

parkinson's NEWS



AUTUMN EDITION 2023



Parkinson's Awareness Month

Pictured: L-R CEO Yasmin Naglazas, Dr Katrina Stratton and Clinical Nurse Manager Janet McLeod

April was an exciting month for Parkinson's WA as we took charge leading the way to promote the lesser-known symptoms associated with Parkinson's, discussed the importance of exercise and spoke about all things Parkinson's in the community.

Parkinson's WA CEO Adjunct Professor Yasmin Naglazas and Clinical Nurse Manager Janet McLeod, OAM met with Dr Katrina Stratton, Labor Member for Nedlands at The Niche building at QEII Medical Campus, to speak about the future of the organisation under new leadership.

Dr Stratton took the time to engage with the community as she met with the Western Suburbs Parkinson's WA Support Group and heard from their members and leader.

Leader, Pete said he was pleased that in Dr Stratton, the community had a Local Member who reflected their values and listened to their questions with warmth and integrity.

Dr Stratton said it wasn't just about who you knew with Parkinson's, it was a condition that touched the lives of so many.

At Parkinson's WA, we aim to support all people living with Parkinson's across WA and talking about the condition has been an important part of raising that awareness in the community.

Continued on page 4-5...

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Yasmin's Bulletin



Pictured: L-R PNS Fiona, Jo and Amanda and CEO Yasmin

As I have taken on the role of CEO, I have been impressed with the amount of activity that is currently underway to ensure that Parkinson's WA is meeting its remit of providing support to those living with Parkinson's.

We are very privileged to have employees who are dedicated to their work and producing some wonderful outcomes that contribute to the organisation's work and its future plans.

Our plans will focus not only on the work that is underway, but also (in response to the feedback of those living with Parkinson's and their carers) where we may be able to address gaps in service delivery. Feedback has been so important in formulating our plans and along with ongoing discussions with our key partners from government, donors and the research sector, we believe that we can maintain a sharp focus on the initiatives we undertake.

I have been amazed by the commitment of our Support Groups, specifically the Support Group Leaders who assist in coordinating forums each month to provide support, information and friendship for those living with Parkinson's and their partners/carers. On 28 February, a very successful forum for the Support Group Leaders was held with an exceptional group of leaders. The day was very informative with the welcome addition of a drumming circle for the group's relaxation and entertainment!

Research remains one of the areas of interest and applications of funds by Parkinson's WA. This year, the intention is to establish more of a focus on where Parkinson's Australia's research dollar is spent as well as strengthening collaborations with our research partners.

Continued on page 3...

Update from the Parkinson's WA Office

Welcome to Autumn!

Under our new leadership, we've had some changes in the way we are looking to the future. This includes reflection on and amendment of our Strategic Plan and assessing our priorities when it comes to the best use of our time and what energy we put into specific projects and initiatives.

We are heading into a growth period that will look to boosting funding opportunities within the team and organisation.

Our team will focus on creating business plans to align with the new strategic plan and to create transparency and streamline our offerings and to build on collaborative collegial relationships with other like-minded organisations and people within the sector.

Watch this space for Parkinson's WA!

Sadly, our Donor Relations Manager Dorothy Koh will be leaving the Parkinson's WA team after handing in her resignation recently. You can read her final Newsletter contribution on page 12.

Parkinson's WA CEO, Adjunct Professor Yasmin Naglazas said Dorothy would be missed after almost four years of service in the role and we wished her well with her next endeavours.

"In that time, Dorothy has shown a significant commitment to the organisation's reason for being, with the many initiatives that she has as part of her portfolio."

We are celebrating the 25th year of our esteemed Parkinson's Nurse Specialist Service and are planning many exciting initiatives as we head towards our Anniversary Celebration on 24 November.

Look out for updates about how you can get involved and stay connected to our news through our website **www.parkinsonswa.org.au/news** and follow us on our social media channels for 'real-time' updates about what we are getting up to in the community.

Thank you as always to our Members, supporters, donors, carers/partners, family and friends and those living with Parkinson's.

From the Parkinson's WA team

Yasmin's Bulletin cont...

Research tends to be in the background of our daily activities; however, Parkinson's WA actively encourages and supports research into the causes, treatments, and consequences of Parkinson's and this requires the appropriate resourcing and attention.

As I become more familiar with the role of CEO at Parkinson's WA and meet more of you who have an affiliation with us, I am sure that I can contribute positively to our future strategy. And this cannot be done without my wonderful team!

