

OUR NEWS

Huntingdonshire Branch

April 2021

www.huntspds.org.uk



Thoughts of Chairman Malcolm

I write this on the day following the welcoming of British Summer Time, by putting our clocks forward an hour. It's slightly strange for a while when the body clock adjusts to the change and the seasonal rebirth of everything starts, the trees sprout new greener leaves, plants flower, and animals such as chicks and lambs are born. This year, there is even greater significance to the ritual, as we have the introduction of vaccines which will rid us

of the cursed Covid virus which has brought untold unhappiness and suffering throughout the world. I wonder, is it just coincidental that it coincides with Easter?

By now, I hope you have all had at least your first jab and will be able to feel confident enough to engage in the "freedoms" it brings to society. Or should I say, participate as far as possible in what we used to regard as a normal existence, able to move around the country and visit friends and family.

Thanks to Zoom and other such electronic wizardry most of you have been able to participate in facial contact and discussion with others, but there are some who have been trapped indoors, possibly frightened and very lonely, if you think there is anyone in that position near you, please reach to try to help them.

I am with Boris on one thing, I can't wait to go out for a pint in a pub and stop looking like the wild man from Borneo, by having my hair pruned and I use that word intentionally.

Malcolm

Not Everybody Zooms!

In this post Covid world, it seems that keeping in contact with each other has focussed on technology. But not everyone is comfortable with this, and meeting face to face is currently difficult. For those who find it easier talking on the phone, please remember we have a Branch mobile. Due to data protection rules we cannot call you direct without your permission, but if you have any queries about the Branch, or would like a catch-up chat, please call the branch mobile on **07724 400527**. If busy, please leave your contact number and we will call you back.

This Month and Next

Dates for your Diary...

At present we are still not having face to face group meetings, but you can join us virtually with an online meeting via Zoom the 3rd Monday of each month. Members from all our groups are welcome! Our next meetings are -

19th April, 2021

10th May, 2021

Now that your Committee have arranged an upgrade to Zoom Pro, we can now have longer meetings and invite speakers.

Please contact David Rudd to receive an invite and passcode to the meetings.

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Please see our Activity Dates on Page 2 for other Online Opportunities.



## Activity Dates

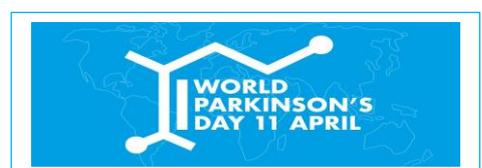
(Please check before joining with the organiser that they are going ahead, due to current circumstances)

| Dates                                                                                                                                                                                                           | Activity                                                                                                                                                                                  | Contact                                                                                                                                              |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>April 19<sup>th</sup></b><br>Guest Mayor of St Neots<br><b>May 10<sup>th</sup></b><br><br>Third Monday of the month                                                                                          | <b>Branch Zoom</b> all group Meeting                                                                                                                                                      | David Rudd 01480 474795<br>Email <a href="mailto:dirudd@talktalk.net">dirudd@talktalk.net</a>                                                        |
| <b>April 6<sup>th</sup>, 13<sup>th</sup>, 20<sup>th</sup>, 27<sup>th</sup></b><br><b>May 4<sup>th</sup>, 11<sup>th</sup>, 18<sup>th</sup>, 25<sup>th</sup> at 11am</b><br>Every Tuesday                         | <b>Online Zoom Exercise Group</b> with Sarah-Jane                                                                                                                                         | Email Sarah-Jane at <a href="mailto:Sj-performing-arts@hotmail.co.uk">Sj-performing-arts@hotmail.co.uk</a>                                           |
| <b>April and May Monday, Tuesday, Wednesday and Friday at 11am</b><br><b>Thursday 2.30pm</b><br>Monday to Friday                                                                                                | Kim Hall's <b>Love to Move Online Exercise Groups</b>                                                                                                                                     | Telephone 07715081402 (Mon-Thurs) or email<br><a href="mailto:Kim.hall@britishgymnasticsfoundation.org">Kim.hall@britishgymnasticsfoundation.org</a> |
| <b>April 2<sup>nd</sup>, 9<sup>th</sup>, 16<sup>th</sup>, 23<sup>rd</sup>, 30<sup>th</sup></b><br><b>May 7<sup>th</sup>, 14<sup>th</sup>, 21<sup>st</sup>, 28<sup>th</sup> at 7.30 pm</b><br>Every Friday Night | Invite to <b>Dave's Friday Night Quiz</b> – invitation from Peterborough Branch                                                                                                           | Email Ruth Brinkler-Long at <a href="mailto:ruthbrinkler@hotmail.com">ruthbrinkler@hotmail.com</a>                                                   |
| <b>April and May Monday and Thursday</b>                                                                                                                                                                        | <b>Hannah at Home Exercise Groups</b> – Peterborough Branch Invite                                                                                                                        | Email Ruth Brinkler-Long details as above                                                                                                            |
| <b>April 9<sup>th</sup> and 23<sup>rd</sup></b><br><b>May 14<sup>th</sup> and 28<sup>th</sup> 10.30 – 11.30 am</b><br>2 <sup>nd</sup> and 4 <sup>th</sup> Friday of each month                                  | <b>Cuppa and Cake Zoom Meeting</b> – Cambridge Branch Invite<br>9 <sup>th</sup> April Classical Guitarist Tom Bryans<br>23 <sup>rd</sup> April Professor Roger Barker Brain Repair Centre | Email Keith Howlett<br><a href="mailto:keithparkinsonscambridge@gmail.com">keithparkinsonscambridge@gmail.com</a>                                    |
| <b>Monthly Meeting</b>                                                                                                                                                                                          | <b>Carers Zoom</b> via Caring Together Carers Support                                                                                                                                     | Please contact Arda at <a href="mailto:Hello@caringtogether.org">Hello@caringtogether.org</a>                                                        |

