



# ANNUAL REPORT 2016-17

PARKINSON'S SOUTH AUSTRALIA INC

IN THIS TOGETHER  
**parkinson's**  
SOUTH AUSTRALIA

# Our Team

## PATRON

His Excellency the Honourable  
Hieu Van Le AC  
Governor of South Australia

## AMBASSADOR

Amelia Mulcahy

## PRESIDENT

Assoc Prof John Power

## TREASURER

Steve Whitehouse  
(resigned 27/3/17)  
David Perrott  
(appointed 22/5/17)

## BOARD MEMBERS

Gus Abimosleh  
Paul Davies  
John Doyle  
Geoff McKinnon  
Alison Perrott  
Neil Holthouse  
(resigned 27/2/17)  
Helena Kyriazopoulos  
(resigned 27/2/17)

## CHIEF EXECUTIVE OFFICER

Christine Belford (retired Jan 17)  
Jan Chorley (until Aug 17)  
Olivia Nassaris

## GROUP PROGRAMS COORDINATOR

Anne Heard

## CLIENT SUPPORT/EDUCATION

Paula-Jean Hayes  
Margie Stevens (until May 17)  
Jo White

## ADMINISTRATIVE TEAM

Simone Ridge-Cooke  
Judy White  
Isobelle Brett (retired Aug 16)  
Bethany Foster

## OFFICE VOLUNTEERS

Sandie Clarke  
Kate Schkabaryn  
Tracey Leaney  
Pat Mueller  
Barb Hand  
Monika Kruger  
Josephine Kirby  
Lyndon Radbone



A Walk in the Park 2016



Parkinson's SA in Canberra with  
Parkinson's Australia



Tumby Bay Walk & Run  
on the Beach 2017



SA's Parkinson's Nurse Specialists with  
Nat Cook MP at the  
World Parkinson's Day breakfast  
11 April 2017

# Sponsors & Supporters



Government of South Australia  
Community Benefit SA



abbvie



# From the President , JOHN POWER



The last twelve months have been a most demanding year for both the Board and the staff of PSA. At the last AGM I announced the retirement of Christine Belford who had been the CEO for the last 10 years. The Board conducted an extensive series of interviews and appointed Jan Chorley as the CEO. After some months she resign due to family health issues.

Shortly after the Board appointed Olivia Nassaris as the CEO of Parkinson's SA. Olivia has great energy and a deep passion for the Parkinson's community and many of our members have welcomed her appointment.

Throughout the year Parkinson's SA hosted many successful social and fundraising events, such as the quiz night and A Walk in the Park, which contribute significantly to the operating budget of the organisation.

I am pleased that during this financial year we saw the commitment from the state government fulfilled, with all four Parkinson's Nurse Specialist roles filled at the Royal Adelaide Hospital, Flinders, Modbury and one positioned at SA Country Health. Parkinson's SA will continue to lobby for a community-based Parkinson's Nurse Specialist to see clients outside of the public hospital system.

Parkinson's SA remains a strong supporter of Parkinson's Australia, it's policy platform and advocacy efforts. We thank both the Chair of Parkinson's Australia, Vince Kelly, and the CEO, Steve Sant, for their commitment to improving the lives of people with Parkinson's.

Parkinson's SA also changed our representative on Parkinson's Australia board, John Doyle has taken up this responsibility.

In May 2017 we saw Kevin Weeks and his wife, Val, off on the most challenging personal goal - to cycle from Adelaide to Rockhampton and raise money for Parkinson's SA to purchase stationary cycling equipment, and refurbish an area that can be used for clients to cycle and enjoy other forms of exercise and activities.

Kevin and Val raised over \$60,000 on their travels. This campaign was significant for many reasons. As a well-known South Australian Kevin attracted a lot of media attention which helped raise the profile of Parkinson's SA and awareness regarding the condition. It also helped to publicise the benefits of cycling and exercise for people living with Parkinson's.

To our finances, Steve Whitehouse resigned from his position on the board as Treasurer. During his time he worked on projections and reports that allow the organisation to have a very accurate reflection of our financial position showing an improvement to the last financial year. On behalf of the Parkinson's SA community I thank Steve for service and input into the board, not only related to his field of expertise in accounting but also for his insights as a carer and as active member of our community.

