

Questions from Members and Support Group Participants Prior to the Annual General Meeting

Annual General Meeting vs Extraordinary General Meeting

Q1: Why did you disregard the will of your Members for an Extraordinary General Meeting?

A1: We are holding an Annual General Meeting that includes all of the resolutions that were put forward for an EGM but without the considerable expense of holding two meetings within weeks of one another.

In fact, legal advice we received indicated that we were not obliged to deal with all the issues raised at an EGM at all.

We are respecting the Member's wishes by putting the resolutions to the Annual General Meeting which had already been scheduled.

A separate EGM would have cost more than \$74,000. That sum is sufficient for Parkinson's NSW to co-funding a Parkinson's Specialist Nurse in a community of need for one year.

We strongly doubt that Members with the the best interests of the Parkinson community in mind would be comfortable with this expenditure of funds on a meeting that is not required, being so close to an Annual General Meeting.

Q2: This is a matter for individual Directors to resolve. Surely, as they are honorary Directors, it is inappropriate to use Parkinson's NSW funds to defend their positions.

A2: The people who mounted this attack on Parkinson's NSW sent a letter to all Members bringing into question the reputation of the organisation – including the Board, Leadership Team, employees, and volunteers.

The feedback from vulnerable Members – including donors and bequestors as well as employees – who received this letter amid a pandemic made it clear to the Board and Management that they perceived the whole organisation was under attack.

When one makes such allegations about an organisation which depends on donations and bequests for 90 percent of its funding, it is perceived as an attack on the charity as a whole – not individual directors.

This perception is particularly reinforced by the fact that the instigators of this attack have had no previous engagement with Parkinson's NSW through receiving services or making any significant contributions.

So, when we are protecting our people, sources of funding and our organisation from reputational damage, expenditure on legal defence is required.

And the fact that we took the initiative to save the organisation expenditure of more than \$74,000 on an additional meeting that was not required, shows we have the best interests of Parkinson's NSW at heart.

Accuracy of Financial Report

Q3: Why are there two page 17s in the Financial Report sent to Members?

A3: This was a simple error in the document prepared by the Auditors. The second page 17 is in fact page 18.

A corrected version is now available on the Parkinson's NSW web site. It does not affect the accuracy of the financial information in the report.

Q4: Why in the Notes to the Financial Statements in the Financial Report I received no Note 10 or 19?

A4: This was a simple error in numbering of the notes provided by the Auditors. A corrected version is now available on the Parkinson's NSW web site. It does not affect the accuracy of the financial information in the report.

Q5: How can we trust you to properly manage the finances of Parkinson's NSW if you allow such basic errors to creep into Financial Report?

A5: I agree with you that these errors should not have occurred.

Parkinson's NSW outsources its accounting function to AccountingForGood. The Auditors, StewartBrown, were appointed by Members Resolution for three years at the 2018 AGM.

The Auditors are tasked with the preparation of the Consolidated Financial Statements and a corrected version is now on the Parkinson's NSW web site.

Financial Performance

Q6: Why have administration expenses – including salaries – nearly tripled over the past three years?

A6: The expenses you reference are not just administration expenses. They include operating expenses, fundraising expenses, service development, joint funding for community-based Parkinson's Specialist Nurses and employee salaries.

We acknowledge that there has been a 34 percent increase in Salaries and Employment Costs from June 2017 to June 2020.

This reflects a shift from mainly part-time staff to full time staff as quality and volume of service delivery grew in response to demand. It also takes into account the hiring of more qualified and experienced staff.

In addition, we invested in a 5-year Strategic Plan aimed at growing the organisation's base of donors from the original low of 1,500 to a target of more than 8,000 engaged regular givers. As of the end of the fiscal year, we had achieved a 55 percent increase in our base of regular givers.

We also invested in marketing, telemarketing, and direct mail campaigns in support of this donor acquisition campaign. It will diversify and strengthen future sources of revenue – reducing dependence on bequests.

Increased engagement with and assistance for Support Groups drove a 30 percent growth in the network.

Also, geographic coverage has been expanded to provide better support to people living with Parkinson's in regional and rural areas – correcting the previous administration's skew towards the Sydney metropolitan area.

It should also be noted that Parkinson's NSW the charity declared a significant \$264,663 net profit in 2019-20.