For full information on how to join Zoom Meetings, please see our December/January Newsletter article. As not everyone can or wishes to Zoom, we hope to list face to face activities as soon as it is safe to run them. Not Zoomed before or want more information? The charity has guidance on how to Zoom [here](#).

### World Parkinson's Day

This year the theme is **Together Apart**. To celebrate, communities across the world are gathering virtually together, to put on events throughout the day. You can tune in at 11am on the 11<sup>th</sup> April, where you will hear from Sky Sports Presenter Dave Clark and health Professional Clare Addison, who both have Parkinson's. You will be able to listen to stories from other people with Parkinson's, share your experiences, learn about latest research, and hear what you can do to reach out to other people. For more information click [here](#).



## Parkinson's Nurse Update

Not a tip this month, but I thought this quote was nice to kind of sum up better times to come for us all right now. Winter has gone and we are now seeing lighter and brighter days now we have entered spring. Covid is now improving and we are a bit like these flowers coming out of hibernation for better days to come.

No winter lasts forever; no spring skips its turn.



## Becky Slimmon, Parkinson's Specialist Nurse

Our local specialist nurses are continuing to work throughout the current situation. They are beginning to start face to face appointments in emergencies, and it is hoped this will increase as the situation allows. In April they plan to work on the recovery of their service plans.

If you need Parkinson's Nurse support, please contact them as you would normally on **0330 726 0077**.

## Branch Volunteers

Can you help us? Can you or any of your family spare time for join us for Committee and also non-Committee roles? We are still looking for a Membership Secretary, a Branch Fundraiser and more Branch Volunteers. Please contact Lisa Lowe on 0344 225 3614 or email [lowe@parkinsons.org.uk](mailto:lowe@parkinsons.org.uk) for more information.

## Cherry Tree

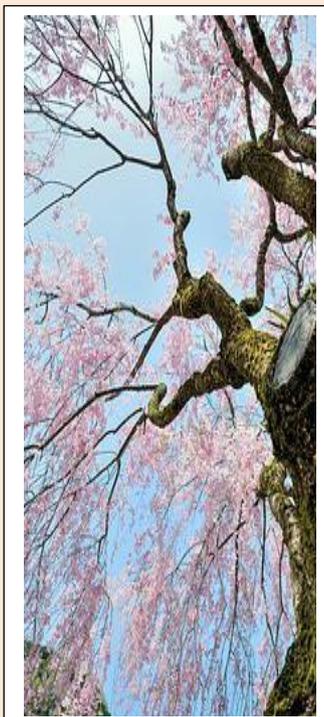
Last night the moon was full and bright  
Out, shining, haloed, mystic, gold;  
Tree stark brown-twigged winter mode  
Daffs line-dancing breeze's tune.

A shock at dawn from window view  
The tree in pink, bright-clothed anew  
In pink now clothed its blossom bright,  
Anew the tree, new my delight.

A shock delight to see this thing  
Agreed between the tree and moon  
In secret enclave in the night.  
A floral cymbal clash to detonate the Spring.

