GBS ……..CIDP **Issue 80. October, 2012.**

INFORMATION

GETTING BETTER SLOWLY
NEWSLETTER OF THE IN GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC.
Supporting sufferers from acute Guillain-Barre Syndrome(GBS) & Chronic Inflammatory Demyelinating Polyneuropathy(CIDP)

ANNUAL CHRISTMAS LUNCHEON
And Dutch Auction
Balwyn Library Meeting Room, Whitehorse Road, Balwyn 12.30pm.
SUNDAY, NOVEMBER 18TH, 2012. $20 PER HEAD

The fun is on again. Come along to our Annual Christmas Luncheon. RSVP by 11th November to either Margaret 9802 5319 or Melva 9707 3278. A small wrapped gift (with an indication of value to aid the auctioneer) would be appreciated. All who attend are guaranteed a great meal with friendly company.

ANNUAL GENERAL MEETING HELD 19th AUGUST, 2012.

The President welcomed thirty one members to the meeting and extended a special welcome to Associate Professor Richard Stark and Dr. Janet Keys-Brown.

Apologies: Barbara Clifford, John DeRavin, Joe and Melva Behr, Tom and Barbara Rivett and Russell Wilson.

President's Report by Margaret Lawrence.

Once again it is my privilege as President of The IN Group to give this report.

Thank you to a wonderful Committee that are always there to assist in any way possible.

Our Christmas Luncheon last year was a great success and raised $1048. The mid year luncheon held on 17th July, 2011 raised $470.

The donations from our members never fail to amaze us, they are so generous. A big "thank you" to all those kind people.

Gwen McInnes is a tireless fund raiser, always coming up with craft ideas to sell bringing in a substantial amount each year and now is working on a 'Cook Book' which hopefully will be out soon.

Members continue to provide moral support to one another with visits and phone calls. Lots of net-working takes place when people are having treatment.

The website is well used and we get calls from therapists wishing to gain information for patients. We also have inquiries from new patients recently diagnosed.

Our guest speakers have been most interesting and the members always enjoy an open discussion group.

The newsletter is well received by everyone. My thanks to Melva and Joe. This is really a big job and it provides great information. Many people for various reasons cannot attend our meetings so the newsletter is very important.

I look forward to all the continued friendship and support from everyone. Many people give up time and money in the hope that one day a lot can be done about these debilitating illnesses. My great thanks to all the good people who make up The IN Group.

Treasurer's Report

Income for the year ending 30th June, 2012 was $6,821.
We received The Government Self Help Grant of $2000.
Expenses included increased printing costs and the purchase of a new printer for $350.
A donation of $10,000 was given in November to be used for research into CIDP/GBS by Associate Professor Andrew Kornberg at the Royal Children's Hospital.
Current Bank Balance $2,664.
In the Financial Year 2011/2012, donations in excess of annual subscriptions totalled $3,270. We are humbled by the generosity of our members.

Special thanks to CSL who continue their generous assistance with our website costs.

Committee

As there were no further nominations received, all committee positions will remain the same for 2012/2013. Rebecca Engsmyr did not seek re-election and we wish her well with the impending birth of her baby. Thank you so much Bec for all your help and support especially to newly diagnosed patients and their families.

Talk by Associate Professor Richard Stark.

Due to technical difficulties we were unable to obtain a successful recording of this most interesting and informative presentation. The members present were very appreciative of the talk and the answers to their many and varied questions. If it is possible to use the pieces of data we have obtained, these will be included in a later newsletter.

Quick Green Salad Dressing (from Gwen's recipe book to be published later in the year.)

2 dessertspoons of sugar
½ cup of vinegar
1 tablespoon of condensed milk
1 teaspoon of mustard
½ teaspoon of salt
1 whole egg

Shake together until mixed

The following excerpts are from the GBS/CIDP Foundation International's **Medical Issue** of their Summer 2012 publication "**The Communicator**."

CIDP: An Update

David R. Cornblath, MD

Member GBS/CIDP Foundation International Medical Advisory Board and Board of Directors

As many of you hopefully heard, the GBS-CIDP Fl has sponsored a series of talks around the country entitled, "CIDP, an Update." Supported by two anonymous donors, this program sponsors a member of the Medical Advisory Board to give a talk to people with CIDP and their supporters. So far, programs have been held in Baltimore, St. Louis, Chicago, Boston and Philadelphia. Held on a Saturday, the purpose of the talks is several fold.

First, members of the MAB believe that diagnosis of CIDP can be improved in the **US**. Based on experience from the Centers of Excellence program, there are a number of people who carry a diagnosis of CIDP but in fact have another diagnosis. Thus the talk starts with What is CIDP, How do doctors diagnose CIDP, and What looks like CIDP but is not. We ask those with CIDP to compare themselves to standard diagnostic criteria.

Second, people with CIDP should get the right treatment. There is a substantial body of medical evidence on "best" treatment for CIDP which is reviewed. Many people are being treated but possibly not optimally. People with CIDP should not be getting IVIg or other treatments if it does not help them.

Third, those with CIDP should always try to get off treatment. This initially sounds crazy, but the word "chronic" in the name CIDP refers to the onset of the disease not the fact that one has this forever. There is no reason to think you cannot be cured and eventually off all treatment. Strategies for this are discussed.

Fourth, those with CIDP plus another linked disease need additional thought especially if the other disease involved unusual blood proteins, which everyone with CIDP should be checked for. These tests are simple blood and urine tests and in some cases simple skeletal x-rays. Knowing whether or not you have a "paraprotein" can make a large difference in your treatment.

