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NEWSLETTER OF THE IN GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC. Supp
sufferers from acute Guiilain-Barre Syndrome (G3S) and Chronic Inflammatory Dernyelmaiing Poiyneuropathy (CIDP'i

EMG IN INFLAMMATORY

DEMYELINATING NEUROPATHIES

Richard Macdonell, MD, FRACP
Neurology Department, Austin Hospital

Inflammatory demyelinating neuropathies be they either of the acute variety also known as the Guillain Barre syndrome or the chronic variety called for short CIDP (chronic inflammatory demyelinating polyneuropathy) both cause a loss of the myelin or insulation sheath from peripheral nerves. As a result of this the sufferer experiences weakness of muscles which are supplied by the nerves affected as well as alterations in sensation causing either tingling or numbness.

The story of the illness together with the findings on examination of weakness, loss of reflexes and sensory loss often suggest the diagnosis. There are only two tests however which can confirm a process affecting the peripheral nerves. The first of these is the one most widely used and that is EMG and nerve conduction studies.

The other test is a nerve biopsy which is reserved for patients where the diagnosis is not clear after nerve conduction studies are performed.

Nerve conduction studies involve the application of electric current to a peripheral nerve. All nerves are electrically excitable and the stimulation produces a current within the nerve which then travels down to the muscle. This in turn causes muscle contraction and a visible twitch. By measuring the speed with which the current passes down the nerve to the muscle it is possible to determine whether any abnormal process is affecting the nerve. The finding which characterises a demyelinating neuropathy from other forms

than where the nerve can commonly compressed by overlying ligaments tendons. Conduction block is where nerve may be stimulated at the periphery such as at the wrist and normal muscle response obtained. If nerve is then stimulated further up arm but only a much smaller respon can be obtained, this indicates a co duction block within the nerve. Co duction block is the hallmark of demyelinating neuropathies. This blo can be quite close to the spinal co and one way of searching for this is look at what are known as F-wave F-waves are evoked in the same way in other stimulations of the nerve b involve the passage of current alo the nerve to the spinal cord and th back again to the muscle. Small mus contractions are evoked by this tec nique and the time it takes for the to occur can be used as a marker something affecting the portion of nerve closest to the spinal cord.

Typically in the earliest phases the Guillain-Barre syndrome, ner conduction studies in the periphery a normal but F-waves are either abse or prolonged. This may be the on indication of a process affecting nerves. As the disease progresses more particularly in the chronic fo of the inflammatory neuropathies co duction block in the forearm or in calf are more commonly found.

In addition the size of the mus potential obtained gives a reflection the number of surviving nerve fibr

the nerve the more severe is the illness and this is our best guide as to how long it may be before any recovery is expected. A further test which may help in this regard is to use a small needle, a bit like an acupuncture needle, inserted into muscles. If the nerve fibres of axons have been damaged or destroyed as well as the myel-in sheath, one sees discharges occurring from the muscle as a result of loss of its nerve supply. If these are profuse it is likely that recovery will be more protracted than if no evidence of loss of axons is found.

By doing EMG tests it is usually possible to distinguish a neuropathy as a cause of weakness rather than something affecting the muscles primarily and also to distinguish a demyelinatihg neuropathy from other forms of neuropathy. Repeat studies after treatment for the inflammatory neuropathies may be of some value but unfortunately there is not a strong correlation between the results of follow-up nerve conduction studies and recovery from the illness. One may still see evidence of conduction block even in patients who seemingly make quite good recoveries and therefore it cannot be used as a guide as to whether further treatment would be effective.

In conclusion therefore, even though these tests can be quite uncomfortable, particularly in patients with inflammatory neuropathies because of the higher intensities that often need to be used to make sure that all nerve fibres are being stimulated, these tests are invaluable in obtaining the correct diagnosis and instigating appropriate therapy, be it plasma exchange, or Int-ragam or steroids at an early stage and also with a reasonable chance of having a beneficial response. *This article is based on the presentation given by the author, which included illustrative slides and a demonstration of the EMG test machine, to the May meeting of The IN Group.*

Annual Subscription now due

The annual subscription to The IN Group is due from 1st July 1994. (New members who have joined in 1994 are covered until 1/7/95.) A form is enclosed. A prompt renewal (and a donation - which is tax deductible - if you think our efforts deserve more support) saves a lot of secretarial work.

