

3 December 2019

Dear members of the Parkinson's NSW community,

The Parkinson's NSW Annual General Meeting was held on Friday 22 November.

It was well-attended and we heard from Members on a variety of topics of interest and concern. As you would expect, many different viewpoints were expressed and not all were in agreement.

In the interests of open communication and transparency we have summarised the main points discussed in the attached *Questions & Answers* document. This covers the topics raised and the answers provided during and after the Annual General Meeting. We will also make available a transcript of the meeting upon request.

During the Meeting I observed that many of the matters raised could easily have been resolved by a phone call or email to Parkinson's NSW.

There is no need to wait until the next Annual General Meeting to share your views or ask your questions; we are always open to hearing what is on your mind.

For Parkinson's health, medication, therapy and support-related questions, call the Parkinson's NSW InfoLine: **1800 644 189**

For other inquiries, call **02 8051 1900** and ask to speak to the person responsible for your area of interest -- finance, administration, marketing, media and communications, Support Groups, advocacy, fundraising, etc.

To contact us by email, use this address: pnsw@parkinsonsnsw.org.au

Another option is to use the response form found on our web site here:
<https://www.parkinsonsnsw.org.au/about-us/contact-us/>

I hope you find the attached *Questions & Answers* summary interesting and useful. Please contact us if you have any follow-on questions or comments.

Regards,



David Veness
President

Responses to Questions Asked During 2019 Parkinson's NSW Annual General Meeting Friday, 22 November 2019

Q: Why did the auditor express “material concerns about Parkinson's NSW as a going concern”?

A: In the *Independent Auditor's Report*, the auditors StewartBrown stated that because The Parkinson's NSW Trust financial statements had not been included in the Parkinson's NSW 2018-19 financial report, it was not compliant with the *Australian Accounting Standards Board 10 Consolidated Financial Statements*.

Purely on the basis of this, StewartBrown was required to issue a qualified opinion. The Parkinson's NSW Trust is considered a Related Party and therefore its financial statements are required to be consolidated as per AASB10.

The fact that the financial statements were not made available meant they could not be consolidated into the Parkinson's NSW financial report as required. Hence the qualified opinion.

The auditor also drew attention to Note 2 of the Parkinson's NSW Director's Declaration which stated that “In the opinion of the Directors there are reasonable grounds to believe that the company will be able to pay its debts as and when they become due and payable”.

In relation to Note 2, the auditors stated that without modifying its opinion, they drew attention to the deficit for the year and uncertainty exists that may cast significant doubt on the company's ability to continue as a going concern.

Addressing the Annual General Meeting, an Audit Partner of StewartBrown stated that Parkinson's NSW has a strong balance sheet so there is no concern. The company can pay debts when they fall due.

She also commented that the uncertainty referred to the fact that The Parkinson's NSW Trust had been audited separately, when in fact it should have been consolidated with the accounts of Parkinson's NSW.

Q: Why has the Parkinson's NSW Trust not been included in this audit and financial report?

A: The Parkinson's NSW Trust is a separate entity and has previously been audited separately from Parkinson's NSW. It did not share information with Parkinson's NSW.

It is anticipated that in future the Trust and Parkinson's NSW will be consolidated and audited together.

Q: Parkinson's NSW expenses keep rising. Do you plan to take money from the Parkinson's NSW Trust to cover those expenses?

A: No. The Parkinson's NSW Trust will continue to operate under the terms of its Trust Deed and be managed by an independent Board. It is a separate entity from Parkinson's NSW and will remain so.

Q: How much in funds is currently being held by the Parkinson's NSW Trust?

A: \$3.7 million

Q: It seems to me there was tighter management of Parkinson's NSW when it was governed by the regulations of NSW Fair Trade. Things seem different now it is operating under the regulations of the Australian Charities and Not-for-profit Commission (ACNC).

A: The audit requirements of the ACNC are much more rigorous than those of NSW Fair Trade. They are also more transparent because audit results are posted on the ACNC web site for public viewing.

Q: Cash flow is key to continuing operations of Parkinson's NSW. What is management doing to ensure the required cash flow continues?

A: We have invested in a proactive, ongoing fundraising strategy that includes building a far larger database of potential donors. We have a Bequest Officer in place who so far has developed a pipeline of more than 50 confirmed bequests and another nine estates mentioning Parkinson's NSW are currently in probate.