Adj Professor Yasmin Naglazas
Chief Executive Officer
Parkinson's WA



April is Parkinson's Awareness Month - cont...

Over April, the Town of Cambridge have offered their support to the local Parkinson's community by hosting an information corner at the Cambridge Library with pamphlets, posters, flyers and informative content all about Parkinson's to promote awareness and understanding of the neurological condition that affects so many.



Town of Cambridge Mayor Keri Shannon said she was delighted to support the local Parkinson's community.

Pictured: Clinical Nurse Manager Janet McLeod, OAM with Town of Cambridge Mayor Keri Shannon

"Parkinson's Awareness Month reminds us that Parkinson's WA is here year-round providing wonderful support to members of our community who are living with the condition," Mayor Shannon said.

"Whether it's delivering a Parkinson's Nurse Specialist service, hosting support groups or sharing advice through seminars, Parkinson's WA makes a huge difference in our community, across Perth and around the State."

"As a show of support for the service, we had a dedicated display in place at Cambridge Library with information about the condition, the assistance available and how we can all get behind Parkinson's WA."

We heard from our Parkinson's Nurse Specialists (PNS) about living with Parkinson's and our South West PNS Donna Mallaby explains how a new Parkinson's diagnosis is a life-changing thing, but it is not life-ending. You can read this story on pages 18-19.

PNS Fiona Roscoe gave us some interesting insights about Parkinson's in her latest blog: 5 things you never knew about Parkinson's, which you can read on page 14.

We learnt more about the history of the Parkinson's tulip through a blog written by Clinical Nurse Manager, Janet McLeod OAM who told us that the tulip had been adopted as a symbol by many Parkinson's organisations around the world and the European Parkinson's Disease Association chose the tulip as the symbol for its logo in 1996.

"The tulip is an ideal flower to adapt and modify in relation to Parkinson's, as several interesting observations and connections can be made. The stylised format of a tulip so frequently used as a symbol for Parkinson's organisations is clearly divided into two equal halves - this represents the two sides of the brain," she said.

Going Purple for Parkinson's



Together with Main Roads Western Australia and the WA Government on World Parkinson's Day, we joined forces in solidarity to light up the Metro landmarks in Parkinson's purple. Going purple for Parkinson's, we lit up Matagarup Bridge, Mount Street Bridge, Sky Ribbon, Joondalup Drive Bridge and Northbridge Tunnel, which was a fitting display of unity and strength.

Clinical Nurse Manager Janet McLeod had a series of radio interviews on World Parkinson's Day, chatting about the regional offerings of the service and understanding what the day was about and why we needed to acknowledge, honour and remember the great James Parkinson.

Janet also gave us some wonderful, thoughtful advice about what to do next after a new Parkinson's diagnosis, which has been recently added to our YouTube Channel:

www.youtube.com/@parkinsonswa8583

It has been an amazing month, and we have you to thank, the community and our followers, where we will always focus the core of what we do and who we are. We are Parkinson's WA, and we are in this together.

You can find out more about what Parkinson's WA has been up to, through the news page on our website at: www.parkinsonswa.org.au/news

Pictured: Clinical Nurse Manager Janet McLeod, OAM on the radio (above) Parkinson's WA community members (below) Matagarup Bridge (left inset)

From the Nurses' Desk

Dear All,

It is very true that the year seems to speed past as we get older. This year is flying past and has had some great highlights to date.

April was busy with Parkinson's Awareness Month being full of speaking commitments including radio sessions in Narrogin and the Goldfields. The seminars in Bunbury and Perth for those of you who are newly diagnosed attracted significant numbers - this is not something we celebrate but it reflects the worldwide increase in the number of people being diagnosed. It was also great to see the bridges and the Stadium lit in Parkinson's Purple on World Parkinson's Day April 11th. Hopefully this can become an annual event.

Research has been highlighted globally this month and the a local study into the efficacy of boxing as therapy is explained in greater detail on page 11. The Parkinson's WA Research Committee is looking forward to the first face-to-face meeting of the year.

May is the month when we survey those of you who have had a visit from our team. Thank you for getting your surveys back to us as promptly as you can. We have already surveyed your consultants and will be including General Practitioners when your surveys are posted. These surveys form part of our six-monthly reports to the Health Department, so your co-operation is greatly appreciated.