ANNUAL GENERAL MEETING

The Annual General Meeting of The IN Group is to be held on Tuesday 9th August at 7.30pm at 4 Alandale Avenue 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 enclosed leaflet.

Following this business, hopefully by 8pm, we will be addressed by Cindy Shaw, Social Worker from the Department of Social Security, Camberwell, on "How the Disabled can be Socially helped". Details are on an enclosed leaflet. GBS Support Group of Tasmania formed

Our congratulations to member John Stanley of Devonport for forming this Tasmanian Support Group. And he did it in style - a public launch at the Launceston General Hospital on Sunday 15th May at which their Consultant Neurologist Dr Stan Siejka gave a talk and our member and Collingwood football star Graham Wright kindly participated. Graham's support attracted the media, the launch being featured in the two Tasmanian papers (one reprinted back page) and TV stations. John Stanley has sent me a video of the launch which I expect to show at our August meeting.

As a result of the launch, the Tasmanian Group now has 35 members and has arranged its first support visit to a sufferer in Launceston. Great work, John. Help from Australian Brain Foundation

The Australian Brain Foundation, through its National Executive Director, Mrs Sandra Tidd, has kindly offered the use of their facilities at 746 Burke Rd, Camberwell - telephone, mailing, photocopying, meeting venue - as a means of aiding The IN Group. We will keep this in mind for the future if we find our present facilities can no longer cope.

GBS foundation international

This support organisation is USA based (PO Box 262, Wynnewood, PA 19096). Its Spring 1994 newsletter "Communicator" is devoted to medical issues witb__ _six pages of articles written by members of their Medical Advisory Board. Photo copies will be available at our August meeting or by contacting me: James Gerrand, 138 B Princess St, KEW 3101 tel/fax modem 853 6443.

DIRECTOR' REPORT Year 1993/4

The IN Group has continued to justify its existence, particularly through the personal support given to GBS and CIDP sufferers and their families. 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 87 to 120 which includes 88 past and present IN sufferers. Quarterly Meetings.

These meetings have continued to be popular. Quality speakers for the Tuesday evening meetings - BARBARA BURZAK-STEFANOWSKI, Chief Physiotherapist, Fairfield Hospital, on "Physiotherapy of the IN Patient" 10/8/93, "LU CRAVEN, Occupational Therapist, Fairfield Hospital on "Occupational Therapy for the IN Patient" 8/2/94 and Dr RICHARD MACDONELL, Neurology Department, Austin Hospital, on "EMG in Inflammatory Neuropathies" 10/5/94 -were very helpful both through their addresses and also subsequent questions and discussion. The Sunday daytime meeting 14/11/94 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 Brennan, Betty Gerrand and Fred Hooton for help with the mailing. Purchase of Fax/Modem and Printer

Thanks to the generous donations from many members The IN Group has now a fax/modem to send and receive faxes and an inkjet printer to print received faxes, this newsletter and correspondence. Both work in conjunction with an IBM compatible computer. IN CONTACT Network

It has proven difficult to maintain and develop this network, planned to *be* the means of The IN Group quickly being advised of IN patients needing support and being able to quickly respond. The problem is maintaining a Hospital Contact person to advise us due to IN disorders being relatively rare and so easily lost sight of amongst many other afflictions. There is also the necessary factor of protecting patient privacy which can set a barrier to ready communication. Epidemiology Study

The interviews of the trial 25 volunteers for this study are nearing completion. These will be analysed to see if any changes are needed before proceeding to interviewing the others who have responded. The interviews are based on a questionnaire prepared by our Consultant Neurologist Dr Bruce Day assisted by our Consultant Epidemiologist Dr Allen Christophers.

