

ANNUAL REPORT 2021-22



About Fight Parkinson's

Who we are

As a leading not-for-profit organisation founded in 1980 as Parkinson's Victoria, Fight Parkinson's strives to realise possibilities for people living with Parkinson's and Atypical Parkinson's (MSA, PSP and CBS) through support, information and education.

Living with Parkinson's and Atypical Parkinson's as they progress is a fight. The foundation of Fight Parkinson's lies in our collective support for one another. No-one has to fight Parkinson's or Atypical Parkinson's alone.

Our multi-disciplinary team provides specialist advice and support to people living with Parkinson's and Atypical Parkinson's, their families, carers, and healthcare professionals through:

- an extensive health education program
- a free and confidential health information service
- comprehensive web-based information
- a local peer support group network.

Fight Parkinson's is also committed to funding and supporting advances in research for a cure and for effective therapies and treatments that will empower our community to live full and active lives until a cure is found.

Living with Parkinson's as it progresses is a fight. Our name puts our community - and our vision for it - first. The fight is multilayered and though priorities may shift from one day to the next, the collective motivation is unchanged - to support and empower each other to live full and active lives, towards a Parkinson's free future.

Purpose

Improve the lives of people living with Parkinson's and Atypical Parkinson's through advocacy, research and support.

Vision

A world free of Parkinson's, and until a cure is found, for those living with Parkinson's to be empowered to live full and active lives.

Mission

Empower people living with Parkinson's to get the most out of life, to be their advocate and to raise funds to support research in delivering effective therapies, treatments and a cure.

What is Parkinson's

Parkinson's is a chronic neurological condition of unknown cause, with a range of complex symptoms unique to the individual. Neurological disorders are now the leading cause of disabilities in the world and Parkinson's is the fastest growing of them.

The most common symptoms include stiffened muscles, slowing movement and changing posture. Many people also experience a resting tremor. Other symptoms can include pain, depression, anxiety, speech changes and loss of facial expression.

Medication and support from healthcare professionals can help manage these symptoms, however there is no way to slow progression or cure Parkinson's.

57,000

Victorians are living with Parkinson's

&

219,000

People Australia wide are living with Parkinson's

Atypical Parkinson's

Atypical Parkinson's are rare conditions that initially present like Parkinson's, but which have different causes, symptoms, and rates of progression. They include Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Corticobasal Syndrome (CBS).

There are currently no known treatments to cure or slow the progression of PSP, MSA or CBS, or to prevent them. Treatments, therapies, and strategies are available to help people manage their symptoms to make the most of living with these conditions.

What drives us



The Parkinson's and Atypical Parkinson's community is at the heart of everything we do. We understand this diverse community and that their individual experience of Parkinson's is unique, wide-ranging and ever-changing. We are inclusive of this diversity in all aspects of our work.

As leaders within the Parkinson's community in Australia, we have a deep understanding of the needs and challenges of people living with Parkinson's and Atypical Parkinson's and their families.

Our **knowledge** has been richly informed and curated. Through community engagement, evidence and best practice, we are enabling our community and driving their capacity for **empowerment** to self-manage and make informed choices.

We champion a learning culture of **innovation**. This culture of **advancement** allows us to provide the highest quality support and services. It affects everything we do and is supported by our global connections, collaborations and research partnerships.

Our **courage** and **leadership** are inspired by our community. We are committed to making a positive difference to all those living with Parkinson's or Atypical Parkinson's (PSP, MSA, CBS). We are confident in our expertise, reputation and ability to create systemic change.

CEO & Chair Report

Lifting our voice to empower community



Fight Parkinson's CEO Emma Collin



Fight Parkinson's Chair Philip Thomas

A clear purpose reinforced by a new name and update of Parkinson's prevalence data marked FY2022 as a time to strengthen and elevate the Parkinson's fight while continuing to offer the high standard of support our community has come to expect from us.

Parkinson's Victoria changed its name to Fight Parkinson's in November 2021 after extensive consultation with the Parkinson's and Atypical Parkinson's (PSP, MSA and CBS) community.

We asked what they needed from us and how we should do it. The response was that we needed to lift the voice and profile of Parkinson's in the community and strongly lead sector coordination.

Based on this feedback, we repositioned ourselves to better represent and meet the needs of our community, making a very considered decision to adopt a new name - *Fight Parkinson's* and tagline, *together we can*.

Our community is at the forefront of all we do. We believe that with strong sector coordination and leadership, and greater community and government support, we can realise better outcomes for people living with Parkinson's.

Our name puts our community first. The fight is multilayered and may shift from day to day, but the collective motivation is unchanged - to support and empower each other to live full and active lives, towards a Parkinson's free future.

Our fight will elevate the voice of our community and create an even stronger awareness and recognition of Parkinson's. Together we will fight for better services, and to support more research to deliver effective therapies, treatments, and a cure.

Fight Parkinson's is about all of us. Because together we can do so much more. When our community stands together, we empower all lives touched by Parkinson's or Atypical Parkinson's.

Engaging and educating

True to this commitment, we established a new Consumer Engagement and Advisory Committee to formally engage and seek feedback from people with a lived experience of Parkinson's.

This committee provides advice as we advocate for system improvements, develop education and information resources, and create programs that accurately reflect the reality of living with Parkinson's.

We were also proud to appoint two community representatives on our Research Committee, a move that has added a depth of knowledge to the committee and the decisions it makes.

As we broaden community engagement, the opportunity to empower people through knowledge increased as we formalised online education through development of the Fight Parkinson's Learning Hub.

The Learning Hub greatly extends our education reach, offering a central point to develop and grow online, on-demand education for individuals and families living with Parkinson's and Atypical Parkinson's and the healthcare professionals caring for them.

While the Learning Hub, and our ongoing Positive Life and Ask the Expert webinar series, continue to remove traditional boundaries to accessing education and information, we recognise the strong desire for human connection.

This was evidenced with commencement of our Community Seminar program in 2022, bringing expert knowledge of the Fight Parkinson's health team, and prominent guest speakers, direct to the Parkinson's community.

Returning in March 2022, A Walk in the Park also offered an opportunity to reconnect face-to-face for the first time since 2019. It was a day of empowerment and celebration and reinforced the importance of the collective fight.

Reflecting on the achievements and the challenges, we thank everyone who stepped up for the Parkinson's fight in FY2022, including the passionate fundraisers, sponsors, donors and volunteers without whom we could not support the community to the extent we do.

We acknowledge the commitment of volunteer Parkinson's Peer Support Group leaders, who strived to keep their groups engaged, active and safe across pandemic-related uncertainty. This included learning and implementing mandated COVID-19 meeting requirements.

We look forward to supporting these dedicated individuals and committees to continue to revitalise this important support network into the coming year.

It is with much appreciation that we thank the individuals who bravely share their lived experiences with others as Fight Parkinson's event speakers, ambassadors and appeal heroes. It is through you that our mission is brought to life.

We also acknowledge with gratitude, the prominent researchers, medical and health practitioners who shared their time and expertise with the community through our Ask the Expert online series.

We thank the Fight Parkinson's leadership team and staff who live our values every day and even as many of them were personally affected by COVID-19, continued to serve the community with passion and commitment.

Funding forecast

Despite a significant stock market correction prior to the end of the financial year that resulted in our first reported deficit in more than five years, our strong financial position enabled us to invest in priority programs to support the Parkinson's community.

However, a substantial decrease in investment returns combined with increased operating expenses means that we must reinforce our commitment to advocate for government funding for the vital services the Parkinson's community needs and deserves.

Parkinson's is now the world's fastest growing neurological condition. In February, a review of the most current research available on the prevalence of Parkinson's enabled us to update our data to reflect the true incidence of people living with the condition.

Based on ABS statistics and scientific peer reviewed prevalence data, we estimate that there are now 57,000 Victorians living with Parkinson's and 219,000 nationally.