As we approach the colder winter, please remember to keep your vaccinations up-to-date. Exercise as much as you can and keep healthy.

Yours,

The Nurses



Dear Nurses,

I heard recently from a friend in the Parkinson's Support Group that there is a new medication in the treatment of Parkinson's. All my friends could tell me is that it is a dark blue colour. Do you know anything about this?

Yours,

"Bill of Bentley"

Dear Bill,

We are always amazed at how quickly word gets around members at support groups. They are great places for swapping experiences and learning how others manage life and its challenges

As Nurses, we prefer for people to avoid comparing one another's medications if possible. Having said that, a new medication becoming available is always big news! You are correct Bill, a new drug was listed on the Australian Pharmaceutical Benefits Scheme in February this year.

The medication you refer to is Ongentys also known as Opicapone and it is available in one dose only (50mg). It belongs to the family of medications known as COMT Inhibitors which includes Comtan. Another form of a COMT Inhibitor is Stalevo but that is slightly different because it also contains levodopa.

Ongentys is unique among COMT Inhibitors because it is only taken once a day and is recommended to be taken at night a few hours away from levodopa preparations. It makes more levodopa available by 'blocking' the enzyme COMT.

Another difference is that this medication does not stain the urine dark red/orange as is the case with both Comtan and Stalevo. You are correct in the pills are an unusual shade of dark blue!

We are aware that some of our specialists here in WA are beginning to prescribe this new medication, so we will have some anecdotal evidence soon.

Your Parkinson's Nurse Specialists

Assistive Technology for life: Indigo Solutions

Parkinson's WA Survey findings

Assistive Technology is a broad term that covers the assistive products, devices and programs that maintain or improve someone's functioning and independence.

As part of Parkinson's Awareness Month, which is acknowledged in April each year, Indigo has partnered with Parkinson's WA to research how those with the condition use assistive technology, and how AT can be used to help them in the future.

Approximately 100,000 people in Australia are living with Parkinson's, a progressive neurological condition that affects the brain, muscles, and overall movement of the body. While Parkinson's affects many people over the age of 60, young people can also develop the condition, and it affects both men and women.

Discovering what types of assistive technology those with Parkinson's use, and their experiences using AT in different areas of their life, can not only help others with the condition, but also inform and educate allied health staff so they can better support Parkinson's clients.

For a full list of the recommended products, visit our article: [Product in Focus: Parkinson's Essentials](#) on Indigo's website.

As part of the survey, we have collated the top assistive technology devices that were recommended by the respondents – here are the best AT products for those with Parkinson's around the home and in the community.



- Electric Recliner/Lift Chair - make sitting down and standing up more accessible with remote control recline and standing support.
- Electric Bed - can make getting in and out of your bed easier and more comfortable.
- Shower Chair - enables those with decreased balance or mobility to use a shower safely and independently.
- Bathroom Rails - can reduce the risk of injury, particularly in wet and slippery environments.
- Walking Aids - wheelchairs, walkers, or walking sticks can not only assist in getting around the home, but also enable greater independence in the community as well.



Picture courtesy of Indigo

One of Indigo's integral services is working with allied health staff and clients to provide tailored solutions and assistive technology that promotes independence and improves our client's daily life. We are looking to partner with other organisations in the disability and aged care sectors to research the impact that AT has on those with lived experience, and what assistive technology they find helpful. If you would like to partner with Indigo, please contact Indigo Solutions at www.indigosolutions.org.au

Parkinson's Nurse Specialists in the Community



Pictured: Parkinson's Nurse Specialist, Donna in Esperance.
(supplied)

We take you into the Parkinson's community, where we get to know more about the Nurses and what they do.

From Esperance with Donna Mallaby the South West Inland Parkinson's Nurse Specialist was in Esperance in March on an outreach visit to the region.

"It's been my pleasure visiting people with Parkinson's in their homes and at the Esperance Aged Care Facility," she said.

"Esperance is such a beautiful place with beautiful people to match. They are a community that looks out for one another."

"I have also visited local GP practices, Esperance Hospital and Esperance Home Care and delivered education sessions to staff at Esperance Aged Care Facility. Thanks for having me Esperance, I am already looking forward to my return."

Janet promotes Brain Awareness Week Clinical Nurse Manager Janet McLeod, OAM, came back to the Parkinson's WA office after her talk for Brain Awareness Week, saying what a privilege it had been to be part of the Neurological Council of WA's (NCWA) very successful morning. She spoke about learning more about maximising brain health when living with Parkinson's and other movement disorders, including how to live well after a diagnosis by accessing support.

