

## InTouch Newsletter

July 2021

### My [Parkinson's] Life

#### Fran Hayes

Fran Hayes was the second of five children and spent her early years in Hoxton Park – then full of market gardens and dairy farms on the outskirts of Sydney.

“My father thought he’d have a go at dairy farming, but this was short-lived as government policy changes made it untenable for us to keep it up,” said Fran. “Dad ended up going back to work in town.

“It was a very free and enjoyable childhood. Then that area was rezoned light industrial, and my grandparents were starting to need care, so we moved to Rockdale.”

Fran attended Catholic girls’ schools at Liverpool, Hurstville, and Ashfield, and was the first in her family to go to university, studying social work at Sydney University.

“It was a very exciting and enjoyable time,” said Fran. “I met my partner of 48 years there. He had a teaching scholarship. I didn’t want to work in a hospital setting when I finished.

“I’d done an arts major in Government and had a real interest in politics. I was interested in community work; organising and advocating for people needing help.”

After graduation Fran worked in a number of community work positions and in 1977 began working as a volunteer for the newly formed Australian Social Welfare Union becoming the New South Wales delegate to the National Award Committee in a matter of weeks.

“I was encouraged and told I could do it,” says Fran. “Women were rare in union leadership positions back then.

“I was soon involved in the campaign to negotiate a national award. This took four formal hearings before going to the High Court in 1983. It was a unanimous decision in our favour and is now in textbooks – a real David and Goliath battle, because at the start we were a bunch of social workers knowing nothing about industrial relations.

“I had become the National Organiser and President and spent three very interesting years with the union. I learned so much. Unfortunately, the costs of fighting each court case led to disputes over how the union was spending its money. I had to get another job before the final victory.”

In 1981 Fran began as the first female training officer at the new Clyde Cameron College, the national training centre of the Trade Union Training Authority (TUTA).

“I loved the College,” said Fran “I met lots of wonderful people and was able to teach to my strengths.”

Fran worked for TUTA till 1988, when she had her daughter. Some of these years with TUTA were spent based in Sydney. Within this period, Fran also worked as an organiser with a public sector union for two years.

After a period of maternity leave, Fran worked in a NSW public sector policy position for three years. She returned to TUTA in 1992 and was there till its abolition by the newly elected Howard government in 1996.

Fran proceeded to establish her own business, Fran Hayes Workplace Solutions, assisting organisations to understand their legal rights and obligations in employment, which she continues to run today.

“In 2011 I realised I had developed a limp in my right leg,” she recalled. “I couldn’t work out what it was. A friend told me that there was something wrong with my right arm, I was holding it strangely.

“I went to a doctor I knew who said it was a side effect of some medication I was on. I wasn’t convinced and over the next couple of years saw a neurologist and had a lot of tests and scans done. I was told they were looking for Parkinson’s but didn’t think I had it.

“In the end it was diagnosed as Parkinson’s in early 2014. I asked what it meant, and he told me it wasn’t fatal, but I had 15 years.”

With no experience of Parkinson’s, Fran began researching the condition and found the counselling service at Parkinson’s NSW.

“I had a phone counselling session with Shushann Movsessian, and she told me she thought I’d like the Ultimo Parkinson’s Support Group,” says Fran. “She said there were a lot of very intelligent professional people there, being close to Sydney University, so I joined.

“I also discovered Dance for Parkinson’s in Alexandria and started going weekly. That also became very important in my life.”

Fran soon made friends in the group and began assisting Chris Davis, the long-standing leader of the group, with aspects of his role. Fran phased into the Group Leader position when Chris was ready to retire from the role in 2019.

“Groups evolve as some people’s condition deteriorates and others pass away, but we still had 25 to 30 people at our meetings before COVID-19,” said Fran.

“Zoom meetings didn’t suit everyone and we lost some active members in the last year. We also had to move meeting locations twice. Now we only have half a dozen at face-face meetings, which makes it hard to get speakers.

