

# Cork Parkinson's Association Activities and achievements

# What have we been up to?

# Cork Parkinson's Association Activities and achievements

October 20<sup>th</sup> 2021 - CPA AGM to elect / confirm committee members.

We bid farewell to committee members who stood down having done amazing work over the past number of years: Mary O'Sullivan, Mags Garvey, Mary Beecher, Margaret Curtin. Ted Horgan stood down as Chairperson but is remaining on the committee. We are extremely grateful to have his knowledge and experience to draw on and that of the former committee members.

The new committee is as follows:

## Committee members

- **Chairperson:** Tony Wilkinson
- **Vice Chair:** Virginia Conrick
- **Secretary:** Kate Wilkinson
- **Treasurer:** Mick Burke

## Other Committee Members

- Jerome Maume – **Young Onset** Advisor
- Ted Horgan – Advisor
- Mary O'Callaghan
- Kevin O'Donovan
- Dr Suzanne Timmons – Health Advisor
- Rita Kearney – Grant Applications
- Monica Navarro Hickey – Mental Health Advisor

# Cork Parkinson's Association Activities and achievements

Achievements: embracing technology to keep in touch

- ❑ Cork Connect Zoom calls - April 2020
- ❑ First group to hold weekly support calls for members during lockdown
- ❑ First to run online classes: Rebel Warriors, Wide Awake Club, Chair exercises, Physio exercises
- ❑ Some of the speakers on Cork Connect: Dr Sean O'Sullivan, Prof. Suzanne Timmons, Dr Emma O'Shea, Pat Harkin (HSE psychotherapist), Michael Healy (HSE Living Well), Prof Luke O'Neill (TCD), John Lonigan (living in a pandemic) .....

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Achievements: Launch of CPA website

## Why?

- ❑ Raise awareness and promote Cork Parkinson's Association
- ❑ Members wanted up to date, local information relevant to their needs
- ❑ Needed something designed specifically for people with Parkinson's
- ❑ Healthcare professionals can direct PWP to local support
- ❑ PWP/family/friends know what is available in Cork and who to talk to
- ❑ Latest research news and activities
- ❑ Communication
- ❑ Respond to queries in a timely and knowledgeable way
- ❑ Advocate and promote focus on Parkinson's
- ❑ Library of podcasts and recordings

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## Achievements: Conferences

- ❑ Spring Conference - 11 April 2021 - actual Parkinson's Awareness week
- ❑ Four Keynote speakers
  - ❑ Dr Sean O'Sullivan: Update in medication and device assisted therapies in Parkinson's
  - ❑ Dr Ruth McCullagh: The crucial importance of physiotherapy and exercise
  - ❑ Dr Emma O'Shea: The amazing findings in the first ever national survey of Parkinson's disease in Ireland
  - ❑ Dr Suzanne Timmons: Sleep issues and the effect on cognition and memory
- ❑ 135 attendees
- ❑ Hugely successful 'Question Time' in the evening

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## Achievements: Research

- ❑ Cork Parkinson's Association raises €50k for research!
- ❑ Mapping Parkinson's Disease Needs and Services in Ireland (MapPD)
  - ❑ Initiated and seed funded by CPA
  - ❑ First fully recognised mapping of all PD services and needs in Ireland
- ❑ Wireless monitoring in Parkinson's
  - ❑ Seed funded by CPA and pick up by SENDOC, Norwegian Government and Tyndall Institute Cork and UCC
- ❑ Parkinson's sleep well campaign to encourage a better night's sleep
- ❑ PD Active - Dr Trish O'Sullivan
  - ❑ New chair exercises specifically designed for PWP

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## Achievements: Advocacy and promotion

- ❑ Two qualified European Patient Forum (EPF) advocates (Stella McVeigh, Tony Wilkinson)
- ❑ Ted Horgan - CPA Chairperson talks about living with Parkinson's
- ❑ Southern Star and The Corkman promote CPA
- ❑ Engagement with local TDs to drive better care for PWP
- ❑ Speaking on local radio promoting CPA - C103 and 96FM

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## Achievements: Fundraising

- ❑ €8,000 donation from DD Williamson
  - ❑ To mark the retirement of John Curtin
  - ❑ Specifically for CPA approved projects
- ❑ Arlene Williams Fund-raising in Malaysia for Bandon
  - ❑ Specifically for CPA approved projects - purchase of laptops for members
- ❑ Ciara Cummins and daughter complete mini marathon for CPA
- ❑ Mary Ita O'Connor and friends - complete mini marathon for CPA
- ❑ Kevin and Mary complete the GAA pitch Challenge
- ❑ ... and many more ...



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## Achievements:

Planning workshop October 9th 2021 committee met and planned activities for the next few years - near term and long term projects such as;

- ❑ Outreach to Care homes (near-term focus)
- ❑ Local groups; management and development (near-term focus)
- ❑ Member Events/Recruitment/Membership (near-term focus)
- ❑ Therapies / Consultant appointments (near-term focus)
  - ❑ Speech Language and Occupational Therapy
- ❑ Research (near-term focus)
- ❑ Parkinson's Nurse (ANP) (near-term focus)
- ❑ Radio Advert (near-term focus)
  - ❑ Raise awareness and profile of Parkinson's
  - ❑ Engage with GPs
  - ❑ Training evenings for medical professionals
  - ❑ Parkinson's awareness week - April 2022
- ❖ Section 39 funding (local Cork/Kerry HSE) (long-term focus)
- ❖ Respite Care (long-term focus)
- ❖ Fundraising (long-term focus)
- ❖ Repurpose our Bus (long-term focus)
- ❖ Perpetual Motion Choir go to World Parkinson's Event: Barcelona 2023 (long-term focus)

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## Achievements: Headspace

Our psychotherapist Monica Navarro-Hickey joins the Cork Connect call every 2<sup>nd</sup> Monday of the month to talk about Mental Health issues and living well with Parkinson's.

- ❑ Looking after yourself in Lockdown
- ❑ Cocooning - how to stay safe
- ❑ Being diagnosed with Parkinson's
- ❑ Living with Parkinson's part 1
- ❑ Living with Parkinson's part 2
- ❑ What has happened to you?
- ❑ Sharing your life living with Parkinson's
- ❑ Intimacy with Parkinson's
- ❑ Loneliness
- ❑ Taking Control
- ❑ Choosing your path

# Cork Parkinson's Association Activities and achievements

Q: How many people does CPA employ?

A: 0

This amazing work is all done by volunteers whose sole purpose is to represent our members and support their wellbeing.

# Cork Parkinson's Association Activities and achievements

Always driving forward



# Cork Parkinson's Association Activities and achievements

Do we deliver?