Building on the systems that Steve put in place, the board will continue to closely monitor the finances of the organisation. The

board welcomed David Perrott at the May meeting as the new Treasurer. David's goal is to assist the organisation to streamline any financial processes and to produce a 5 year financial plan.

As always, I commend the Parkinson's SA staff and volunteers - who put together and deliver a full program of support, education and recreational activities for people affected by Parkinson's. It must be recognised that they do this with limited resources and great professionalism.

Kind regards,

Associate Professor John Power,  
President

# From the CEO, OLIVIA NASSARIS

The beginning of the financial year saw Parkinson's SA's turnaround from a bleak financial situation to a more stable position. This was due to overwhelming support from the community, donations from corporate supporters and two large bequest that allowed us to reopen the doors again on Fridays and return to five days a week.

The Parkinson's community remained committed to fundraising in the lead-up and on A Walk in the Park 2016. The event raised a record breaking \$54,500 with 450 registrations. The organisation was extremely grateful to have The Weeks Group as the gold sponsor of the event along with many Bronze level and in-kind support. Parkinson's SA would not be able to carry out the event if not for the time and effort donated by volunteers before and on the day.

In November we were pleased that the Minister for Health confirmed it's election promise from April 2014 by confirming the final two Parkinson's Nurse Specialist positions. At the time there were two in place at Modbury Hospital and Flinders Medical Centre, with the other two positions at the Royal Adelaide Hospital and SA Country Health - to service the 8 regional areas of South Australia.

Parkinson's SA recognises that people affected by Parkinson's are doubly disadvantaged by lack of relevant medical services as well as an inability to attend our metropolitan seminars. To help address this, Parkinson's SA successfully obtained funding to produce videos of 6 seminars presented by allied health professionals on issues related to living with Parkinson's.

Parkinson's SA was proud to participate in the world-wide World

Parkinson's day campaign Unite for Parkinson's on April 11 to mark 200 years of Parkinson's history. PSA also held a breakfast for health professionals and politicians and also a very well-attended event in the afternoon with an informative and entertaining presentation by Dr Rob Wilcox on the history of Parkinson's.

In staffing it was a year for retirements and many changes. Christine Belford retired after a decade of service and Parkinson's SA appointed Jan Chorley as CEO but she left unexpectedly due to family illness. I was appointment to the position by the board in August 2017.

Isobelle Brett also retired and the office welcomed Simone Ridge-Cooke into a full time administrative role. Simone worked very hard on preparing the meticulous documentation required for the organisation to gain our Australian Services Excellence Management certificate.

Judy White continues to maintain high standards of excellence and took the organisation through the auditing process and ensures that our reporting for recurrent granting meets the government standards.

Margie Stevens moved on to full time employment and was replaced by Jo White, who is a counsellor and has ably taken over the delivery of the Aged Care Training Package. Paula-Jean Hayes continues counselling and put time, thoughtful effort into restructuring the Finding Calm curriculum to be better suited for carers or people living with Parkinson's. As such, the organisation now offers two programs called *Caring with Calm* and *Finding Calm*.



Anne Heard continues to find innovative and exciting recreational programs for our clients to enjoy and successfully introduced a creative writing course with support from the City of Unley Council. Dance classes for people living with Parkinson's and carers is also available in more areas, including the Fleaurieu. She works tirelessly to ensure that Group Support Leaders get the support and information they need from the organisation in order to perform their role effectively.

Parkinson's SA continues to learn more and educate clients about My Aged Care and National Disability Insurance Scheme. However, the future of specialised support service block funding with these two schemes in place is uncertain. State funding is only guaranteed until June 2018 and federal funding until June 2020. With this in mind it is important that the organisation plans carefully for the future.

PSA is a proud member of Parkinson's Australia and actively supports the advocacy efforts of the peak body. Monica Hall represented the SA Parkinson's community at a Neurological Alliance of Australia event. She also eloquently presented the issues and experiences of living with Parkinson's in lobby meetings with Senator John Williams, the Opposition Leader, Bill Shorton and the Prime Minister.