“Because my condition has deteriorated, I looked for someone to help out so I could step down. Some others are now willing to help. Parkinson’s NSW is helping us

transition to monthly lunches at a café for social contact. Maybe new members will emerge from that.”

Fran says her partner and her family have been very supportive as her condition has progressed.

“I also have excellent friends, mostly ex-social workers,” she said. “I’m very well provided for. My doctor is currently telling me I should be getting a walker, but I’m sticking to a walking stick for now.

“It is hard to face up to deteriorating abilities – such as finding it difficult to put on my cardigan or find something in my handbag. I still want to wear nice clothes and jewellery and go to activities and be involved with things.

“But I could be a lot worse. I still have lots of things I’m involved in and projects to do.”

## **New round of Club Grants funding opens soon**

Applications for the next round of Club Grants funding open on Monday, 5 July 2021.

To find out more information, or to apply, visit the [Office of Responsible Gambling website](#)

Victor Dominello, the Minister for Digital and Minister for Customer Service, said funding will go towards projects across sport and recreation, arts and culture, disaster readiness and essential community infrastructure.

“This is an opportunity to provide a boost to local economies and grassroots organisations who perform invaluable work for their communities. We are pleased to be able to provide this much-needed support,” Mr Dominello said.

The Club Grants program re-invests profits from registered clubs’ gaming machines into community projects.

If your group could benefit from a grant to pay for your activities or for your room hire, click on the link, and read the information.

Please contact Fiona Jessiman, Fundraising Manager at Parkinson’s NSW on 8051 1900 or [Fiona.jessiman@parkinsonsnsw.org.au](mailto:Fiona.jessiman@parkinsonsnsw.org.au) if you would like to apply for a grant after viewing the information via the link. All Support Groups wanting to apply for a grant must have the hoped-for funds marked against an activity or expenditure in their Annual Plan.

## Put your heart into it!

### *The importance of aerobic (cardiovascular) exercise*

Cardiovascular (cardio) exercise – also known as aerobic exercise – is any activity that makes you puff. It works the heart, lungs, and muscles – all of which help the body to burn calories.

The current exercise recommendations for Australians aged 18 to 64 years are:

- Adults should be active most days, and preferably every day.
- Each week, adults should do either:
  - 2.5 to 5 hours of moderate intensity physical activity – such as a brisk walk, golf, mowing the lawn or swimming, or...
  - 1.25 to 2.5 hours of vigorous intensity physical activity – such as jogging, aerobics, fast cycling, soccer, netball, or an equivalent combination of moderate and vigorous activities.

For people aged 65 years and over:

- A minimum of 30 minutes of moderate intensity physical activity on most, preferably all, days. If 30 minutes is difficult now, start with just 10 minutes once or twice a day. After 2 weeks, increase to 15 minutes twice a day. If you can do more than 30 minutes, the benefits will be greater.
- Try to do a variety of activities and reduce the time you spend sitting down.

Moderate intensity cardiovascular/aerobic fitness activities include:

- Brisk walking
- Swimming
- Golf (no cart)
- Aerobics or water aerobics
- Cycling – indoors or outdoors
- Gardening
- Tennis
- Mopping and vacuuming
- Dancing

You can calculate your heart rate range to determine whether you are working at a moderate to high intensity. However, a simpler method is if you are puffing and able to continue for 30 minutes, that means you are working at a moderate level.

Cardiovascular/aerobic work is important for everybody but it's even more essential for people with Parkinson's.

Click on this link for more information: [For maximum benefit in people living with Parkinson's, research suggests that aerobic activity should be at a moderately-high to high intensity or pace.](#)

## Trial of new compound NLX-112 to ease Dyskinesia

Parkinson's UK and The Michael J. Fox Foundation have partnered with biopharmaceutical company Neurolix to support a clinical trial testing the safety, tolerability, and early efficacy of [NLX-112](#).