To see is duty privilege and joy.  
It did not ask to be admired.  
It is. It's something understood,  
and not diminished by my clumsy words.

David Rudd



## We are Spreading the Word!

We are advertising to increase our membership over the next few months.

We have an ad going in the Villager Magazine in April and May, and we also have a radio advertisement on Huntingdonshire Community Radio that has been running since February and continues until the end of April.

Welcome to any new members if you found us this way, and hope to see you soon.

## The Gretschen Amphlet Memorial Lecture



Gretschen and John Amphlet were once members of the Cambridge Branch, and in memory of his wife, John established with Parkinson's UK a yearly Memorial Lecture.

This year's Lecture on 24<sup>th</sup> March, was based around research into the use of Canabidoil in treating Parkinson's psychosis. If you were unable to see the lecture live, this is the link to watch the video (80 mins). [Parkinson's UK | 24th March 2021 - YouTube](#)

## New Parkinson's UK equipment Catalogue

Is launching in April with a wide range of daily living equipment to help keep you independent. Products help with a range of Parkinson's symptoms, and all have been selected for their quality and reliability.



Call **0345 124 3250** to order your copy.



## Parkinson's UK Charity T Shirt

Next have teamed up with Parkinson's UK to produce T Shirts and bags, and 100% of profits go to the charity. It says "If nothing else be yourself" and comes in blue and also white, for men and women and costs £20. It was designed by Genna, who herself has Parkinson's. To find out more, click [here](#), and to buy, click [here](#).

## ~~~~~ Springtime Wordsearch ~~~~~

|   |   |   |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|---|---|---|
| P | T | S | H | O | W | E | R | S | N | B | R |
| O | N | O | P | A | S | O | U | E | X | U | S |
| T | E | E | D | A | P | S | S | E | B | L | S |
| H | C | G | F | B | S | W | B | D | I | B | L |
| Y | S | G | U | I | A | F | L | S | R | S | I |
| A | T | Z | C | R | O | C | U | S | D | Y | D |
| C | Z | R | M | S | T | O | O | H | S | M | O |
| I | A | R | O | B | I | N | T | N | O | G | F |
| N | E | S | T | W | E | R | A | E | N | I | F |
| T | U | L | I | P | E | P | I | U | G | D | A |
| H | M | O | O | L | B | L | A | M | B | U | D |
| L | R | E | W | O | L | F | R | E | S | H | Z |

Bee  
Bud  
Birdsong  
Bloom  
Bulbs  
Buzz  
Crocus  
Daffodils

Dig  
Egg  
Flower  
Fine  
Fresh  
Hoe  
Hyacinth  
Iris

Lamb  
Nest  
Narcissus  
Pansy  
Pot  
Robin  
Sap  
Scent

Shoots  
Seeds  
Showers  
Spade  
Sow  
Trowel  
Tulip  
Warm



## Speech and Language Team News

Speech and Language Therapists are part of your Parkinson's support Team. They specialise in all aspects of communication, including non-verbal communication such as facial expressions and body language. They can provide tips, techniques and information on equipment to help with swallowing or any other communication issues you may have.



Our Local Team has continued to support people with urgent needs during Covid, including swallowing problems. But there has been a pause for routine patients, meaning that many patients with Parkinson's would not have received any input in relation to their communication. These patients have been placed on a waiting list. The Loud Crowd, a group to assist with communication and volume, was also unfortunately suspended during this period.

Face to face appointments have been restricted to those urgent patients who could not use technology to access a video appointment, for others they have been using a video appointment platform called Attend Anywhere.

As restrictions ease, they are reviewing their waiting lists and will be gradually contacting patients according to need. They look forward to resuming service delivery as restrictions reduce and would advise that any patients with concerns contact them. They continue to operate an open referral system, and can be contacted either by telephone on **0330 726 0077** or email [cpm-tr.AdultSLT@nhs.net](mailto:cpm-tr.AdultSLT@nhs.net).

If you would like further information on Speech Therapy in general, you can link to the Parkinson's UK Factsheet on their website [here](#), or contact the Parkinson's UK Helpline on 0808 800 0303 to request that a copy be sent to you.

## Caring Together – Carers Support Update

If you are supporting someone with Parkinson's, Caring Together is the Carers organisation that can support you locally. It covers Cambridgeshire, Peterborough and Norfolk.

