

## Submission: ACT Government – ACT Budget 2025- 26

April 2025

### About The Hospital Research Foundation Group Parkinson's

The Hospital Research Foundation (THRF) Group fights against disease and illnesses by funding vital medical research and patient care services in the community.

THRF Group has a proud 60-year history, starting as The Queen Elizabeth Hospital Research Foundation in 1965 which supported a single hospital patient services and research initiatives. Now, THRF Group support research and patient care activities across all public hospitals, universities, and medical research centres in South Australia and at specific interstate locations.

Parkinson's ACT was founded in 1986 and joined THRF Group in 2022, it is the peak body for support, services and advocacy for people living with Parkinson's, their families and carers in the ACT and surrounds. THRF Group Parkinson's seeks to continue the work to collaboratively work with the ACT Government to advocate and support people living with Parkinson's, their families and carers in the ACT and surrounds.

### Introduction

The Hospital Research Foundation Group - Parkinson's (THRF Group Parkinson's) provides supports, services and advocacy for people living with Parkinson's disease, their families, and carers.

Parkinson's ACT was founded in 1986 as a fully funded volunteer organisation. It has since joined THRF Group in 2022, with a dedication to delivering improved services for individuals living with Parkinson's disease in the ACT and surrounds.

Currently, up to 150,000 Australians are currently impacted by Parkinson's disease, making it the second most common, and fastest growing neurological disease impacting Australians after dementia. Incidence rates of Parkinson's disease increase by 4% worldwide each year, creating immense impact on both economy and healthcare systems.<sup>1</sup>

---

<sup>1</sup> Parkinson's Australia. Statistics, March 2025. [Statistics - Parkinson's Australia](#)

With over 3,500 people living with Parkinson's in the ACT<sup>2</sup>, there are only few Government funded services that provide care and support for the community.<sup>3</sup> In South Australia, THRF Group – Parkinson's has worked collaboratively with the South Australia State Government to address the unmet need in the community. THRF Group Parkinson's have been successful in delivering a specialist nurses grant that has provided free specialised support to over 1,700 people living with Parkinson's disease in metropolitan and regional areas.<sup>4</sup>

Their support includes education about Parkinson's, what treatments are available, managing symptoms, health and wellbeing counselling, family, and carer support, and more.

This has helped boost quality of life for people living with Parkinson's through specialised advice and hospital avoidance, and helped close the gap for clients based regionally.<sup>5</sup>

Implementing a similar model in the ACT will contribute to Canberra Health Services strategic plan priorities, delivering world class care through partnership to achieve more inclusive care for ACT residents.<sup>6</sup>

## The Hospital Research Foundation Group Parkinson's ACT priorities:

### 1. Funding for the current commitment of the community-based Parkinson's (advance practice nurse)

Parkinson's ACT has been consistent with advocating for community-based specialist Parkinson's nurses over the past 10 years, the need and prevalence of Parkinson's disease continues to increase, yet the services are at a standstill.

With continued advocacy the need for specialised support for people living with Parkinson's disease in the ACT was recognised in the correspondence from Health Minister Rachel Stephen-Smith in October 2024 who said: "I am pleased to let you know that we are committing to the delivery of expanded movement disorder services including establishing a

<sup>2</sup> Ayton D, Ayton S, Barker AL, Bush AI, Warren N. Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism and Related Disorders*, 2019 Apr;61:198-202

<sup>3</sup> Canberra Health Services, Services & clinics search, March 2025. [Services and clinics search - Canberra Health Services](#)

<sup>4</sup> The Hospital Research Foundation Group – Parkinson's, 2025. [Specialist nurses helping hundreds of South Australians with Parkinson's - THRF Group - Parkinson's](#)

<sup>5</sup> South Australian Premier and Cabinet, Media release, 17/02/2025, [Specialist nurses helping hundreds of South Australians with Parkinson's | Premier of South Australia](#)

<sup>6</sup> Canberra Health Services, Strategic Plan 2024 – 2029 [Canberra Health Services Strategic Plan 2024 – 2029](#)



community-based Parkinson's Disease service for patients in the ACT through the Brindabella Day Service. A re-elected Labor Government will support an additional Advanced Practice Nurse position to facilitate integrated care for people living with Parkinson's"

THRFG Parkinson's ACT welcomes this election commitment and is keen to see it budgeted for 2025/26 to ensure it is implemented and services are available to the Parkinson's community as soon as possible.

