STICK WITH IT
SLOW BUT SURE

INFORMATION

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Glen Waverley, 3150
Victoria, Australia

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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) and other Inflammatory neuropathies

OUR ANNUAL GENERAL MEETING IS SCHEDULED FOR 2PM ON SUNDAY, 11th OCTOBER, 2020
AT THE ASHBURTON LIBRARY COMMUNITY CENTRE,
154 High Street, Ashburton.

A small plate to share for afternoon tea would be appreciated.

Dates to Remember – General Meetings

Sunday, 6th December, 2020 at 12 noon. Christmas Luncheon

Hello to all 'IN' Group members.

This is a trying time for everyone. I hope you and your family are safe and well and that we can get through this pandemic by supporting each other. In the meantime, it seems all we can do is "eat up" and "keep warm" and look forward to being together before too long. There are two meetings scheduled for October and December of this year but the way things are at present they may not go ahead. It is a day to day situation.
We had a Zoom committee meeting to get us back into running the Group as it is very important we keep in touch.
At time of writing some areas in Victoria are in "lockdown" and we are seeing more deaths, including young people.

We would be interested in learning your stories during this Pandemic. Please send them to Melva Behr, 44 Mavis Ave., Beaconsfield, 3807 or via email behrsden@iinet.com.au.
The Committee is available at any time if we can be of assistance.
My very best to everyone.
Margaret Lawrence,
President

Ultrasound for diagnosing CIDP.

Dr Nick Crump will be familiar to some of you who attended his talk to our group some time ago.

Nick spoke about his research into the use of ultrasound for diagnosing CIDP and some of our members have been along to take part in his research.

Nick's research is up and running again and you can still enrol in this study at the Austin Hospital. Speaking with the people who have already been, they believe it was an easy and worthwhile thing to do.

I would encourage more of you to get in touch with Nick and join his research program. If you are interested and would like further information, please contact Dr Nicholas Crump on: 9496 2845 or nicholas.crump@austin.org.au

COVID -19 and GBS/CIDP

From the Medical Advisory Board of the GBS Support Group New Zealand Trust

A FURTHER COVID-19 UPDATE

by **Dr. Gareth Parry (**ONZM, MB, ChB, FRACP)
Emeritus Professor, Department of Neurology, University of Minnesota, USA.
Clinical Senior Lecturer, Otago University, Wellington, NZ.
Research Professor, Nelson-Marlborough Institute of Technology, NZ.
Visiting Neurologist, Wellington Hospital, NZ.

In the 6 weeks since my last report, the world-wide numbers of new COVID-19 cases and deaths continues to burgeon which, at the time of writing, had reached nearly 6.5 million confirmed cases, with an estimated equal number of unrecognized cases in developing countries where reporting is inaccurate, and nearly 400,000 deaths, also an almost certain under-recognition.

While numbers of both new cases and deaths is on the wane in many countries, particularly those like NZ that have practiced aggressive isolation strategies, they continue to rise unabated in others.

A few individual cases of GBS possibly triggered by COVID-19 infection continue to be reported through social media such as physician chat rooms but there have been no further series of cases as reported previously. There have been no reports of CIDP relapse associated with the infection. Thus, it seems that COVID-19, like many other infectious illnesses can rarely trigger GBS, but there is not an increased risk as is seen with bacterial and viral infections such as Campylobacter (bacterial) and CMV and EBV (viruses). This is reassuring for the GBS/CIDP community.

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GBS/CIDP INTERNATIONAL ASIAN/PACIFIC LIAISON DEVELOPMENT CONFERENCE by Melva Behr

In February I was fortunate to attend the Liaison Development Conference of the GBS/CIDP Foundation International held on the 28th and 29th February in Sydney. It was the first meeting for Asia/Pacific and was attended by liaisons from New Zealand, India, Pakistan, Japan, Singapore, Malaysia and together with those from South Australia, Tasmania, New South Wales, Western Australia and Victoria.