We have already met our bequest income target for 2019-2020 and we are only five months into the financial year.

Our advocacy program now includes putting a case to the NSW Government for recurring funding for other Parkinson's NSW services in addition to Parkinson's Specialist Nurses.

We have become a Registered Service Provider of the National Disability Insurance Scheme and are looking into the opportunities provided by My Aged Care.

In addition, we are tightly controlling expenses. This includes reducing staff hours, staff taking unpaid leave, and in one case temporarily seconding our database manager to another organisation.

Q: I don't believe enough management and staff time has been allocated to fundraising, which is where your operating funds come from. What are you doing about this?

A: See answer to question above.

Q: I think relying on bequest income is like betting on a horse race – you never know when someone will die, so you have no guarantee of when the money will come in. What are you doing about that?

A: It is not the same as betting on a horse race. There is industry-standard science and evidence supporting our methodology.

We employ experienced, professional fundraisers and have now added fundraising expertise at Board level with the appointment of Margaret Scott as one of three new Board members.

Margaret has more than 30 years of experience in fundraising for not-for-profit organisations and was on the Board of the Fundraising Institute of Australia for 12 years.

Q: You mentioned staff hours have been reduced. Why should staff suffer just because of your poor management and budgeting?

A: We do not accept the allegation of poor management. See responses to questions below. Staff members who reduced hours volunteered to do so. They have also volunteered to take leave without pay. In one case we have also seconded a staff member with technology expertise to another organisation.

Q: Will any community-based nursing staff be cut under these cost-saving measures?

A: No.

Q: Why have the administration expenses of Parkinson's NSW risen year to year?

A: We have increased the delivery of a range of services including the volume of InfoLine calls and emails, the number of consultations of our Parkinson's Specialist Nurses, counselling engagements, education seminars, publications and social media engagements.

To support all these activities PNSW has appointed skilled staff and invested in infrastructure.

See the *Parkinson's NSW Annual Report* and *Parkinson's NSW Corporate Brochure* – both available on the web site – for more information.

Visit: <https://www.parkinsonsnsw.org.au/about-us/annual-reports/>

Q: What can you do to generate more publicity about the real experiences of people living with Parkinson's?

A: PNSW attempts to generate publicity through the following channels:

- Maintaining a corporate web site with regularly updated information
- Maintaining a presence on a variety of social media platforms including Facebook, Twitter, Instagram, LinkedIn and YouTube.
- Conducting high-profile awareness-building and fundraising events such as World Parkinson's Day and Month, and the annual Unity Walk in the Park – each cross-promoted via the media described above.

While PNSW would like to invest more in public awareness campaigns the organisation currently does not have the resources to do so.

In addition to focusing on the above initiatives we spend time and effort on:

- Publication of a quarterly Parkinson's news magazine called *Stand by Me*. Each edition is read by more than 7,500 people in hard copy and online. It goes to a wide variety of stakeholders including political influencers and decision-makers, the medical community, the broader Parkinson's community, and Members of Parkinson's NSW.
- Publication of a monthly newsletter called *InTouch* which is distributed via email to Support Groups and Carer Groups throughout NSW. This newsletter reaches more than 1400 Support Group participants each month.

Traffic to the Parkinson's NSW web site recorded significant 480 percent organic growth in email subscriptions over the 2018-19 fiscal year, with a retention rate of 95 percent.

Social channels also recorded significant growth:

- Facebook 38 percent
- Instagram 66 percent
- LinkedIn 57 percent

Social media plays a key role in the communications strategy of Parkinson's NSW. It allows us to connect with many of the family members, relatives and friends of people living with Parkinson's – as well as a broad range of other stakeholders with an interest in Parkinson's.

They include Primary and Allied Health practitioners, researchers, political influencers and decision-makers, and health and aged care influencers and bureaucrats.

In terms of specifically communicating the challenges of Parkinson's we achieved great success with a compelling video titled *Dear Family and Friends* which was created for Parkinson's Awareness Month by the Parkinson's NSW Marketing & Digital Team.

Its objective was to raise awareness of Parkinson's by showing viewers what living with the disease really looks like.