THRF Group Parkinson's recent collaboration with the Health Care Consumers Chronic Conditions Network's has allowed us to connect our advocacy with like-minded organisations and we hope to have the Parkinson's community voice heard louder to have more services to address the unmet needs for the Parkinson's ACT community.

THRF Group Parkinson's has recognised the unmet need which is why it has made the investment in employing a part time community-based Parkinson's specialist nurse to begin services and support so that the ACT Parkinson's community is not left behind.

## **2. Funding for two community-based Parkinson's specialist nurses that offer supports and services to the community for people living with Parkinson's.**

With over 3,500 people living with Parkinson's in the ACT<sup>7</sup>, there are only few Government funded services that provide care and support for the Parkinson's community. Therefore, it is imperative that the Government invest in community based, holistic and person centered supports that address unmet needs. The people living with Parkinson's, their families and carers, deserve it.

In South Australia there are over 8,000 people living with Parkinson's disease, in partnership with the South Australian Government, THRF Group Parkinson's were provided a grant in 2022 to address the unmet community need. The Parkinson's Nurses grant has allowed THRF Group Parkinson's to employ five specialist nurses to provide support and services to the Parkinson's community.

The community-based specialist nurses have serviced over 1,700 people living with Parkinson's, since 2023. Through consultations with members and supporters of the ACT THRF

---

<sup>7</sup> Dyton D, Ayton S, Barker AL, Bush AI, Warren N. Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism and Related Disorders*, 2019 Apr;61:198-202



Group Parkinson's office, it has been identified that similar model for specialist Parkinson's nurses is needed.

This is why THRF Group Parkinson's is proud to have invested in employing a part time community-based Parkinson's specialist nurse to begin services and support so that the ACT Parkinson's community is not left behind.

To better service the Parkinson's community in the ACT we are seeking ACT Government's commitment to partner and provide \$1.5 million over four years to deliver a Parkinson's specialist nursing service program that adequately provides supports and services to the over 3,500 people living with Parkinson's, their families and carers.

We look forward to working with the ACT Government to implement this vital service.

### 3. Support for the ACT Parkinson's Infoline

Investment in adequate supports for the servicing of the information phone line is imperative for people with Parkinson's disease. It can significantly improve the lives of thousands of people impacted in the ACT. By investing in this service that is specifically designed for people living with Parkinson's disease their families and carers, we can ensure that regardless of their location, they can receive the timely, relevant, up to date information and person-centered care that they deserve.

THRF Group Parkinson's is seeking \$250,000 per year for four years to successfully operate and address enquiries received from the national information line directed into ACT.

The operation of the ACT information line will leverage information and communication to better address the geographical barriers and enhance access to:

- expert Parkinson's information
- providing personalised support for referral pathways
- connection with Parkinson's community and connection to community support services
- providing healthcare navigation support

To enhance the ACT Parkinson's Infoline's impact and long-term sustainability, integrating artificial intelligence (AI) solutions is proposed. Specifically, an AI-powered chatbot would be

---

#### SA/NT Office

25 King William Road  
Unley SA 5061

#### ACT Office

Unit 6, 32 Thesiger Court  
Deakin ACT 2600

P 1800 644 189

[www.FightingParkinsons.org.au](http://www.FightingParkinsons.org.au)

**TOGETHER. FIGHT.**



implemented on the Infoline's website and integrated into phone systems. This chatbot would provide immediate answers to frequently asked questions, offer foundational information about Parkinson's disease, and direct users to relevant resources. Furthermore, it would also perform initial triage, gathering essential details to prioritise urgent calls and streamline the process before clinical staff intervention.

