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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.

**ANNUAL CHRISTMAS LUNCHEON & DUTCH AUCTION
SUNDAY, 2ND DECEMBER AT 12 NOON
BALWYN LIBRARY MEETING ROOM,
WHITEHORSE ROAD, BALWYN**

RSVP to Margaret 9802 5319 or Melva 9707 3278 by 25TH November.

Presentation of cheque to Assoc. Prof. Andrew Kornberg.

BUFFET LUNCH - \$15pp

As our major fund raiser for the year, a wrapped gift for the Dutch Auction with a tag indicating value to aid the Auctioneer would be greatly appreciated.

Come along and enjoy an excellent buffet lunch with lots of fun and good company.

Minutes of the Annual General Meeting held 19th August, 2018.

Apologies: Ken Clarke, Gwen McInness and Peter Males.

2017 Minutes as published in the Newsletter last year. Carried.

President's Report for Year 2017/18.

Another year of The 'IN' Group and our group is as keen as ever to assist our members and any new people joining the group.

The debilitating problems cause much distress to people just diagnosed. We try our best to help as they often need people just to listen.

The Newsletter is welcomed by everyone four times a year as it has information most helpful to those unable to attend the quarterly meetings and I would like to thank Melva and Joe for the amazing work they put in to send these out.

My thanks also to the Committee who have been my helpers for many years and I greatly appreciate all their assistance.

Over the past year we have had interesting speakers and I'm sure the members have gained information from their talks which can be used in the future.

The Christmas Luncheon in the Ashburton Library was well attended. Beautiful food was made and donated by our Committee. Only chickens and drinks are purchased out of our money so a big thank you to these kind people.

To all our members who send in donations towards research, a very large THANK YOU as we raise so much money from our small group to send off to research which is done at the Royal Children's Hospital.

I look forward to another productive year and thank you for your kindness to me. I think The IN Group is a very worthwhile organization.

Treasurer's Report for the 12 months ended the 30th June, 2018.

I am pleased to be able to report that income was up on last year by \$3,800 to \$11,569. The big movers were subscriptions up \$520 and donations up a huge \$2,380. Also received during the year was a grant from the Department of Health for \$1,500. Expenses increased by \$916. There was not one expense item that stood out, as small increases were spread over many items. The nett result for the year was a surplus of \$9,346 and added to our carried forward balance from last year, our equity at June 30 this year was \$13,415.

We are now in a good position for the Committee to consider a healthy donation this year to the Royal Children's Hospital via Assoc. Prof. Andrew Kornberg to be used for research purposes.

I would like to comment on the donations we have received this year. There has been a number of memorial donations, plus so many donations from our members. From The 'IN' Group we say a very big "Thank You" to all those people who have donated.

I would also like to highlight the work done by our Committee Member, Gwen McInness and her Ladies Group who raised \$769 from the sale of dolls throughout the year and once again a huge thank you to all our Committee Members for their support and donation of food etc. which has been adding to our surplus for the year.

My final "thank you" is to Committee Member, Neil McCoy, who has taken the burden off me for all the IT work. Neil now maintains our Website and has brought us into the 21st Century with Twitter, Meetup, etc. Thank you Neil.

The Committee for 2018/19.

President: Margaret Lawrence

Vice President: John Burke

Secretary/Treasurer: Doug Lawrence

Other Committee Members: Gwen McInness, Joe and Melva Behr, Peter Males, Barbara Rivett, Brian Boyd, Len Waters, Ken Daniels, Neil McCoy and new member, Mary Clarke.

Meeting closed.

Following the AGM **we enjoyed the humour of Don Jones.** There were lots of hearty laughs and happy faces. Thank you, Don, for dishing out "**Laughter – The Best Medicine**".

A light afternoon tea followed with lots of chatter and **we welcomed those seeking information and support for new patients.**

Next Meeting: Assoc. Prof. Andrew Kornberg and our Patron, Assoc. Prof. Richard Stark, will be attending our December meeting/Luncheon. Their support over many years is greatly appreciated.

We are happy to report member Gwen McInness is back home and doing well after breaking her ankle.

