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Council of CBS/CDIP Support Groups of Australia?

Newsletter No.18 - March 1997

*By James Gerrand,
Director, The IN Group*

I believe what is now needed is a national Council representing the State GBS/CIDP support groups that will meet annually, and, on occasions, specially, to establish agreed policies to promote national support for GBS/CIDP sufferers.

As well, such a Council would have two ongoing responsibilities. The first would be to endeavour to establish a support group, "cluster" (a small sub-group) or, at least, one representative, in Canberra ACT to particularly and personally lobby the Federal Government on matters of concern, such as the present shortage of gammaglobulin. When some 18 months ago I had discussions with the then manager of CSL's Bioplasma Division, Mr Jack Woods, he suggested we form a national body with a representative in Canberra for such a lobbying purpose.

The second ongoing responsibility would be to establish and run a national data-base, listing all members belonging to Australian support groups and including details of those members prepared to support current GBS and CIDP sufferers. This is what is done to a varying degree by those state organisations that presently exist. A national data-base will cover states that have still to establish GBS/CIDP support groups - Queensland and Western Australia. Having an agreed format for the data base will assist the support efforts. The IN Group would be prepared to take on this task on behalf of the Council - our committee member Melva Behr has already volunteered to take charge and member Robert Baird has agreed to prepare the data base. State support groups would provide the data as supplied by their members and would be able to readily obtain desired data from this base.

I have prepared a draft of a proposed constitution for this Council.

After receiving general agreement by your committee and by members attending our quarterly meeting of the 11th February, I have sent this proposal to the other three State groups presently existing - the GBS Association of NSW (Inc), the Neurological Resource Centre of South Australia Inc. and the GBS Support GBS Support Group of Tasmania - for their consideration and comments, with the earnest hope that the above (with possible amendment) will be acceptable as being a means of further assisting the sufferers from GBS and CIDP.

GBS/CIDP Awareness Day

May 1st 1997

Following the lead of the US support group, the GBS Foundation International, it is hoped to establish this **GBS/CIDP Awareness Day** on a national basis, to be celebrated on May 1st each year.

MELVA BEHR, Public Relations Officer for The IN Group has already written to two Senators, Judith Troeth and Rod Kemp, and is contacting local MHR Bernie Finn.

A great means of publicity is to have an article published in the local paper featuring the experiences of a member with photo. **CLAIRE BROOKS** has already led the way by volunteering for her area of Malvern.

If you can help this way please contact Melva Behr tel 9740 8983.

Independent Living

Due to illness, our scheduled speaker from the Independent Living Centre was not able to be present at our quarterly meeting on the evening of Tuesday 11th February. So, instead, members who had been helped by the Centre were asked to tell and be questioned of their experiences.

James Gerrand led off, relating how he and wife Betty had used the Centre to design their home some five years ago to suit James diagnosed with CIDP and a possible prognosis of ending up in a wheelchair. They had been living in a two storey townhouse.

The advice of the Centre was very beneficial. It included wide doorways, open living areas, ramps to outside doors and easy access from the garage, all to facilitate a wheelchair.

Betty informed members of just some of the helpful ideas they obtained from the Centre - knock-on action taps, drawers to hold utensils, etc rather than shelves in the kitchen cupboards, an oven door that opened sideways rather than downwards, windows that wind out rather than up and down, an opening under the kitchen bench top to allow a person in a wheelchair to be close to the bench top, higher toilet seat, shower with no lip on the floor surface with pull around curtains and handbasins that extend past the vanity area to allow for wheelchair access. There are bathroom and kitchen designs available.

Every kitchen appliance and gadget is on display at the Centre. The Centre recommends Pegulan floor covering in the kitchen as it is easily maintained and not slippery. Short pile, not shaggy, wall-to-wall carpet is recommended for living areas.

The Centre has a variety of wheelchairs and motorised models as well as ejection chairs on display.

If you make an appointment with the Independent Living Centre - 52 Thistlewaite St SOUTH MELBOURNE tel 9254 5400 - the staff will spend an hour or two with you giving appropriate advice for your situation.

Various other matters - a National Council, Linen Party, Cluster Groups, GBS/CIDP Awareness Day, Gammaglobulin Shortage - were discussed and reported elsewhere in this issue.

The meeting ended with informal discussion over the usual pleasing supper.

Linen, Basket and Hydrotherapy Party

Members are invited to attend the Linen and Basket party with our Secretary **VILMA CLARKE** as demonstrator to be held at the home of **MELVA** and **JOE BEHR**

3 Briarwood Court, SUNBURY
Saturday 15th March at 2pm.
tel 9740 8983

A large range of table linen and towels, baskets and other items, will be available for purchase.