Q7: Is it true that recurrent fixed administration expenses do not include service provision or research?

A7: No. (See also answer to Q9).

Q8: Why has cash declined to extremely low levels, despite a record high in bequests?

A8: Parkinson's NSW ended fiscal 2019-20 in a strong cash position.

This was the third year of our Five-Year Strategic Plan. While tight quarter-by-quarter financial goals are the norm in commercial organisations, the not-for-profit model operates slightly differently.

For example, the majority of revenue for not-for-profits falls in the final two quarters of the year – not consistently by quarter.

For that reason, we need to keep our eye on the bigger picture – acknowledging the realities of the business model while exercising fiscal responsibility over the entire year.

Looking at one or two early quarters as indicators of the full year's performance is not a productive approach in our sector.

As noted above, a longer-term Strategic Plan is also required to overlay the annual goals and performance. For example, following a significant profit in fiscal 2017-18 we operated at a Board-approved loss in 2018-19 before returning to profit as planned in 2019-20.

Q9: Why did the Parkinson's Trust declare a loss for fiscal 2019-20?

A9: This was due to the impact of COVID-19 on the financial markets.

Investments by the Parkinson's NSW Trust delivered lower returns than in previous years. Although the charity (Parkinson's NSW) delivered a profit, its consolidation with the Trust as a related entity resulted in a loss of \$309,249.

Q10: What is the relationship between the Parkinson's Trust and Parkinson's NSW?

A10: Parkinson's NSW Ltd is the current Appointor of the Parkinson's NSW Trust. The Trust appears in the financial accounts of Parkinson's NSW Limited as a 'related entity'.

The two organisations have separate Boards.

Q11: Why did the Auditor issue a Qualified Opinion on the accounts of Parkinson's NSW for fiscal 2019-20. Is this a reflection of lack of sustainability or poor transparency in reporting?

A11: Neither. The Qualified Opinion was issued because:

- The Auditors were unable to obtain appropriate audit evidence of the accuracy and completeness of cash, revenue, and expenses for Support Group fundraising appeal activities.
- The Auditors were unable to satisfy themselves about the compliance of accounting and associated record keeping requirements by Support Groups.

These Support Group issues are being addressed with a new Support Group Operations Manual and stronger governance around Support Group bank accounts and financial reporting.

- The Parkinson's NSW Trust did not comply with Section 30 of the Public Ancillary Fund Guidelines, requiring a trustee to prepare and maintain a current investment management strategy (IMS) for the fund.

The new Board of Parkinson's NSW Trust appointed a new Investment Manager in July following a rigorous and extensive RFT process. The Board are currently working with the new Manager on an IMS and Distribution Policy and proper Governance.

Q12: Is it true that money received from bequests has not been spent on service provision?

A12: No.

As shown in the CEO's AGM presentation, there has been consistent growth in service provision over the past three years.

The methods of service provision changed in the latter half of 2019-20 due to COVID-19 restrictions, but still continued at a very high level.

Q13: Is your financial management – as claimed by Michael Shepherd – poor and not transparent?

A13: No. Parkinson's NSW as a charity recorded a significant net profit of \$264,663 in fiscal 2019-20.

With the under-performance of the 'related entity' Parkinson's NSW Trust due to the impact of COVID-19 on financial markets the consolidated result was a loss of \$309,249

We have in place a very capable and independent Board with strong governance processes in place.

In terms of transparency, Parkinson's NSW adheres to the reporting standards of the Australian Securities and Investment Commission (ASIC) and the Australian Charities and Not-for-Profits Commission (ACNC).

Q14: Is it true – as claimed by Michael Shepherd – that there is doubt about the survivability of Parkinson's NSW?

A14: No. Less than 10 percent of Parkinson's NSW funding comes from Government grants.

As a modern, well-managed not-for-profit we are diversifying our fundraising strategies to build a stronger pipeline of bequest funding, balanced by new revenue streams from digital fundraising and telemarketing.

We also have in place a very capable, high-performing Board comprising professionals with a variety of commercial and not-for-profit skills. Those Board Members were introduced to you today.

Board members engage in robust discussions about the future growth of Parkinson's NSW, develop strategy and rigorously monitor performance.

Q15: Fundraising, without bequests, has increased \$556,000 or 57%. Is this a good or bad result?

A15: A 57 percent increase is a positive result. We have also increased our base of regular givers by 55 percent over the past year.

