

**Telecommunications Legislation
(Unsolicited Communications) Bill 2019
Senate Standing Committee on Environment
and Communications Legislation Committee Inquiry
Submission By
Parkinson's NSW
February 2020**

Executive Summary

Parkinson's NSW recommends that the Senate Committee **reject** the proposed amendments to the Do Not Call Register charity exemption on the grounds that:

- Self-regulation is already effective.
- There is no financially or logistically viable alternative to respectful, self-regulated telemarketing which offers an immediate and clear option for potential donors to opt out.
- Parkinson's NSW and charities like it are financially dependent on ethical telemarketing in order to continue funding vital services which are not available through the public health system.
- In the event of Parkinson's NSW closing, the burden would immediately be placed on Federal and State Governments to finance, staff, develop and deliver the same or a higher level of services to the Parkinson's community.
- That would amount to an additional cost to Government of more than \$1.3 million per annum – a burden which would steadily increase in line with the ageing of the Australian population and the increasing rate of diagnosis of Parkinson's disease.
- Parkinson's NSW does not 'prey' on the elderly. It respects, supports and provides services essential to the wellbeing of that cohort.

About Parkinson's NSW

Parkinson's NSW is a for-purpose organisation striving to make life better for people living with Parkinson's disease, their carers, families and communities.

It is the peak body for the Parkinson's community of NSW.

Parkinson's is a progressive, degenerative condition of the central nervous system. Nerve cell damage in the brain causes dopamine levels to drop, leading to the symptoms of Parkinson's.

Parkinson's symptoms can include tremors, slow movement, stiffness and loss of balance – as well as fatigue, apathy, depression, disturbed sleep, loss of sense of smell, and issues with speech and swallowing.

Symptoms can be managed with medication, exercise and other forms of therapy and support. However, as yet there is no cure.

The average age of diagnosis is 60. About 10 to 20 percent of people diagnosed with Parkinson's are under the age of 50 and about half of those are diagnosed before the age of 40.

There are currently an estimated 65,000 people living with Parkinson's in NSW and 37 new cases are diagnosed every day across Australia.

Importance of Fundraising to Parkinson's NSW

Parkinson's NSW relies on fundraising to develop and deliver essential services including:

- An InfoLine staffed by Parkinson's Registered Nurses
- Community-based Parkinson's Specialist Nurses who support people living with Parkinson's across multiple settings including home, clinics, hospital and residential aged care facilities.
- A network of more than 70 peer-support groups across the state managed by Parkinson's NSW and involving more than 1,400 participants.
- Counselling
- Education Seminars and Residential Aged Care Staff Training
- NDIS advocacy
- Social work
- Exercise physiology

With the support of donations, these services are offered at no charge or highly subsidised to the consumer – but cost Parkinson's NSW \$1.3 million to deliver in fiscal 2018-19.

Fundraising also underwrites regular grants to Australian researchers working on projects with the potential to improve the quality of life of people living with Parkinson's.

Parkinson's NSW is among Australia's 26 percent of charities which rely on donations and bequests for 50 percent or more of their total annual income.

Specifically, in fiscal 2018-19 Parkinson's NSW derived 93 percent of its income from fundraising.

Impact of the loss of DNC exemption

1. Prior to any telephone fundraising campaign, Parkinson's NSW 'washes' its contact lists against the Do Not Call (DNC) Register.
2. In addition to asking for support, Parkinson's NSW telephone contacts with potential donors include:
 - Education and raising awareness about Parkinson's – a condition that despite its prevalence in the community and the disability it causes, is not deemed a national health priority
 - Education about the individual's right to privacy and how they can ensure they receive no further communications when requested. This gives the donor an insight into how the charities work and provides them with the opportunity to opt in or opt out.

Once people contacted via telephone voluntarily register with Parkinson's NSW as a Regular Giver, the cancellation rate of donors from the program is around 23 percent – a clear indicator that people are willing to be contacted and are happy to give.

3. Many donors to Parkinson's NSW have some connection to or experience with Parkinson's. That includes people living with Parkinson's (predominantly elderly), their carers, family, friends and communities.

Therefore, Parkinson's NSW and charities like it have deep respect for elderly people. They are not 'prey' as Senator Griff has suggested; they are the community we serve and the broader network of individuals who know and support older Australians living with Parkinson's. They understand the cruel nature of the disease and want to give back.

4. There is no viable alternative to fundraising via telephone contacts.

Direct mail is slow, expensive, wasteful, has a negative impact on the environment and is less effective because it lacks the element of personal interaction.

To provide context, our most successful program seeking new donors acquired just 154 new donors through the distribution of 100,000 mailers – an acquisition rate of just 0.15 percent.

On the other hand, respectful telephone campaigns have enabled Parkinson's NSW to grow a base of 1,372 donors to 4,673 donors over a two-year period. Similarly, it has managed to grow 74 regular givers to more than 400 over the same period.

No complaints about Parkinson's NSW telemarketing were registered with the Australian Communications and Media Authority over that two-year period.

5. The results of the phone campaigns noted above directly enabled the provision of \$1.3 million worth of services to the Parkinson's NSW community last financial year. These are services not provided by the public health system.

In the event that Parkinson's NSW loses its DNC Register exemption, it will be at risk of financial failure.

The burden would then be on the Federal and State Governments to finance, staff, develop and deliver the specialised services and supports previously provided by Parkinson's NSW.

Recommendation

Parkinson's NSW recommends that the Senate Committee **reject** the proposed amendments to the Do Not Call Register charity exemption on the grounds that:

- Self-regulation is already effective.
- New legislation would penalise organisations already in voluntary compliance.
- There is no financially or logistically viable alternative to respectful, self-regulated telemarketing.
- Parkinson's NSW does not 'prey' on the elderly. It respects, supports and provides services essential to the wellbeing of that cohort.
- Passing the proposed legislation would place Parkinson's NSW and charities like it at risk of financial failure.
- In the event of Parkinson's NSW closing, the burden would immediately be placed on Federal and State Governments to finance, staff, develop and deliver the same or a higher level of services to the Parkinson's community.