It was very special for liaisons to meet those they connect with from the GBS/CIDP Foundation International; Executive Director Lisa Butler, Vice President of International Activities Patricia Blomkwist-Markens, Outreach & Engagement Manager Kelly McCoy and Communications & Program Associate Meg Francescangeli. The Conference was very welcoming to us all and very well organised.

Notes from a Talk on Research and Clinical Trials for CIDP given by Jeff Allen at the GBS-CIDP Foundation International Asia/Pacific Conference.

The first case of what we now call **CIDP was described before GBS** where a patient with **this nerve problem evolved over a period of time** and **relapsed again and again** and over subsequent decades **similar patients were reported**. **Clinicians were very astute in distinguishing this problem from GBS** which was described as an explosive problem **which evolved over a few weeks but then slowly improved**. **These two clinical entities differentiated from each other.**

Over many years **data collected from patients with both GBS and CIDP could better define this disease**. Such things as how the **spinal fluid** was; how the **protein was in the spinal fluid; nerve conduction tests; etc**. Over time patients were exposed to **new drugs such as steroids** and some of these patients improved. They saw that **this chronic disease seemed to be inflammatory based** on how patients were **after being exposed to steroids and looking under a microscope at nerve biopsies**. It seemed to be **demyelinating**, which is the part of the nerve which covers the outside of the nerve that helps the electricity travel down the nerve. It seemed to be a **myelin problem**. It was a nerve problem, **Polyneuropathy. Chronic disease, inflammation, demyelinating, neuropathy. CIDP**.

In the 1970's the term CIDP was adopted and since then, over the last 40 years, these principal features of the disease haven't changed a lot. **These are the defined critical features of the disease from which the diagnosis is made. "A disease that evolves over two months or more, where patients get numb and weak and is progressive**." Then the other pieces of the disease fill out the profile. What the EMG looks like; when we see a myelin problem; what the spinal fluid looks like; nerve biopsies, etc. None of this is really needed to make the diagnosis. **The diagnosis rests on the clinical features and what the EMG shows.**

CIDP has a typical profile and also an atypical profile. **CIDP is more than one single clinical picture** but there are other **variants of the disease** that fall under this heading. They are still locked together with CIDP but have some **unusual clinical features**. Some of these unusual clinical features are **atypical variances** are those that may still have **numbness and weakness as core features** but will **differ in which part of the body they affect most**. **With typical patients it is the same on both sides of the body with arms and legs both affected**. We now know **there is a distal variant of CIDP which mainly affects people below the knees, below the wrists and their gait can be affected** and it can lead to a lot of clumsiness and gait problems and we call that **Distal CIDP**.

There is an **asymmetrical form of CIDP** which **affects one side of the body more than the other**. Still numbness and weakness but patchy and we call that **Asymmetrical CIDP** and also goes by the name **Lewis Sumner Syndrome**.

There is probably **an atypical variant which is of a purely an abdominal sensory variant** where people can get **very numb, sometimes clumsy,** have **some bowel problems**. They **don't feel weak**. It is a **sensory variant**.

There is also a **Motor variant** where people can get **very weak** but **it still affects the body, both the right side and left side.**

These are clumped together as CIDP. **The thing they all have in common is the defining features of numbness but they differ in which part of the body is affected most severely.**

Fatigue can really be a problem. It happens more than we give it credit for but **it can really be a problem for quality of life**. Like GBS **it can continue on for a long, long, time.**

Pain can happen in CIDP. Typically, it is mild but **sometimes it can be quite severe**.

Trauma can happen. **This can be quite problematic with some patients with variants of CIDP**. Sometimes cranial nerves can be affected but it is **very rare for the respiratory system to be affected with CIDP**.

When someone develops CIDP the questions can go in a number of directions. Sometimes things **can get bad and then they reach the peak** and **then improve over time**, similar to the way GBS does, but maybe it takes a little longer to get to that peak of severity. **More commonly** the course is one that is **either slowly progressive over time or** one that sort of **goes up and down** where you get worse and then **get progressively better over time.**

The most common is a combination of the three. People can slowly have relapses, times when they get better and worse and then over a longer period of time they start to correct. This can be challenging and sometimes this has something to do with the medications used.