Q16: Is it true that Parkinson's NSW has failed to secure a significant corporate sponsor since Bendigo Bank?

A16: Bendigo Bank slowly decreased its level of sponsorship from the mid 2000's to the mid 2010's.

The last sponsorship received was in 2015 at a third of the value of the initial sponsorship – two years prior to the current Leadership Team joining the organisation.

Corporate sponsorships account for less than 5 percent of the total fundraising pool in Australia.

The Parkinson's NSW strategy involves building a broader network of supporters and finding within this network those who have the capacity to give gifts or connections to other funding sources.

However, we welcome any suggestions or links to realistic sponsorship opportunities.

Q17: Was proceeding with your *Sydney Morning Herald* mail out in the midst of a pandemic a waste of money?

A17: The *Sydney Morning Herald* campaign involved the insertion of donation envelopes into a Monday edition of the paper to coincide with World Parkinson's Day in April 2020.

The campaign was booked and paid for in late 2019 following the success of a similar campaign in June 2019.

We could not anticipate that less than two weeks prior to this campaign launch, the State would be in shutdown.

Given the timing and cancellation terms of the contract with the *Sydney Morning Herald*, there was no possibility to withdraw the campaign at such short notice.

Despite the unusual circumstances, the campaign acquired 148 new supporters and income will exceed costs by the end of fiscal 2020-21.

Strategy

Q18: Has your management adopted an approach of 'going it alone'? And if so, why did you separate from Parkinson's Australia?

A18: The Senior Leadership Team of Parkinson's NSW *does not* have a policy of 'going it alone'. It *does* have a policy of rigorously evaluating the benefits of potential partnerships with its stakeholders.

The split from Parkinson's Australia was driven by a lack of results, consultation, and transparency from that partnership over a 14-year period.

The Board therefore decided that the nearly \$50,000 per year in annual fees paid to Parkinson's Australia would be better spent on direct service provision.

For additional perspective, it is useful to note that Parkinson's Victoria split from Parkinson's Australia in 2018 and it is our understanding that other States are also reconsidering their membership of the organisation.

Parkinson's NSW also enjoys a close relationship with Parkinson's South Australia – for which we provided InfoLine services for a 6-month period while it was restructuring. We also work closely with Parkinson's Tasmania, Western Australia, and Queensland.

Q19: Is it appropriate to continue the current 5-year plan to build donations based on the results obtained after 3 years?

A19: It is absolutely appropriate because we are meeting all of our Board-imposed milestones for the current 5-year plan to grow donations.

In early 2017 when the current CEO took office, the Parkinson's NSW database had just 1,399 donors who had made recent donations.

As of the end of fiscal 2019-20 (2.5 years into the program), there are more than 8,500 people actively supporting the work of Parkinson's NSW – including 4,000 new givers sourced via the telemarketing program.

This represents an overall growth of more than 600% in the donor base of Parkinson's NSW.

Q20: Is it true that there is doubt about the reputation of Parkinson's NSW?

A20: No. Like all modern organisations, Parkinson's NSW has multiple communications channels and monitoring systems to track feedback and reputational issues.

Results are routinely communicated to the Board so Members can monitor the reputational health of the organisation. No significant issues have been identified.

The Board has also instituted a Consumer Satisfaction Survey which will be periodically conducted as another tracker of both potential issues and stakeholder needs.

The results of this survey can be seen in the CEO's Report on this web site.

Q21: Why was there no investment in research during 2019-20, despite it being named as a priority in your 5-Year Strategic Plan?

A21: Parkinson's NSW Mission is to enhance the quality of life of people living with Parkinson's.

Our Purpose is to connect people living with Parkinson's with life-enhancing support and services.

Therefore, we do not focus on theoretical research in partnership with universities or compete with foundations like Shake it Up for funding to search for a cure. Our work is complementary with theirs, not competitive.

Instead, we focus on research that will provide outcomes with the potential to improve the wellbeing of people living with Parkinson's now, as the search for a cure continues.

We have a long-standing research partnership with the Faculty of Nursing, Midwifery, and Indigenous Health of Charles Sturt University.

Last year we jointly concluded a two-year study on the viability of the community-based Parkinson's Specialist Nurse model.