No money was spent on producing or promoting this video, but it made a significant impact. It was the single most popular Facebook post in April, delivering:

- A reach of 36,400 (the number of individual Facebook feeds it appeared on)
- 5,700 engagements (how many people liked or shared the video, or left a comment)

The *Dear Family and Friends* video can be viewed on Facebook or YouTube here:

www.facebook.com/parkinsonsnsw/videos/416747442460525/

<https://www.youtube.com/watch?v=B4QHmRgL1RA>

Q: The new *Support Group Manual* says the main purpose of Support Groups is to support the purpose and Parkinson's NSW. That is not true! The purpose of Support Groups is to support people living with Parkinson's!

A: The new *Support Group Guidelines* from which you are quoting is a legal document linked with the Constitution of Parkinson's NSW.

The Constitution states:

The principal purpose of the company is to promote and advance the prevention, management, cure and control of Parkinson's Disease.

The Constitution further includes a list of activities of Parkinson's NSW. These include:

- *Support, provide and develop tools and support services that help people with Parkinson's Disease, their families and carers.*
- *Facilitate sharing of information and other resources relating to Parkinson's Disease.*
- *Promote a deeper understanding and awareness of Parkinson's Disease within the medical and broader community...*

Therefore, the purpose and activities of Parkinson's NSW align with the purposes of Support Groups – primarily supporting people living with Parkinson's.

Q: The amount of information and requirements in the new Support Group Manual are overwhelming for Support Groups. Do we really have to do everything the Manual requires?

A: The manual is a living document and we are currently undertaking consultation with the Parkinson's NSW Support Groups to make it more accessible and adaptable for a variety of needs and sizes of Groups.

Q: Can Parkinson's NSW provide financial reporting on the first quarter of the year so we can see how the organisation is progressing?

A: Yes

Note: This was moved as a motion and adopted by Members. Parkinson's NSW committed to deliver the information within one calendar month of the Annual General Meeting

Q: Why did Parkinson's NSW turn down an offer of \$250,000 from the Parkinson's NSW Trust for nurses?

Note: This question was raised by former Board members of the Trustee of Parkinson's NSW Trust who claimed to have minutes of a meeting at which an offer had been made to Parkinson's NSW.

A: (From the President of Parkinson's NSW).

Please provide a copy of minutes of that meeting you are referring to and we will be pleased to communicate the details to the Members of Parkinson's NSW.

Q: The proposed new Board of the Trustee of the Parkinson's NSW Trust comprises two independent directors and three directors from the Board of Parkinson's NSW. For the purposes of good governance, wouldn't it be better to have three independent directors and two from Parkinson's NSW?

A: Parkinson's NSW is improving the transparency and governance of the Trustee of the Parkinson's NSW Trust. We operate within the requirements of the Corporations Act 2001 (cth) and the new Board structure is in compliance with this Act.

Parkinson's NSW believes the structure of two independent Board members without any relationship to Parkinson's NSW or interested parties, plus three current Board members is a significant improvement and a much more transparent arrangement.

**Q: Why are Support Groups required to fundraise for Parkinson's NSW?
We already have enough financial stress from paying for our treatment.**

A: Support Groups are not required to fundraise for Parkinson's NSW. It is done on a purely voluntary basis.

However, we encourage Groups to reach out in their own communities to raise broader awareness of Parkinson's and the challenges of living with this disease.

Raising awareness of Parkinson's is an indirect form of fundraising because it may promote increased giving.

Q: What are the qualifications for a Parkinson's Specialist Nurse?

A: A Parkinson's Specialist Nurse is required to:

- Be a Clinical Nurse Consultant – Level 2
- Provide expert clinical consultancy and services within the defined speciality of Parkinson's Disease
- Provide complex client-centred consultancy within a mixed clinical environment and across multiple services and specialities including hospitals, community, multidisciplinary Parkinson's clinics and speciality nurse clinics, aged care, dementia care, psychiatry, medicine, surgery, mental health and continence.
- Provide leadership in the ongoing review of clinical practice for the complex service of Parkinson's disease, including:
 - Clinical procedures for Apomorphine
 - Development and implementation of procedures for the care and management of people with Parkinson's admitted to hospital
 - Membership of the Australian Neurological Nurses Association (including attending quarterly meetings)
 - Initiating and participating in collaborative ventures with academic institutions.
- Adapt and apply scientific research to the clinical speciality of Parkinson's Disease
- Conduct ongoing comprehensive analyses of current practices and the impact of new directions on the clinical speciality service
- Manage complex projects related to significant practice changes e.g. Apomorphine and Duodopa.