

**IN THIS NEWSLETTER:**

- **Thoughts from the Chair**
- **Recent Branch Meetings**
- **Radio Gloucester Interview**
- **Research News**
- **Team Parkinson's:  
Membership Changes**
- **Conductive Education  
Sessions in Cheltenham**
- **News on Carers Services**
- **One-Off Events**
- **Future Events**
- **Future Branch Meetings**
- **Branch Contacts**
- **Useful Contacts**

**THOUGHTS FROM THE CHAIR**

I like Billy Connelly and have always found his humour and laughter infectious. I have taken a special interest in his TV programmes since he disclosed his Parkinson's.

There were two programmes recently about the debt he felt to his Scottish roots. He ended the second programme reflecting on how Parkinson's had in so many ways cramped his style. Not least it meant no more leaping about the stage to act out his jokes. The programme ended with his reflection, not just on his Parkinson's, but also on the physical costs to him of growing old.

In the light of these reflections many viewers contacted him about what had seemed to them his swan song. He appeared at the end of the news the next evening to reassure his fans that he wasn't dying! He apologised if it had all sounded too depressing!

In contrast, PD has led Paul Mayhew Archer (best known for co-writing the Vicar of Dibley) to go on tour with a one man show based on his Parkinson's experience called 'Incurable Optimist'. Dr Peter Fletcher, our President saw him at the Edinburgh Fringe and found him hilarious!

What is so good about celebrities talking, and even joking, about their PD is it raises public awareness about what it means to have PD and how they are coping with it each in their own way.

No two people with PD have exactly the same symptoms and we each have our own way of dealing with it. For me it's the half hour each way walk to Waitrose and twice weekly table tennis. I really think I am whacking Parkinson's on the nose when I put energy into a good return!

In 2014 Dr Atul Gawande gave the Reith lectures on Radio 4. He ranged far and wide; from being inspired by the pre-take off pilots' check list to invite surgeons to do the same, to palliative care of the terminally ill.

He discovered that patients who said to themselves "What do I have to do to make this a good day?" on the whole lived longer than those who simply looked to an uncertain future. It seemed to me a good question with which to start the day whether you are ill or not.

**What do I have to do to make this a good day?**

**Simple: set off for Waitrose with a table tennis bat in hand! (But don't alarm the cashier at the till!)**

## RECENT MEETINGS

On January 29th Ruth Henderson Cash spoke to us about the ways in which taking part in Yoga exercises can benefit anyone who has Parkinson's. She explained how the practice of yoga can improve balance, muscle flexibility and posture.

Half her presentation was given to a practical session for us. This even included exercises for face muscles in order to combat the fixed expression that sometimes accompanies the condition. The session was very well received although some members confessed that they almost nodded off because the breathing & relaxation exercises were so effective!



26th February 2019 was our 35th Branch AGM but was also the 50th Anniversary of Parkinson's UK. At our annual branch meeting the chairman and treasurer presented reports and the following were voted on the Committee: Harry Matthews - Chair, Dot Simpson – Treasurer, James Howell - Minutes Secretary and Didi Jepson, Clive Corke and Val Corke.

Mary Marston retired from the Committee and was presented with a bouquet of flowers. The Chair, in his thanks to her, recalled Mary's years of valued service, especially all she did as an advocate for Conductive Education.

After the AGM was a fund raising talk by Sarah Wakeman, Parkinson's UK regional fundraiser. Sarah's family experience of the disabling effects of PD has led her to be PUK fund raiser for the South Midlands. She remarked how members of the public are more likely to pass by our cyan blue cans in supermarkets when almost everyone gives to cancer charities.

Sarah has established four successful fundraising events in her region, the money from which helps pay for Parkinson's UK helpline and our local advisers:

- Cotswold Walk raised £9000 last year
- Packwood House Walk raised £16000 last year
- Cirencester Golf Day
- Taste of Leamington Spa : participants enjoy three courses in different restaurants

Most Parkinson's UK income come from bequests. Sarah made the point that such bequests could take the form of works of art or stamps, coins or jewellery. Sarah made suggestions as to how we might follow some fundraising ideas such as hosting a Garden Gathering, a Celebration coffee morning or Dress Down Fridays.

Sarah closed by telling us about the launch of a film by Parkinson's UK on April 11<sup>th</sup>, World Parkinson's Day. It is purposely hard hitting showing the really difficult aspects of PD.

## RADIO GLOUCESTER INTERVIEW

The photograph is of our new Committee member, Clive Corke, who in January was interviewed by Radio Gloucester about how Parkinson's affects his mobility. Clive's interview really raised public awareness of the problems of freezing when out and about. For him the nightmare scenario was freezing whilst crossing the road. His clear and frank answers on the radio fitted in very well with the current plans for Parkinson's UK to inform the general public about how serious a condition PD is.



