

CONTACT: Secretary, Barbara Morris, 39 Appleby Street, Balcatta, W.A. 6021 *OR*
EMAIL: junepngroup@gmail.com
PHONE: 0459 972 246 and leave a message as phone is not manned continuously.

NEWSLETTER AND P.N. MINUTES for 12th February, 2024.

The meeting opened at 10.05 am. Phil R welcomed a new member Barbara Ziembinski and she discussed her PN symptoms and her reasons for joining our group.

ATTENDANCE: Faye Holloway, Barbara Morris, Margaret Hunt, Barbara Ziembinski, Philip Surtees, Ron Gascoigne, Murray Cox and Phil Reed.

APOLOGIES: Eileen Senn, Laurel Morris, Celia Miraglia, Lindsay Gibson, and Mike Kiff.

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

Accepted: Murray Cox

Seconded: Philip Surtees.

CORRESPONDENCE:

There was an email and phone call from a John Connors in Sydney. After being diagnosed with PN, he visited various institutions around Sydney looking for some kind of help for his P.N. He discovered there is no research or backup groups in that field, so his 12-year-old daughter, Halle and her friend, Chelsea, decided to canvass for funding to put towards research into PN. After discovering a contact connecting to our group and a subsequent phone call for more information etc., they decided to donate the collection of \$120 to our group. Faye, who answered the call, was told by Mr. Connors that he gained a lot more knowledge from her phone call than he had received from any of his previous efforts.

1. The C.E.O of A.C.N.C. Vicki Vass has gone and Amanda Miller has taken over.
2. Events happening in 2024. Rare Diseases Day Expo takes place next month (February) at Fiona Stanley Hospital and Perth Children's hospital.
3. The launch of other internal programs allowing more time to help the team to allocate time to engagement and service delivery.
4. More initiatives have been lined up for next year with some new faces on the team.
5. The 2024 program for Rare and Undiagnosed Disorders has been set up. Training begins 22/2/24 and is an accessible opportunity for support groups and organisations to upskill their staff and volunteers. Subscriptions for training programs were open until 1st February 2024.
6. News that the Connect Group will be in Albany in February. They can offer advice to Albany residents on starting a support group and grants and funding will be available.
7. Connect Group will travel to Geraldton at the end of March 2024.
8. Pay it Forward for Groups (funding) is now available and closes 15th March 2024

An Email from Phil – He will be unable to chair the March meeting.

Accepted: Murray Cox

Seconded: Phillip Surtees

TREASURER'S REPORT AS AT 31/01/2024

RECEIPTS	\$	PAYMENTS	\$
Attendance	20.00	Morning Tea	20.00
Membership	30.00		
Donation	20.00		
TOTAL	70.00		20.00
Balance b/f			1428.08
BANK			
Cheque A/c paid	20.00	Deposits	70.00
Balance c/f	1478.08		
TOTAL	1498.08		1498.08
Balance c/f			1478.08

ACCOUNTS FOR PAYMENT

Postage	85.70
Morning Tea	0.00
Labels	55.00
Stationery	3.00

Accepted: Barbara Morris Seconded: Philip Surtees.

GENERAL BUSINESS

Phil R tabled a document containing a list of ground rules for him to ensure are followed at each meeting. The list amounted to general common sense in showing common courtesy and respect to everyone attending the meeting. No bullying, violence, cell phones silenced, one person at a time speaking and no conversation monopolies, amongst other courtesies. This document is available to interested parties:

Contact: Phil R.
Mob: 0417 186 337
E-mail: phil@pgrsystems.net

The Treasurer's report was discussed as Phil R wanted one small point cleared up, which Faye H (Treasurer) was able to do.

It was decided that unfortunately members who haven't paid fees for 12 months, will have to be cut off the mailing list, as postage has become quite expensive. We will ring first to find out why, and if there is a reason for non-payment then we may be able to help.

Another idea was to charge postage for new members, but this wasn't accepted by those present.

Members who wish to pay their past and current membership fees can do so using online banking:

Account Name: Peripheral Neuropathy Support Group
BSB No: 633 000
Account No: 125154856

In accordance with Phil R's notes which he tabled to bring up at the meeting, the following items came up.

