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OR

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NEWSLETTER AND P.N. MINUTES for 11th December, 2023.

The meeting opened at 10.00 am.

ATTENDANCE: Barbara Morris, Laurel Morris, Eileen Senn, Philip Surtees, Faye Breslin, Margaret Hunt, Lindsay Gibson, Ron Gascoigne, Celia Miraglia, Mike Kiff and Phil Reed.

APOLOGIES: Jenny Wilkins, Faye Holloway and Murray Cox.

Accepted: Eileen Senn

Seconded: Celia Miraglia.

CONFIRMATION OF MINUTES OF LAST COMMITTEE MEETING as circulated as being true and correct.

Accepted: Celia Miraglia

Seconded: Faye Breslin.

CORRESPONDENCE:

A.C.N.C. Latest news.

Accepted: Celia Miraglia

Seconded: Faye Breslin

TREASURER'S REPORT – 1/07/2023 TO 30/11/2023

RECEIPTS	\$	PAYMENTS	\$
Attendance	24.00	Accident Cream Purchase	191.30
Membership	40.00		
Joining Fee	5.00		
Accident Cream Sales	107.50		
Membership D.D.	20.00		
Joining Fee D.D.	5.00		
TOTAL	201.50		191.30
Balance b/f			1422.88
BANK			
Cheque A/c paid	191.30	Deposits	196.50
Balance c/f	1428.08		
TOTAL	1619.38		1619.38
Balance c/f			1428.08

ACCOUNTS FOR PAYMENT = nil

Accepted: Philip Surtees

Seconded: Mike Kiff.

A copy of the Treasurer's report was handed out for discussion to each attendee then handed back after the discussion had concluded.

GENERAL BUSINESS

Phil R began the meeting.

Phil R. explained that he's recording the meeting (both video and audio) with the aim of, if it works out, giving members the opportunity of viewing the meeting should they not be able to attend in person. He continued to explain that if things with the recording go according to plan then he will set up a Zoom teleconference for each future meeting. However, he said, due to the amount of time and work involved he will only continue should a sufficient number of our members want this service.

So, any member who would like to use the Zoom service to virtually attend future meetings will need to let Phil R. know by either phoning, texting or e-mailing him on:

Mob: 0417 186 337.

E-mail: phil@pgrsystems.net

How Members Are Trying to Control Their PN

We then discussed the different types of aids tried to help cope with the symptoms of PN. Members offered the following information:

1. Medical Cannabis was mentioned and it was reported that the benefits were varied. It's worth mentioning here that one of our members, Murray Cox, has written a detailed document on Medical Cannabis. This document is freely available to us all in PDF form. Should a member require a copy and does not have access to a mobile phone /computer with Internet connection and does not have a friend or family member with a mobile phone /computer then they are to contact Phil R and he'll arrange for a paper copy to be posted out.

Phil R.

Mob: 0417 186 337.

E-mail: phil@pgrsystems.net

2. Phil R. mentioned that he had bought a small tube of Kunjea (cream), as set out in last month's minutes. He found that it is a good moisturiser however it did little to help his PN and Kunjea cream cost six (6) times that of Accident Cream. He also said that just because Kunjea didn't work for him doesn't necessarily mean it wouldn't work for someone else.

The PN Booklet and Application Form:

1. The PN book is now online in PDF form and the PNSG Application form will also be to be available soon in PDF.
2. There is still large number of hard copies of our Living with PN book to be distributed should anyone require one. If a member wishes to place some with their local pharmacy, then please let us know.

More subjects on Phil R's agenda which were discussed were:

1. Phil R is prepared to help any member who has difficulty in opening a PDF on their phone or computer.
2. Ron to do the AIS (Annual Information Statement for the ACNC) and have Phil registered as a Responsible Entity in the ACNC database.
3. A suggestion was to place our PN display board in shopping centres, pharmacies, doctors etc. Also, to approach radio stations (local and regional) to promote PN awareness. Phil R is to research and advise us of his findings at a future meeting.