This is more than double the previous reported figures of 27,000 Victorians and 100,000 Australians.

Despite this, since the State Government transferred all disability services to the Federal Government in 2018, our funding commitment has been inconsistent.

Two 12-month funding extensions were followed by a two-year commitment of \$323K per annum from July 2021 – June 2023 to fund Fight Parkinson's as a secondary health consultancy service.

As a peak Parkinson's body, we support early intervention and preventative health strategies that in fact help alleviate pressure on government health systems still coping with the impacts of the global pandemic.

Sustainable funding of not only our Parkinson's services but the specialist Atypical Parkinson's support we offer nationally is required to ensure, at the very least, continuity of current services.

So, we will continue to advocate for funding as we live our mission and fight to ensure every person diagnosed with Parkinson's, PSP, MSA and CBS is supported and empowered with the knowledge and tools to get the most out of their lives following diagnosis.



Philip Thomas
Chair



Emma Collin
Chief Executive Officer

Community and inclusion



We know that our community and their experience of Parkinson's is unique, wide-ranging and ever-changing, and we seek to include this diversity in all aspects of our work.

Celebrating community

A Walk in the Park 2022

A Walk in the Park, Australia's largest community event dedicated to improving the lives of people with Parkinson's, has provided an uplifting opportunity to celebrate connection and empowerment since 2008. It provides a platform to unite people living with Parkinson's, their family, friends, colleagues and medical and healthcare supporters, to create a genuine sense of belonging and celebration of community.

The Parkinson's community is at the heart of everything that we do

On 27 March 2022, A Walk in the Park returned to Federation Square after a two-year hiatus. The event was staged across two separate start times to meet COVID safety guidelines.

A total of 1513 registered participants joined A Walk in the Park, with 257 electing to do a virtual walk, offered as an alternative for those concerned about joining the event in Melbourne's city centre.

General reluctance to be part of a crowd continued to impact large-scale events across Victoria in FY2022, including A Walk in the Park, with numbers down on previous years but the spirit of those who attended more positive than ever.

A focal point for positivity was the involvement of several Carlton Football Club AFL greats who walked in support of their friend and former team-mate, Alex Jesaulenko, diagnosed with Parkinson's in late 2021.

Alex's daughter, Kate, an official event ambassador, together with former players Jim Buckley, Alex Marcou and Wayne Harmes, attracted media coverage across Seven News, Sunday Footy Show, 3AW and The Herald Sun, resulting in 5.3M media reach.

A Walk in the Park's most well-known ambassador Shane Jacobson was unable to attend due to work commitments but recorded a special video message played on the day.

Community representative Matt Pettifer spoke about living with Young Onset Parkinson's and Geoff Constable was acknowledged by Fight Parkinson's and the City of Melbourne Lord Mayor Sally Capp, for his involvement in the Moomba Birdman Rally.

Several individuals openly shared their personal experiences of Parkinson's publicly 'on the spot' with MC Ellen Smith at the walk start line on the day and via social media.

The 2022 walk also marked a change in date from the traditional month of August to allow for a six-month space from the second 27forParkinson's online event in October 2021.

This March date proved popular and as a strategic pathway into World Parkinson's Month in April, A Walk in the Park will be held at the same time of year in 2023.



Regional walks

A Walk in the Park Geelong has grown to become Victoria's largest regional walk since its inception in 2018 thanks to a dedicated working group, led by Kirsten George whose father Graeme lived with Parkinson's for 20 years.

Held in May 2022 for the first time since 2019, the walk attracted strong local community support through sponsorship and donations, with 371 participants, including Walk Ambassador John Eren MP, completing the scenic route through Eastern Park.

A committed organising committee, Howard Philpott, Emily Corrolan, Kaye and Graeme Hemley, Judy Hayes and Marilyn and Martin Moore - and strong team of volunteers also support the Geelong walk.

One of Victoria's longest running regional walks, the **Mildura Slow Walk** returned in April 2022, with a strong turn-out of 150 people supporting and celebrating the local Parkinson's community.



The Mildura walk encourages participants to wear red in recognition of the Mildura Peer Support Group and is ably organised by the Mildura Peer Support Group (PSG), led by Cheryl Barnes and her organising crew of Lynne, Carol, Lois, Carol and Cynthia.

Also keen to reconnect was a passionate group of 45 people who came together in April for **A Walk in the Park Wodonga** at Sumsion Gardens.

The collective fight will elevate the voice of our community

Leanne Torpey, leader of the Albury/Wodonga & District, Corryong and Beechworth Parkinson's peer support groups, said the walk provided an opportunity to reconnect after two years of isolation, helping to rebuild people's confidence and social networks. Fight Parkinson's thanks Kirsten, Cheryl and Leanne, their organising teams and volunteers for their passion and community contribution to raising Parkinson's awareness and funds in the Geelong/Bellarine, Mildura and Wodonga regions.

27forParkinson's

Due to the success and connection generated through the 2020 event, 27forParkinson's returned in 2021 and proved as popular as ever.

Held across 27 days in October, the concept was extended to include be connected or make positive change, incorporating a broader range of engagement activities and encouraging inclusion across all abilities. As an online event, 27forParkinson's is not restricted by location, with more than 50 participants from outside Victoria.

Strong media coverage across all mediums was driven by community ambassadors.

Olympian Steve Moneghetti, spoke on Channel Seven's Morning Show about his Mum's Parkinson's and the impact it's had on her and the family. Steve also spoke to ABC Ballarat and on 3AW's Weekend program.

Other ambassadors interviewed on 3AW were Christine Anderson on Overnights with Tony Moclair and Steve Watts on Nights with Denis Walter.

Steve also joined Belinda Zipper (whose personal story ran in Take 5 magazine) and Fight Parkinson's CEO Emma Collin on the ABC Radio Mornings program.

The Herald Sun newspaper ran two pictorials – one with Mimi Morgan and her two four-legged walking companions and the other, featuring skateboarder and young Dad, John Wijsma, who also featured on The House of Wellness TV program.

Lawrence Atley was creating a painting a day for Parkinson's from his aged care residence in Rye, a story covered by Aged Care News and The Senior magazine.

Community and inclusion

Karyn Spilberg and Isa Adams shared their stories in an article in Australian Jewish News.

A number of other community ambassadors also shared their insights into their personal journeys via the 27forParkinson's Facebook group. This safe space connects community who inspire and encourage each other by posting and commenting, with membership growing from 200 in 2020 to 307 in 2021.

A Walk in the Park and 27forParkinson's

\$622K
total funds raised

2127
registered participants

7413
supporting donors

In total members of this group created 787 posts and made 2405 comments.

This collective fight against Parkinson's will elevate the voice of our community and create even stronger awareness and recognition of Parkinson's.



John Wijsma

Fight Parkinson's thanks the following Corporate Partners for their support of our community fundraising events:

abbvie

ucb Inspired by patients.
Driven by science.

ST JOHN OF GOD
Frankston Rehabilitation
Hospital

Homestyle

We also thank the Rotary Club of Glenferrie for once again hosting the ever-popular sausage sizzle; Hooman Ebadi and Rina Sawaya for leading the warm-up sessions and all the volunteers who help to make A Walk in the Park a success.

Peer support program

The COVID pandemic continued to influence community activity across Victoria, particularly in the second half of 2021 and beginning of 2022.

This included the community-based Parkinson's Peer Support Group (PSG) program which is vital to local connection, education and support.

As groups moved to reintroduce face-to-face meetings, some participants chose not to attend during peaks of community infection. Others experienced a decline in health and were no longer able to return.

Throughout this period, Fight Parkinson's worked closely with PSG leaders, supporting them to keep their group participants engaged. We acknowledge the efforts so many of them went to, in order to do so.