- a. **Peripheral Neuropathy Support Group:** Philip S. raised a good point that whilst the PNSG has a management team it doesn't have a committee. Ron mentioned that we are within our legal rights to say we do already have a committee. The committee comprises of the members who attend our AGM. It was agreed that we are too small a group to have a separate committee.
- b. **PN Books and Application forms:** These have now been scanned and are available as a PDF.
- c. **Our Application Form** states that our annual membership fee is \$10. One small problem with that was that if the membership fee were raised, then it would be necessary to change our hardcopy membership form by either reprinting or applying a sticker with the revised annual fee. This is not a problem for our softcopy membership form as the fee can be over written.

Phil R's Job Description and Other PNSG Documents:

At the December 23rd's meeting, Phil R asked the attending members at the meeting what tasks do the attending members believe he should perform and Phil R's accountable tasks. Members told him they expect him to:

1. Encourage PN research by organisations such as NCWA (Neuropathy Council of WA) including Regional Centres etc. to speed up the likelihood of finding better control and hopefully a cure for PN sufferers.
2. Promote PN awareness to the public by making presentations to e.g. aged care villages, providing P.N. books and application forms to GPs etc.
3. It's planned that any members at any time can look at Phil's job description to see how he's going or look at any other relevant documents. It is intended that general PNSG documents will be readily available online. Those members who do not have Net access on their computer, iPad or mobile phone can request a hardcopy of any published PNSG document and the document(s) shall be mailed.
4. Phil R has started setting up a centralised collection of PNSG documents on Dropbox so those members with a computerised device with Net access can easily access.
Once up and working the centralised system will provide a well-protected place that will give us better control and remove potential misunderstandings and errors.
Whilst there are quite a few documents available to all of us Phil R has yet to resolve a security / connection issue before the documents can be accessed.
5. Providing our group can get sufficient funding then it is hoped we can set up our very own website and incorporate our general documents as well as other helpful features for our members. This is likely to take at least 12 months.

Odds and ends of information:

1. We did have a Facebook account at one stage and Phil R. asked if we needed it to be set up again. All members said an emphatic NO.
2. Phil will be away in March and Ron is kindly going to chair the meeting. Phil R said that his probation ends in March and him being away will be a good opportunity for the members attending our March 2024 meeting to give Ron some feedback on him. Phil R said, please be kind and go gentle with him.
3. To make the newsletter more personal, perhaps a collective (group) photo of the officials may be a good thing. No one wanted a single photo or mugshot.
4. Phil R asked who has access to our PNSG e-mail account – Only Barbara M - PNSG (Secretary) has access.

5. In November we had a competition for the best suggestion for PNSG. Murray Cox's name was drawn for the prize of one year's free membership. His idea was to make the P.N. book and Application form available as PDF then they can be attached to an e-mail address in response to the sender asking for membership information.
6. Phil R is planning on doing a phone-around of 10 calls to members each month at random to determine the effectiveness of PNSG'S newsletter. Phil R will develop questions to ask members:
 - a. Are you receiving the PNSG newsletter?
 - b. Are you able to open it? In its PDF form?
 - c. Is the Newsletter easy to read and understand?
 - d. Any suggestions how PNSG can serve you better?
 - e. Do you want more information on what our group is about?

How Members Are Trying to Control Their PN

1. Vicks Vapor Rub as well as Cannabis were discussed. There's nothing new from what we've heard at other meetings except that it works for some people and not for others.
2. Phil R said that he finds it painful to sit or stand for more than about 20 minutes. He tried kneeling (on *both* knees) at his computer instead of sitting and finds it acceptable in short sessions. He said his pain reduces for several hours after the kneeling sessions.

N.B. Please understand that what suits Phil R may not suit you especially as you may find it difficult to standup after kneeling for a while and you may experience stability issues and possible injury.

3. Compression socks are widely used for people with PN. They come in all kinds of configurations and sizes; different compression ratings, open-toed, closed-toed, long and ankle length, warm and cool and different colours.

Whilst the Net is awash with suppliers you can't try-before-you-buy and technical information is scant and may not be accurate. Don't get drawn in by the heavy discounts e.g. 80% off.



If you're prepared to pay more then go visit:

The Rehab Shop (APE Medical)
Unit 1/ 61 Gutherie St,
Osborne Park WA 6017
Ph: 1300 799 171

Their staff will spend time to measure you up,
get relevant details to try to make sure you end up with what's
best for you.