Finally, we ask those attending the meeting to consider Advocacy and Donations. The amount of research spending on neuropathy in general and CIDP in particular is very small in relation to the number of people affected……..We plan more of these talks and will eventually place the talk on the internet.

12th International GBS/CIDP Symposium 26 – 28 October, 2012.

This Symposium will be held in **Fort Worth, Texas**. 23 workshops will be conducted. For more information, visit GBS/CIDP Foundation International website at **www.gbs-cidp.org**.

The GBS/CIDP Foundation International forward Australian enquiries on to various people in Australia for follow up. They are an amazing organization and we wish them well with their forthcoming symposium.

What is MMN?

Carol Lee Koski, MD

Medical Director, GBS/CIDP Foundation International

MMN is an abbreviation for Multifocal Motor Neuropathy, a rare pure motor slowing progressive neuropathy reflecting focal damage to nerves that is primarily distal in the arms in two thirds of patients and in the distal legs in half the patients.

Males from ages 22 to 66 years are 2.7 times more frequently effected than females. Only 0.6 individuals/100,000 population are involved at any one time. It is one of the least common of the inflammatory neuropathies. Since the process is focal, it involves some nerves more than others; it typically involves one arm or leg more than that on the other side of the body. Patients may note weakness or fatigue in muscles resulting in difficulty turning a key in a lock, dropping things out of their hand, not being able to retain a thong sandal while walking, or having a foot drop. Facial, swallowing and breathing muscles are not involved. Deep tendon reflexes are decreased or absent in the involved extremities while sensory function (i.e. pain, light touch) are normal. Patients do not die from the condition but do experience significant disability over the chronic course of this condition. Other conditions such as primary motor neuron disease (Lou Gehrig's Disease) and inflammation of blood vessels or vasculitis can sometimes look like MMN and lead to a delayed diagnosis and treatment resulting in axonal damage and disability. In a recent study in the Netherlands diagnosis was on average delayed by five years in MMN patients.

The cause of MMN is not fully understood. It is proposed that an immune system targets specialized areas of the motor axon or fiber. The axon extends from motor nerve cells located in the spinal cord out to muscle fibers. The specialized areas of the axon are rich in sodium channels that allow electrical impulses to travel rapidly down the motor axon and stimulate the muscles to contract or shorten leading to movement in the arms or legs. Damage to the axon causes focal muscle wasting and weakness. Antibodies to the lipid ganglioside GM1 occur in 60-80% of patients and are higher in some patients with more severe weakness. Diagnosis of MMN requires recognition of the clinical signs discussed above and a well done series of nerve conduction studies that demonstrate focal block of the electrical impulses in motor but not sensory nerves at other than entrapment sites such as those at the wrist associated with Carpal Tunnel syndrome or at the elbow with ulnar nerve compression.

Treatment options for MMN are limited. In contrast to other inflammatory neuropathies, patients with MMN do not respond to corticosteroids and plasma exchange and may worsen with these treatments. Cytotoxic cancer therapy drugs such as cyclophosphamide can be effective but use over the long term is restricted by toxicity and potentially lethal side effects. High dose intravenous immune globulin on IVIG is generally safe and effective as demonstrated by a series of now five randomized, double blind and placebo controlled cross-over trials in MMN. The last of these trials involved 44 MMN patients from North America and Denmark and was completed in 2012. It demonstrated not only significant improvement in muscle strength but also in functional disability. The trial has been submitted to the FDA to support an indication of IVIG use in MMN patients which is currently off label. Delaying treatment with IVIG can result in irreversible physical impairment and supports the need for early diagnosis and treatment. IVIG maintenance treatment can be successfully used over years. However, over time and despite a regular IVIG treatment, a mild or slow decline in function can occur and be associated with signs of more widespread disease. This progression can be limited by increasing the IVIG dose or dose frequency. The median dose of IVIG gradually increases over years and may become as high as 1.6 grams/Kg per week. Early diagnosis and treatment will limit progression and disability in this chronic neuropathy.

Subscriptions - Our thanks to those members who have paid their subscriptions for the 2012-2013 year. For those still outstanding, please use the form below to make your payment.

ANNUAL SUBSCRIPTION
THE 'IN' GROUP
The Inflammatory Neuropathy Support Group of Victoria Inc.
Supporting sufferers from acute Guillain-Barre` Syndrome (GBS and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Registered Charity No: A0025170R

1st July 2012 – 30th June, 2013.

Annual Subscription			$ 15.00
Other Items			
Booklets	- The Road to Recovery A-Z	$6	$
	- Boy, Is This Guy Sick	$2	$
	- CIDP	$2	$
	- GBS	$2	$
Donation to support medical research			$
(Donations of $2 or more are tax deductible)			_____
(Tick if receipt required …….)			
	Total Payable:		$_____

Enclosed is a cheque/money order (payable to The IN Group)
Membership Details
Name: _____
Address: _____
_____
_____Postcode _____
Telephone: (Home) _____Work) _____Email Address: _____
Signed: _____Date: _____
Thank you. Please forward this form along with your payment to:
The Treasurer, The IN Group, 26 Belmont Rd., GLEN WAVERLEY 3150.

Disclaimer Information presented in "INformation" the Newsletter of the Inflammatory Neuropathy Support Group of Victoria Inc., is intended for information only and should not be considered as advising or diagnosing or treatment of Guillain-Barre Syndrome, CIDP or any other medical condition. Views expressed in articles are those of the authors and do not necessarily reflect the opinions or Policy of The IN Group.

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Newsletter of THE 'IN' GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC.

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