TREASURER'S REPORT for the Year ending 30/6/94 (30/6/93)

INCOME and EXPENDITURE

INCOME: Membership fees and donations	$2057.00	(1602.00)
Bank interest	22.50	(20.21)
Total income	2079.50	(1622.21)
EXPENDITURE: Postage	$374.00	(334.45)
Stationery		
Copying, word processing, facsimiles	75.48	(27.14)
Telephone	349.95	(114.00)
Secretarial	57.50	(30.00)
Incorporation charges		(80.00)
Purchase of Printer & Fax/Modem & Software	29.00	(91.00)
Bank charges and miscellaneous	1069.40	
	20.27	
Total expenditure	$2053.05	($676.59)
Total income over expenditure	$26.43	($945.62)
Bank balance at 30/6/94 (30/6/93)	$964.40	($945.62)

N.A.Blyth, Treasurer.

IN CONTACT

Support in the Latrobe

Stuart Vincent, Traralgon reports:

Following your phone call I got in touch with Bill Lucier (suffering from GBS) at the Latrobe Regional Hospital -Rehab Ward. Bill is 65 and contracted GBS in Dec'93 and sent to Royal Melbourne where he recovered well (according to him) following Intragam treatment. He returned home but was struck down again in early April. Bill is confined to a wheel chair and has numbness in his hands as well. The Rehab Centre is making modifications to his home to enable him to spend weekends at home.

Bin was most appreciative of my visit and the Newsletters" you forwarded. I will keep in touch with Bill and will be visiting again.

Support at Fairfield

Following a ring from Fairfield physio, I visited Ian Hawkins after he was transferred to a general ward after being in Intensive Care from contracting GBS. Ian was pleased to see me particularly as we found we were fellow engineers and Skeptics!. Ian is now a member of The IN Group.

North East Victoria

Our Secretary, VILMA CLARKE of Wangaratta, has been busy covering this territory. She is making regular contacts with other members - JOHN WARD of Beechworth, JILL GRIMMOND of Wodonga and LURLENE BUTLER of Lavington.

LETTERS

Dear James,

Sharing the good news

I want to share with The IN Group some wonderful news... I'm IN REMISSION!!! The verdict was given at my last visit to the Doctor. The previous visit I was told "it appears that you are in the 5% who may not need the extra boost each week of plasma". I found all this news rather exhilarating.

How was all this achieved you say -I believe it was a very large slice of networking. Firstly the specialist, then the hospital of course. Then in after care sc to speak I have received so many suggestions.

The Chiropractor and CRS combined and asked me to be a guinea pig for them - virtually practising the holistic approach which is getting all parts of you right, not just your disorder.

I was then put on to some books by Louise Hay "Heal your Life" and the sequel. Whilst not going along with everything she writes I found the majority made sense.

So positive thinking became even stronger for me while recognising that various stresses in my life could have helped to bring about this disorder". With a lowered immune system - it was then suggested by my podiatrist to take certain vitamins as I had had a series of perhaps serious infections - I have not had any more for perhaps a year. The podiatrist was a great help to me and removed my first lot of pain in my feet.

Some more help came my way by virtue of the occupational therapist who provided me with a tool to cut my toe nails - I was independent again -and special pegs for the washing.

A special friend called for me and we went walking every day which I didn't like but enjoyed her company.

Finally Barbara Burzak-Stefanowski whom you all know gave me some little, simple exercises to do which have been a great help. What is left for me now is doing exercises at our heated pool which should play a big part in keeping mobile. My close friends have been a great support - I only do things I enjoy.

The above is my recipe for a Remission - thank you for letting me share it with you.

VILMA CLARKE, Wangaratta.

PS I forgot to mention (how could I) The IN Group was ever a source of medical knowledge and have found it most stimulating and have made friends through it, and the great support and understanding of my husband. SO EVERYONE GO FOR IT, BE POSITIVE; IT'S THERE FOR YOU.

Dear James,

Thrilled there is a Support Group

When I first contracted GBS in 1988 I was always searching for information about the disease. Specialist visits seemed so distant and far apart and It was during the in-between times that I would get weird sensations, different aches, numbness, etc, that I would

worry and wonder if they were normal sensations. For this reason I kept a record of my progress and at the same time I wondered if maybe there was someone else going through the same trauma.

After 9 months I returned to work (I was a teacher - homecrafts to disabled students). I think it was a turning point going back very gradually as I ached and tired after about an hour's activity - however students and teachers were so understanding and helpful.