## RESEARCH NEWS

Parkinson's drug research is taking place in three main areas which are known as the 3 "R's":

**1: RELIEVE** – drugs for the symptoms of PD, this includes research into more effective delivery of existing drugs.

**2: RETARD** - drugs which slow down the progress of PD

**3: REPLACE** - drugs which restore lost neuron damage

Parkinson's UK sends out a monthly summary of research work. There are currently around 200 drugs being investigated in the field of Parkinson's research.

The January summary featured a rogue protein in the brain called alpha-synuclein, which misfolds and has a toxic effect on brain cells. The hope is that drugs could be developed to target this rogue protein and thereby slow down the progression of PD. There are four drugs currently being developed with this aim.

A different misfolded protein is involved with Alzheimer's disease and a drug has been developed to target this misfolding protein which might have beneficial effects on Parkinson's.

### STOP PRESS:

Did you see **'The Parkinson's Drug Trial: A Miracle Cure?'** This fascinating, but very challenging, two part, programme on BBC 2 recently showed the Parkinson's UK funded, Stage 2, GDNF (Glial cell-derived neurotrophic factor) drug trial at the Brain Centre, Southmead Hospital, Bristol led by Professor Steven Gill. If you did not see it you can catch up on BBC I-player until the end of March.

One can have nothing but profound admiration for the bravery and commitment of the 42 trial participants and the dedication of the clinical and research staff. This trial involved the use of experimental, major brain surgery introducing a triple catheter arrangement deep into the brain to feed the GDNF drug deep into the brain.

Particularly moving was the, almost super-human, determination of Tom Isaacs, who had been diagnosed with early onset PD in his 20's and by the start of the trial had advanced symptoms, particularly dyskinesia. He had co-founded the Cure Parkinson's Trust in 2005 and was deeply committed to the work of Steven Gill and the GDNF trial, so much so that he endured a second brain surgery introducing a revised catheter design as the first one had not worked effectively. Tragically he died suddenly, from unrelated causes, not long after the end of the GDNF trial, aged only 49.

For more information, including details of the recently published trial results, see:

<https://www.parkinsons.org.uk/research/clinical-trial-gdnf>

<https://www.cureparkinsons.org.uk/news/gdnf-trial-toms-story>

## TEAM PARKINSON'S: Membership Changes for Parkinson's UK

In response to a gradually falling membership Parkinson's UK has decided to replace the fixed membership fee of £4 per year with a voluntary donation, in the hope that this will attract more members. Our branch committee have, however, voted to continue with our branch membership fee of £6 per year, which can be paid along with your national membership.

New members can now join on-line at <https://parkinsons.org.uk/about-us/join-team-parkinsons> or ask for a membership form at branch meetings or from Dot Simpson, Acting Membership Secretary, on 01242 583894 or [dsimpson.parkinsons@googlemail.com](mailto:dsimpson.parkinsons@googlemail.com).

Revamped membership is called **Team Parkinson's**. Parkinson's UK say: "It's a new way of showing the world that we're one big community, uniting to end Parkinson's for ever".

Parkinson's UK have formulated **Refreshed Values** in order to "better reflect us as a charity" and have written:

**UNITING:** We're scientists and supporters, fundraisers and families, carers and clinicians. We're working side by side to improve the lives of everyone affected by Parkinson's

**PEOPLE FIRST:** We're a strong movement for change, informed, shaped and powered by people affected by Parkinson's.

## **CONDUCTIVE EDUCATION SESSIONS IN CHELTENHAM - Places available**

Brian Rawnsley, one of our Branch members, writes:

What is Conductive Education you may ask? Conductive Education is a technique for those with neurological conditions. The technique was invented by Dr Peto, a Hungarian, in the 1940s. The trainers (known as conductors) are highly trained, many having studied at the Peto Institute in Hungary. They work their way through a series of physical exercises designed to improve movement and coordination.

Currently there are a few vacancies in the Cheltenham Conductive Education classes, held fortnightly on Monday mornings, in term time, at the Cheltenham Civil Service Club on the Tewkesbury Road near Aldi. The classes are run by trainers from the National Institute for Conductive Education (NICE), Centre for Movement Disorders, which is headquartered in Birmingham.

The sessions are good humoured, with lots of personal attention. The sessions run especially for Parkinson's participants last for 90 minutes (10.00am to 11.30am), with extra time at the start and end for a chat over tea or coffee.

The conductors lead the group of attendees through a series of actions/exercises. In our case the actions/exercises are specifically aimed at those people with Parkinson's. The exercises help Parkinson's people to remain mobile, with better movement co-ordination, for longer. The classes are very 'hands on' with the attendees continually being shown the correct movement detail by the trainers.

A number of the members from the Cheltenham Parkinson's branch attend these classes. The session fee is roughly equivalent to attending a personal trainer session, but there is a subsidy for part of the session fee available from the Cheltenham and District Parkinson's UK Branch for any person with Parkinson's living locally. This subsidy is reviewed regularly, depending on availability of Branch funds.