## From the Treasurer, DAVID PERROTT

### CEO's report cont'd...

I would like to thank the members of the board for their service to the organisation as volunteers and John Power, the President, for his strong leadership and commitment to staff and the community.

I must give recognition and thanks to the special group of people who donate their time, skills and experiences to Parkinson's SA - our network of committed and talented volunteers.

Thank you to each and every volunteer of Parkinson's SA including the ones who work in the office, who lead and take responsibility for support groups, who help set up and pack up, who assist with recreational groups, ones who come to assist with mailouts. Also to the volunteers that take responsibility for some of our fundraising activities by contributing to planning, collecting donations, catering and ensuring the events run smoothly on the day.

**"Volunteers don't necessarily have the time, but they have the heart, so they make time."**

**-UNKNOWN**

I look forward to leading Parkinson's SA through the next few years of change to ensure the sustainability and longevity of the organisation and our services.

Kind regards,

Olivia Nassars  
Chief Executive Officer



It is with pleasure that I present my first Treasurer's report for Parkinson's South Australia Inc for the year ended 30 June 2017.

The association had a net surplus of \$50,437 for the 2017 year compared to a deficiency of \$52,426 for the 2016 year. The changed result from first appearances would appear to be a great result for the organisation.

Whilst it is fantastic that we are not running at a loss the result more accurately reflects a reduction in services provision during the 2017 year as necessitated by a reduction in revenue.

The reduction in the income from \$809,000 to \$686,416 is principally due to the one-off receipt of a \$141,000 Aged Care Service Improvement grant in the 2016 year.

Services relating to this specific funding were not able to be provided during the 2017 year and is reflected in a reduction in Selling & Administration, Services Provision, Wages and Superannuation Expenses.

There was also a reduction in the wages and superannuation expenses in the 2017 year due to staff changes, as well as the retirement of the CEO resulted in the payment of annual leave

and long service leave that had been over provided for in previous years.

We are currently reviewing strategies to become less reliant on grant funding, particularly in light of the introduction of the National Disability Insurance Scheme (NDIS) and the government shift to a user pay environment.

The level of services that we are able to provide is dependent on the income that we are able to generate from donations, bequests, sponsorship and other fundraising activities. It is also important that fundraising activities are targeted to the broader community, rather than reliant on the smaller base people affected by Parkinson's.

It is also important for Parkinson's South Australia Inc to have a certain level of reserves to give us a level of security and comfort regarding the ongoing provision of services. It will be necessary to ensure that we generate small surpluses each year, without affecting the level of service provision, so that we can put aside funds to meet the medium and longer term objectives.

We are currently reviewing the effectiveness of the services we currently provide to ensure the needs of members are met, so that we can continue to grow and improve services in a financially sustainable manner.

Thank you for your ongoing support,

David Perrott  
B Com(UNSW) CA CTA  
Treasurer

# From the CLIENT SUPPORT TEAM



The client service support team worked closely beside Anne Heard, Group Programs Coordinator to engage with clients in a range of contexts.

## INFORMATION, EDUCATION AND SUPPORT

Information, counselling and support was provided to community members by social workers Margie Stevens and Paula-Jean Hayes (PJ). In February, Margie left the organisation and in June, Jo White joined the team, bringing with her valuable nursing skills. Core responsibility remains provision of information, counselling and support, responding to inquiries and concerns chiefly via support line calls, but also through pre-arranged and drop-in face-to-face sessions, email inquiries from Parkinson's websites, and some home visits.

More than 1100 separate counselling/support sessions were given by the support team. Often, information was sought about staying independent at home, moving into residential care, understanding Parkinson's and adjusting to changed symptoms. Clients also sought referral to appropriate programs and services.

## TEAM MEETINGS & PROFESSIONAL DEVELOPMENT

Weekly team meetings enabled vital planning and communication,

sharing issues of concern, information, fresh ideas and reflecting on practice. Occasionally, representatives from community organisations updated support workers on services and resources for clients.

## SUPPORT SERVICES SURVEY 2016

In November 2016, a survey was sent to a random sample of clients who had contacted the support team in the previous year. This survey aimed to evaluate PSA support services as part of our commitment to continuous improvement.

