

IN THIS NEWSLETTER:

- **New Year Thoughts from the Chair**
- **We are Sad to Report**
- **Research News – Good News about Funding**
- **Oxford Branch Website**
- **Parkinson's and Coronavirus - Obtaining Help or Advice**
- **Coronavirus Vaccine and Parkinson's**
- **And Finally**
- **Branch On-line Events**
- **Branch Contacts**
- **Useful Contacts**

NEW YEAR THOUGHTS FROM THE CHAIR

Just after Christmas, I listened to a radio discussion about New Year's resolutions. As you might imagine, the talk drifted towards diets. Everyone agreed that by week three, biscuits would start making guest appearances around their morning coffee cup. Succumbing to the chocolate hobnob was the first step on the road to perdition.

One contributor suggested that we all would have a better chance of keeping our resolutions if we started on June 1st, rather than in the bleak mid-winter when we are more than likely to compensate for the cold and dark by raiding the remnants of the Quality Street tin.

Someone else claimed that resolutions centred upon doing positive things had a better chance of success than attempting to reshape our waist line.

Moving in the same sort of area, Radio 5 aired a thread highlighting the kindness of neighbours in lockdown. They provided many examples of random acts of kindness performed by people resolved to improve the lockdown experience of others. Whatever, we feel about the current lockdown, we will find we know much more about our local community than we did when we started the first one last March.

Living in lockdowns has reminded us how important relationships are to us. Not just the obvious ones of friends and family but those whom we meet in clubs and choirs. Those, who together with friends and family, create a sort of protective network of good will around us and shape for us a positive experience of the world.

In the week after Christmas writer Margaret Atwood was a guest editor on the Radio 4 Today programme. One of her contributions was an interview with an Inuit woman who was trying to preserve her language. I loved the revelation that in the woman's language the translation of "Hello" when you are greeting someone is

"THERE YOU ARE!"

It somehow implies that you had been searching especially for that person and at long last have found him/her.

It's clear that being in lockdown most certainly cuts us off from meeting that network of friends and acquaintances who together provide us with a strong sense of self. I hope it's not too long before we too can say 'There you are' to those whom we are missing the most.

WE ARE SAD TO REPORT:

The committee have been informed of the deaths of two long serving and committed former committee members, both of whom had been branch members for over fifteen years:

Mary Marston

Mary was an enthusiastic and committed advocate for the benefits of Conductive Education for people with Parkinson's.

At first Mary and others used to travel up to NICE (The National Institute for Conductive Education) in Birmingham for sessions. Mary then campaigned and fundraised hard to set up a satellite hub in Cheltenham providing Conductive Education sessions for those with Parkinson's. Links were formed with local branch of the MS Society to provide sessions for those with MS.

Mary ran this Cheltenham Hub for about eight years until 2011 when the running of it was taken over by NICE (and more recently by Meghan Baker House). The branch continues to assist local people with Parkinson's with the cost of attending these sessions.

In 2011 Mary was presented an award by NICE for her commitment and hard work in promoting the benefits of Conductive Education.

Tributes to Mary from those who attended CE sessions with her include:

'Mary always struck me as a positive, assertive but always friendly advocate for people with Parkinson's. She made a massive contribution to bringing Conductive Education to the Cheltenham area' and

'Mary achieved so much for Parkinson's UK as well as Conductive Education in Cheltenham. She was a determined lady who would not be beaten by her disabilities. We have a lot to be grateful for in her campaigning for PD sufferers. She will be missed.'

Tony Paxton

Tony volunteered for the Cheltenham Branch when he retired, although he did not have any personal connection with Parkinson's. He nonetheless became a committed and knowledgeable Branch Chair who, along with the then Branch Secretary (the late Audrey Pound), campaigned and fundraised hard for the appointment of the first Parkinson's Nurse in Gloucestershire.

RESEARCH NEWS - GOOD NEWS ABOUT FUNDING

In 2020, in common with other charities, Parkinson's UK's income was well down on previous years not least due to the cancelling of fundraising events such as the London Marathon. But it has not been all doom and gloom for global Parkinson's research funding.

Until last year there had been a big pull away from Parkinson's research from a few of the biggest American drug companies. They felt the brain was too complex to cost-effectively produce new drugs that work, not least because some large and expensive trials had failed.

However, in the past year, some of the biggest companies have taken over smaller companies that are already majoring in neurological research including Parkinson's.

