

# Help Wanted!

The Horsham branch of Parkinson's UK are planning a major **3-in-1** fund raising and public awareness day on Sunday 4<sup>th</sup> June 2023.

We need your help to spread the word and with the event itself.

We want everyone affected by Parkinson's in our area to know we are here to support them.

The **3-in-1** event is to be held in Mannings Heath and will comprise a 5km fun run/walk starting at 10am, afternoon cream tea from 3pm, and a party on the village green from 2:30pm with bouncy castle, face painting, live music, craft stalls.



### HERE'S HOW YOU CAN HELP.

#### Fun run/walk

- marshals needed to help the runners/walkers get safety across the roads
- tail-end walker to make sure we don't lose anyone enroute
- someone to man the water stations

#### Afternoon tea

We need help:

- baking cakes,
- decorating the hall,
- serving tea, and
- clearing up afterwards



#### Party in the Park

- Have you a gazebo we could borrow for the day?
- Help to erect gazebos
- donate chocolate and bottles for the tombola
- man the tombola



- marshal the bouncy castle
- are you a crafty person, would you like a stall on the green or do you know someone who would
- help take down the gazebos and tidy up at the end of the day

#### Awareness desk

- man the awareness desk

#### Advertise the event

- do you live on a main road or well used route? Would you be willing to have an estate agent type board outside your house advertising the event?

If you can help in any way, please contact Sue West e-mail: [westsamilloy@btinternet.com](mailto:westsamilloy@btinternet.com) or tel 01403 273064 or Maija Bruce e-mail [majja.bruce@me.com](mailto:majja.bruce@me.com) or tel 07976 506825.

#### Dates at a glance

3<sup>rd</sup> May: Argentine Tango

5<sup>th</sup> May: Branch meeting with Pets as Therapy

11<sup>th</sup> May: Working age group meeting - open to all

2<sup>nd</sup> June: Branch meeting, Jeremy Collyer returns to talk more about his passion for photography.

**4<sup>th</sup> June: 3-in-1 fund raising and awareness event in Mannings Heath – 5km fun run/walk, afternoon cream tea, party in the park.**

7<sup>th</sup> June: Argentine Tango

8<sup>th</sup> June: Working age group meeting - open to all

5<sup>th</sup> July: Argentine Tango

7<sup>th</sup> July: Branch meeting with Rachael Fairs, physiotherapist in neurology

8<sup>th</sup> July: Hilliers garden centre collection

13<sup>th</sup> July: Working age group meeting - open to all

For further information and details of weekly activities see pages 4 and 5

## Aimee draws a crowd for Art Workshop

The art workshop in March, run by Aimee Bleach assisted by Carolyn Dodd, was a roaring success. With about 40 attendees, it was great to see the hall buzzing with people after so many lean events following covid.

We started with a brief review of the CUE1 by Mike Onley.

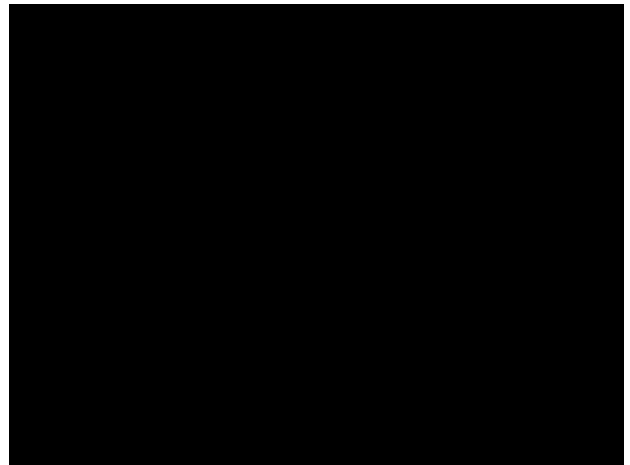
CUE1 is a non-invasive, wearable, medical device for people with Parkinson's, to improve movement and quality of life. It combines the principles of focussed vibrotactile stimulation and cueing, both evidenced by scientific literature, to improve motor performance and alleviate freezing of gait for people with Parkinson's.

Developed by Team Charco Neurotech, testing has shown clinically significant improvements in motor symptoms whilst using the CUE1. Testers have also reported a wide range of benefits including:

- Smoother walking and movement
- Regaining the ability to dance
- Helping fine motor tasks

Within the Horsham branch it has helped some people and not others. (For a review of the CUE1 device by Denise Baldwin see page 6).

The art workshop itself was great fun. We lost ourselves in a swirl of colour and beautiful music. It didn't matter whether you consider yourself artistic or not. Aimee and Carolyn coped magnificently well with the large number of people there. Thank you, I hope we have another soon.