Additionally, an AI-driven knowledge base would be developed to rapidly access and synthesis information from diverse sources, ensuring Infoline operators can deliver accurate, up-to-date, and personalised information to callers. Furthermore, AI can aid individuals in navigating the complex healthcare system by offering tailored recommendations for specialists, therapists, and support groups within the ACT.

To facilitate the development and implementation of these AI-powered solutions, an additional budget allocation of \$300,000 over a four-year period is proposed, ensuring the ACT Parkinson's Infoline remains innovative and provides optimal support to those living with Parkinson's disease.

#### **4. Funding for accessible Brain Body Fitness Studio sessions**

Exercise benefits all people with Parkinson's, regardless of how long you have been living with the condition. The precise benefits of exercise are dependent on the type of exercise you undertake and how far Parkinson's disease has progressed.

THRF Group Parkinson's in South Australia has developed Brain x Body Fitness Studio which is an innovative exercise facility focused on the elements of active ageing – neuroplasticity, flexibility, strength, balance and social wellbeing.

The Brain x Body Fitness Studio has a unique membership framework, encouraging our members to attend regularly throughout the week to maximise the benefits of the program.

Members have unlimited access to group sessions where they are able to complete their individualised exercise program under supervision by our qualified Exercise Physiologists. Members also have access to a broad range of social group classes including yoga, dance, boxing, Pilates and more.

---

#### **SA/NT Office**

25 King William Road  
Unley SA 5061

#### **ACT Office**

Unit 6, 32 Thesiger Court  
Deakin ACT 2600

P 1800 644 189

[www.FightingParkinsons.org.au](http://www.FightingParkinsons.org.au)

**TOGETHER. FIGHT.**



THFR Group Parkinson's is seeking \$1.6 million over four years to successfully operate a subsidised program for people living with Parkinson's disease in the ACT.

The investment would support the employment of qualified exercise physiologists to deliver individual personalised exercise programs and small group classes in the studio and at home for people living with Parkinson's disease.

## Conclusion

THFRG Parkinson's ACT is committed to support the Parkinson's community in the ACT and surrounds with specialised care and supports that improves the lives of people living with Parkinson's, their families and carers.

We look forward to working with the ACT Government to implement these initiatives and address the unmet and growing need for vital supports and services.

---

### SA/NT Office

25 King William Road  
Unley SA 5061

### ACT Office

Unit 6, 32 Thesiger Court  
Deakin ACT 2600

P 1800 644 189

[www.FightingParkinsons.org.au](http://www.FightingParkinsons.org.au)

**TOGETHER. FIGHT.**



## Supporting documents

1. Chronic Conditions Network Coordinator | Health Care Consumers' Association Inc – joint submission,  
[https://www.budgetconsultation.act.gov.au/\\_data/assets/pdf\\_file/0010/2814823/64ab1e99e67ee321a317dda7b6f039a7d993218b.pdf](https://www.budgetconsultation.act.gov.au/_data/assets/pdf_file/0010/2814823/64ab1e99e67ee321a317dda7b6f039a7d993218b.pdf)
2. [Specialist nurses helping hundreds of South Australians with Parkinson's | Premier of South Australia](#)
3. [Exploring Parkinson's disease prevalence in regional, rural and remote Australia: A systematic scoping review](#)
4. [Final Report Evaluating the impact of 2 specialist PD nurse positions 2019.pdf](#)
5. [Movement Disorder Nurse Specialist Pilot Final Evaluation Report and Addendum | Australian Government Department of Health and Aged Care](#)
6. <https://rdcu.be/efg1H>
7. <https://www.parkinsons.org.au/wp-content/uploads/2024/02/Ecosystem-of-Parkinsons-Part-1-2024.pdf>
8. [Ecosystem of Parkinson's Part 3.1](#) – page 20, table 6

---

### SA/NT Office

25 King William Road  
Unley SA 5061

### ACT Office

Unit 6, 32 Thesiger Court  
Deakin ACT 2600

P 1800 644 189

[www.FightingParkinsons.org.au](http://www.FightingParkinsons.org.au)

**TOGETHER. FIGHT.**