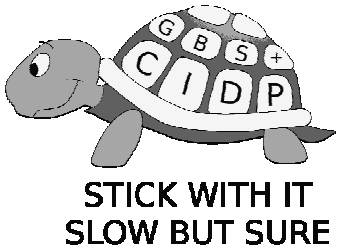
Issue No: 96. October, 2016



INFORMATION

www.ingroup.org.au
info@ingroup.org.au

26 Belmont Road,
Glen Waverley, 3150
Victoria, Australia

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)

NEXT MEETING
ANNUAL CHRISTMAS LUNCHEON, AND DUTCH AUCTION,
SUNDAY, 20TH NOVEMBER, 2016 AT 12 NOON
$20 AND A WRAPPED GIFT (with indication of value) FOR THE AUCTIONEER KEN CLARK
AT
ASHBURTON LIBRARY, ASHBURTON COMMUNITY CENTRE, 154 High Street, Ashburton
Ample parking is available in High Street and behind Pharmacy and in side streets.
There is a very good ramp outside the building in High Street and on entering the building our meeting room is just on the left through glass doors.

RSVP to Margaret 9802 5319 or Melva 9707 3278 by Wednesday, 16th November.

COME ALONG AND ENJOY THE COMPANY, LOVELY LUNCHEON AND THE FUN OF THE DUTCH AUCTION.

Dates to Remember **NOTE: ALL MEETINGS NEXT YEAR WILL BE HELD AT ASHBURTON.**

Feb	**Sunday, 26th February, 2016 at 2pm**	
May	**Sunday, 28th May, 2016 at 2pm**	
August	**Sunday, 27th August, 2016 at 2pm**	**Annual General Meeting**
November	**Sunday, 26th November, 2016 at 12 noon.**	**Annual Luncheon & Dutch Auction**

NOTES FROM THE ANNUAL GENERAL MEETING

Welcome. Thank you for all coming today and a special welcome to our guests from CSL, Dr. Wayne Adcock and Adele Kelly. Thank you for joining us today.

Apologies: Dorothy Brennan

The Minutes of the 2015 meeting as published in the Newsletter were accepted.

President's Report

Another year has gone by with The IN Group. We have enjoyed guest speakers and our usual "catch up" with friends with many exchanging helpful ideas regarding their illnesses while enjoying afternoon tea.

The Christmas Luncheon as always was full of fun, good food and of course our Auction which was run by Ken Clark at a great pace bringing in the money we are able to give towards research.

Dr. Andrew Kornberg accepted a cheque for $10,000 for the year. What a wonderful effort from our small group. It really is because everybody is so good.

We received a "Thank You" from the Children's Hospital and a booklet with The IN Group listed as donations. Dr. Kornberg spoke on the work and knowledge being obtained from research.

From myself and the Committee it is a great pleasure to say "thank you " for the wonderful donations received from our members. The Committee are a caring group who support me and show great interest in running our happy group.

I have been a very fortunate guest at two celebrations to mark 100 years of CSL Behring. These evenings were so interesting and of course very much a part of our members lives with the products.

The Newsletter is a great source of information (for country members in particular) and many locals who are unable to attend our meetings, giving reports from speakers and many interesting facts. Melva and Joe do a wonderful job producing the Newsletter. Melva also arranges visits and phone calls for our new members and people wanting more information, sometimes just to have a chat.

It is with pleasure I submit my report with thanks to all our members and especially the Committee.

Thank you very much.

Treasurer's Report

On the Income side once again we had a very good year financially, particularly in respect to donations. Whilst the subscriptions were up by only $165 for the year our donations exceeded last year by $2093. The exceptions to the income level were the State Government Grant which was removed last year. We received the previous year $1458 so that is one reduction in income. The other reduction of $1418 was from not having a mid-year function. Therefore our nett total income was a reduction of $400 compared to last year which was very reasonable considering we lost two major ones.

From the expenditure side the total expenses for the year were maintained with only a drop of $8. An excellent result considering the price rises that beset us all.

We were again very pleased to be able to make a donation of $10,000 to the Royal Children's Hospital, through Dr. Andrew Kornberg to assist him and his staff, particularly for research into GBS and CIDP and I am confident that a donation will be able to be made to contribute to this work again this year.