Ken Clarke will have completed his term as Mayor of Wangaratta before again joining us at the Luncheon. He is looking forward to the fun, frivolity, food and fundraising as our **Auctioneer for the Dutch Auction.**

The Committee advise there are limited funds available to assist members to attend meetings or for medical aids. Contact Margaret or Doug on 9802 5319 if this could help you.

Special Committee Meeting - The Committee are having a special meeting in November to discuss **the future of The 'IN' Group and where we see ourselves in 5 years**. If you would like to pass on your thoughts, please contact Ken Daniels either on his email kendaniels007@gmail.com or mobile 0475 876 397. The following article is from a lovely lady who attended a meeting some months ago. At the time she was in Rehab. At the Royal Talbot. We are so glad she is now home and on The Road to Recovery.

Gaye's Journey

Six months ago, I was diagnosed with CIDP. We had just returned from 4 weeks in Europe where we were walking in icy conditions. This would not have helped my CIDP which was in my system well before we went away. Like most CIDP patients my symptoms were and still are tingling and pain in my hands and feet.

I sought the best medical treatment possible which is the neurological team at the Austin Hospital in Melbourne. They are world leaders in the treatment of CIDP. Within 2 days of admission I was diagnosed with the condition after exhaustive physical examinations, nerve conduction tests and a lumbar puncture.

Then I began a series of treatments. Fortnightly infusions of IVIG seemed to work and I was sent to rehab where my condition slowly worsened. The neurology team then explored giving me plasma exchange and 'Rituximab'. Nerve biopsies were carried out on my ankle, hip and skin, however nothing seemed to work. I was sent backwards and forwards from hospital to rehab and over the next 6 months medical staff became my family and hospital wards became my home.

Family played a major role in my treatment. My husband was and still is the best husband in the world. Since mid-January he has twice daily: massaged my feet; aided me in carrying out bed exercises; brought homemade muesli and probiotic yoghurt for breakfast; and cooked a gourmet dinner for me every night. He has been by my side every inch of the way.

Our niece who is a naturopath sent a sample of my hair to a laboratory in Sydney. The results were staggering and revealed a totally unbalanced gut - high copper levels way off the chart yet an almost non-absorption of other minerals such as zinc.

We sent the results to a naturopath in NZ who has a considerable reputation in treating auto immune conditions. He believes the origin of my CIDP can be traced to a childhood infection which surfaced pre-Christmas when my body was under significant stress. His recommendation was to take both the Rituximab/IVIG treatments plus mineral supplements. Similarly, the doctors were happy to accommodate my use of both.

Then something miraculous occurred in June. I woke up feeling strong, my toes moved, I was able to slide board instead of using hoists, could lift my own body weight and got stronger and more confident every day.

Everyone is asking what caused this sudden change. I believe it's a combination of everything - the best medical team, the combination of Rituximab and IVIG, an excellent diet of fresh fruit and vegetables, mineral supplements to balance my body, daily massaging my fingers and feet plus the constant love and support of my family, especially my husband.

So, I say to all of those GBS/CIDP sufferers - look outside the square and be open to all suggestions. Seek the best medical treatment wherever it is (Skype makes consultation so easy). Eat the freshest and most healthy diet. Explore complimentary medicines (making sure they don't conflict with Western medicine). Use massage as part of your therapy and try and have your best friend by your side. Most importantly **NEVER GIVE UP. A**

POSITIVE, DETERMINED ATTITUDE plays the biggest role in your recovery.

Two months ago, I returned home after eight months in hospital and rehab. It has been challenging as I'm in a wheelchair having to make my own decisions for the first time since Christmas. My husband is adjusting to our new life but we're on the upward trajectory. Every second Friday I visit the Austin Hospital for an afternoon of IVIG treatment. My weekly schedule is packed with visits from physios, hand therapists and Occupational Therapists plus attending hydro and physio sessions on a one-to-one basis at Royal Talbot rehab centre in Kew. Their dedication to getting me well again is awesome.