Janet enjoyed the opportunity to share her passion for all things Parkinson's and to have the opportunity to further collaborative work alongside NCWA.



Pictured: Etta Palumbo, CEO of NCWA (left) with Janet

Janet delivered another great session at Chung Wah Community Care to a great audience of seniors at the Balcatta Hub in April. They

were very interested in knowing more about Parkinson's and asked for copies of information sheets following the session.

Janet always enjoys speaking at Chung Wah and she valued the opportunity to represent WA's multi-cultural Parkinson's community.



Pictured: (supplied) Chung Wah presentation



Save the Date ● ● ●

Legal Planning Seminar (FREE)

When: Tuesday 15 August 2023

Time: 10am-12pm (approx)

Location: The Niche, 11 Aberdare Road, Nedlands

Presenter: Hugh Cahill, Head of Practice, Cullen Macleod Lawyers

RSVP: Call the Parkinson's office on 6457 7373 or email info@parkinsonswa.org.au to RSVP by 10 August.

Postcards from Barcelona

When: Thursday 31 August 2023

Time: 10.30am -1pm

About: Feedback from the 6th World Parkinson's Congress with speakers Fiona Roscoe and Kayleigh Rawle, Parkinson's Nurse Specialists

Location: The Niche, 11 Aberdare Road, Nedlands

Cost: Members - \$10, Non-Members - \$15

RSVP: Call 6457 7373 or email info@parkinsonswa.org.au to RSVP by 24 August.

A Walk in the Park

When: Sunday 10 September 2023

Time: 10am -1pm (approx)

Event: Join us for the one and only community outreach event and fundraiser for Parkinson's WA, A Walk in the Park, for the 13th year.



JOIN THE CONVERSATION
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media channels

Would you like to receive your Parkinson's WA Newsletter digitally?

Parkinson's WA is working towards providing our members with the opportunity to receive digital versions of the Parkinson's WA newsletter. We can assure you this will be an opt-in process and if you would like to continue receiving physical copies of the newsletter, this will still be available.

Through choosing to receive your newsletter by email, you will be helping Parkinson's WA to reduce costs, including printing and mailing related expenses. You will also be helping to reduce your carbon footprint!

If you would like to receive your Parkinson's WA newsletter via email, please contact the office by email -info@parkinsonswa.org.au or phone - (08) 6457 7373.



Calling all Assistive Technology (AT) story-tellers!

Our friends at AT Chat love Assistive Technology (AT) and they are keen to get in touch with story-tellers who use a range of AT in their lives to manage their Parkinson's symptoms effectively.

Find out more about AT on page 8 in this edition.



AT Chat is keen to pay people to write content for them which would be hosted on their website as they talk about their 'AT experience'.

Are you the next AT story-teller from the Parkinson's community?

Please visit AT Chat to find out more: www.atchat.com.au or contact Engagement Officer Gail Stacey at gail.stacey@ilaustralia.org.au

FIGHT-PD boxing training study for Parkinson's published - Perron Institute

Results of FIGHT-PD: A feasibility study of periodised boxing training for Parkinson disease, have been published in PM&R, the official journal of the American Academy of Physical Medicine and Rehabilitation.

FIGHT-PD (Feasibility of Instituting Graduated High Intensity Training) was originally developed by Clinical Professor David Blacker (Perron Institute Medical Director and Parkinson's WA Board Member) and Rai Fazio (former Golden Gloves champion and now a highly regarded fitness trainer), and was further enhanced by Exercise Physiologist Dr Travis Cruikshank from Edith Cowan University and Perron Institute.

The study has shown that non-contact boxing training for people in the early stages of Parkinson's is well tolerated, safe and provides a stimulating all round work out.

Boxing training has become a popular form of exercise for people with Parkinson's but until now, there has been little high-quality data on its feasibility, safety and efficacy for this neurodegenerative disorder.

The study participants, averaging 60 years of age, all with early-stage Parkinson's, completed a 15-week exercise program with three one-hour sessions per week, using the Fightmaster-training device and a detailed, carefully measured exercise program.

Training technique was the initial focus. Intensity was increased to a high intensity level in phase two, and cognitively challenging dual task training was introduced in the third phase.