This is a new compound being assessed for its ability to ease dyskinesia and the severity of some non-motor symptoms of Parkinson's.

Data from this study may allow Neurolix to rapidly move NLX-112 into a larger Phase 3 trial, aiming to generate sufficient positive results to support the therapy's approval.

A two-year study will involve the experimental therapy for [levodopa-induced dyskinesia](#) (LID) being given to Parkinson's patients for a first time.

LID is a condition in which patients start having involuntary muscle movements – such as jerking or twitching – that affect their ability to perform even simple tasks. It is a common side effect of levodopa-based therapies – the main forms of treatment for Parkinson's – among those who have been taking these medications for years.

LID is also thought to be associated with a dysregulation of serotonin-producing neurons. Recent studies have shown these neurons can take up levodopa and convert it into dopamine in an uncontrolled manner, contributing to the onset of the unintended movements that characterise dyskinesia.

Serotonin and dopamine are two types of brain chemicals (neurotransmitters) that neurons use to communicate with each other.

NLX-112 is a new compound that is able to selectively activate a sub-type of serotonin receptor called the [5-HT<sub>1A</sub> receptor](#), which is usually found in serotonin-producing neurons.

Once active, this receptor interferes with serotonin signalling in these nerve cells, lowering their activity. By reducing the activity of serotonin-producing neurons, NLX-112 is expected to alleviate symptoms of dyskinesia in people with Parkinson's.

Preclinical studies have shown that NLX-112 was effective at easing dyskinesia in animal models of Parkinson's. These findings provided the foundation for the launch of clinical trials testing NLX-112 in patients.

The clinical trials will also assess whether NLX-112 can ease some of the typical non-motor symptoms of Parkinson's – including mood and sleep issues.

Study findings may enable NLX-112 to move into Phase 3 clinical testing, and potentially a request for its approval as a new disease treatment.

**Source:** [Parkinson's News Today](#)

## Support for Parkinson's community in State Budget

On 22 June it was announced that the NSW State Budget includes an \$8.6 million package to support people living with movement disorders – including Parkinson's.

The funding will start with \$1.8 million in 2021-22 with the full amount being spent over four years.

The package will fund 15 specialist nurses and Allied Health staff across NSW to improve access to treatments and quality of life for people with movement disorders – particularly in regional and rural areas.

It also includes \$650,000 in funding for Parkinson's NSW for information, education, and service delivery.

We will use this funding for:

- Increased services delivered via the Parkinson's NSW InfoLine
- Education seminars and online learning for consumers, GPs, Allied Health professionals and Aged Care nurses and support workers
- Capacity-building support for Parkinson's NSW Support Groups across the state
- Research and evaluation of service delivery

Parkinson's NSW will negotiate with the Treasurer and the Minister for Health on the specific model to be used and priority of placement of the specialist nurses and Allied Health staff.

This exciting outcome is the result of four years of advocacy and profile raising around the work of Parkinson's NSW.

In particular, Board President Margaret Scott acknowledged that the foundations of this success were laid by Vice President David Veness who has campaigned tirelessly for the placement of more Parkinson's Specialist Nurses.

She also thanked CEO Jo-Anne Reeves who spearheads the organisation's ongoing advocacy initiatives – including the May Parliamentary reception where she very effectively raised the profile of Parkinson's NSW at a critical point in the State Budget planning cycle.

John Watkins, former Deputy Premier of NSW, who is living with Parkinson's, also spoke eloquently at the reception about the many challenges of this disease. His passionate speech had a decisive impact on the audience of Ministers, MPs, and their staff members.

If you have any questions about this announcement, please call Mirelle Brockett on 8051 1900 or email [supportgroups@parkinsonsnsw.org.au](mailto:supportgroups@parkinsonsnsw.org.au)

## Support Group News Roundup

### ***Chinatown Bilingual Support Group***

In March 2021, the Chinatown Bilingual Parkinson's Support Group met face-to-face for the first time since COVID began for a lunch at a popular restaurant in Chinatown.