In particular, we note their willingness to learn and work within Government-mandated guidelines for face-to-face meetings, with 75% attending online COVIDSafe training in the second half of 2021 for safe meeting resumption.

In 2022, a new PSG leader webpage was launched, along with a range of comprehensive resources to enable them to fulfil their roles confidently and professionally. This included the updated PSG Leader Manual.

We have actively involved local PSG leadership as part of the Fight Parkinson's Community Seminar program to help stimulate participation and activity in their local communities.

The seminars provide an invaluable opportunity for Fight Parkinson's to directly engage with PSG leaders in their local communities and run small group leadership training and instruction sessions. They also provide a regional networking opportunity for the PSG leaders and co-leaders.

This important collaboration will continue as a feature of the program in FY2023 as we support groups to recruit new members to ensure viability now and into the future.



Kaye and Helen from Melton PSG at the Williamstown Community Seminar

The move to virtual meetings has been a positive one for the specialist Parkinson's PSGs, with a 20% growth in attendance.

In particular, the move to online meetings continued to extend and enhance support of the Atypical Parkinson's community in FY2022. The Atypical Parkinson's Peer Support group (PSG) previously met bi-monthly in Melbourne but moved to an online platform in 2020.

This has enabled greater participation, extending reach beyond state borders and ensuring those in need have access to the information they deserve.

Fight Parkinson's is the national organisation providing a support and education service for people living with PSP, MSA and CBS and their families.

The Atypical Parkinson's PSG provides specialist information and facilitates communication and information sharing between members, who can experience unique challenges and experiences.

Families affected by a diagnosis of PSP, MSA or CBS can feel isolated by the rarity of these conditions, with many unaware of their existence prior to diagnosis.

Fight Parkinson's also hosts two specialist advanced therapies PSGs for people who have undergone or plan to have infusion therapy or Deep Brain Stimulation (DBS) treatments for their Parkinson's.

Both the Infused Therapies and DBS PSGs meet bi-monthly online and have also remained online, removing the restriction of geographical boundaries.

The Infused Therapies Peer Support Group is designed to support people already using infusion therapy – and provide information for those who have been recommended this treatment by their neurologist.

Infusion therapy, also known as device-assisted therapy, involves medication administered continuously either by needle under the skin or through a gastrostomy tube surgically placed in the stomach.

The DBS Peer Support Group is for people who have undergone Deep Brain Stimulation (DBS) or are planning to do so. DBS may help to reduce some movement symptoms of Parkinson's, such as slowness of movement, stiffness and tremor.

DBS uses mild electrical impulses to stimulate a specific area of the brain within the Basal Ganglia. These electrical impulses are delivered by fine probes, which are surgically placed into the brain.

Community seminars

As Fight Parkinson's strives to support our community, we know greater levels of social participation are needed now more than ever.

Our Community Seminar program commenced in April, providing a key activity to support reconnection and engagement within communities

The community seminar program is a grassroots offering, bringing the Fight Parkinson's health team and prominent guest speakers direct to suburban and regional areas.

Representatives from local PSGs are also on hand to meet people and provide information about their groups.

"It was lovely to meet face-to-face & gave me (as a carer) confidence to reach out to the Fight Parkinson's staff if/when needed."

- Williamstown attendee

Our community seminar program is central to our commitment to realise possibilities and better outcomes to help people with Parkinson's to live full and active lives following diagnosis.

Connecting with community, including those diagnosed in the last two years, is particularly important. In April and May, more than 165 people attended community seminars in Williamstown, Malvern East and Ringwood.

Our appreciation is extended to guest speakers, neurologists Laura Perju-Dumbrava (Williamstown), Dr Mina Ghaly (Ringwood), neurobiologist Prof. David Finkelstein (East Malvern) and community representatives, Mimi Morgan, Ian McFarlane and Sheenagh Bottrell who shared their personal experiences of Parkinson's.

A further community seminar in Mildura, organised by the Mildura Parkinson's Peer Support Group the day after their popular Mildura Slow Walk, featured local practitioners, neurologist Dr Richard Peppard, and OT Belinda Dixon.

Knowledge and empowerment

As leaders within the Parkinson's community in Australia, we have a deep understanding of the needs and challenges of people living with Parkinson's and Atypical Parkinson's, and their families.

We always use evidence and best practice to educate and empower our community, building their capacity to self-manage and help them make informed choices.

Fight Parkinson's has the most comprehensive and advanced information, education and support programs that empower people living with Parkinson's and Atypical Parkinson's to get the most out of their lives.

Our aim is to provide equitable access to experienced Parkinson's educators via online or onsite training, providing practical ways for people to optimally manage living with these conditions, while also building the confidence of families, healthcare professionals, researchers and community organisations to better support their needs.

We empower our community to make informed choices

Online Learning Hub

The Fight Parkinson's Learning Hub is the Centre of Excellence the Parkinson's community needs. Funded and developed in FY2022, it was officially launched in August 2022.

The Learning Hub greatly broadens the reach of the Fight Parkinson's education offering and marks the delivery of a significant strategic priority for Fight Parkinson's to build a centre of excellence to increase understanding of Parkinson's.

Our expansive education offering exists to inform the community, and in doing so develop confidence that supports and improves the quality of life of a person living with Parkinson's, or Atypical Parkinson's.

The new Learning Hub creates a central source of truth for all Fight Parkinson's education, where individuals and organisations source the most current Parkinson's education available.

By building knowledge about Parkinson's and Atypical Parkinson's beyond geographical boundaries, we create change by reducing stigma and empowering those living with these conditions to use the best strategies, treatments and therapies to live well.

The Learning Hub is a central point to develop and grow our reach through online, on-demand education programs for individuals and families living with Parkinson's and Atypical Parkinson's.

An important premise of the Learning Hub is to ensure free, equitable access to the same quality, evidence-based information about condition for

anyone living with Parkinson's, regardless of their personal circumstances.

The first two community learning courses offered focussed on understanding Parkinson's and its impact, and information for those recently diagnosed, based on the highly popular Fight Parkinson's Recently Diagnosed seminars.

The Hub also hosts education programs for the healthcare sector, commencing with a specialist online education program for registered nurses (RNs) and personal care assistants (PCAs) working in aged care (see page 17)



Health information service

Free and confidential health information tailored to individual circumstances is a mainstay of the Fight Parkinson's offering.

This service extends to provide essential support and information for people living with the rare Atypical Parkinson's conditions, PSP, MSA and CBS; the only such service currently available in Australia.

Most people prefer to connect with this service via telephone, with a small number asking questions via email and a handful reaching out via our social media channels.

The complexity of the calls – and the length of time taken to help resolve them – continued to be high across FY2022 as the health system continued to be affected by the COVID-19 pandemic.

We have witnessed a more rapid and irreversible decline in health conditions than ever previously seen, with disruption to regular health care services across the pandemic, especially Parkinson's-specific care, impacting our community.

Calls to the health services line were more complex requiring a multi-disciplinary response across the Fight Parkinson's Health Team.



Mimi talks about living with Parkinson's with Victor, Victoria, Rachel and Janet from Fight Parkinson's

Concerns about continued impact on specialist appointments, including telehealth and the level of care in hospital and aged care settings continued to feature predominately in calls.

Encouraging understanding around Parkinson's and COVID-19 vaccines and providing clinical advice on how to manage Parkinson's when someone had contracted COVID were another feature of calls.

Calls for assistance to help access and navigate the complex My Aged Care and the NDIS schemes also remained constant from both people with Parkinson's and Atypical Parkinson's.

Health professionals increasingly accessed inter-professional support on the health line to better support people with Parkinson's and Atypical Parkinson's. This included complex symptom management and discharge planning.

Palliative care consultancy for the acute and aged care sector was also significant, particularly in relation to people in aged care who contracted COVID.

Fight Parkinson's also received a number of calls and emails from Australian residents stranded overseas due to the COVID-19 pandemic, as well as Australians concerned about family members living with Parkinson's in other countries with differing levels of care and support.