Lead author, Clinical Professor David Blacker (Perron Institute Medical Director, Sir Charles Gairdner Hospital and The University of Western Australia), is a strong advocate for exercise and has a personal perspective as someone living with PD.

“Exercise has significantly helped to reduce my symptoms,” Professor Blacker said.

“The WA study provides a depth of feasibility and safety data, methodological detail and preliminary efficacy for periodised non-contact boxing that is not described elsewhere. It provides a useful basis for future studies of boxing training for PD.”

The FIGHT-PD team included:

Dr Cruickshank, Rai Fazio, senior neurophysiotherapist Claire Tucak (Perron Institute and Sir Charles Gairdner Hospital,) Georgina Holbeche (Perron Institute clinic), ECU PhD student Mitchell Turner, ECU Honours students Phillip Beranek, Connor Pollard and Tegan Shelley, and UWA Medical student Sanathraj Rajandran.



Pictured: Professor David Blacker and other FIGHT-PD Members at the Perron Institute (supplied)

Article supplied by Perron Institute

Fundraising updates by Donor Relations Manager, Dorothy Koh

Rottnest Swim We are so proud of our swimmers, they have done so well, together they raised \$15,000 to support our Parkinson's Nurse Specialist Service, including:



Kate Raston, Team 'Wetter The Better' (Adam, Brooke, Chenae and Matt) and Chalise Pratt.

Thank you so much, your efforts mean a great deal to Parkinson's WA.

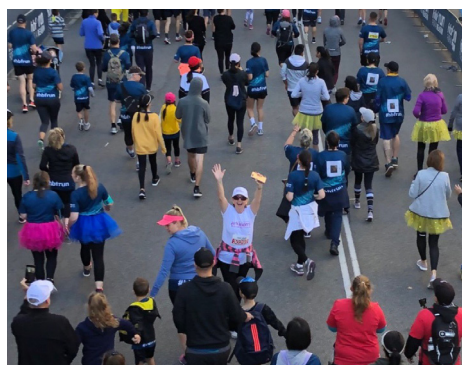
HBF Run For A Reason is back on 21 May. We are so pleased to have:

* Debbie Lamb

* Victoria Meadows

* Team SSKN – Samantha McCourt, Nicole Brough, Katie Lussenburg and Samantha Misedale

* Team AIM Dental – A very big team of 32 runners: Jess, Helen, Sammy, Erica, Kayla, Paige, Pearl, Lauren, Aja, Kelsey, Jane, David, Jarryd, Alice, Shay, Giorgia, Conor, Emidia, Kyra, Jess, Kim, Morgann, Diane, Karen, Wendy, Philip, Jacqueline, Alicia, Kodee, Taz, Meg and Theo.



If you or your family members are participating, please do consider running to support Parkinson's WA.

A Walk in the Park is back! 10 September at our favourite Perry Lakes Reserve in Floreat. Save the date, come join us in Parkinson's WA's, one and only outreach event. Let us show everyone who lives with Parkinson's that we are a community and that we can all still enjoy a lovely family event outdoors.

All walking aids, mobility scooters and your fur babies are welcome.

We have your favourite food trucks, the magnificent WASAMBA drummers and llamas joining us for the walk so come down with your family, it will be a glorious day.

The Annual Support Group Leaders' Workshop on 28 February was a great get together and sharing session. The leaders spoke about their groups and shared what worked for their group and exchanged recommendations of great speakers.

We were treated to a circle drumming session that we all thoroughly enjoyed. For support groups out of Perth metro areas, we shared the minutes which was appreciated. We had a great time, can't wait for the next one in 2024.

Pictured: (Top) Team 'Wetter the Better' (Right inset) Catherine Raston and father, (Bottom) Clinical Nurse Manager Janet McLeod at Run for a Reason

Elizabeth's second year in purple

For the second year, our amazing fundraiser Elizabeth Curtis is flying the purple flag for Parkinson's WA. She and her cycling group ventured through country Victoria and NSW on a 16-day trip, raising funds and awareness for our Parkinson's Nurse Specialist program along the way.

They kicked off their ride leaving from Corryong in Victoria to Jingellic, in NSW, and Liz said it was a good start to the trip where everything went well, and all the cyclists arrived safely at their accommodation.

"It was great to meet with everyone and get the show on the road. The mountainous views have been breath-taking, with a sprawling, beautiful undulating countryside." Liz said.

The energetic riders continued to journey across the East Coast of Australia and the bike club covered some terrific distances, including from Corowa to Barooga on day four and Barooga to Echuca.