So the good news is that in the USA sizeable investment has returned for Parkinson's research.

Other good news on the funding front also comes from ASAP (Aligning Science Across Parkinson's). Last August they granted \$161M funding for 21 Parkinson's research projects.

There are currently 264 active research projects centred on either better relief of symptoms or slowing progression.

Also the US government increased its funding to Parkinson's research to \$224M (in 2016 it was \$161M).

OXFORD BRANCH WEBSITE

We have been reminded that the Oxford Branch has its own, very comprehensive website <https://oxfordparkinsons.org.uk/index> which you may find interesting to explore.

Some of their activities and resources are only available to their branch members or Oxfordshire residents but others are open to all.

For instance they have a good range of exercise videos you can access via:

<https://oxfordparkinsons.org.uk/covid/exercise-videos#gg-videos>

PARKINSON'S AND CORONAVIRUS - OBTAINING HELP OR ADVICE:

There is support on offer for anyone affected by Parkinson's from the **Parkinson's UK helpline, Website** and **Parkinson's Local Advisors** (See **Useful Contacts** below).

The Parkinson's UK website advice on **Coronavirus and Parkinson's** is regularly updated as Government and NHS policies and advice change.

<https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons>

Parkinson's UK have a booklet with information and support about Parkinson's and coronavirus. You can [order a copy of this booklet, free of charge, here](#).

The following guidance from the Parkinson's UK Website was **up-to-date on 19th January**

What should I do?

Follow the guidance where you live

You must follow the guidance where you live. You can find out about local restrictions on the relevant government websites:

England. A new national lockdown began on 4 January, and will remain in place until at least mid-February. Everyone must stay at home, leaving only to buy necessities, exercise, provide care, or for other permitted reasons.

<https://www.gov.uk/guidance/national-lockdown-stay-at-home>

Stay at home and limit social contacts as much as possible

Guidance for people who are clinically vulnerable, including people with Parkinson's, says that it's important to stay at home and limit social contacts as much as possible. Follow distancing and hygiene guidelines if you do go out.

If you do need to leave your home, the UK government advises people to think '**Hands. Face. Space**':

- You should wash your hands regularly, for at least 20 seconds.
- You should wear a face covering in enclosed spaces.
- You should give people outside of your household space of at least 2 metres, or 1 metre where other measures are in place.

Where can I find up to date information and guidance?

- **England** - follow advice from the [NHS](#) and [Government](#).

These sources reflect the most up-to-date information and will be updated as the situation progresses.

CORONAVIRUS VACCINE AND PARKINSON'S

The following guidance from the Parkinson's UK Website was **up-to-date on 11th January**:

<https://www.parkinsons.org.uk/news/coronavirus-vaccine-and-parkinsons>

On 2 December 2020 the UK became the first country in the world to approve a coronavirus (COVID-19) vaccine. The Pfizer/BioNTech vaccine offers up to 95% protection against coronavirus.

On 30 December, the UK medicines regulator approved a second vaccine. The Oxford University/AstraZeneca offers 62% to 90% protection against coronavirus, and was shown to prevent serious illness in all volunteers taking part in the clinical trial.

The UK approved the Moderna vaccine on 8 January 2021. It's 94% effective and is expected to be rolled out in the spring.

Who is getting the vaccine first?

The roll out of the vaccination for those in the highest priority groups began on 8 December.

You will be invited for a vaccination when it is your turn, probably by letter. Your age, underlying health conditions, and any caring responsibilities will determine your priority level.

The Joint Committee for Vaccinations and Immunisations (JCVI) sets out the following priority levels for people to get the vaccine based on clinical need:

- Older adults resident in a care home, and care home workers.
- All those 80 years of age and over, and health and social care workers.
- All those 75 years of age and over.
- All those 70 years of age and over, and those who are considered clinically extremely vulnerable.
- All those 65 years of age and over.
- High-risk adults under 65 years of age, including people with Parkinson's and their carers.
- All those 60 years of age and over.
- All those 55 years of age and over.
- All those 50 years of age and over.

If you are the main carer for someone with Parkinson's but don't receive a carer's allowance, make sure to let your GP know so that you don't miss out on your vaccine.

The availability of a second vaccine is set to significantly speed up vaccinations across the UK. It is cheap, easy to mass produce, and easy to store and transport. It is expected to be rolled out rapidly to GP surgeries and care homes.

How will I get the vaccine?