Parkinson's NSW Support Group Coordinator Felicity Jones was an invited guest. The group joined in for a tai-chi session and music therapy before having a delicious Yum Cha luncheon.

The group also had their annual outing to Tanglin Lodge Alpaca Farm, followed by the Fire Museum at Penrith, in early May. There were 35 people on the trip, and they enjoyed the opportunity to get together.

While they were on their outing the group leader Rosanna Ng presented their Parkinson's Community Hero Award to ex Support Group Leader and Group founder Julia Fry.

### ***Illawarra North Support Group***

Ten participants from the Illawarra North Parkinson's Support Group joined a bus outing in April. They stopped for a delicious lunch and browsed amongst antiques, and nik naks at Greendales Cafe/Restaurant and Jindyandy Handcrafts on Greenwell Point Road, Pyree.

### ***Northern Rivers Ballina Support Group***

Early in May, the Northern Rivers Ballina Parkinson's Support Group joined in a demonstration of the seated form of Dance for Parkinson's at Summerland Farm in Alstonville.

A local Dance for Parkinson's teacher is starting up classes for people living with Parkinson's and their carers in the area. Everyone at the Support Group meeting joined in the activity which brought them great joy. It was also a terrific way to stay warm on a chilly morning.

### ***Port Macquarie Support Group***

Port Macquarie boxing coach Dean Groth was awarded the Parkinson's Community Hero award by the Port Macquarie Parkinson's Support Group. Dean regularly hosts Boxing for Parkinson's classes for the group participants to attend.

## Steve Schiemer raises more than \$1,000 for Parkinson's NSW in the boxing ring

Parkinson's NSW Board Member and professional personal trainer Steve Schiemer – who is living with Parkinson's – climbed into the ring for the Sydney Contender Boxing Match on 29 May.

Steve not only won his match, but he also raised more than \$1,000 for Parkinson's NSW via his GoFundMe page in the process.

"Boxing has been one of the greatest tools to help my fight against Parkinson's," said Steve. So I used this amateur boxing opportunity to raise awareness about Parkinson's and the importance of exercise in managing the condition.

"I also wanted to raise funds to support others living with Parkinson's," he said.

Steve trained intensively for three months to prepare for the match. His training regime included HIIT (High Intensity Interval Training) sessions on the stationary bike.

This involves pedalling as fast as possible for 30 seconds, followed by a 30 second rest. Plenty of sparring was also used to help get him fighting fit.

## Are you watching our Wellness Wednesday's videos?

*Wellness Wednesday's* videos are hosted by Parkinson's NSW Exercise Physiologist Alyson Blanks.

Topics include short and easy exercises you can do anywhere, nutritional advice, tips on mindfulness and other health matters.

You can join in on Facebook every Wednesday at 1pm by clicking this link:

<https://www.facebook.com/parkinsonsnsw>

Or you can view the growing collection of short videos at your leisure on YouTube here:

[https://youtube.com/playlist?list=PLNNFUfiPBotL3pJw0XD3zgLEtkc\\_juZIG](https://youtube.com/playlist?list=PLNNFUfiPBotL3pJw0XD3zgLEtkc_juZIG)

Topics covered so far include:

- Balance exercises
- Daily stretching exercises
- Neuroplasticity
- Getting started and maintaining an exercise routine
- Movement for Motor Symptoms and posture checking
- Stretches to target stiffness
- The importance of Speech Therapy



Go to the Parkinson's NSW YouTube Channel to view all of our zoom meeting recordings on the Living Well Playlist at:

<https://www.youtube.com/user/ParkinsonsNSW>

For the upcoming Zoom meetings, see the schedule on the Parkinson's NSW website at:

<https://www.parkinsonsnsw.org.au/online-meetings-for-support-groups>