They are a network partner of Carers Trust, providing support for family carers and the people they care for. They provide a wide range of services including a listening ear, help and advice, homecare, training and the setting up of What If? Emergency plans to support the carer.



During Covid, they have developed some new initiatives that may be of interest.

**Carers Groups** – Direct group meetings have been suspended, but they have started a monthly online Zoom group. At present, these are once a month, and the group includes members from Huntingdon, Peterborough and Wisbech. Please see Activity Dates page 2 for more information.

**Help with Carers Covid 19 Vaccinations** – Caring Together will assist you to get to your appointment if you are struggling. This includes door-to-door travel for you or the person you look after to and from appointments, professional homecare so you can attend the appointment knowing the person you care for is being looked after and support from a care worker to assist the person you care for to attend their own appointments safely.

**Mindfulness and Gentle Exercise sessions** – A new online group of one hour session a week over 6 weeks has started, this is open to all carers.

To find out more about any of the above, or what other support is available, please contact them on **0345 241 0954**, email on [hello@caringtogether.org](mailto:hello@caringtogether.org), or visit their website [caringtogether.org](http://caringtogether.org). You can also join up to their mailing list on [caringtogether.org/maillinglist](http://caringtogether.org/maillinglist), or receive a copy of their quarterly magazine by registering at - <https://www.caringtogether.org/cambs-pboro-carers-magazine>. The same link will provide you with an electronic version of their latest edition.

## Research Opportunities and News

### Join East Midlands RIG Spring Research Event

Saturday 17 April, 10.30am: Please join the [East Midlands RIG](#) as they hold a Spring Research Event on 'improving physical and mental health for people with Parkinson's'. Keynote speakers include Dr Bhanu Ramaswamy OBE (exercise for people with Parkinson's), Dr Rob Skelly (investigating the benefits of physiotherapy at different stages of Parkinson's) and Dr Jennifer Foley (mental health and Parkinson's). You can read more and register to attend online [here](#)

**Investigating Factors Associated with Impulse Control Disorder's in Parkinson's** – Research by The University of Birmingham is exploring the relationship between genetics and different behaviours which might underlie the development of impulse control in some people with Parkinson's. They are looking for 60 people with Parkinson's who are currently taking any form of dopamine agonist medication. To take part you need access to a laptop or computer to complete online questionnaires and tasks. You will also be sent a saliva sample kit, and they will arrange a courier to return it.

To take part contact Alison on [axh485@adh.bham.ac.uk](mailto:axh485@adh.bham.ac.uk) before 31 July 2021.

**Best Practices of Parkinson's Self Care** – The University of Oulu in Finland together with research teams across the world are looking at self-care and the strategies people with Parkinson's and their carers have used to help manage the condition. They are looking for 500 people either with Parkinson's or are a carer to complete a one-off online questionnaire, to provide and submit self-care information, and finally assess items others have entered. This will take about 20 minutes.

If you want to know more contact Elina by email on [elina.kuosmanen@oulu.fi](mailto:elina.kuosmanen@oulu.fi) or phone (+358504821517) before 31 December 2021.

### GDNF Update

Many of us will recall the GDNF research that appeared to hold such promise, and the disappointment when the outcome, when published in 2019, was inconclusive. Some participants advise they are still feeling benefits of the trial years on, and the GDNF participants group have championed and fundraised so this trial would not be forgotten.



Parkinson's UK have continued to work with them, and in response have launched a new company, Vivifi Biotech, tasked with planning a new trial. Through Parkinson's Virtual Biotech, the charity's drug development arm, we will be investing up to £800,000 over the next 2 years in the hope this will lead to a new clinical trial and ultimately a life changing new treatment for people with Parkinson's.



### Fundraising News

In October's Edition we advised a local Branch Member Bernadette England was raising money for Parkinson's UK making facemasks. She has increased her total and has now raised **£2,538**. The masks are in S (infants), M (pre-teens), L (ladies) and XL (Men) in a variety of styles, minimum £4 donation. Find out more on her Just Giving page [here](#).

### Useful Contact Numbers

**BRANCH CHAIR** Malcolm Ryman

**07720 080749**

**VICE CHAIR** David Rudd

**01480 474795**

**PARKINSON'S UK CONFIDENTIAL HELPLINE**

(Also access to Parkinson's Local Adviser)

**0808 800 0303**

**PARKINSON'S DISEASE SPECIALIST NURSES**

**0330 726 0077**

**BRANCH MOBILE**

**07724 400527**

**Facebook Page**

**Parkinson's UK Huntingdonshire**