In closing I wish to thank all members for their generosity in supporting The IN Group with their many great donations and I also wish to record my thanks to our Committee who have worked so very hard throughout the year to keep the group financially viable and for their personal fundraising efforts. So I thank you all.

Committee

We welcomed Neil McCoy to the Committee.

Meeting closed.

Guest Speaker Dr. Wayne Adcock spoke on the history of CSL Behring and the production of Ivig.

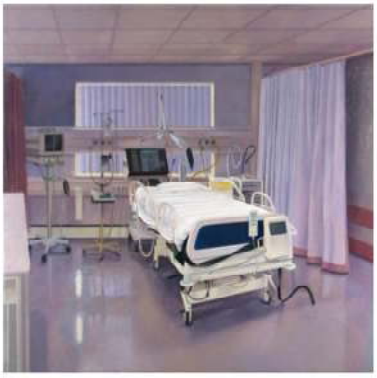
He gave a very comprehensive presentation accompanied by slides showing various procedures undertaken during the production of 'Intragam' which most of our members receive or have received.

He spoke in depth on the way fractionation was achieved and the safety of the product.

The NZ GBS SUPPORT GROUP will be holding their CONFERENCE from 5-7TH MAY, 2017 at the NOVOTEL/IBIS COMPLEX, ROTORUA. If you wish to attend, register at deyoungs@xtra.co.nz

We wish to thank Dr. Annette Forrest, Member of the Medical Advisory Board of the NZ GBS Support Group for her permission to reprint the following pages.

GBS Patients In ICU
BY Dr. Annette Forrest , Conference Presentation



Definition

- No clear definition
- Clinical presentation varies widely
- Commonly is a a progressive ascending paralysis caused by nerve demyelination by macrophages

Incidence in tertiary ICU New Zealand

- Two to four patients a year
- Data from last 10 years

Causes

- Infections
- Acute illness
- Surgery
- Vaccination
- Miscellaneous

50 % of patients present following a prodromal respiratory or Gastrointestinal infection
Infectious causes include viral, bacterial and parasites
Common infectious agents include campylobacter jejuni and mycoplasma

Clinical Features

- Paraesthesia
- Back pain
- Symmetrical ascending weakness in legs, arms, respiratory muscles and facial muscles
- Diminished or loss of deep tendon reflexs

Paraesthesia often described as numbness, creepy crawlies, tingling burning

Three phases

- Acute
- Plateau

Acute: onset of first symptoms, progression until no further symptoms develop. Acute phase can be rapid where patient progresses over a 24 to 48 hour period or lasts up to 4 weeks. Normal nadir for muscle weakness is about day 10
25 to 30% of patients will require intubation in this acute phase
Plateau Phase: symptoms remain but don't worsen can be days to weeks
Recovery from a few weeks to 2 years

Diagnosis

- No specific test
- Combination of patient history, clinical symptoms, excluding other conditions,
- nerve conduction studies,
- Lumbar puncture to rule out other conditions

LP normally has an elevated protein with no increase in lymphocytes. Investigations can often lag behind symptoms by a week
Albuminocytologic dissociation of LP i.e elevation of CSF protein with only a few wee

GBS Patients In ICU
BY Dr. Annette Forrest , Conference Presentation

Management

- Symptom Management
- Prevention of Major Complications
- Treatment : Plasmapheresis and intravenous immunoglobulin

Indications for admission to ICU

- Respiratory Failure
- Oropharyngeal muscle weakness
- Autonomic dysfunction

Respiratory failure secondary to respiratory muscle weakness, mainly diaphragm with phrenic nerve paralysis
Oropharyngeal muscle weakness leads to impaired swallowing of secretions and aspiration

Intubation and mechanical ventilation

- 30% require intubation secondary to respiratory failure
- 25% require intubation secondary to oropharyngeal muscle weakness

Guidelines say FVC < 15ml/kg or Maximum inspiratory force < 25 cm H20, actually more interested in tiredness, is the carbondioxide rising . Hypoxia is not generally the reason for intubation. If a patient is heading towards intubation, try to discuss with them and their family that there will be an early tracheostomy