Members are also invited to try the hydrotherapy pool and spa Joe and Melva have had installed. (I can recommend it. Editor)

A percentage of the sales will be donated to The IN Group.

Cluster Groups

Thought I would run a little idea past you that is working in the North East Victoria and could work in Melbourne. The idea is "**Cluster Groups**". Under a Convenor, perhaps once in 3 months after our General Meeting, people within, say, a 20 minute drive of the central point could be invited for afternoon tea, supper or whatever so that they could get to know each other and exchange ideas, information and just good camaraderie. When there is any new "patient" someone can be elected to visit and welcome him/her. The Convenor can then report to the General Meeting and bring along new members.

Up our way we go out to lunch and have become quite close friends. We were asked to speak at one of the private hospitals about the two disorders and what we as patients would like the hospital to do or not do for us.

I think we could have say 3 groups at this stage - Sunbury/Footscray area, the Peninsular and Glen Waverley/Box Hill/Nunawading. Can we have feedback on this? Call me 0357221633 (W) or 0357221183 (H) or write PO Box 709 Wangaratta 3676. Also perhaps there is someone who would like to be a Convenor and start the ball rolling.

VILMA CLARKE, Secretary.

(Note. MELVA BEHR phone 97408983 has volunteered to be the Convenor for the Sunbury/Footscray area.)

Shortage of Intragam

I first learnt of the recent shortage of Intragam, the gammaglobulin produced by CSL Pty Ltd and a favoured treatment for GBS and CIDP, when I was "short-changed" 5 weeks ago being given only 24gm instead of the usual 30gm on my fortnightly visit. Then I was informed the day before my next visit that there would be no Intragam for me. Fortunately on my next visit a week ago I was treated with 36gm, the extra amount given to make up somewhat for the previous deficiencies.

I am informed by Dr Patrick Coghlan, Acting Director of the Red Cross Blood Bank Victoria, that the shortage has been due to the extra demand from Intragam being used for an increasing variety of ailments. What is needed is more donors.

We can assist by talking to family, friends and social acquaintances about the importance of Intragam to many lives, thus encouraging many to donate.

For more information call (03) 9694 0300.

Membership

We continue to grow, our membership now 215. We would like to thank all those who continue to support the efforts of The IN Group and to welcome the following members, particularly those from interstate and overseas.

Victoria: Suzanne Adams, Black Rock; Douglas Carter, Reservoir; Sheryl Worrell, Frankston; Colleen Nulty, Greensborough.

Interstate: Martin Carr, Bridgetown WA; Nancy O'Brien, Launceston.

Overseas: Isao & Takako Kanai, Aichi Japan; Leonard Gerstein, Boca Raton Florida USA; Phyllis J. Oling, Longmont Colorado USA; Hoyt D. Staton, Selma Alabama USA; Linda Booth, Ipswich Suffolk UK.

Generous Donations to Medical Research

The IN Group wishes to particularly thank two members for recent generous gifts to our Medical Research Fund helping Dr **ANDREW KORNBERG** with his research into GBS and CIDP at the Royal Children's hospital: Brigadier Keith Colwill (\$250) and **IRMA HANNER** (\$20).

Sales of our Xmas Cards last year of about 200 packets have nearly covered the costs of our order of 500 packets so selling another 200 packets in 1997 will bring in some \$2,000 to the Fund.

Chatting on the Internet

At least one other of our members, **MARGOT BROWNING** together with her husband **GEORGE**, has found it fascinating to connect to the Internet and subscribe to a particular "chat club" GBS.etal@gbs.org . About a hundred members subscribe, mainly from the USA, and pass messages seeking help about problems they encounter with their GBS or CIDP such as pain, choking when eating, costs of treatment (in the USA). It is the next best thing to having personal support and with the support coming from anywhere in the world.

As well lighter messages such as how their kid is getting on at school, or the prospects of getting a job can be aired.

Then there are numerous items to cheer one up. Here are two recent ones.

Four Bodies

Once upon a time there were four people. Their names were Everybody, Somebody, Nobody and Anybody. Whenever there was an important job to be done, Everybody was sure that Somebody would do it. Anybody could have done it, but Nobody did it. Everybody got angry because it was Everybody's job. Everybody thought that Somebody would do it but Nobody realised that Nobody would do it. So consequently Everybody blamed Somebody when Nobody did what Anybody could have done in the first place. (from Arlene M Miller)

Fortunately The IN Group is nothing like the above. Then there is this tale for those in the USA who have had to fight with insurance companies.

At Heaven's gate

Three people were waiting in line at Heaven's gate to get in. The first was called up and asked what he did to get in and he replied "I was a doctor and I helped people". St Peter said "Okay come in". The second one approached the gates and upon the same question being asked the same question answered "I was a nurse and helped people to get better". She got in. The third one approached and answered the question "I was CEO of a medical insurance office". St Peter thought for a minute and said "Okay, you can come in for a month, then you're out". (from Marie Feliciano)

I fear this is the way our hospitals may be going.