91 replies were received, mostly from people living with the condition, plus family carers. The main reasons reported for contacting PSA related to obtaining information, about (a) Parkinson's or another movement disorder generally (b) PSA support and exercise groups and seminars; and (c) Treatment & management of symptoms.

Contact with PSA was usually made soon after diagnosis or within the first 5 years.

PSA support services clients found most helpful were that:

- they could speak to a staff member in a timely way
- this person understood them/ their situation, and
- they could learn more about Parkinson's and other community services.

Pleasingly, results showed that most clients were satisfied or very satisfied overall with PSA support services received.

## AGED CARE STAFF TRAINING PACKAGE

PSA delivered the National Training package for upskilling staff in 24

Aged Care Facilities around the state, improving care for residents who have Parkinson's.

## GROUP WORK

Small group counselling was a regular offered across the year for people with Parkinson's (*Finding Calm*) and family carers (*Caring with Calm*). Facilitated by PJ, the program uses the ACT therapy model to teach ways to better handle difficult thoughts and feelings.

Support workers facilitated the Family Carer, 20's to 50's and Parkinson's Plus support groups, and the Women with Parkinson's group.

PJ led and facilitated Learn Now Live Well seminars for people relatively newly diagnosed. A Bereavement group was initiated: single, stand-alone gatherings for those in the Parkinson's community who have recently experienced loss of a family member. Importantly, the message is that PSA support does not end when a significant relative dies.

## PARKINSON'S NURSE SPECIALIST MEETINGS

In June, Jo initiated a Parkinson's specialist nurse group meeting 6 weekly at PSA. These have proven a valuable forum to discuss practices and innovations, tackle barriers and find ways to enhance medical care for Parkinson's patients. It also strengthens ties between PSA and Parkinson's nurse experts for advocacy and referrals.

Where time permitted, support staff visited community PSA support groups to speak on topics of interest and explain assistance provided.

Paula-Jean Hayes & Jo White,  
Client Support Team

# From the GROUP PROGRAMS COORDINATOR



## GROUPS

Groups across the state continue to provide valuable information and support, as well as recreational and exercise programs for people affected by Parkinson's. In areas where there is no current group, key health professionals have been identified to provide support and information to people with Parkinson's and their family members and to refer them to Parkinson's SA. Of the 24 Support/Education groups wmeeting identified needs.

These include those with Young onset Parkinson's (20's – 50's group) and those who experience movement disorders other than Parkinson's (e.g, Dystonia, Progressive Supranuclear Palsy, Multiple System Atrophy, Cortico-Basal Degeneration). The Focus on Family Carers' Group continues to support those caring for a relative with Parkinson's. The Deep Brain Stimulation group provides a valuable forum for discussion about DBS surgery between those who have undergone the treatment and those considering the surgery.

The Women with Parkinson's group which commenced early in 2016 has continued to grow and offer a supportive forum for women to share their issues and concerns.

A new Riverland group based in Barmera was established in February this year in response to interest expressed at several Community Seminars held in the Riverland in 2016. An awareness and fundraising initiative of Peter Atkinson, a person living with Parkinson's in Whyalla led to two Community Information seminars and training for local health professionals, and subsequently to a new support/ education group being established in Whyalla. Sue Sharrad, the newly appointed Regional Parkinson's Clinical Practice Consultant for the Country Health Network accompanied PSA staff to Whyalla and met with local health professionals.

Recreational groups include the weekly Brushlines Art Group, the Photography Group, five weekly Dance with Parkinson's Groups and the Parkinson's Pedallers' Cycling Group. PSA refers clients to a growing number of organisations which provide Parkinson's specific exercise programs.

## GROUP LEADER CHANGES

The passion and commitment of the many group leaders across the state continues to be vital to the effectiveness of groups in meeting the diverse needs of people living with Parkinson's in the community. There have been many leadership changes in the last year.