4. It was said at the meeting that 'distractions' are an extremely potent way for PN sufferers to take their mind off their PN pain and find temporary relief from their symptoms. Phil R asked do we have any musos who sing or play a musical instrument? or those who have done so in the past? A member may find that playing an instrument or singing etc. (alone or in the presence of others) may find playing music a good distraction for their PN symptoms. He also said that statistically speaking we must have 20+ members who are musically inclined.
Phil R said that he'd like to hear from you.
5. Finances - The PN Group needs to find ways to cut down on expenses and/or increase our income. The biggest cost we have being postage. Some ideas are:
 - a. Increase membership Fees,
 - b. Request members to maintain their annual subscription.
6. Contact NCWA (Neurological Council of WA) regional Offices, make sure they are aware of the problems our members are experiencing and encourage the NCWA to carry out more PN research.
7. Phil R and other members to attend NCWA monthly meetings which are held on 3rd Friday of the month.
8. Generally, to encourage PN awareness and research for new treatments.

A couple of interesting pieces of news coming from the Connect Group Information was as follows:

Act now and gain the support of a UWA student intern in 2024

The McCusker centre for citizenship is now accepting new roles for UWA student interns in Semester 1, 2024. Submit your role now to increase your chances of attracting the perfect student. The McCusker Centre will match your role with a talented motivated intern for your project intern's volunteer 100 hours through the program – more than 3000 internships have been undertaken to date with a 97% recommendation from host organisations.

Rare, Genetic, and Undiagnosed Sector Development Program:

Following a successful first year of the Rare, Genetic and Undiagnosed (RGU) Sector Development Program, ConnectGroups is excited to announce the 2024 program.

The co-designed program aims to support RGU groups and organisations to increase their capacity and capability to remain sustainable and continue to provide their invaluable services to the wider community.

EOIs (expressions of interest) are open until Friday 2nd February 2024 for Support Groups and organisations Australia-wide in the Rare, Genetic and Undiagnosed Conditions sector.

The meeting closed at 11.50 am.

The next meeting is on Monday, February 12th 2024 at The Niche, cnr of Hospital Avenue and Aberdare Rd, Shenton Park, W.A. 6008

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From Maurie Fields - Dinkum Aussie Jokes

A school teacher bent down to pick up her chalk and her dress rode up a bit. *Miss* a little boy said with his hand up. *I just saw your lovely knees. You naughty little boy* she said. *Go home and don't come back for the rest of the week.*

Then she leaned over and another boy said *Miss, I just saw your cleavage. GET OUT!* she said *and don't come back for a month.*

Then the teacher caught her skirt on a nail and it came off completely. A little boy started packing up his books. *Where are YOU going?* She asked. He said *Well, with what I just saw, my school days are over* 😊 😊 😊

Here's another one for you...

A knockabout bloke was down on his luck and couldn't find work, so he caught a bus to Vacluse, a very ritzy Sydney, suburb to knock on people's front doors, asking for odd jobs. He walked up the driveway to a huge mansion and rang the doorbell. When a man answered, he asked *Got any odd jobs need doing.* | *Actually,* said the gent, *I need my porch painted. It's around the back. No worries,* said the bloke.

So, the man gave him a 10litre tin of green paving paint and sent the bloke around to paint the back porch. About three hours later, the bloke came round the front and rang the doorbell again.

I've finished, he said. *Nice job too. Two coats.*

Fine, said the gent, *here's twenty bucks. Thanks,* said the bloke and began to leave. As he was walking down the driveway, he turned and shouted *by the way, I don't think it was a Porch, it looked more like a Ferrari* 😊 😊 😊.

Computer Keyboard Shortcuts

Computer keyboard shortcuts are a great way to speed up the way you work on your computer.

Whether you have a PC (Windows) or Apple then this is for you.

Just rest your mouse cursor on the link below, hold down the Ctrl key (Win) or Command key (Apple) and tap the left mouse button.

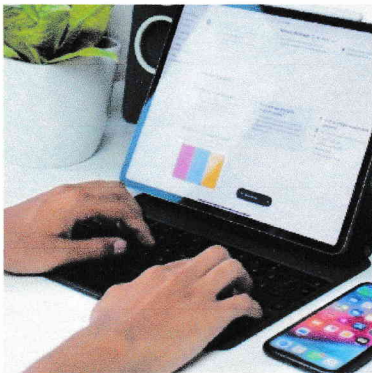
If you're interested in exploring other phone and/or computer tips and tricks then get in touch with:

Phil R:

Mob: 0417 186 337 (call or text)

E-mail: phil@pgrsystems.net

Happy computing!



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