A news item from the Internet

Andy Leitch of the UK supplied this report from the Daily Mail (London England) 7/1/97.

"For the first time, doctors have reported the case of a mother and her new-born son being severely affected by a nervous system disease called Guillain-Barre syndrome, a rare consequence of a viral infection. The woman was 29 weeks pregnant when she developed it, became paralysed and unable to breathe without mechanical help, says a report in The Lancet. Her son was born at 38 weeks whilst she was still unconscious and he developed the syndrome at 12 days. Both improved after treatment."

GBS is regarded as an acquired condition and not inherited. Do the newly-born have the same immune reactions as their mothers until they develop their own? I will try to get the article and report back. 30/1/97.

Report on Miami Symposium

Andy Leitch of the GBS Support Group of the UK and editor of their journal "Outreach" sent me by e-mail 19/2/97 a 10 page report on the Miami Symposium on GBS and CIDP of last November organised by the USA GBS Foundation International. The report was made by a fellow member of the UK Support Group, Sandra Stellman, who attended the Symposium. Andy has sent it to the GBS Foundation International for vetting, expected to be cleared within a fortnight.

I found it quite interesting and will send it at cost, \$2 inc. postage, to those who wish it, once it is cleared.

A virus attack

I was warned by a friend who had sent me a 3 1/2 disk that I may have a virus in the computer. I thereupon consulted my friend and computer guru, Greg Keogh, who posted me a program VET on loan to check for and possibly eliminate the virus. Well a "junkie" virus was found and eliminated.

To guard against future virus attacks it is necessary to purchase this VET program, a product of a company CYBEC.

I am pleased to announce that CSL has verbally agreed to pay the initial one year's cost of \$126 for this program.

Thank you, CSL, for your continuing financial support of The IN Group.

Support - The Name of our Game

Our member **BRIAN LUSCOMBE** has continued his support through fortnightly visits to **BARRY STEEL** recovering in Intensive Care from a paralysing bout of GBS at the Royal Melbourne Hospital. Barry's recovery is slow but he is tenacious and determined to get back on his feet and the farm, particularly now that wife Linda has given birth to twin daughters to add to their two sons.

KEITH COLWILL reports "*Of the four GBS patients I have been visiting at Caulfield General Medical Centre, only **BILL EADES** is still in hospital. He has had some serious setbacks and has made just slight progress as a result. But his determination to improve is as fine as ever. He is to be admired for his optimistic resolve. ... The other three patients were hospitalised for relatively short periods and made good recoveries. They were Bill White, Bryan Marriott and Jeff McGinty.*" **BRYAN MARRIOTT** gave a "pat on the back" to Keith for his support and has joined the Group.

MARGARET LAWRENCE was the first to let me know of a cry for help in the Women's Day "Helpline" of 10/2/97, from **Sandy Henderson** of Queensland, seeking support from fellow-sufferers from GBS. I sent her information on The IN Group - brochure and newsletter.

PAULINE WHITELAW and **CLAIRE BROOKS** have been supportive of Edna Laidlaw, laid low with GBS at the Monash Medical Centre and then recuperating at Cedar Court Private Hospital. Claire reports "*James rang me and asked me to visit Edna ... Her daughter rang the "IN Group" and wanted someone to go and speak to her mother. We had a good talk about her attack of GBS. I have rung her each week and she asked me lots of questions and she seems to be going well. ...like me she will be living alone. ... I gave her information regarding the council. ...*"

I visited **BROOKE TAYLOR** at St Vincent's Private Hospital. Brooke unfortunately has suffered a recurrence of GBS but fortunately she appears to be recovering - that day she was able to get out of bed with help and sit in a chair. I was pleased to meet her mother Jan Litchfield and grandmother.

A letter from **ALISON CARTER** "*...Thank you for your time on the telephone and for supplying us with information on CIDP. It has helped answer some questions ... Doug is going to the Royal Melbourne and having treatments fortnightly. ... Knowing that there is a support group and knowing that others have to deal with CIDP helps us.*"

And from member **PATSY KELLY** of Dallas, Texas USA. "*I finally graduated from Baylor Pain Management Program. It taught us how to deal with pain. It was like going back to school. We had a test 3 times a week and I had a binder at least 5 inches thick. ... My doctor, nurse and friends and myself really look forward to reading the newsletter 'INformation'.*" Patsy has sent me a set of 25 drawings illustrating the physio exercises that were part of her course.

JAMES GERRAND

Last Updated: 15 Oct 2007 17:49