2916
health services line calls

31
minute average call duration

158%
increase in call duration
over three years

Knowledge and empowerment

Health education service

A change of name for the Living Well conversation series to Positive Life reflected our drive and vision to empower people to live positively with Parkinson's until a cure is found.

Knowing more about practical strategies, treatments and therapies and where to find the right support all contribute to enabling people living positively and confidently with their Parkinson's.

Online delivery of this series via Zoom continued in FY2022, but with a reduced program of 13 sessions (compared to 28 in FY2021) as we balanced our online offering with re-commencement of our face-to-face program.

The series attracted 670 registrants. The short one-hour online sessions covered a range of topics, including driving, medication, getting active, sleep, mobility equipment, communication, cognition, advanced therapies and the NDIS.

The Ask the Expert webinar series continued to attract strong interest, providing a unique opportunity for people to interact with some of Australia's leading research, medical and health professionals who specialise in Parkinson's.

Driven in large by a focus on presentations by leading researchers, this series saw a 72% increase in attendance, illustrating a strong desire for collective knowledge of advances towards finding effective therapies, treatments and a cure (see page 15).

Among the medical and health-based presenters were neurologists:

- Assoc. Prof. Jim Howe – demystifying palliative care
- Dr Richard Blaze – medicinal cannabis and Parkinson's
- Dr Laura Perju-Dumbrava – insights into infused therapies
- Dr Kishore Kumar – Young Onset Parkinson's

Psychologist Dr Louise Cooper presented on the impact of Parkinson's on sex and intimacy and digital health researcher Dr Roisin McNaney talked about Parkinson's and the use of technology to help manage symptoms.

In recognition of the growing demand for information from the Atypical Parkinson's community, we introduced a quarterly Ask the Expert presentation specifically for people living with PSP, MSA and CBS.

This included a presentation on communication, saliva and swallowing presented by Fight Parkinson's speech pathologist and occupational therapist.

The move of the Recently Diagnosed Seminar program to a two-part virtual program also demonstrated the value of online delivery, effectively doubling the number of people able to attend the program.

Seminars were delivered at regular intervals (every six weeks) throughout the year, with each attracting 20-30 participants and one dedicated to Young Onset Parkinson's (YOPD) attended by 275 people.

The online delivery model enables people to attend from any location, with the information offered complementing the online program available on the Learning Hub.

The RDS is free and participants can attend 'anonymously', something particularly welcomed by individuals who have not widely disclosed diagnosis.

A key part of the program is a presentation by an individual openly sharing their story of diagnosis and we thank Ian, Janette, John, Matt, Sheenagh and Tom for so openly sharing theirs with the wider community in FY2022.

5490

Community education registration

1143

Ask the Expert

263

Maurice Blackburn YOPD

670

Positive Life

275

Recently Diagnosed Seminar

84

Education events delivered

Innovation and advancement

We champion a learning culture of innovation and continual improvement. This culture allows us to provide the highest quality support and services to the Parkinson's community. It affects everything we do, and is supported by our global connections, collaborations and research partnerships.

New model of care



The roadmap towards introduction of a best practice, multi-disciplinary model of Parkinson's care in Victoria and Australia took a step forward in May, with delivery of a review and analysis report investigating implementation of the internationally regarded ParkinsonNet model in Victoria.

The report was the first major milestone of a collaboration between Fight Parkinson's and ParkinsonNet International.

ParkinsonNet was developed in 2006 as the Dutch national system of regional multidisciplinary networks to improve Parkinson's care delivery in the Netherlands. It has resulted in improvements to quality of care, health outcomes and reduced healthcare costs. It has since been implemented in parts of the USA, Norway and Luxembourg.

The aim of ParkinsonNet is to enable people with Parkinson's and their caregivers to have the best possible quality of life by empowering patients, professionals and regional networks to provide the best possible care.

In order to achieve these goals, ParkinsonNet offers Parkinson's-specific knowledge and training to healthcare professionals and education to patients and their families, as well as evidence-based guidelines and technological innovations that improve ability for self-management.

The ParkinsonNet model was first presented at the Fight Parkinson's Smart Health event in November 2019, by Prof. Bas Bloem, medical director of the Parkinson's Centre Nijmegen (the Netherlands) and co-founder and board member of ParkinsonNet.

He spoke of the evidence-based benefits of this multi-disciplinary healthcare model and the need to transform health care into a patient-centred approach with the neurologist part of a treating team of specialised medical and allied health care professionals.

Following this event, Fight Parkinson's sought feedback from the 430 participants with 99% indicating resounding support for the ParkinsonNet model of care.

Based on the review and analysis, together with an analysis of financial feasibility of implementation of the model in Victoria by PricewaterhouseCoopers (PWC), ParkinsonNet International has expressed confidence to move on to the next step of a feasibility pilot phase and development of a feasibility pilot project.

Global collaboration

International collaboration and connection builds on our collective knowledge, enhancing support for community as we build on our reputation as a consistent and reliable source of the latest information for people living with Parkinson's and Atypical Parkinson's.

Fight Parkinson's is an official Organisational Partner of the World Parkinson Coalition and is represented on planning committees and forums for the World Parkinson Congress (WPC), to be held in Spain in 2023.

The Fight Parkinson's team is represented on the Executive, Leadership Forum and comprehensive care committee and will co-present and chair sessions during the event.

Fight Parkinson's is also represented on a number of initiatives of the International Parkinson and Movement Disorder Society (MDS), chairing and presenting at both the virtual World and Asia Pacific meetings.

Fight Parkinson's Health, Clinical and Community Services Manager Victor McConvey chairs the MDS taskforce on palliative care in Parkinson's and also on a global taskforce looking into early onset Parkinson's.

Through collaboration with Christine Jeyachandran, an Australian who lived with Parkinson's in South America, Fight Parkinson's has joined forces with CETRAM, a non-profit academic medical centre linked to the University of Santiago.

Alianza Iberoamericana de Parkinson, a CETRAM project, and is a pioneer in education, networking and research in Parkinson's in Latin America.

We have been working to strengthen links between Fight Parkinson's and Alianza partners in Peru, Mexico, Columbia, Argentina and Chile to share existing and build new education and awareness of Parkinson's disease in Latin America.

Innovation and advancement

We are seeking grant funding to deliver a project to support shared information and knowledge to improve the lives of people with Parkinson's in these countries, while improving support for Spanish-speaking communities in Australia.

Fight Parkinson's clinical specialists and managers are also represented on:

- Parkinson's Foundation (USA) global rehabilitation medicine taskforce developing guidance and recommendations for multidisciplinary care for people with Parkinson's
- University of Padua PD_PAL (Italy) trans-European project to improve health professional education to improve the palliative care for people with Parkinson's

Research

Through the Fight Parkinson's research program, we partner with and support universities and institutions in:

- Scientific research that aims to discover more about the cause and potential cure for Parkinson's and Atypical Parkinson's; and
- Applied research to improve the lives of people currently living with Parkinson's and Atypical Parkinson's.

All requests for research support are reviewed by our research committee to ensure the proposal has scientific rigour and is underpinned by ethics approvals to ensure investment fits within the aims of our strategic plan and mission.

Fight Parkinson's welcomed two community members to our Research Committee in FY2022 to increase representation of people living with Parkinson's.

Mark McAuley has worked in research and development environments for many years, with responsibility for securing investments, facilitating collaborations, executing projects and communicating with stakeholders.

Sue Casey's professional career spans community health, local and state government and non-government organisations. Her work has included policy development, advocacy and direct service delivery.

Fight Parkinson's thanks Mark and Sue for this invaluable volunteer contribution that has added depth of knowledge to the committee and the decisions it makes.