The NHS will invite you for a vaccination when it is your turn, probably by letter.

You might get the vaccine:

- In your local hospital
- At a nearby vaccination hub
- Via your GP or pharmacist
- At your care home

The injection is not compulsory.

Be alert to fraud. A text message with a link to book your vaccine online has been circulating, claiming to be from the NHS. Similarly, there have been reports of phone calls asking people to pay for the vaccine over the phone. There is no charge for the vaccine and the NHS will not ask you to share any financial details.

Is the vaccine safe?

The UK has some of the highest safety standards in the world. Both vaccines meet the strict standards of safety, quality and effectiveness set out by the UK's medicines regulator, the Medicines and Healthcare products Regulatory Agency (MHRA).

The MHRA has considered these license applications as quickly as possible without cutting corners, because a vaccine to protect people against coronavirus is a priority.

The Pfizer/BioNTech vaccine is the fastest ever to go from concept to reality. This is partly because companies shared trial data with the MHRA throughout development, which shortened the assessment process.

Is the vaccine safe for people with Parkinson's?

Our Clinical Director, Dr Donald Grosset, advises:

"The vaccine is safe for people with Parkinson's. There is no interaction with Parkinson's medication. Parkinson's is specifically included as one of the conditions that is in a 'clinical risk group' and every adult with Parkinson's should get the vaccine."

If you've had the vaccine

If you've had the coronavirus vaccine and are experiencing side effects, please report it on the government's Yellow Card website <https://coronavirus-yellowcard.mhra.gov.uk/>

NB: For updates on the vaccine rollout in Gloucestershire:

See the Gloucestershire CCG website:

<https://covid19.glos.nhs.uk/gloucestershire-extends-covid-vaccine-programme/>

AND FINALLY....

We are all trying to find ways to deal with a further lockdown and you might find distraction and amusement by posts on social media. For instance you might enjoy this compilation of 'Soon may the Wellerman come' originally recorded on Tik Tok by Nathan Evans, a Shanty Singing Postman:

<https://youtu.be/UgsurPg9Ckw>

It might remind some of you of the very enjoyable branch meeting some years ago when we were entertained by the Harry Browns of Bristol Shanty Singers. It is good to recall enjoyable things we once did and to look forward to once more enjoying our former activities and the company of others.

Meanwhile Lord David Blunkett when interviewed on TV this week was asked how he was coping with a further lockdown and he said:

'I KEEP GOING BY KEEPING GOING'

USEFUL INFORMATION

BRANCH ON-LINE EVENTS (on Zoom)

Parkinson's Cafe on Zoom 11-00am Thursdays - February 4th & 18th, March 4th & 18th

Table Tennis 'Chat and Quiz' on Zoom.....2.00pm Fridays - February 12th & 26th, March 12th & 26th

An invite and zoom link details will be emailed to the branch mailing list before each session

BRANCH MEETINGS & REGULAR EVENTS

NB: All face to face meetings/events are cancelled until further notice.

The Branch Committee are currently looking at detailed guidance, issued by Parkinson's UK, about how, and when, we can restart face to face meetings/events in a Covid secure manner.

BRANCH CONTACTS

Branch Chair: Harry Matthews 07515 857110 or parkinsonshjm@gmail.com

Branch and Membership Secretary: Ian Jones 07903 850597 or ianjones.parkinsons@gmail.com

Branch Treasurer: Dot Simpson 01242 583894 or dsimpson.parkinsons@googlemail.com

Committee Members: Val & Clive Corke, James Howell, Joy & James Ingram,
Didi Jepson, Hilary Moody

Branch Website: <http://www.cheltenhamparkinsons.org.uk/>

USEFUL CONTACTS

Parkinson's UK Website: <http://www.parkinsons.org.uk>

Parkinson's UK Helpline: (phone free) 0808 800 0303 or email hello@parkinsons.org.uk

Parkinson's Local Advisor Service: contact our helpline on 0808 800 0303 or email hello@parkinsons.org.uk to be put in touch with a local adviser.

Parkinson's Nurse Specialist Service: 0300 421 8109 or parkinsons.team@ghc.nhs.uk

Age UK Help Team: Monday – Friday 9am – 4pm 01452 422660

Age UK Gloucestershire Website: <https://www.ageuk.org.uk/gloucestershire/>

Mind: Infoline: 0300 123 3393 or www.mind.org.uk/information-support

Samaritans: call free any time, from any phone, on 116 123.