to receive literature from yourself.

Ray was very tired and drifted off to sleep a couple of times so I didn't stay long. Some one else had visited the other chap so I only saw Ray. Ray was still able to move his arms, and his legs only slightly. He was suffering from general weakness and pins and needles. He comes from Mt. Beauty and was diagnosed immediately which was fortunate. He had received Intragam. I will be in touch with him again.

During the course of my visit I was asked to give a talk on GBS. There were about eight nurses who showed a lot of interest in my story and GBS in general. They videoed my talk so they could show any nurses not present at a later date.

They asked about specialised Rehab for GBS patients and as I didn't know much on that subject I told them I would mention this to the support group. Perhaps you may be able to find out if the Rehab is specialised, ie different from stroke victims and pass any info on to them. They seemed eager to give the best available care.

I'm sure the Staff and patients appreciate the help of the support Group.

It certainly makes it easier for the patients if they understand their illness.

JILL GRIMMOND

A pleasing appreciation

Dear James,

Thank you for contacting people within our area to discuss GBS with the two gentlemen on our Rehabilitation Ward.

They also appreciated receiving the valuable information you sent to us as did our nursing staff.

Your consideration and co-operation has been much appreciated so once again, thank you very much.

JEANNE O'NEILL, Nursing Unit Manager

JILLIAN REID, Registered Nurse

Rehabilitation Ward, Albury Base Hospital

1st International Neurocare Conference

The Conference is being held in Adelaide 3-5 September and its theme is "Models of Care and Management in Neurology". HEATHER TRENORDEN, of the Neurological Resource Centre of South Australia, will be, as Vice-President of the Council of GBS/CIDP Support Groups of Australia, will be promoting the support for such Care and Management provided by the Council and its member Societies (which includes The IN Group) by a display of material on a stall.

Video - CHALLENGES AND CHOICES

This video "Exploring the non-physical issues of Guillain-Barre Syndrome and Chronic Inflammatory Demyelinating Polyneuropathy" (duration 27.5 minutes) was produced as an Occupational Therapy student project for the Neurological Resource Centre of South Australia with sponsorship by CSL Pty Ltd.

The video was shown at the Winter Social Luncheon held Sunday 28/6/98 at the home of MARGARET and DOUG LAWRENCE to general acclaim.

Its next presentation will be at the Summer Social Luncheon to be held Sunday 15th November at the Balwyn Library Meeting Room. See wrapper for details.

Internet's World-Wide Help

Being on the internet, thanks to CSL Ltd's continuing generous support, is a wonderful means of quickly and personally helping people world wide, afflicted with GBS and CIDP.

The most recent and telling example comes from Spain. The email tells the story.

28/8/98 VERY URGENT

Dear:

Doctors here tell us very bad news. The said that time, Vanessa has not posibility de recourver. They said she has not ayounal capacity to recouver.Yesterday they tell that movement on her eyes, tongue, jam was a little signal of recouver. But now they said it does not import. Now has past 12 days and beguns the second series of gammaglobuline in next five days.Heart is ok. but little taquicardia. (120 140 C.) Please can yuo call to hospital JUAN XXII of Tarragona (Spain) telefon number: 977295800. conect with U.C.I. , Doctor. ALONSO. or Dra. BoquQ and talk with themi.

Were very gratefull to you. We relay on you as dor only hope.

Thank you very much.

All VANESSA'S family

Reply 28/8/98

Dear All Vanessa's Family,

I will do what I can as Director of The IN Support Group. I shall be telephoning the hospital at 10am your time today Thursday to tell them you have contacted The IN Group for help.

I shall say I am pleased that Vanessa is evidently having the right treatment (gammaglobulin intravenous drip). I will tell them I am surprised to hear of talk of doubt about Vanessa's recovery as our experience is that practically all cases of GBS do recover except for the one or two percent that might develop pneumonia or such like.

If I can't communicate with the hospital staff in English I hope to get my eldest son Peter to do the talking as he is fluent in Spanish. How old is Vanessa and how soon was she diagnosed?

Best wishes to Vanessa and family,

Regards,

James Gerrand.

At 10am (Spain time) I managed to talk to the doctor treating Vanessa who spoke English.

Dear Vanessa's family,

At 10am your time I spoke to an English speaking doctor, Dr Constansa?, who explained the treatment given to 24 year old Vanessa and her present condition. I told him I was impressed how Vanessa had been given all the right treatment as I understood it, including plasmapheresis (5 times), and the gammaglobulin. They are proposing further treatments of gammaglobulin.

I told the doctor our and other published experience was that some GBS patients did get very severely affected a number of our members have been so paralysed that they could only move their eyelids but they all slowly recovered after going down to a bottom plateau.

I thanked the doctor for his willingness to discuss the case with me. My best wishes to Vanessa. Have patience, Vanessa family, and I believe she will slowly get better.

Let me know how she gets on. I can airmail you a GBS booklet published by the GBS Foundation International (a US body) which The IN Group has reprinted if you send me your address.

Regards,
James Gerrand
28/8/98

Vanessa's family's response

Juan XXII Hospital TARRAGONA (SPAIN)

uci@hjxxiii.ece.es.

THANK YOU VERY MUCH

ALL VANESSA'S FAMILY

Now, a lighter note from the "Chat Club"

JACQUELINE TRAPP from the USA gave some new definitions of some 36 medical terms. I print the first 9 below, with the remainder being published in successive issues of "INformation".

Artery...The study of paintings.

Benign...What you be after eight.

Bacteria...Back door to cafeteria.

Barium...What doctors do when patients die.

Caesarian Section...A locality in Rome.

CATscan...Searching for kitty.

Cauterise...Made eye contact with her.

Colic...A sheep dog.

Coma...A punctuation mark.

I welcome any local additions, Editor.

See you at the Summer Social Luncheon

Sunday 15th November at 1pm, Balwyn Library Meeting Room, 336 Whitehorse Road

And a reminder for the Film Luncheon Thurs. 17th Sept. 11am "Washington Square".

Last Updated: 15 Oct 2007 17:49