Participation

The unprecedented challenges of the COVID-19 pandemic affected clinical trials nationally and internationally, reflected in a reduction in the number of requests we received to support participation in Parkinson's related research projects.

We were able to provide \$10K to co-fund a University of Melbourne feasibility study into the development of an online version of the evidence-based ParkinSong program, a scientifically proven activity-based peer support program to improve voice-related quality of life for people with Parkinson's.

Extension of the program to online will greatly improve access to the voice strengthening benefits of the program beyond the 10 established ParkinSong groups.

The feasibility study found an online ParkinSong trial was possible, with the trial protocol published in the peer reviewed Neurology Journal.



This has enabled us to proceed with a larger clinical trial that will investigate whether the benefits of ParkinSong can be replicated in an online environment. This remains an ongoing trial with results expected in early 2023.

Through our website and social media channels, Fight Parkinson's also supported calls for interested parties to participate in:

- a Monash University survey study focussing on understanding self-care practices in Parkinson's
- a Maurice Blackburn Lawyers investigation into links between the herbicide Paraquat.

We champion a learning culture of innovation and improvement

Translation and collaboration

We empower our community with knowledge and hope by demystifying research, to enable them to learn more about the mechanics of their condition and the efforts to find cause, better treatment and a cure.

The Ask the Expert research and clinical science series was designed to showcase some of the interesting and promising research into Parkinson's being carried out in Victoria.

In FY2022, these presentations continued to attract strong attendance as we collaborated with some of Australia's leading researchers to bring them direct to community via an informal Q&A style webinar.

Presenters and topics offered:

- Assoc. Prof. Scott Ayton from the Florey Institute of Neuroscience and Mental Health discussed his latest research into the relationship between iron and Parkinson's
- Assoc. Prof Michael Lazarou from Monash University spoke about his research into mitochondrial dysfunction in Parkinson's
- Monash University PHD candidate Lewis Johnstone, provided an insight into his research on sex and relationships for people with Young Onset Parkinson's

- Prof. David Finkelstein from the Florey Institute of Neuroscience and Mental Health and Dr Lucy Vivash, a Research Fellow in the Department of Neuroscience at Monash University, provided updates on their research into MSA and PSP
- Prof. Meg Morris from La Trobe University spoke about the emerging evidence of exercise as a beneficial therapy for Parkinson's
- University of Melbourne researchers Dr Jeanette Tamplin and Prof. Adam Vogel explained more about ParkinSong and the next phase of an online singing trial
- Assoc. Prof. Grant Dewson provided an update of his research at WEHI (Walter & Eliza Hall Institute) into the role of the Parkinson's gene Parkin and ubiquitin signalling
- Consultant neurologist, Assoc. Prof. Dr Wes Thevathasan, who specialises in deep brain stimulation (DBS), spoke about the procedure and research being undertaken to further advance this important treatment option.

Attendees also had the opportunity ask questions, providing an opportunity for tangible connection between researcher and the people whose lives they are striving to improve.

Brain Bank

Fight Parkinson's continues to collaborate with the Victorian Brain Bank (VBB) supporting their ongoing efforts to secure long-term funding to re-establish an Australian Brain Bank network.

The VBB provides vital tissue samples to support research into Parkinson's and Atypical Parkinson's, but funding has been insufficient for continuation of all services. As a result, the VBB is no longer accepting new donor registrations.

Our FY2022 financial contribution to VBB supports direct costs associated with maintaining the existing Parkinson's and healthy control tissue collection and preparation for new or ongoing approved Parkinson's research projects.

Courage and leadership

We are committed to making a positive difference to all those living with Parkinson's. We are confident in our expertise, reputation, and ability to create systemic change.

Advocating for government support

Following a review in February of the most current research available on the prevalence of Parkinson's, we updated our data to reflect the true incidence of people living with the condition in Victoria and Australia.

Based on ABS statistics and scientific peer reviewed prevalence data, there are an estimated 57,000 Victorians living with Parkinson's and 219,000 nationally.

This is more than double the previous figures of 27,000 Victorians and 100,000 Australians.

A publication used as the basis for our prevalence update was *Parkinson's disease prevalence and the association with rurality and agricultural determinants*.¹

This Monash University and University of Melbourne-led research, published in the international *Parkinsonism and Related Disorders* journal in 2019, estimated the current prevalence of Parkinson's disease in Victoria to be 0.85% of the population.

Using this more recent prevalence estimate, 2021 ABS population data was extrapolated to determine a more realistic indication of incidence, not only in Victoria but nationally.

The number of Australians affected by Parkinson's is growing steadily. The sector is grossly underfunded, and we believe that with better sector coordination, resources could be used more efficiently to provide greater impact.

Fight Parkinson's is part of a global community concerned about the increasing incidence of Parkinson's and lack of recognition of this growing evidence by governments around the world.

When applying estimates from *The Parkinson's Pandemic*², the number of people living with Parkinson's is projected to double to 12 million by 2040, making Parkinson's a chronic disease of significant concern.

As reported in *The Emerging Evidence of the Parkinson's Pandemic*³ neurological disorders are now the leading cause of disabilities in the world and Parkinson's is the fastest growing neurological syndrome.

It's within this context that we continue to strengthen advocacy efforts to ensure the State and Federal Governments address the growing impact of Parkinson's and Atypical Parkinson's.

Fight Parkinson's and Parkinson's NSW have joined to lobby the Federal Government for better services and supports for people with Parkinson's.

This approach has been reinforced with a Memorandum of Understanding (MOU) signed between the two organisations.

“As Parkinson's peak bodies, our work is with people living with Parkinson's – we know their needs, issues, challenges, and barriers as we deal with their many unmet needs.”

A joint submission was made to the Federal Government prior to the May election via the former Health Minister Greg Hunt and then Shadow Health Minister (now Minister) Mark Butler.

This bid focussed on the need for funded access to vital health information and education supports for people living with Parkinson's and Atypical Parkinson's. These rare conditions, PSP, MSA and CBS, currently receive no federal or state government funding.

Federal advocacy is ongoing to discuss the increasingly urgent need for service funding.

At the state level, Fight Parkinson's continued a joint advocacy approach with Epilepsy Foundation for ongoing funding security and equity. We are aligned in our approach, offering similar models of care to our communities.

Our essential secondary health consultancy services meet the needs of 122,000 people who live with Epilepsy and Parkinson's disease, both of which are neurological conditions.

The State Government transferred disability funded services to the Federal Government in 2018. Since then, two 12-month funding extensions were followed by a two-year commitment of \$323K per annum from July 2021 to fund Fight Parkinson's as a secondary health consultancy service.

As a peak body, Fight Parkinson's addresses the needs of those living with Parkinson's, many of whom would be otherwise left feeling vulnerable and isolated.

The services we offer support early intervention and preventative health strategies that in turn helps to alleviate pressures on the government health system.

1. Ayton, D., et al., Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism Relat Disord*, 2019. 61: p. 198-202.
2. Dorsey, E.R. and B.R. Bloem, The Pawon Pandemic-A Call to Action. *JAMA Neurol*, 2018. 75(1): p. 9-10.
3. Dorsey ER, Sherer T, Okun MS, Bloem BR (2018) The emerging evidence of the Parkinson pandemic. *J Parkinsons Dis* 8, S3-S8.

Sustainable funding is required to ensure continuity of current services, including development and dissemination of health information resources, knowledge translation and best practice information and reliance-based support programs into the future.

We extend our appreciation to retiring State MP, Member for Lalor, John Eren for his support for our endeavours to raise awareness of the Parkinson's within the State Government.

Fight Parkinson's was also proud to support a successful University of Melbourne submission to the Medical Research Future Fund (MRFF) as part of its Stem Cells Therapies Mission.

The \$952,873.50 grant will allow the Melbourne University researchers to investigate next generation stem cell therapy for Parkinson's.