We don't have any arrangement with the shop, so no special deals.

<https://www.apemedical.com.au/contact-us/the-rehab-shop/>

4. Cork /Leather/Rubber Sole Sandals
Birkenstock Sandals (German) make a whole range for men and woman. There scalloped cork inner supports your feet well; sadly, they cost and arm and a leg (sorry excuse the pun).



The meeting closed at 11.20 am.

**The next meeting is on Monday, March 11th 2024 at The Niche,
cnr of Hospital Avenue and Aberdare Rd, Shenton Park, W.A. 6008**

PNSG'S LIBRARY

In addition to our booklet Living with PN we have the following books. They are freely available to all members however if you're unable to pick up and you want a book posted out to you then you will need to pay postage and an Aust Post envelope each way. If the cost of the postage is prohibitive then you may be able to get from your local library:

1. Numb Toes and Other Woes by John A. Senneff.
2. Nutrients for Neuropathy by John A. Senneff.
3. PN - Into the Light by Gerard Said.
4. Rewire Your Pain by Dr Davies, Dr Cooke and Julia Sutton.
5. The Care of Neuropathic Limbs by Grace Warren.

Anyone interested in borrowing from our small collection of books (donated by members) they can contact Phil R.

N.B. you must contact Phil R if you wish to pick up so Phil R can bring to the meeting for you to collect from him:

Phil R
Mob: 0417 186 337
E: phil@pgrsystems.net

Windows BitLocker

All computer owners have to occasionally download and install updates. Also, sometimes when you're on the Net some sad person may intentionally try to do unpleasant things to your computer, and increasingly to your iPad (and/or other tablet) and mobile phone.

I know this can happen because it happened to me a few days ago and it wasted eight hours of my life at the worst possible time.

If your computer potentially has been comprised or if the new update downloaded can possibly crash your computer, then Windows will intentionally invoke Windows BitLocker and you will not be able to run your Windows computer until you enter your key code. Should this ever happen to you and you can't fix it yourself (and not even with the help of your eight-year-old grandchild) then give me a call and I may be able to help save you eight hours trying to fix a ten-minute problem.

<https://support.microsoft.com/en-au/windows/finding-your-bitlocker-recovery-key-in-windows-6b71ad27-0b89-ea08-f143-056f5ab347d6>

American Academy of Neurology



Annual Meeting coming in April, 2024 and can be viewed, live, online.

Hopefully we'll hear (and see) what the USA can offer us PN sufferers to spur us on.

<https://www.aan.com>

CLEAN JOKES



A child asked his father, "How were people born?" So, his father said, "Adam and Eve made babies, then their babies became adults and made babies, and so on." The child then went to his mother, asked her the same question and she told him, "We were monkeys then we evolved to become like we are now." The child ran back to his father and said, "You lied to me!" His father replied, "No, your mom was talking about her side of the family."

What happens to a frog's car when it breaks down? It gets toad away.



Kid 1: "Hey, I bet you're still a virgin." Kid 2: "Yeah, I was a virgin until last night." Kid 1: "As if." Kid 2: "Yeah, just ask your sister." Kid 1: "I don't have a sister." Kid 2: "You will in about nine months."

Teacher: "If I gave you 2 cats and another 2 cats and another 2, how many would you have?" Johnny: "Seven."

Teacher: "No, listen carefully... If I gave you two cats, and another two cats and another two, how many would you have?"

Johnny: "Seven."

Teacher: "Let me put it to you differently. If I gave you two apples, and another two apples and another two, how many would you have?"

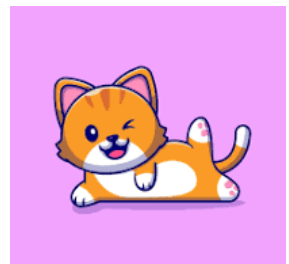
Johnny: "Six."

Teacher: "Good. Now if I gave you two cats, and another two cats and another two, how many would you have?"

Johnny: "Seven!"

Teacher: "Johnny, where in the heck do you get seven from?!"

Johnny: "Because I've already got a freaking cat!"



Your feedback on any aspect of our group is always welcome.

So, until our March, 2024 Newsletter – Make every day count!