"On day four, we had lunch at the Mulwulla Bakery where I spoke to the staff about fundraising for Parkinson's WA," Liz said.

"Five dollars was given to me by the coffee barista because someone came up and took my hot chocolate, so she made me another one and gave me the money back for the inconvenience. I said that I'd put it towards my Parkinson's fundraising, and she said that was great!"

Liz said the recent floods had greatly affected small communities and highlighted what a good opportunity the cycle trip had been to support local businesses.

"Now they are all trying to get back on their feet again and look forward to the future to rebuild and flourish," she said.

Being in the great outdoors was a big highlight of the trip which Liz said she was grateful to have had the opportunity and was so fortunate to cycle across this beautiful part of Australia with their friends.

Liz said on their final day of their 16-day trip, they left bright and early catching a beautiful sunrise before taking off. Many of the riders who joined them, lived in various places and it was finally time to say goodbye.

Thanks for sharing your adventure and journey with us Liz! We look forward to celebrating more of your fundraising work next time. Thank you from all of us at Parkinson's WA.

This year has already seen Liz raise an incredible donation total of \$2,187 so far.

You can make a donation directly to Liz through her page on our website: www.parkinsonswa.org.au/my-fundraising/1/elizabeths-year-of-fundraising



Pictured: Elizabeth's cycle club on the ride. (supplied)

Five things you never knew about Parkinson's

Written by Fiona Roscoe, Parkinson's Nurse Specialist

Parkinson's Nurse Specialist (PNS) Fiona Roscoe gives us some interesting insights into lesser-known Parkinson's information.

Movement Disorder or more?

Parkinson's is categorised as a 'Movement Disorder' however it is much more than this! The movement related symptoms include slowness, stiffness and tremors, but did you know the non-motor symptoms such as mood disorders, sleep problems, bladder and bowel complaints and speech and swallowing problems can often be experienced some time before the diagnosis? Treatments are available for both the movement and non-movement related symptoms of the condition.

Who was Parkinson?

Parkinson's was first described in the 1817, by a British physician James Parkinson who detailed his observations of patients and people on the streets of London in his 'Essay on the Shaking Palsy"! 60 years later, Jeane Martin Charcot, a French Neurologist renamed the condition 'Parkinson's Disease.'

Not just a tremor...

Despite the association with shaking, not all people with Parkinson's will experience tremor. In fact, scientific literature reports that perhaps 70% of people will have tremor and 30% will never experience the symptom.

Not just an older person's condition...

While Parkinson's is often thought of as an 'older persons' condition and incidence increased with advancing age, the average age of onset is actually mid-50s to mid-60's. Younger people can also be diagnosed and the term Young Onset Parkinson's is often used to describe onset before the age of 50.

Search for a cure or management?

While there is currently no 'cure' for Parkinson's, the symptoms of the condition are treatable and new therapies are in development. Many people actually feel significantly better after beginning treatment due to this. This is the so called 'Honeymoon Period'. In addition, promising research suggests we may be able to delay the progression through targeted exercise therapy.

Talk to your Parkinson's Nurse Specialist or Medical Specialist for more!

We need Volunteers!

Have you ever felt like you wanted to belong to something bigger than yourself and contribute your spare time to meaningful work? Your Parkinson's WA team need you!

We have openings within the Nedlands-based office that need willing sets of hands. Can you contribute your time to support the Newsletter mailout four of five times a year or general admin tasks?

For our upcoming A Walk in the Park event on 10 September, we are short many volunteers and need more people on the ground to support our wonderful community. If you know of anyone who could help, please reach out to us and help us make this a wonderful day out at Perry Lakes for the whole family!



Please contact the office on **(08) 6457 7373** or email **info@parkinsonswa.org.au** for more information.

Parkinson's WA is looking for input from our community

to create a series of Parkinson's 'hacks' to benefit people in Western Australia living with Parkinson's. A 'hack' is a novel idea which could benefit others by sharing. If you have a 'hack', tip or trick that has helped you manage your Parkinson's, and you would like to share with other people living with Parkinson's, please reach out to us - we would love to hear from you!

You can send us an email at communications@parkinsonswa.org.au

Support for Parkinson's

With a side of drumming

Our Support Group Leader's Workshop gave us a chance to check in with the Leaders, exchange ideas, support one another and make plans for the future.

