

## DUBLIN BRANCH AGM

2pm Saturday 20th February 2021

Online Via Zoom Meeting ID: 874 8005 2761

Passcode: 722537

We look forward to a big online attendance for this important meeting in our annual calendar.

The AGM will be followed by a brief introduction to Siel Blue and a demonstration of exercises

**NEXT WEBINAR: Neurologist Prof David Bradley  
Speaking about Parkinson's Medication**

2pm Saturday 30th January

Zoom Details: Meeting ID: 870 2367 2036

Passcode: 335540

If you have questions about your medication email in advance to: [dublinchairperson@parkinsons.ie](mailto:dublinchairperson@parkinsons.ie)

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## MEMBERSHIP RENEWAL REMINDER

A reminder to all members that the annual membership fee of €25 was due on 1st January.

Thank you very much to those who have already renewed. To those of you who have not would it be possible to pay by the end of February please? It's important to renew every January to maintain your position on our database and continue to receive correspondence from us. If you would like to pay directly into our bank account please do. *Renewal form with bank details enclosed* This is a preferable way of paying but it is most important that you put your name as a reference otherwise we have no idea who sent the payment. Please do not put 'Membership' as a reference.

I'm urging all who have not yet renewed to do so as soon as they can.

Thank you and best wishes,

Sinéad O'Kane, Membership Secretary

## SIEL BLEU CLASSES

Siel Bleu classes are continuing via Zoom every Thursday morning at 11am.

Everyone is welcome. Why not give it a try? If you're interested, contact Richelle Flanagan 087 779 0760 or email: [richelleyopd@gmail.com](mailto:richelleyopd@gmail.com).

Your email will then be sent to Siel Bleu who will contact you with a link to click to join the Zoom class.

*Note: you should download Zoom onto your phone/PC or tablet.*

## TWO NEW COMMITTEE MEMBERS

We'd like to welcome two people who have volunteered to join the committee: **Kieran Connolly**, from Carpenterstown is a project manager and programmer with an experience in banking.

**Gillian Connolly** has a Business Degree and an MA in Event Management. She is currently completing a certification in Digital Marketing.

Kieran and Gillian will be formally proposed at the AGM. If anyone else would like to put their name forward for the committee please contact: [dublinchairperson@parkinsons.ie](mailto:dublinchairperson@parkinsons.ie)

## NUTRITION SURVEY RESULTS

Thanks to all of you who responded to Dietician Richelle Flanagan's survey about nutrition which we enclosed in the Winter Newsletter.

81 people responded and, shockingly, **nearly eight out of ten said their neurologist had never asked them about their diet**. Nearly nine out of ten said their GP had never asked them about diet either.

The survey also showed:

- More than eight out of ten have never been **referred to a dietician** since their diagnosis. Only one in ten asked to be referred to a dietician. Of the 19 who have seen a dietician, more than two thirds were happy with the advice they received.
- With regard to **weight**, only four in ten have been weighed by their GP or neurologist. Given that more than 60% of respondents have lost weight unintentionally since their diagnosis, this would appear to be a significant gap in care.
- Between thirty and forty per cent of people have **difficulties** with either **holding utensils or cutting/preparing food**. Almost one in four experience problems with choking or coughing when swallowing food. These are issues that can lead to weight loss and the risk of aspiration pneumonia.
- Almost half of respondents were not taking a **Vitamin D supplement** which is concerning given Vitamin D is very important for people with PD, in particular those over 70 and isolating.
- With regard to **bowel problems**, the most common problems were constipation, wind and/or incomplete bowel movements. Constipation was by far the most common problem, cited by six in ten people. As constipation can cause symptoms to worsen due to poor diet and poor medication absorption, it is an issue that should be addressed.

*Note: 8 out of 10 respondents were over 64 years of age and most have had Parkinson's for less than 15 years.*

## ISOLATION SURVEY RESULTS

Eighty five members responded to our survey about your experiences since the Covid-19 pandemic began in March of last year. (Not everyone answered all the questions.)

The results showed that, of those who responded:

- Almost half have found it difficult living with Parkinson's
- About the same number feel their symptoms have worsened during this period.
- More than half feel their mood has declined
- Almost half have been able to speak to their neurologist/nurse/GP about this
- The vast majority, nearly nine out of ten, are living with at least one other person
- 30% of respondents said they would like to get a phone call from a member of the branch committee. As a result, we have been contacting these members during January.

## Welcome To Dyskinesia Land

By Oliver Nolan

*(Dyskinesia is the medical term used to describe the tics, and other involuntary movements associated with the Parkinson's condition.)*

9:00 am Almost comatose  
With rigid leaden limb,  
I struggle to place a tablet in my mouth.

Then a drink;  
Mustn't spill the water.

10:15 am The tablet works,  
Dyskinesia kicks in  
And lo I'm in Rugby Winger mode!

Movement, Action  
now take over.