Craig and Sue Bastian stepped back from leadership of the Southern Fleurieu Parkinson's group and continued to have informal gatherings for lunch in Victor Harbor. Their dedicated involvement in Parkinson's support groups over many years is acknowledged. The facilitation of the Southern Fleurieu group was assumed by Amelia Dix and Caroline Tenny from Resthaven

early in 2017 and the venue moved to Port Elliott.

Lorraine Flanagan commenced a monthly Carers' group in the Holdfast Bay area and linked with Brighton Parkinson's group.

Tracy Leaney assumed leadership of the Western group, which relocated to ECH Seaside Wellness which runs a Parkinson's exercise program.

Glenys Badger commenced leadership of the new Riverland group.



## GROUP LEADERS' SEMINARS

Group leaders participated in four Group Leaders' seminars over the year and had the opportunity to attend Learn Now Live Well, Moving Ahead with Parkinson's and |Caring Matters seminars on a range of topics. These are opportunities for group leaders to update their knowledge about relevant issues as well as share ideas about programming and group facilitation strategies.

## PROGRAMS FOR FAMILY CARERS

Programs have been expanded for family carers this year. In addition to the monthly support/ education group and Caring with Calm programs, a series of Caring Matters Seminars was organised for 2017 to focus on services and particular issues of relevance to family carers.

## GROUP PROGRAMS report cont'd...

A special group gathering was also held to provide information and support for bereaved carers. Two local support/education groups, Brighton and Adelaide Hills have taken the initiative to set up separate gatherings for family carers, recognising that it is sometimes difficult for carers to raise sensitive caring issues in the regular meetings.

Parkinson's SA continues to seek opportunities to partner with other organisation to increase awareness of Parkinson's and support those living with the condition. Funding was again received from the Carer Support and Respite Centre, through the 'It's Your Life' Dementia Project to hold a Dementia and Parkinson's Seminar and Pampering Day in June this year.

## CREATIVE ARTS PROGRAMS

### Living Stories Colourful Lives Project

Following the success of the Inspiration Exhibition of art, photography and poetry earlier in 2016, funding was sought from the City of Unley for the Living Stories Colourful Lives Project for 2017. Parkinson's SA was again successful in receiving a Community grant to support a creative arts program. This year the Living Stories Colourful Lives Project encompassed tuition from resident artists in various techniques for the Brushlines Art group as well as a facilitator for a 4 week creative writing program. These programs generated inspiring artworks and writing for the Living Stories Colourful Lives Exhibition in the second half of 2017.

## Photography

The Photography group continues to enjoy monthly meetings and outings and plans to recruit new members through a 6 week Into Photography course in July/August facilitated by Geoff Thompson, an experienced photographer and instructor.

## Dance



**Dance with Parkinson's Program**  
The development of programs based on the Dance for Parkinson's model has continued with two new programs being commenced through liaison with local councils.

After the success of a program earlier in the year in Port Noarlunga, the City of Onkaparinga established a second Moving into Dance program in Aldinga. Funding sought through the City of Alexandrina supported the pilot Southern Fleurieu Dance 2 Move program in Goolwa in July 2016, which became an ongoing program in January this year.

A fortnightly Parkies Dance group was commenced in Mount Gambier in June, complementing the ongoing support offered to those in the South East by the Mount Gambier Parkinson's Group. These three new groups are in addition to two previously established groups at Burnside and Clarence Park.

## REGIONAL OUTREACH

During the year, the Client Services team has visited groups and conducted seminars and/or professional training in the South East, Southern Fleurieu Peninsula, Yorke Peninsula, Eyre Peninsula, Riverland and the Lower North.



## SEMINARS

Parkinson's SA has continued to conduct monthly Learn Now Live Well seminars for those with a recent diagnosis of Parkinson's and their family members, monthly Moving Ahead with Parkinson's seminars, with topics relevant to those who have experienced Parkinson's for several years, are now also being held monthly. As well as 19 Community Information seminars held in various metropolitan and regional areas, bi-monthly Understanding Parkinson's seminars at Parkinson's SA were scheduled as a general introduction for people with Parkinson's, their family members, friends and the wider community.

An Infused Therapies Seminar was held to address the needs of those considering or receiving various infused therapies, and their family members.

Anne Heard  
Group Programs Coordinator