I used up all my long service leave during the next few years and it was during one of these spells that I wrote to the Queen Elizabeth Hospital in Adelaide and immediately Rona Kvick'lys sent me a book written by Joel Steinberg and backdated Newsletters. So I then learnt how valuable a support group can be and have the opportunity to meet Rona when in Adelaide in 1993.

I had no idea that one disease with similar symptoms could have such varying effects or degrees of severity . I realise I am fortunate to be leading a fairly normal life. However this does not deter me from wishing to learn more, eg why after so many years one still becomes so achy and exhausted after exercise or why your hands and arms tingle and pain when under emotional stress. Perhaps one day we will have an answer that may help others.

I would be happy to participate in any questionnaire, etc, but because I haven't received the intravenous injection of gammaglobulin the study by Dr Day would not be appropriate.

Thank you for your invitation to meet you, maybe I will be able to attend a meeting sometime. I am amazed to read that there are 111 members.

JUNE CATHCART, Stawell.

Dear James,

A border hopper

You would have heard of me through Vilma Clarke.

I don't know if it makes any difference being a member of The IN Group of Vic as I live over the border in Albury, NSW. I was treated at the Austin, both trips to Melbourne. (No; welcome, Lurlene, we have a number of border hoppers. James)

I would like to keep up with new or past patients that have been through the Albury Base or private hospitals here. Being a member of The IN Group can make a difference.

If it is possible to get any back copies of Newsletters, I would be grateful. The medical information Vilma sent me including membership form was invaluable both to me and medical staff who helped me with my rehabilitation.I felt a lot better knowing more about the symptoms after meeting with Vilma.

If I can do the same for someone else I would like to.

LURLENE BUTLER, Lavington NSW.

Dear James,

Contact from the West

My apologies for lack of communication of my activities.

As is said "There is no fool etc"; I have taken on Secretary of the local Golf Club which has turned out to be a little bigger load than expected. Am still involved with Legacy which requires a fair bit of travelling but the rewards from my widows are worthwhile.

Have heard there were two children in Tim boon (east of Warnambool) affected by GBS but the doctor concerned is away for 12 months leave. Nothing else happening but I hope to get a paragraph in the "Warnambool Standard" soon.

GREG GILLESPIE, Peterborough.

GBS Support Group of NSW

David Paine, Secretary of the GBS Support Group of NSW, has kindly sent me an article on the experiences of a CIDP sufferer published in the newsletter "Reaching Out" of the GBS Support Group of Great Britain. This is republished in this issue pp. 6 & 7.

Nerve Research Foundation

The Annual Report 1993 of the Nerve Research Foundation includes reports on its research in the field of inflammatory neuropathy (GBS and CIDP). Our Patron Associate Professor John Pollard is now its Director; our Patron Professor Jim McLeod,AO is on its Scientific Committee and its immediate past Director.

Its newsletter "IMPULSE" reports that an epidemiological study shows that the incidence of Multiple Sclerosis is higher in cold climates; a six-fold increase from Tropical Queensland to Hobart.

Chronic Inflammatory Demyelinating Polyneuropathy

by Mrs ELLEEN EVERS,
Uplands, Warren Drive,
Kingswood, Surrey KT20 6PZ ENGLAND

Reprinted from "Reaching Out", the newsletter of the GBS Support Group of Great Britain.

Recent articles in "Reaching Out" and letters to know CIDP members have suggested the formation of a penfriend network to put CIDP sufferers in contact with one another. It had also been suggested that more CIDP news should be included in the newsletter. Without knowing all this I recently contacted the Group with an offer of help and was quickly volunteered to try and get something going.

I myself have suffered from CIDP for over five years, although it was only aBout one year ago, when I first saw Professor Hughes at Guys', that I was given this label. For me the symptoms came on very gradually over a period of several years with loss of strength and feeling spreading up my arms and legs. Much of the last five years has been a nightmare with long stays in hospital or at home unable to look after myself or do much.

I seem to have a very active form of CIDP, which requires a lot of treatment to keep it under control. However it. is not all bad news. I am lucky to have the sort of CIDP which does respond to treatment (both plasma exchange and immunog1obu1in infusions, supported by prednisol one). So I do get better as well as worse! At its worst, I have been unable to lift my hands and feet off the bed, have had difficulty swallowing and breathing (but have never been put on a ventilator), and have had problems with double vision. At. its best, in between bad times, I can walk several miles, and if you met me you would not know that there was anything wrong.