We're committed to making a positive difference to everyone living with Parkinson's

This research seeks to establish a novel strategy for removing unwanted cells prior to transplantation of therapeutic stem cells into the brain to replace those lost in Parkinson's.

We also continued to support the Western Region Movement Disorder Better Care pilot, developed with Western Victoria Primary Health Network, Rural North West Health, Wimmera Health Care Group, South West Healthcare and Grampians Community Health.

The Federally funded pilot enabled appointment of movement disorder nurses in Horsham, Warracknabeal, Stawell and Warrnambool.

Our Health Team is supporting the professional development of these specialist nurses by providing bi-weekly clinical supervision and ongoing membership of the Movement Disorder Nurses Community of Practice.

Peer and sector leadership

Improving knowledge of Parkinson's in the healthcare sector is a focus for Fight Parkinson's.

Our multi-disciplinary health team works closely with a wide range of health disciplines to help ensure best practice health care for people with Parkinson's and Atypical Parkinson's.

This is done via our health information service and through more structured training opportunities, including four Communities of Practice (COP) groups.

These groups bring together more than 200 practitioners across five professions – movement disorder nurses, physiotherapy, exercise physiology, occupational therapy and speech pathology.

These are key disciplines often involved in caring for people with Parkinson's. Participation ranges from entry level practitioners to experts in their field who come together to build Parkinson's knowledge and share clinical practice in an environment focused on professional development.

"The CoP is one of the support programs Fight Parkinson's offers to improve clinical knowledge, skills and thus to achieve a better clinical outcome for patients with movement disorders."

- Physiotherapy CoP participant.

The move to online meetings has resulted in participation growth, including interstate representation, and improved access to online education such as the annual joint community of practice meeting.

Last year's joint meeting keynote presentation focussed on cognitive and behavioural symptoms and how to effectively manage them.

The ability to improve knowledge of Parkinson's in the sector is greatly enhanced with the development of the market-leading Fight Parkinson's Learning Hub, funded for and established in FY2022.

The Learning Hub is a centre of excellence and hosts training courses that can be purchased by organisations and individuals who can develop and increase their Parkinson's knowledge and self-report Continuing Professional Development (CPD) points.

UP TO 8%

of the population in aged care are living with Parkinson's.*

The first professional training courses developed for the Learning Hub focus on building skills and capabilities of Personal Care Assistants (PCAs) and Registered Nurses (RNs) working in aged care.

The aim of the course is to provide an overview of the many facets of Parkinson's and an understanding of the need for individualised care. As a result, we hope to see residents experience a better quality of life.

Upskilling aged care workers' knowledge around Parkinson's-specific care will help improve some of the shortfalls identified in the Aged Care Royal Commission, particularly around nutrition, restraint, dementia and palliative care.

* Goetz, C G and Stebbins, G T, Mortality and hallucinations in nursing home patients with advanced Parkinson's disease in Neurology, 1995, p. 669-71

Courage and leadership

Community leadership



The Parkinson's community has been built on the contribution of volunteers who offer their time, insight and experience to inspire and support others in their community.

The Fight Parkinson's Recognition Awards acknowledge the commitment, leadership and outstanding contribution of individuals who support people living with Parkinson's and their families in their local communities.

These awards are presented at the Annual General Meeting in November.

Sir Zelman Cowen Award

Kyabram Parkinson's Peer Support Group (PSG) leader Christine Anderson was named the 2021 recipient of the Sir Zelman Cowen Award.

This award is the highest honour offered and is awarded to a person who has shown outstanding service to the Parkinson's community.

Christine, whose father Jack also had Parkinson's, is known as a passionate supporter and advocate who shares her own story with openness and humour.

As a founding member and leader of the Kyabram PSG for more than seven years, Christine has grown the group and built support for others in her community.

Christine has been a strong advocate locally, building awareness of Parkinson's in the local press and social media. However, that passion and commitment has not been limited to Kyabram.

She has made an invaluable contribution to the broader Parkinson's community, as an ambassador for A Walk in the Park and 27forParkinson's, raising awareness and more than \$12K in funds. Christine was also the face of the 2019 mid-year appeal, which raised more than \$95k.

Sharing her story with others has been constant, as has her generosity in sharing her expertise as a teacher to help improve online education program delivery.

She has spoken openly at many events about living with Parkinson's and does not shy away from any topic.

"A diagnosis of Parkinson's does not mean your life is over. The next chapter may be more challenging but can also be more meaningful and more fulfilling."

- Christine Anderson

Harold Waldron Award

The Harold Waldron Carer's Award honours a family member or friend touched by Parkinson's, who's made a significant difference to the Parkinson's community – an apt description of Keith Anderson.

Keith's wife Margaret was diagnosed with Parkinson's in 2012 and after initially joining the Ringwood Parkinson's Peer Support Group (PSG), they discovered a new group had started closer to home in Doncaster.

Keith and Margaret joined the Manningham PSG in 2014, where Keith became group leader. In 2017, he brought the community together to acknowledge 200 years of Parkinson's Disease at a special anniversary dinner.

The event raised more than \$15K for the community. Keith and Margaret have also been key supporters of A Walk in the Park, bringing family and members of the Manningham PSG together each year.

More recently, Keith provided advice and support to help inform Fight Parkinson's projects, including updating the Peer Support Group Leaders' manual.

"I consider the Manningham Parkinson's Support Group to be a very important part of our life. We have met some very loving, supportive people since we joined in 2014 and I will continue to serve the group for as long as possible." - Keith Anderson



Volunteer Recognition Awards

Honorary Life Members

Jill Goss – Essendon PSG

Nola Matuschka – Portland PSG

Service Awards

Recognises continuous service of volunteers in an administrative, project or service capacity, particularly PSG coordination.

15 Year Service Award

Warrnambool - Barbara Lester and Graeme Mason

Essendon - Margaret Nickson, David Goss

Echuca - Moira Lewis

Moe - Gwenda Husson

Beechworth - Pam Crosthwaite

South Gippsland - Palma Noblet

10 Year Service Award

Warrnambool - Lyn Gardner, Laurice Young, Fran Rankin, Narelle McLean and Tania Tinker

Mildura - Geoff and Lyn Bales

Werribee - Alan Flavell

Essendon - Max McPherson

Wimmera - Rene Vivien

Ballarat - Bev Grant

5 Year Service Award

Williamstown ParkinSong - Kate Marshall

Community Recognition Award

Contribution of an individual or organisation to events or activities.

Jennifer & John Wilson

Michelle Mendes

Dr Luke Smith

Associate Professor Scott Ayton

Val Staddon

Dr Richard Blazé

Rhys Chamberlain

Sheenagh Bottrell

Bobby Danchin

Steve Moneghetti

Certificate of Appreciation

Contribution of an individual or organisation for support of Fight Parkinson's programs, education, fundraising and promotional activities.

Jacqui Raymond

Elizabeth Brown

Recognition of Service



Fight Parkinson's Health Team and Clinical and Support Services Manager, Victor McConvey OAM, was honoured for his services in the Queen's Birthday 2022 Honours List.

An extensive nursing career spanning more than 30 years, including 20 as a Parkinson's clinical nurse consultant, has seen Victor develop into one of Australia's most knowledgeable healthcare professionals on Parkinson's care.

Victor's commitment to the Parkinson's community is evident and his knowledge, compassion and dedication is well acknowledged by the community he serves.

His combined passion for nursing and supporting people marginalised in the healthcare system, including those with HIV AIDS and Motor Neurone Disease, led him to Parkinson's and Atypical Parkinson's (PSP, MSA and CBS).

Today, his dedication and expertise are recognised nationally and internationally through involvement in global research and education development, and for his drive to enhance knowledge and skills of those caring for patients with Parkinson's and Atypical Parkinson's.

Fight Parkinson's thanks Victor for his passion and commitment as a valued member of the team for the past 17 years and congratulates him on this commendable recognition for a life-time career helping and caring for others.