CIDP can be a difficult diagnosis to make. **People can go far too long with symptoms before they get the diagnosis.** When a clinician talks to a patient they **find out what symptoms are most important to them and then during examination that has to fit the profile of typical CIDP or atypical CIDP.** We need to do **tests to see if we find the right things** which can be very helpful to make a diagnosis. Then we might fill in the blanks with other testing, **but there is no real test, which is a challenge right now.**

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COVID-19 EXPERIENCE OF ONE OF OUR MEMBERS. A daughter and a grand-daughter, were contacted, tested and self-isolated for 14 days. They lost their senses of smell and taste, one had sore eyes and the other a headache. Both had fatigue. Within half an hour of being told she could come out of isolation, my daughter drove to the supermarket (masked and gloved). Within minutes she was contacted as they knew she had left her home. She explained that she had been given the all clear, but it did show that the system was working. As fatigue was still a problem they chose to remain in insolation for a further 7 days. Both donated their plasma. (Plasma from patients who have recovered from Covid -19 is being collected to help treat seriously affected patients fighting the virus.)

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ANNUAL SUBSCRIPTION

Item	Each	Payable
Annual Subscription	$15	
(Due 1 July each year)		
GBS Booklet	$3	
CIDP Booklet	$3	
The Road to Recovery Booklet	$6	
Recipe Book	$16	
Donation to support Medical Research (Donations of $2 or more are tax deductible) Tick if a receipt is required		
TOTAL Enclosed a cheque/money order (payable to The IN Group)		

Thank you. Please forward this form along with your payment to:
The 'IN' Group, 26 Belmont Rd., GLEN WAVERLEY 3150

BSB / Account: **063142 / 10006285**

Account Name: **The IN Group**

(Include Your Name in "Description / Reference")

MEMBERSHIP DETAILS (please Print)

Name:	
Address:	
Suburb:	
Postcode:	
Mobile:	
email	
To receive your Newsletter by email sent an email to John@bal.net.au	

ANNUAL GENERAL MEETING
The Inflammatory Neuropathy Support Group of Victoria, Incorporated
Ashburton Library Meeting Room, High Street, Ashburton. At 2pm on 11/10/20.

Agenda

1. Confirmation of Minutes of 2019 AGM.
2. Reports from President and Treasurer
3. Election of Officers and Members of Committee.
4. Any special business of which 21 days notice has been given.

Positions to be filled are: President, Vice-President, Secretary, Treasurer,
Public Officer, Membership/Newsletter Co-ordinator, General Committee Member/s

Nomination form for Committee

Position: ……..

Nominee: ……..

Date: …….

To be returned to: The Secretary,
The IN Group, 26 Belmont Rd., GLEN WAVERLEY 3150 by 18th September, 2020.

From one of our members

My Favourite Things – Senior
Music by Richard Rogers. Lyrics by Anonymous.

Maalox and nose drops and needles for knitting,
Walkers and handrails and new dental fittings,
Bundles of magazines tied up in string,
These are a few of my favourite things.

Cadillacs and cataracts and hearing aids and glasses,
Polident and Fixodent and false teeth in glasses,
Pacemakers, golf carts and porches with swings,
These are a few of my favourite things.

When the pipes leak, when the bones creak,
When the knees go bad,
I simply remember my favourite things,
And then I don't feel so bad.

Hot tea and crumpets and corn pads for bunions,
No spicy hot food or food cooked with onions,
Bathrobes and heat pads and hot meals they bring,
These are a few of my favourite things.

Back pains, confused brains and no fear of sinnin',
Thin bones and fractures and hair that is thinnin',
And we won't mention our short shrunken frames,
When we remember our favourite things.

When the joints ache, when the hips break,
When the eyes grow dim,
Then I remember the great life I've had,
And then I don't feel so bad.