Non invasive ventilation

Bipap not often used in GBS because of secretions but can be used temporarily while deciding whether intubation necessary

Ventilator

Tracheostomy

- Early
- Cuffed to protect from aspiration
- Different types
- Several changes with improvement

Annoying but not as bad as an ETT

Tracheostomy and Nasogastric Tube

Tracheostomy tube

Example of the tracheostomy we use, short length cuffed

Flange tracheostomy

Another type of tracheostomy we use, soft, and pliable

Autonomic Dysfunction

- Common
- In up to 70% of patients
- Commonest is Sinus tachycardia and hypertension
- Blood pressure labile

Can get big swings from high blood pressure to low paroxysmally so need to use agents that can be adjusted quickly

GBS Patients In ICU
BY Dr. Annette Forrest , Conference Presentation

Haemodynamic monitoring

Cardiac arrhythmias

- Tachycardia
- Bradycardia
- Heart block
- Cardiac arrest

Some patients require temporary pacemakers
Suctioning can cause vagal episodes with bradycardia

Pacing Box

Ileus and constipation

- Common to get constipation,
- Adynamic ileus

Start laxatives from day 1
Nasogastric tube

Urinary retention

- Urinary catheter

General Supportive Care

- Enterally feed
- Analgesia
- +/- sedation
- Thromboprophylaxis
- Ulcer prophylaxis
- Glucose control

Complications to avoid

- Pneumonia
- Sepsis
- DVT and pulmonary embolism

Patient is supine, not moving not clearing secretions and on a ventilator

Hand Hygiene for staff and visitors

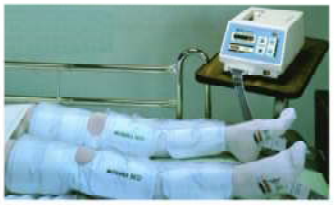
Hygiene to avoid infection

Thromboprophylaxis

- Enoxaparin injections
- Sequential compression devices

SCD's can cause pain in legs with squeezing

Sequential Compression Devices



Pain

- Can be very difficult to treat
- Early on it can be deep and achy
- Later it is more neuropathic and burning feeling
- Involves trunk and limbs
- Can be very severe and overwhelming

Analgesia for Pain

- Treat aggressively
- Oplods
- Gabapentin
- Tricyclic antidepressants
- Cutaneous stimulation
- Ice
- Heat
- Distraction
- massage

GBS Patients In ICU
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Nutrition

- Enteral feeding from day 1
- Nasojejunal tube
- Problems with tube feeding :
  - excessive gastric residual
  - diarrhoea
  - constipation

Nasojejunal tube is smaller and more comfortable, bypasses stomach
Have decreased gastric motility with decreased gastric empting. Start a prokinetic such as metoclopramide and erythromycin early

Skin Integrity

- Prone to skin breakdown
- Watch for pressure areas
- Change position regularly
- Speciality air mattress

Regular wound skin assessments
Changing position every 2 hours but for ventilation and skin but causes pain

Prevent Joint contractures

- Range of motion exercises
- Physio/nursing staff and family
- Proper positioning for joints

ROM important but again can cause pain, splints and orthotic devices to keep joints in a neutral position pain also

UNICATION IN ICU

Communication

- Difficult but very important
- Patients are often anxious and fearful about what is happening to them
- Being unable to communicate leads to frustration and feeling of loss of control

Communicate How?

- Lip reading
- Letter and picture boards
- Non verbal options such as blinking and tongue clicks
- Computer (pad on pillow) needs head movement
- Apps on Phones such as Yes/No app from smartears
- Tracheostomy Passy muir valve or take cuff down

Lip reading is very difficult, patient has to exagerate lip movement and speak slowly
If they have facial muscle paralysis will be unable to communicate in this way
Some phones are easier than others, eg iphone and itouch easier to press
Patients get fatigued easily with speech

ASSEY MUIR VALVE

On tracheostomy can be used as part of weaning , for communication and gives a small amount of peep