We heard from our Clinical Nurse Manager, Janet McLeod on new treatment developments for Parkinson's including 'Light Therapy and Focused Ultrasound'. We were delighted to have the talented and passionate



Martin Phillips from Rhythm Fix who ran an exciting drumming workshop that everyone got involved in and found their inner rhythm including our new CEO! This was one of the first opportunities for the Leaders to meet our CEO, Adjunct Professor Yasmin Naglazas and to share their personal experiences with her, signifying the importance of being heard and having a voice that had a place to use it, but more importantly, a platform to be listened to and valued.



Yasmin said it was encouraging to see such a well-facilitated, organised session with appropriate content and some wonderful discussions that will assist us in our longer-range planning.



Kingsley Support Group Leader Bev said it was a very well attended function which she had enjoyed immensely.

"So much was garnered from talking with others and just sounding out and comparing some of the processes we go through for our individual Support Groups," she said.



Parkinson's WA Board President John McDonald stopped by to meet the community, which gave them an opportunity to discuss matters with him personally.

Thank you to everyone who attended, had the courage to share their story and struggles with us and allow us to celebrate them and all their contributions to the Parkinson's community.

Stay connected to our news through our website www.parkinsonswa.org.au/news

Pictured: Support Group Leaders Workshop

Containers for Change



C10329740



Scan the barcode or provide the above scheme ID at your nearest Containers for Change refund point to donate directly to Parkinson's WA.



Thank you for your support to Parkinson's WA!

Donate the cash that's in your containers to Parkinson's WA

We have been inundated with generous support for our community through the Containers for Change program. All donations are listed anonymously so we are not able to reach out to you personally, however, we thank everyone who has supported us through this scheme.

You can help us in this way by cutting out the voucher on the left and taking it directly to your local centre, nominating Parkinson's WA as your preferred organisation. **Learn more at: www.containersforchange.com.au/wa/where-to-return** where you can find your local drop-off point. Thanks for your support!

Parkinson's Support Groups

Have you ever thought about attending one of our support groups? Trish from Kingsley Support Group told us that life changes with Parkinson's, and it helped to talk about it.

"The community support one another. We come together and talk about the condition and how our lives have changed. We understand each other and that makes all the difference," she said.



Join one of the Parkinson's WA Support Groups today!

NORTH and WEST METRO

KINGSLEY
MORLEY
WESTERN SUBURBS

SOUTH and EAST METRO

SOUTH OF THE RIVER
ROCKINGHAM
MANDURAH
MIDLAND
PARKINSON'S CARERS SOUTH

REGIONAL

BUNBURY
BUSSELTON
COLLIE

55 YEARS and UNDER

KINGS PARK



For more information regarding our support groups, call: **(08) 6457 7373**, email: supportgroups@parkinsonswa.org.au or visit www.parkinsonswa.org.au/page/114/support-groups

Pictured: Clinical Nurse Manager Janet McLeod, OAM, speaking at the Support Group Leaders' Workshop
Above: Parkinson's WA community members

Research Update: Patience Pays Off For Parkinson's

Game-changer for Parkinson's diagnosis - Research News

As you are aware, April is Parkinson's Awareness Month because it marks the anniversary of the birth of Dr James Parkinson. It was very timely that April 2023 marked the announcement of the most exciting research-based breakthrough in Parkinson's in decades. Presently, the diagnosis of Parkinson's is based on the clinical picture of the symptoms as seen by the specialist. There are no biological markers which will determine a diagnosis in spite of us knowing about the presence of Lewy Bodies comprised of alpha synuclein in the brain and elsewhere in the body.

The Parkinson's Progressive Markers Initiative (PPMI) is an international research study launched by the MJ Fox Foundation in 2010. The goal was to recruit a large cohort of people with Parkinson's and a large control group (people without Parkinson's) and to study biological markers over a period of time.

Since 2010, several arms to the study have been developed and monitored:

- People newly diagnosed and not on treatment
- People over 60 who are on treatment
- People who are known to have a genetic predisposition to Parkinson's
- People who have not had a diagnosis of Parkinson's but experience a variety of signs which are considered prodromal (including REM sleep disturbances, loss of sense of smell).

The study has collected data on large groups of people which included not only qualitative and observational records, but also focused on biological markers such as blood and spinal fluid.

As a result of this long-term study with a large number of participants, the researchers are now confident enough to announce, "an enormous leap forward in the understanding of Parkinson's".