I duck and weave,  
I twist and turn;

Now throw passes,  
Then throw shapes;

Jump and shimmy,  
Glide and swivel;

I take some hits,  
Dodge the hard ones,

But - uh oh - the meds are  
running low

*From the Anthology 'Hold open the Door',  
courtesy UCD Press*

## The World Parkinson's Virtual Congress

This is a mini version of the wonderful World Parkinson Congress, which happens every three years and provides an international forum for basic scientists, clinical researchers, health care professionals, people with Parkinson's and others to come together under one roof to discuss, learn, and engage in debate around the latest scientific discoveries, medical and comprehensive care practices related to Parkinson's disease.

**Program dates: Monday - Friday, May 17 - 21, 2021**

**Topics presented during this five-day virtual program will include updates on:**

Basic Science, Clinical Science, Treatment Options, Comprehensive Care, and Living with Parkinson's. The programme will also include **two 4-part wellness series** as part of the week, looking at diet, exercise, speech, mental health and much more.

You can find the programme at <https://www.worldpdcoalition.org/page/WPCVirtual>

**Registration will open on April 1, 2021.** Registration to attend the WPC Virtual congress will be US \$25. This will include access to all 20 pre-taped sessions, with three talks in each session, as well as all 20 live Q&A panels and both Wellness talk series on fitness and voice.

## DUBLIN NEUROLOGISTS AND PD NURSE SPECIALISTS

*Remember, if going privately, to check your health insurance cover*

### BEACON and BLACKROCK CLINIC

Neurologist: Dr Peter Widdess-Walsh: 01 2064632

### BEAUMONT HOSPITAL, Neurosciences Dept: 809 2179

Neurologist: Dr. Daniel Healy, with specialty in Movement Disorders

Dr. Lisa Costelloe, with specialty in MS **Phone:** 8092258

**Email:** [neurologyadmin@beaumont.ie](mailto:neurologyadmin@beaumont.ie)

Dr Norman Delanty, with specialty in Neurophysiology

Dr Ronan Kilbride, with specialty in Neurophysiology

Professor Orla Hardiman National Neuroscience Centre of Ireland

**HERMITAGE:** Neurologist: Dr. Mark Edwards Suite 15: 01 6459580

**Email:** [neurologysuite@hermitageclinic.ie](mailto:neurologysuite@hermitageclinic.ie)

Neurologist: Dr. Brian Murray, Suite 3: 01 6459520

### JAMES CONNOLLY

Neurologist: Dr. Martin Ruteledge 6465000

### MMUH, Mater Misericordiae University Hospital

<https://www.mater.ie/services/neurology/>

Neurologist: Professor Tim Lynch, with specialty in Movement

Disorders. **Phone (8am-4pm):** 803 4544 or 803 4522 or 803 4686

**Email:** [neurology@mater.ie](mailto:neurology@mater.ie)

Mags Richardson, Parkinson's Disease Nurse Specialist

### ST. JAMES'S HOSPITAL, Parkinson's Disease Service Team:

Anna Mullen - PD Parkinson's Disease Nurse Specialist

**Phone (Monday and Wednesdays 9am-1pm):** 428 4091

Geriatrician: Prof Conal Cunningham

Neurologist: Professor David Bradley **Email:** [bradleysec@stjames.ie](mailto:bradleysec@stjames.ie)

(public) or [dbradley@stjames.ie](mailto:dbradley@stjames.ie) (private)

Geriatrician: Dr. Róisín Purcell

Psychiatrist: Professor Iracema Leroi.

### SVUH, ST VINCENT'S UNIVERSITY HOSPITAL

Neurologist: Dr. Seán O'Riordan, with specialty in Parkinson's and

Movement Disorders (MD): **Phone:** 221 3830 or 221 4189 or 221 4209

Siobhán Ryan, Parkinson's Disease Nurse Service, **Phone:** 221 4030

**email:** [parkinsonsnurse@svuh.ie](mailto:parkinsonsnurse@svuh.ie)

### TALLAGHT UNIVERSITY HOSPITAL, Simms Building

Neurologist: Dr. Sean O'Dowd

**Phone:** 414 2443 or 414 2090 for public appointments

**Phone:** 087 160 5298 for private appointments

**Email:** [Mary.Darragh2@tuh.ie](mailto:Mary.Darragh2@tuh.ie) for private appointments

Neurologist: Professor Richard Walsh, with specialty in movement

disorders **Phone:** 414 4061 for public appointments

**email:** [Claire.Oreilly@tuh.ie](mailto:Claire.Oreilly@tuh.ie) Public Secretary

or **Phone:** 087 982 8388 Private Secretary

Nicola Kavanagh, Parkinson's Disease Nurse Specialist

### RIP

We were very sorry to hear of the death of Vincent Roche who was active in the Dublin Branch. Our sincere sympathy to his wife, Terry, and extended family.

### Dublin Newsletter

If you would prefer to receive this newsletter by post please ring Mary on 087 2434990

### 2021 Insight into Parkinson's Online International Conference

(promoted by PD Warrior) takes place 11<sup>th</sup>-13<sup>th</sup> April  
Registration is open  
[www.insightintopd.com](http://www.insightintopd.com)

Speakers include clinicians, academics and people living with PD. The event is FREE to attend for the first three days

### PARKINSON'S HELPLINE

Freephone 1800 359 359 Monday to Friday.  
Nurse callback service also available through this line.