Mobilisation

- Tilt boards
- Chair when able
- Move bed outside

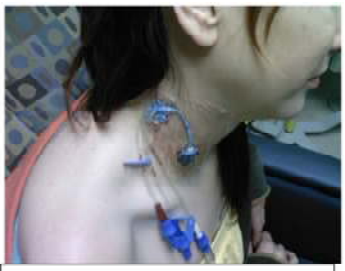
Tilt boards are frightening, tiring and can cause hypotension
Patients can be taken outside on beds when ventilated
Can be moved down to windows

Tilt Board

Psychological

- Anxious
- Stressed
- Fearful
- Feelings of despair
- Feelings of helplessness
- Pain
- Depression common

One of our many lines



Procedures ae multiple and lead to psychological issues

Delirium/ICU Psychosis

- Secondary to sleep deprivation
- Changes in how the patient perceives the environment
- Feel "trapped"
- Hallucinations
- NOISE
- Ward rounds

Sleep deprivation often due to noise caused by machinery and staff, neighbouring patients. GBS vistors help
Loss of sensory input changes how you perceive your environment

GBS Patients In ICU
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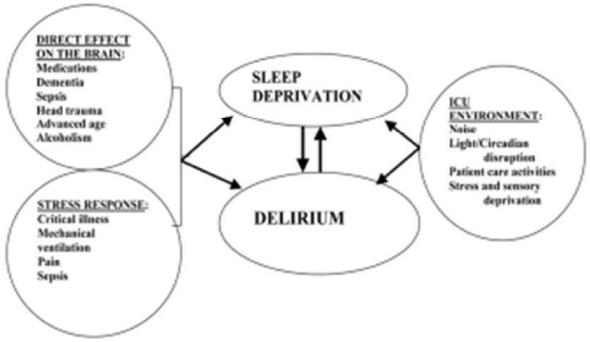
SLEEP DEPRIVATION



SOLUTIONS TO SLEEP DEPRIVATION

- Establish a sleep routine
- Take down to where there is natural light, or outside to establish a day night pattern
- Try to keep noise down, stop signals

EARPLUGS FOR NOISE

OUTCOME

- 80% of patients will make a complete recovery but of these 65% will have persistent problems such as foot drop or distal numbness
- There is a 3 to 5% mortality
- Will require intense physiotherapy and rehabilitation
- 20% will have multiple medical issues

LONG TERM PSYCHOLOGICAL EFFECTS OF ICU

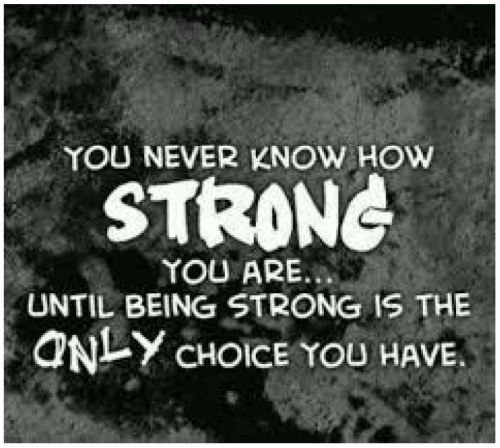
- Nightmares
- Sleep deprivation at home
- Flash backs and PTSD
- Increased anxiety
- Difficulty getting back to work
- Family believe you should be over it

PATIENT COMMENTS

- My wife of 36 years told me that I was just "feeling sorry" for myself and I needed to get on with life
- I felt isolated and excluded at work, no one wanted to be around me
- It has been two years and I am still trying to sort out what was real and what wasn't

ICU DIARY

- Scandinavian
- Nurse and family write in from day 1 with photos
- Particularly good with long term patients



To those who have paid this year's subscription, thank you for your support and your generous donations to research. A reminder now to others that they are now overdue.

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 No: A0025170R

Annual Subscription 1/7/16 to 30/6/17.

Annual Subscription		$ 15.00
Other Items		
Booklets- GBS	$3	$
CIDP	$3	$
After GBS	$3	$
The Road to Recovery A-Z	$6	$
- Boy, Is This Guy Sick	$2	$
Recipe Book -$12 plus postage & handling	$16	$
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 'IN' Group, 26 Belmont Rd., GLEN WAVERLEY 3150

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