Fight Parkinson's thanks the following organisations for their support across education, collaboration, advocacy and research.

Australia Dementia Network
Epilepsy Foundation Australia
Florey Institute of Neuroscience & Mental Health
La Trobe University
Maurice Blackburn
Parkinson's NSW
ParkinsonNet
PWC
University of Melbourne
WEHI
World Parkinson Coalition (WPC)

Fundraising, donations and bequests

Fight Parkinson's is committed to support the search for a cure and until then, to empower people living with Parkinson's and Atypical Parkinson's to live full active lives.

To do this, we rely on fundraising, bequests and donations to allow us to continue to deliver our evidence-based health education, information and supports and services for people living with Parkinson's and Atypical Parkinson's conditions.

Fundraising

Fight Parkinson's is grateful for the efforts of the individuals who actively raise sponsorship dollars in support of their participation in A Walk in the Park and 27forParkinson's.

A total of \$338,131 was raised from 27forParkinson's in October, with 78% of the 614 registered participants actively fundraising, high compared to the industry average of 45%.

Average amounts raised was also high at \$692 per fundraiser and 75 people raising more than \$1000.

A total of \$284,000 was raised from A Walk in the Park in March, with 74% of the 799 participants who signed up to fundraise actively doing so, 31 of them raising over \$1000 to be part of the official \$1K Club.

The total included \$21,536 raised through A Walk in the Park Geelong.

Every dollar raised in these events is greatly appreciated. We acknowledge the top 5 fundraisers in each event:

A Walk in the Park

Julie Trimble	\$7005
Martin Fensome	\$5000
Samantha Layton	\$4359
Karyn Spielberg	\$3411
Damian Rann	\$2794

27forParkinson's

Isa Adams	\$19,956
Luke Ioppolo	\$13,084
Marita Brown	\$11,156
Em Tantau	\$7284
John McBride	\$5302

Bequests

Estate of Leslie Edward Allen
Estate of William John Tyers
Estate of Jennifer Ethal Harte
Estate of John Laver Hill
Estate Betty Edington
Estate Gladys Hannington
Estate of Joe White Bequest

Trusts and Foundations

JEM Research Foundation
PMT Foundation
David Henning Memorial Foundation
George and Irene Meagher Trust
MacKenzie Family Foundation
Handelsman Charitable Trust

Community Fundraisers

Peter Gladstone – PSP Awareness Ride
Corey Tessier – Corey's Cut for a Cause
Kerry Hams – Livestream music gig
Adam Lucci - #Calendar Club challenge
Brei Abbott – Point to Port walk
Simon & Karen – wedding donations
Rotary Club of Melton and Olga Hilton

On 5 June, Bev Gladstone lost her battle with Progressive Supranuclear Palsy (PSP). Bev passed away one month after a special event organised in her honour by husband Peter, who's been fighting to raise funds and improve awareness of PSP.

"PSP needs to be recognised and understood to get people the correct, necessary care as soon as possible," Peter said.

"They need to be referred with ease and not have to fight to be able to get health and social care so they can live as comfortably as possible.

"It's not just about the very end of life, it's also about the bit in between," he added.

Peter has been passionate about raising awareness of PSP since Bev's diagnosis five years ago. In May 2022, he organised his second Show and Shine drive and ride as part of PSP Awareness Month.

It brought together family, friends and car and motorbike lovers for the ride from Wangaratta to Whorouly, raising funds and important awareness for this rare condition.



Financial Report

Fight Parkinson's reported a deficit of \$686K for the financial year FY2022, which was the first reported deficit for the organization in over 5 years.

The financial result was impacted by significant stock market correction prior to the end of the financial year.

The net result for the previous year was a surplus of \$922K bolstered by bequests, government support in response to the pandemic and positive investment income.

Despite the absence of government support payments to mitigate the impacts of the pandemic in FY2022, Fight Parkinson's continued to waive Membership fees until November 2021.

Fight Parkinson's made the strategic decision to invest in the development of an online education platform, the Learning Hub to provide greater equity of access to education of Parkinson's and marketing of our new brand.

With COVID-19 restrictions easing in the later half of 2022, Fight Parkinson's committed to both online and face to face engagements to support the Parkinson's community.

These contributed to operating expenses being \$275K more than last year.

Fight Parkinson's flagship event for community awareness and fundraising, A Walk In The Park was held in March 2022 and together with the virtual community engagement event 27forParkinson's, raised total funds of \$622K.

Our Investment portfolio was impacted by a significant global stock market correction prior to the end of the financial year resulting in a loss of \$391K, which was a decrease of \$1.1 million from last year.

Investment in research was \$87K as we continue to invest in the adaptation and delivery of ParkinsonNet project in the Victorian/Australian environment.

Our net assets remain at a healthy position of \$5.186 million.

Fight Parkinson's strong financial position drawing on the surplus of over \$2.22 million in the previous two financial years enables us to invest in priority programs to support the needs of the Parkinson's community.

Fight Parkinson's Board

The Board sets our strategic direction, providing leadership and guidance. Its members are committed to our mission of enabling people living with Parkinson's to lead active and full lives and to support development of more effective treatments, and a cure, for Parkinson's.

The Board has three committees - Research, Governance and Risk, and Finance and Investment - to ensure it satisfactorily discharges its responsibilities and duties.



Professor David Finkelstein
Chair Research Committee
B.Sc., Grad. Dip. Scientific Instrumentation, M. Sc., Ph.D.
Appointed: May 2014



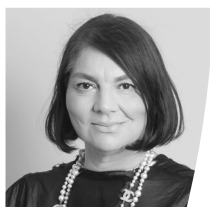
Jason Karametos
Chair Finance and Investment Committee
B Com/LLB (Hons), LLM
Appointed: April 2018



Professor Jennifer McGinley
Member Research Committee
B.App.Sci (Physiotherapy);
Grad Dip (Neurosciences);
Doctor of Philosophy, La Trobe University
Appointed: February 2021



Celia Robinson
Member Research Committee
M.Pub&IntLaw, B.Bus (Local Government)
Appointed: August 2017
Resigned: February 2022



Faye Spiteri OAM
Chair Governance and Risk Committee
B.A., GradCert PubRelations
Appointed: October 2019
Resigned: March 2022



Philip Thomas
Chair
Member Governance and Risk Committee
M. ComLaw, B.Bus., Grad. Dip. CSP., ASA, FCSA, FCIS, F.Fin, MAICD
Appointed: June 2016



Orlando Viola
Member Finance and Investment Committee
BBus (Bachelor of Business – Accounting)
Appointed: September 2019



Steve Watts AFSM
Member Governance and Risk Committee
Australian Fire Service Medal
Grad. Cert. Applied Management
Adv. Dip. Business Management
Appointed: September 2019
Resigned: March 2022

Auditor's Report



Chartered Accountants & Advisors

Walker Wayland Advantage Audit Partnership

Audit, Assurance and Risk Advisory

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INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF PARKINSON'S VICTORIA LIMITED

Opinion

We have audited the financial report of Parkinson's Victoria Limited ("the Company"), which comprises the statement of financial position as at 30 June 2022, the statement of profit or loss and other comprehensive income, statement of changes in equity and statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies and the Directors' Declaration.

In our opinion the financial report of Parkinson's Victoria Limited has been prepared in accordance with Division 60 of the *Australian Charities and Not-for-profits Commission Act 2012*, including:

- (a) giving a true and fair view of the Parkinson's Victoria Limited's financial position as at 30 June 2022 and of its financial performance and cash flows for the year ended on that date; and
- (b) complying with accounting policies to the extent described in Note 1, and Division 60 the *Australian Charities and Not-for-profits Commission Regulation 2013*.