Regular treatment is needed to stop things deteriorating and any infection seems to be paticularly bad news. I can go from being able to do the family shopping at the supermarket to not being able to stand up in two or three days. It. is a bit like living on a roller-coaster, but unfortunately I can't get. off! Other drug treatments, including azathioprine and cyclosporin do not seem to have helped.

For much of the five years I have felt as if my life was completely out of control, often without hope for the future and very isolated because I didn't know anyone else with the same problem. All this in spite of a very supportive family and a good network of friends.

Over the last year we have found a successful treatment regime - regular immunoglobulin infusions together with prednisolone - and everything has become much more stable. I am able to look after myself and my family, and generally be quite active. I have even played golf.

As to the future, nobody knows what it will bring - but isn't this the same for everyone? At the moment things are under control, I can do mo"st of the things I want to do and that is good enough (most of the time!).

By the way, I am 42 and married with two teenage daughters (now aged 16 and 14). Before all this started I worked part-time as a consultant for a computer software house. Since I became ill I have had to give up work as I have been too unreliable. So apart from anything else, having CIDP has meant a great change of life-style.

I know that all our experiences of CIDP are quite different with very different, levels of disability. There are very few of us and we all have our own particular problems. But. perhaps we all have some things in common - the problem of having a rare illness which is difficult to describe, sometimes not taken seriously and difficult to diagnose; the isolation of not meeting other people in the same situation; the enormous impact which a chronic illness has on the rest, of the family; and above all, the uncertain prognosis.

Nearly all the letters received fom CIDP members offer help to the support, group. Perhaps there is a need for mutual support, where those of us enjoying a good patch can in some way help those in a bad patch. Roles could well be reversed sometime in the future!

Anyone who would like to be put in touch with other sufferers please let me know and I will circulate names to all those who are interested. Any sufferer, or family member, who would just like to talk to someone please do not hesitate to call or write to me at any time.

I woula ti-ke _To~ k"nToTf~yoLrr V'i'ews on T^hat t1re~ G r o u p-~~c~OTTtTl fcne— doing. In part i"cTTTar, i f we a-rs going to include more information in the newsletter, this has to com ~~f~r~o~m members. So please write, share your experiences, let. know about on-going problems you may have, particularly about, any success stories.

GBS Support Group of Tasmania formed

Reprinted from The Advocate-, ' Monday; May 16> -1994 - Page

SYNDROME SUFFERERS: *The organiser of the Guillain-Barre Syndrome Support Group, John Stanley (left), looks over some literature with Collingwood footballer and one-time sufferer Graeme Wright.*

Support group formed

COLLINGWOOD champion Graeme Wright knows first-hand the debilitating physical effects and the fear and confusion surrounding the little-known condition Guillain-Barre syndrome.

The premiership player and former Devonport resident was struck down by the syndrome last September but was lucky enough to fully recover.

It was this experience which led Wright to help form the Guillain-Barre Syndrome Support Group of Tasmania in Launceston yesterday.

"The group will offer support and guidance for those

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It started off as pins and needles and numbness in my feet after finishing football last year.

— Graeme Wright

The former East Devonport player had never heard of tKe—condition till he was diagnosed with it last year. __

"it started off as pins and needles and numbness in my feet after finishing football last year," Wright said.

"I went to a doctor who said it was a virus, but it got worse till I couldn't walk anymore."

"I had never heard of it. . . I was fairly well in the dack." he said.

—• Luckily^ "hE~~sTarTed to recover a month later and is now back to normal.

However, some sufferers can suffer residual effects, such as numbness, for several years.

The syndrome, which usually develops quickly, takes the form of muscle

another group exists in N South Wales.

About 240 Australians c tract the condition each y and as yet science has no i why.

Patients are treated having their blood filtered removeTbajl protein_wJiich tacks nerves.

The establishment of Tasmanian support gro was initiated by John Stanl of Devonport, who was alm killed by the condition in 19

Mr Stanley said the gr hoped to set up a network supporters across the St via a register of people w ing to support sufferers a their families