**If you would like further information, please call me, Brian Rawnsley, for a chat, on 01452 856148.**

If you then decide to investigate further, the NICE conductors would be happy to assess you, by appointment, at one of the Monday sessions.

## **NEWS ON CARERS SERVICES**

Roger Hare, Carers Gloucestershire, writes that on **1 April 2019**, the statutory contract for carer services in Gloucestershire will be transferred from Carers Gloucestershire to People Plus Group Ltd. This means that services including information, advice and guidance, carers assessment and support planning, carers' voice, Positive Caring and counselling, peer support and support groups will no longer be available from us; instead you will be able to receive those services from People Plus.

We are working with People Plus and Gloucestershire County Council to make this transition as smooth as possible and for carers to be able to access appropriate support when they need it. To this end, Carers will receive a letter asking for consent for personal details to be

transferred to People Plus, so that they can continue to work with you and contact you with information about their services.

If you choose not to transfer your details then of course you can still approach People Plus directly, after 1 April, if you need carer support services. It is important to note that consent to transfer data to People Plus will not automatically remove you from Carers Gloucestershire's database, and you can certainly be on both databases at the same time. We hope to continue to support carers in ways not covered by the statutory contract and we will be contacting you separately about our future plans.

Carers Gloucestershire, People Plus and the County Commissioners will be working with each other over the next 3 months to ensure as smooth a transition as possible.

We haven't yet heard how People Plus intend to deliver the Carer services in the County, but as soon as we have some definite news about this we'll be sending out information to Carers individually, to support groups and out via social media etc.

**PEOPLE PLUS** has shared with us this message for all adult carers in Gloucestershire: *People Plus is the new provider who will be delivering your Adult Carers Service from 1 April 2019. We are dedicated to deliver services that are carer-led and keep our carers at the heart of everything we do.*

*Be assured that we will be working closely with Carers Gloucestershire, Gloucestershire County Council and the Clinical Commissioning Group amongst your local partners to ensure a smooth transition of services and will start communicating on what that means for you as we move closer to April.*

## REGULAR EVENTS

**Coffee Drop-In Mornings** now take place **from 10.30-12.00 on 2nd Wednesday in the month** at the Norwood Arms, Leckhampton Rd, GL53 0AX. The mornings we have had so far have been well attended and have proven to be a popular innovation. All our welcome. Future dates are April 10th, May 8th & June 12th.

NB: There is disabled access and parking. The new standard, all day, £3 car parking charge for all car-park users (including blue badge holders using the disabled parking bays) will be refunded to customers.



**Table Tennis Club** now takes place **every Friday 2-4pm** in St Luke's Church Hall, St Luke's Place GL53 7HP. Already this has proven to be a popular activity providing wonderful exercise for everyone, especially those of us with PD. Cost £4 pp, £5 couples. All abilities welcome.

## ONE-OFF EVENTS

### 10 April (Wednesday)

**Supper & Quiz at 7-30pm at 'Sup and Chow'**  
Bath Road, GL53 7NB

£10 including Bangers and Mash Supper.  
Tickets at the March branch meeting or from  
Harry Matthews 07515 857 110



### 11 April (Thursday) World Parkinson's Day

**Gloucestershire Parkinson's Conference from 10-30 to 3-30pm**  
Kingsholm Stadium, Gloucester GL1 3AX

Attendees are asked to make a donation towards the  
Conference costs of £15 per person or £25 for a couple.

To express your interest please contact Dot Simpson ASAP on  
01242 583894 or email [dsimpson.parkinsons@googlegmail.com](mailto:dsimpson.parkinsons@googlegmail.com)

## FUTURE BRANCH MEETINGS

### 26 March

Gareth Hooper *How Does Clinical Commissioning Work?*

### 30 April

Sue Watts *Parkinson's Nurse Q&A*

### 28 May

Discussion Sessions for Those with PD & Carers

### 25 June

Speaker tbc *Community Police & Crime Prevention*

### 30 July

Branch Outing *Guided Morning Tour of the Jet Age Museum followed by  
Lunch at 'The Aviator' (both venues are near Gloucestershire Airport)*

### 27 August

Social and Quiz with Bring and Share Afternoon Tea

## BRANCH CONTACTS

**Branch Chair:** Harry Matthews, 07515 857110 or [parkinsonshjm@gmail.com](mailto:parkinsonshjm@gmail.com)

**Branch Secretary:** Post currently vacant

**Branch Treasurer & Acting Membership Secretary:** Dot Simpson 01242 583894 or  
[dsimpson.parkinsons@googlegmail.com](mailto:dsimpson.parkinsons@googlegmail.com)

**Committee Members:** Didi Jepson, James Howell, Val Corke & Clive Corke

**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

**Parkinson's Local Advisor:** 0344 225 9821 or [adviser10.west@parkinsons.org.uk](mailto:adviser10.west@parkinsons.org.uk)

**Parkinson's Nurse Specialist Service:** 0300 421 8109