The Lancet Neurology published the breakthrough and described a test – alpha-synuclein seed amplification assay (SAA) which accurately detected Parkinson's in cerebrospinal fluid (CSF). This was also identified in people with early non-motor symptoms. Sensitivity for the test in people with Parkinson's was 87.7% and specificity for health controls (without Parkinson's) was 96.3%. In the group of people already known to have Parkinson's and lack of a sense of smell, the sensitivity was 98.6%.

The study calls for more research before diagnosis can be based on this marker and also clarifies that the test would need to be performed on blood rather than CSF because collection of CSF is very invasive and carries risks. Nevertheless, the pathological identification of alpha synuclein in early stages of Parkinson's is a game changer for the future!

Reference: www.michaeljfox.org./news/breaking-news-parkinsons-disease-biomarker-found



Picture courtesy of Pixabay



Coping with a new Parkinson's Diagnosis

Parkinson's Nurse Specialist Donna Mallaby

A new Parkinson's diagnosis is a life-changing thing, but it is not life-ending. Find out more about how to manage the news of a new diagnosis from our Parkinson's Nurse Specialist (PNS) Donna Mallaby.

You may not remember much of your appointment after the words, "You have Parkinson's".

You may have just walked out of your doctor's office with a new diagnosis of Parkinson's. Or you may have been diagnosed months ago after noticing your body changing for some time now and you're thinking, "What now?" Those feelings are very common, and you are not alone.

My first thought was, "What the hell happened to me? What am I going to do?" That took time to work through, but I found out that if I could accept what my situation was, and be honest about it, I could move forward. And my happiness grows in direct proportion to my acceptance." — Michael J. Fox, diagnosed in 1991 at age 29

For some, a diagnosis comes as a relief, as you now have a name for how you've been feeling. For others, the unknown can be frightening and challenging with so many unanswered questions.

It is very normal to have a mixture of emotions and feeling of uncertainty such as, "where to from here?"

That is why we are here.

At Parkinson's WA, the team of Parkinson's Nurse Specialists have been supporting people like yourself in the metro, southwest and the regions for over 24 years. We offer education, guidance, support, and nursing assessments in the comfort of your own home.

Here are my top 5 tips for how you can support yourself with a new diagnosis of Parkinson's:

See a Specialist

Seek a referral to a Specialist in Parkinson's. Such as a movement disorder specialist, Neurologist or Geriatrician that specialises in Parkinson's.

They can aid in developing an individualised treatment plan at the commencement of your journey. Depending on your specialist and your individual requirements, you may see your specialist every 6-12 months.



Newly Diagnosed blog continued...

Research and learning

Commence your own learning journey by researching the facts about Parkinson's. Request a visit from your local Parkinson's Nurse Specialist (PNS) so we can discuss and educate you on your symptoms of Parkinson's, as everyone and every journey is different. When completing your own research, make sure to source information from reputable sources such as the Parkinson's WA website, Parkinsons Australia, Parkinson.org and Michealjfox.org.

Build a support system

Isn't it great to know you're not alone in this journey? Building a support group around you can look different for everyone. Some may chat with a partner or family member. Others may attend a local Parkinson's support group or online forum. Your Parkinson's Nurse Specialist (PNS) can also link you in with other allied health professionals such as Physiotherapists, Occupational Therapists, Speech Pathologists and Support Services if you wish. We work in collaboration with your specialists and supporting health professionals to create a professional support system around you.

Exercise

Exercise is your medicine. Daily movement that you enjoy is the key. Whether it is walking, riding a bike or a stationary exercise bike, a gentle gym or yoga class. Regular exercise can assist with your symptom management and aid in reducing stress and anxiety.

Healthy diet

Plan to eat a healthy diet of well-balanced meals of unprocessed whole foods such as fruit and vegetables. Take your Levodopa medication at least 30 minutes before food. Also aiming for 1.5-2 litres of water daily can optimise your medication absorption as well as assist to maintain a healthy bowel.

Most importantly, give yourself time to breathe and process.

Know that acceptance for everyone will be different and not on a perceived timeline. Every day can be different, some days will be amazing, and others will be challenging, but tomorrow always brings a new day.

Everyone's Parkinson's journey is different, but know, we are in this together.

All my best,

Donna.



Caring for you through 25 Years of
Parkinson's Specialist Nursing

1998-2023



We're with you

IN THIS TOGETHER

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