The resulting research highlighted the return on investment by Government in co-funding nurses, the value of multi-disciplinary health teams, and improved health outcomes for Parkinson's patients across multiple settings – including home, clinics, hospital, and Aged Care.

It resulted in an invitation to present at the World Parkinson Congress in Kyoto, Japan in 2019.

We currently have an ongoing project with Charles Sturt University involving our most senior Parkinson's Specialist Nurse who is undertaking PhD research into the optimum models of leadership for effective Parkinson's Support Groups.

The Parkinson's NSW Trust, which has a separate Board, was established to invest and grow bequests directed to the Trust. It provides grants to Parkinson's NSW for research projects.

When such grants are provided, our research projects again focus on improving the wellbeing of people living with Parkinson's e.g. research into falls prevention, improving mobility, managing the side-effects of medication, methods of accurately tracking the progress of Parkinson's so medication can be prescribed more precisely, etc.

Parkinson's NSW monitors and evaluates the research output of institutions in Australia and overseas.

Our Parkinson's Registered Nurses and Parkinson's Specialist Nurses are members of the Australasian Neurological Nurses Association (ANNA), the Movement Disorder Society of Australia and New Zealand (MDS ANZ), and the International Movement Disorder Society.

They attend meetings, participate in educational events and webinars, and attend conferences – then report back to their colleagues on the latest research, trends, projects, and publications.

Parkinson's NSW undertakes joint projects (such as a Telehealth pilot program for Parkinson's Neurology consultations) with – and refers patients and research volunteers to – all major hospitals, and respected neurologists and researchers.

Board

Q22: Three Directors resigned from the Board of Parkinson's NSW Ltd in fiscal 2019-20. Why the turnover in Board members?

A22: One of the objectives of our current 5-year Strategic Plan is the development and retention of a volunteer, skills-based Board. This work is ongoing, and we have retained a consultant to assist and guide this process.

We thank the departed Board Members for their service. They have resigned for a variety of reasons including increased family commitments, and difficulties in balancing Board requirements with their professional responsibilities.

Two Board Members living with Parkinson's remain on the Board.

The Constitution of Parkinson's NSW Ltd specifies that the Board may fill positions with three Appointed Directors. We appointed an independent consultant to recruit Board members with a mix of not-for-profit and commercial skills.

That search was successful, and we appointed four new directors in the second and third quarters of the fiscal year. We now have a very strong Board in place with a diverse mix of commercial and not-for-profit skills.

Support Groups and Memberships

Q23: Is it true that many people in Support Groups do not feel they are included and listened to?

A23: No. We are in daily contact with Support Groups of many different sizes and cultures in metropolitan, regional, and rural NSW.

We also hold regular Support Group Conferences which are attended by representatives from Groups across NSW metropolitan, regional and rural areas.

These Conferences include multiple brainstorming and Q&A sessions during which Support Group participants can engage directly with Board members, the Senior Leadership Team, and the people who deliver services and supports for them.

There has also been a period of adjustment to reporting and governance requirements imposed by the Australian Tax Office, the Australian Charities Not-for-profits Commission and Work Health and Safety legislation.

However, all of the above are part of the day-to-day requirements and operations of a Support Group and we do not have any evidence of “many” people not feeling included and listened to.

In fact, through our publications – including newsletters specifically developed for Support Groups – electronic direct mails, telephone, and video-chat outreach we actively, frequently solicit engagement and feedback from Support Groups.

We have also just completed a Consumer Satisfaction Survey. The results appear in the CEO’s AGM report on this web site.

Q24: Is it an issue that many people in Support Groups are not Members of Parkinson’s NSW?

A24: No, this is not an issue at all. Neither Membership nor participation in a Support Group are a requirement for receiving services and support from Parkinson’s NSW.

This was not the case under the past management of the organisation when Membership was a de facto requirement for receiving services from Parkinson’s NSW.

However, since 2017, the Board and Senior Leadership Team of Parkinson’s NSW have embraced inclusion and the imperative to deliver services that meet the needs of the entire Parkinson’s NSW community.

Over the years, under multiple Boards and Leadership Teams, many overlapping forms of Membership have evolved.

There is now so much duplication and confusion around the concept of Membership that the current Board has commissioned an external consultant to re-evaluate the Membership structure, remove duplication and make it more transparent.

The current Members and other stakeholders will be consulted during this process and the outcomes widely communicated.