In the mornings at home I'm walking with a frame. I've returned to playing the piano and am helping with meal preparation and clothes washing. My husband continues massaging my feet twice daily and a Myotherapist makes a weekly visit massaging my muscles. I'm still taking extra minerals prescribed by a Naturopath and everyday see improvements in my health. It's baby steps but my goal is to walk by Christmas and travel overseas to visit our daughter in 2019.

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Thank you to Kath and Rosemary for the support they gave to Gaye.

INTERNATIONAL INFORMATION

The 'IN' Group has for many years had a Liaison Officer with the **GBS/CIDP Foundation International**. info@gsb-cidp.org www.gsb-cidp.org My name is Melva and as the current Liaison I am honoured to have some amazing friends who work tirelessly for patients with Neurological disorders. One of these is Dr. Khalid Zia the President and Founder of PMWO. In 2016 the Pakistan Society of Neurology awarded Dr. Khalid Zia a Lifetime Achievement Award and declared PMWO best Health NGO in Pakistan.

PMWO is the only Health Organisation with Charitable status working for the welfare and care of patients with Neurological Disorders since 1990 and has completed its 25 years of service. PMWO is dedicated to provide a comprehensive Life saving treatment to poor and needy patients and has been saving thousands of precious lives through **Free Plasmapheresis treatment in Pakistan**.

In 2013-14 PMWO did 8750 Plasmapheresis procedures on critical patients in different hospitals in Pakistan who were on ventilators due to Myasthenia Gravis, GBS, CIDP, TTP, Polyneuropathy and others. PMWO is the only voluntary health organisation of its nature which is providing **Mobile plasmapheresis treatment for the rapid clinical patients with Life threatening conditions and saving lives** of the most vulnerable people suffering from Neurological disorders. Unfortunately, **GBS is creating an alarming situation in Pakistan** and a huge number of GBS patients are being reported from the poor population.

The following is a message sent from Dr. Khalid Zia. Hi GBS/CIDP Supporters around the World. I am happy to share about the outcomes and Summary of Plasmapheresis procedures done by PMWO during 2017. From 1/1/17 total our **mobile apheresis unit** has done 3890 Plasmapheresis Procedures in Pakistan and major number of Procedures done on GBS/CIDP Patients and variants. PMWO is working day and night for the welfare and care of Patients with GBS, CIDP, Myasthenia, Polyneuropathy, AMAN and others.

Dear Melva Behr, Thank you for your kind words. We are very thankful to the Direct Aid Program (DAP) of the Australian Government...through DAP Australian High Commissioner in Pakistan has been providing generous contribution for the establishment of Free Plasmapheresis Facility in Teaching Hospital. Australian Government and PMWO are working in close collaboration for the wellbeing of ailing humanity. Our people from Pakistan are very thankful to the people of Australia and Australian Government for the contribution of financial assistance to PMWO for plasmapheresis machines and disposables. Our people cannot afford the cost of IVIG. PMWO have had 20 years cooperation of DAP through Australian High Commissioner in Pakistan.

IT news – You can find us on https://twitter.com/IN_Group_AU and https://www.meetup.com/IN_Group_AU/

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.

NEW ZEALAND CONFERENCE

VENUE: Ibis Hamilton Tainui, 7 Alma Street Hamilton

DATES: 26th – 28th April 2019 (the weekend after Easter)


To book accommodation at the Ibis (or Novotel, 18 Alma Street) go to the following link:
<https://accorconferences.co.nz/custom-offers/gbsnz-conference-2019> Any queries please contact Peter Scott: peterwscott@gmail.com

This is early notification as the Hotel has a new system and will not be holding accommodation “in block” as it has done in the past. They shouldn’t run out but the earlier you book the better.

NEW MEMBERSHIP AND ANNUAL SUBSCRIPTION

Item	Each	Payable
Joining Fee	\$10	
Annual Subscription (Due 1 July each year)	\$15	
The Guillain-Barre` Syndrome Patient in Intensive Care	\$3	
Boy, Is this Guy Sick Booklet	\$2	
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, or
You can now pay directly via internet or at any Bank Branch using the following information.

	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 please send an email to John@bal.net.au	

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