Basis for Opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the *Auditor's Responsibilities for the Audit of the Financial Report* section of our report. We are independent of the Company in accordance with the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110 *Code of Ethics for Professional Accountants (Including Independence Standards)* (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Emphasis of Matter - Basis of Accounting

Without modifying our opinion, we draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared for the purpose of fulfilling the Company's financial reporting responsibilities under the ACNC Act. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.



Independent Member of

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Liability limited by a scheme approved
under professional standards legislation.



Independent Member of
Walker Wayland Australasia Limited,
a network of independent accounting firms



INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF PARKINSON'S VICTORIA LIMITED (Continued)

Directors' Responsibilities for the Financial Report

The Directors of the Company are responsible for the preparation of the financial report that gives a true and fair view and have determined that the basis of preparation described in Note 1 to the financial report is appropriate to meet the requirements of the ACNC Act, and for such internal control as the Directors determine is necessary to enable the preparation of a financial report that gives a true and fair view and is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the directors are responsible for assessing the Company's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless management either intends to liquidate the Company or to cease operations, or has no realistic alternative but to do so.

The Directors of the Company are responsible for overseeing the Company's financial reporting process.

Auditor's Responsibilities for the Audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with the Australian Auditing Standards, we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Directors.



**INDEPENDENT AUDITOR'S REPORT
TO THE MEMBERS OF PARKINSON'S VICTORIA LIMITED (Continued)**

Auditor's Responsibilities for the Audit of the Financial Report (Continued)

- Conclude on the appropriateness of the Directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the Company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

We communicate with Directors of the Company regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Walker Wayland Advantage

**WALKER WAYLAND ADVANTAGE AUDIT PARTNERSHIP
CHARTERED ACCOUNTANTS**



**AWAIS UR REHMAN
PARTNER**

Dated in Melbourne on this 20th day of October 2022

Financials

STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2022

	2022 \$	2021 \$
INCOME		
Revenue	1,529,960	2,870,729
Research Revenue	39,865	26,914
Victorian Dept of Health and Human Services Grant	336,187	341,000
TOTAL INCOME	1,906,012	3,238,642
EXPENDITURE		
Employee Benefits Expense	(1,576,282)	(1,551,591)
Depreciation Amortisation Expenses	(26,039)	(29,380)
Operating Lease Expense	(39,967)	(64,277)
Finance Costs	(22,624)	(22,301)
Research Expenses	(87,228)	(91,312)
Other Operating Expense	(839,578)	(557,618)
TOTAL EXPENDITURE	(2,591,718)	(2,316,479)
(DEFICIT)/SURPLUS FOR THE YEAR BEFORE INCOME TAX	(685,706)	922,163
Income tax expense	-	-
NET SURPLUS FOR THE YEAR	(685,706)	922,163
OTHER COMPREHENSIVE INCOME:		
TOTAL OTHER COMPREHENSIVE INCOME FOR THE YEAR	-	-
TOTAL COMPREHENSIVE INCOME FOR THE YEAR	(685,706)	922,163
TOTAL COMPREHENSIVE INCOME ATTRIBUTABLE TO MEMBERS OF THE ENTITY	(685,706)	922,163

STATEMENT OF CASH FLOW OR THE YEAR ENDED 30 JUNE 2022

	2022 \$	2021 \$
CASH FLOWS FROM OPERATING ACTIVITIES		
Receipts from Donations, Bequests and Other Income	2,106,571	2,184,143
Government Grant	336,187	341,000
Payments to Suppliers and Employees	(2,662,305)	(2,033,300)
Interest Paid	(4,162)	(3,489)
Interest Received	1,020	2,705
NET CASH (USED IN)/GENERATED FROM OPERATING ACTIVITIES	(222,688)	491,059
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchase for Plant and Equipment	(14,844)	(11,531)
Investment in Financial Assets	166,083	(1,724,537)
Income from Investments	220,619	129,590
Management Fees for Investments	(15,852)	(16,083)
NET CASH GENERATED FROM/(USED IN) INVESTING ACTIVITIES	23,840	(1,622,561)
CASH FLOWS FROM FINANCING ACTIVITIES		
Repayment of Lease - Principal	(11,760)	(67,072)
NET CASH USED IN FROM FINANCING ACTIVITIES	(11,760)	(67,072)
Net decrease in cash held	(210,608)	(1,198,574)
Cash on hand at the beginning of the financial year	1,042,529	2,241,103
CASH ON HAND AT THE END OF THE FINANCIAL YEAR	831,921	1,042,529

**STATEMENT OF FINANCIAL POSITION
AS AT 30 JUNE 2022**

	2022	2021
	\$	\$
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	831,921	1,042,529
Accounts Receivable and Other Debtors	52,677	42,649
Inventories	-	512
Other Current Assets	5,019	3,602
TOTAL CURRENT ASSETS	889,617	1,089,292
NON-CURRENT ASSETS		
Plant and equipment	26,287	37,482
Right of Use Assets	139,970	37,495
Financial Assets at Fair Value through Profit or Loss	4,682,087	5,090,557
TOTAL NON-CURRENT ASSETS	4,848,344	5,165,534
TOTAL ASSETS	5,737,961	6,254,826
LIABILITIES		
CURRENT LIABILITIES		
Accounts Payable and Other Payables	183,677	163,131
Lease Liability	66,390	37,012
Provisions for Employee Benefits	187,894	178,993
Revenue Received in Advance	3,000	-
TOTAL CURRENT LIABILITIES	440,961	379,136
NON-CURRENT LIABILITIES		
Lease Liability	105,466	-
Provisions for Employee Benefits	5,676	4,126
TOTAL NON-CURRENT LIABILITIES	111,142	4,126
TOTAL LIABILITIES	552,103	383,262
NET ASSETS	5,185,858	5,871,564
MEMBERS' FUNDS		
Members' funds	4,699,414	5,240,329
Research Funds	486,444	631,235
TOTAL MEMBERS' FUNDS	5,185,858	5,871,564

**STATEMENT OF CHANGES IN EQUITY
FOR THE YEAR ENDED 30 JUNE 2022**

	Members' Funds	Research Funds	Retained Surplus
	\$	\$	\$
Balance at 30 June 2020	4,288,399	661,002	4,949,401
Comprehensive income			
Surplus for the year	922,163	-	922,163
Other comprehensive income for the year	-	-	-
Total Comprehensive Income Attributable to Members of the Entity	922,163	-	922,163
Transfer between Members' Funds and Research Funds	29,767	(29,767)	-
Balance at 30 June 2021	5,240,329	631,235	5,871,564
Comprehensive income			
Deficit for the Year	(685,706)	-	(685,706)
Other comprehensive income for the year	-	-	-
Total Comprehensive Income Attributable to Members of the Entity	(685,706)	-	(685,706)
Transfer between Members' Funds and Research Funds	144,791	(144,791)	-
Balance at 30 June 2022	4,699,414	486,444	5,185,858

Get involved to Fight Parkinson's together

Fight Parkinson's relies on the generous support of individuals, corporations, government and community groups to deliver our comprehensive range of programs and services to improve quality of life for people living with Parkinson's and Atypical Parkinson's.

Give

Your donation helps ensure people living with Parkinson's and Atypical Parkinson's continue to have access to comprehensive and flexible services encouraging independence and quality of life while the search for a cure continues.

Bequest

By leaving a gift in your Will you are helping fund the ongoing need of health information, education, support services and research to improve the quality of life for people living with Parkinson's into the future.

Fundraise

Choose to be actively involved in a Fight Parkinson's community fundraising event – or organise your own special fundraiser in memory of a loved one or to celebrate a special occasion.

Partner

Corporate partnerships help to support a range of Fight Parkinson's initiatives. Please get in touch if you think we can work together to enhance quality of life for people living with Parkinson's and Atypical Parkinson's.

Volunteer

We accept volunteer requests, particularly to help support delivery of our annual major community event, A Walk in the Park.



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