# EDINBURGH BRANCH PARKINSON'S UK FEBRUARY 2021

PARKINSON'S<sup>UK</sup>
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

### **Upcoming Branch Blethers**

We have some planned Branch Blethers, though we are constantly working to try to get more events lined up, covering a range of topics and interests. Please support us, by coming along. The aim is to last for one hour, to avoid Zoom fatigue.



The confirmed line up so far is:

25th February at 11am: Jean Itier (who runs our Adaptive Yoga class\*\*)

17 March at 2pm: AGM

1 April (time to be agreed) Parkinson's Nurses

(The Zoom link for all these meetings is: https://zoom.us/j/8757219637)

(\*\* Please note Adaptive Yoga day/time is changing. From 25th February they run Thurs from 10-11am).

We hope to have on either 3<sup>rd</sup> or 4<sup>th</sup> March, Claire Wallace (a CPN employed by NHS Lothian)

The Edinburgh Young Parkinson's Support Group (<u>EYPSG</u>) have monthly meetings, the first Thursday of each month. The time is at 6.30pm (they are working age, so evenings are better). For their April meeting, they are having Fran Anderson, a retired Herbalist, who is giving a talk. It is called The Tea of Happiness': Natural Medicine for Health.

## Lockdown Cookbooks: Available Electronically

Our fundraiser Lou Ogilvy is making the Edinburgh Parkinson's Branch Lockdown Cookbook available as a .pdf file, at the fantastic price of £5.

This type of file format is ideal as it allows you to access on computers, but also tablets and smartphones. So you can plan what you fancy making, as you are on the move. Literally you can be in the supermarket checking the ingredients you need, right from the file on your phone!

To get a copy, we ask you to make a donation via our <u>Just Giving Page</u>, ensuring you put in the notes that it's for the Cookbook. Then email Lou at: lou@edinburghparkinsons.org, and she will then send you a copy by return e-mail

#### **Book Blether**

The inaugural book blether went very well, many thanks to Olivia for organising. We had a varied range of books that we discussed. The suggested book list is on the website.

#### **Burns Supper**



The Burns Supper was a great success and Lindsay McDermid had an amazing line up to entertain us. While all were really good, a few stood out. Helen Harris recited Tam O'Shanter, the complete rendition, from memory, with no prompt. No mean feat! We had an incredible talk by Sir Geoff Palmer, who Lindsay had organised to address the Branch. We also saw a Burns inspired piece of animation, done by a relative of Lindsay's. We hope to perhaps get a link to be able to share with you, it really was remarkable, especially for someone so young.

# February 3<sup>rd</sup> Branch Blether

We has a great turnout for our first blether of the month. Genevieve Geffriaud who has Parkinson's talked us through 5 key points. Circadian Rhythms was one, perhaps you are familiar with them? We have a summary of the five areas on the website. We have also added a link to a video about Genevieve. It is in French but has subtitles and is really very interesting.

(There is a website section for Branch Get-Togethers/Blethers where we summarise some Blethers).

### **Edinburgh Community Foods**

At the Young Parkinson's Group meeting on 4th February, Louise Cairns from Edinburgh Community Foods gave a really interesting talk about nutrition. She outlined the Eatwell Guide which is very informative, and seems like something that should be relatively easily to implement.

Edinburgh Community Food is a social enterprise and a charity. Their social enterprise work is all about sourcing and selling the best quality fruit and vegetables. They run stalls in Edinburgh's hospitals selling produce to staff, patients and visitors. They also deliver fresh fruit and vegetables to homes and businesses across the city and have a selection of fruit and veg boxes ready for FREE home delivery 4 days a week. All their profits go back into their charitable work.



### PD Avengers

There has been guite a lot of talk recently, about PD Avengers. They confirm "this is a global alliance of people with Parkinson's, our partners and friends, standing together to demand change in how the disease is seen and treated".

The Oxford Branch of Parkinson's UK held a meeting earlier this month, with the authors of the book Ending Parkinson's Disease (Professors Bas Bloem and Ray Dorsey). It was a very interesting talk. The Oxford Branch have allowed people to watch highlights of the talk.

It appears that based on this book, PD Avengers were formed. They want to unite people to stand together on behalf of the Parkinson's community. Friend of Edinburgh Branch, Paul Mayhew-Archer is a founding member. Details are perhaps lacking specifics – though we did want to let you know that there is also a Scottish branch of PD Avengers. The website is still under construction. We only provide information at this stage, we are not endorsing. You are welcome to undertake more research. Over time, if there is more clarity we will consider a more in-depth coverage, and will provide any details passed onto the Branch.

### Parkinson's and Technology Events

Dundee Research Interest Group (DRIG) and Special Interest Group for Parkinson's and Technology (SIGP@T) are organising 'Parkinson's and Technology' events. The first was in January. If you missed it, a recording of this event is available on <a href="YouTube">YouTube</a>

The next event of the series is on Saturday 27 February at 2pm. The theme of this event is: Managing the Daily Life. The focus lies on tools to manage everyday tasks that can become challenging due to the symptoms of the condition.

Three presentations will address this topic:

- o Dr Katherine Fletcher, Parkinson's UK's Research Communications Manager, talks about non-drug therapies and devices.
- Professor Wan-Fai Ng, University of Newcastle, shows ways to measure and manage fatigue.
- Julie Dodd, Parkinson's UK's Director of Transformation, describes the potential of Apps for people with Parkinson's (PwP) and their limitations.

The organisers want to draw on the wealth of experience of PwP and their carers, to discuss these experiences of using devices and apps to support daily life in smaller breakout sessions.

For participants who want to familiarise themselves with the techniques, a separate technology breakout session is planned.

Attendance at this event is free of charge, but reservations are required. Book Here

#### **New Vice-Chairman Role**

As we have confirmed before, our Chairman intends to step down in 2022. As part of the succession, currently a 'job description' for a Vice Chair is being prepared. If you, or someone you know might want to consider applying for the role, do please let us know.

The plan is to advertise the role, but we will be happy to give advance information to people with a genuine interest in the role. It would entail being Vice-Chair, until David Adams steps down, and then taking over as Chair at some point in 2022.

Whoever takes on the role will join a dedicated group of volunteers, and will find plenty of support and enthusiasm.

We have been lucky to welcome three or four new volunteers recently, but more are welcome. If you can offer your time, expertise or skills, do let us know. Please email Olivia at: <a href="mailto:secretary@edinburghparkinsons.org">secretary@edinburghparkinsons.org</a>

#### **Branch AGM**

As mentioned at the start of the Newsletter in the Branch Blethers section, the AGM is scheduled for 17 March at 2pm. Please do make every effort to attend the Zoom meeting (joining details are on Page 1, but will also be emailed early in March).

#### **ERIG**

If you are interested in research and are not already a member of Edinburgh Research Interest Group, contact <a href="mailto:ERIG">ERIG</a> Chair David Melton (<a href="mailto:davidm@edinburghparkinsons.org">davidm@edinburghparkinsons.org</a>) for information.