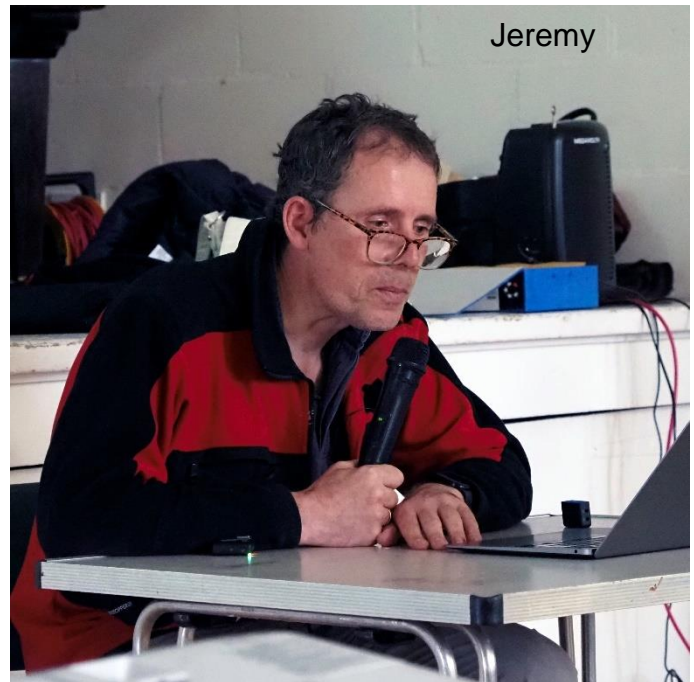


Art workshop

## Jeremy Collyer Surgeon and Parkinson's Patient

The April branch meeting we had an excellent talk by Jeremy Collyer, a retired surgeon.

As a youngster Jeremy's school report said "could do better". He was hopeless at languages but liked sciences, mainly because of the teacher who he described as an excellent trainer.



His father decided he could go on to university but only to study dentistry, medicine or architecture. Jeremy opted for dentistry, figuring it was probably the easiest option. He qualified in 1989. Not content with being a dentist Jeremy went on to study medicine qualifying as a doctor in 1997. After much training he was appointed consultant in maxillofacial surgery in 2006 and was based at the Queen Victoria Hospital, East Grinstead.

Live cello  
music  
was an  
extra  
treat. 2

His career was cut short by Parkinson's, Initially after diagnosis he continued working but diversified away from surgery. He retired in 2020.

Jeremy is a keen cyclist, cycling to Nice with a group of friends. He called his bike Lance after Lance Armstrong. He reckons the optimum number of bikes one should own is S+1 where S is the number you currently own always ensuring you have no more than D-1 where D is the number you can safely own without you wife divorcing you. He hasn't stopped cycling but has diversified into e-bikes.

Jeremy's other passion is photography. He showed us some examples of hi work which were amazing. Along with wildlife stills Jeremy is now making 2 minute videos with tips on how to live with Parkinson's. His website is [www.jeremycollyer.co.uk](http://www.jeremycollyer.co.uk)

Afternoon tea tickets now on sale, contact Sue West [westsamilloy@btinternet.com](mailto:westsamilloy@btinternet.com), tel 01403 273 064 or Maija Bruce [majja.bruce@me.com](mailto:majja.bruce@me.com)  
Tel 07976506825

## Fund Raising

### Town Collection

A huge thank you to all those who took time out to shake a tin for Parkinson's during our street collection on 15<sup>th</sup> April. A special thanks to Dennis, our treasurer, who organised it and stood for hours by the swan in Swan Walk. We raised a total of £1,330, a great result.

### Garden Centre Collections

We have 2 further collections scheduled:

- Hilliers Garden Centre: date 8<sup>th</sup> July
- Newbridge Garden Centre: date 5<sup>th</sup> August

If you can help with either of these please contact Dennis on 01403 259 694 or e-mail [dennissaunders888@btinternet.com](mailto:dennissaunders888@btinternet.com).



Fun run/walk includes part of scenic Kingfisher golf course, register by 26<sup>th</sup> May to attract discount.

In aid of the

## Horsham branch of Parkinson's UK

# Sunday 4<sup>th</sup> June 2023

### 5km fun run/walk

Starts 10am from Mannings Heath Village Hall. Entry fee: Adults: £15 Children: £10. Discount for early registration: £5



### 3-in-1 event



### Afternoon cream tea

Served from 3pm Mannings Heath Village Hall. Price: Adults: £8 Children: £5

### Party in the Park

Manning Heath Village Green from 2:30pm. Free entry, lots of fun for all the family, martial arts display, obstacle course, face painting, bouncy castle, crafts and more.



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

For more information please contact Sue West [westsamilloy@btinternet.com](mailto:westsamilloy@btinternet.com) or Barbara Scarborough [jdn.scarborough@btinternet.com](mailto:jdn.scarborough@btinternet.com)

**cubitt & west**

# What's On

## Monthly Activities

### Branch Meetings

5<sup>th</sup> May 2023, 11:30 at Mannings Heath Village Hall, branch meeting, with members of the Pets as Therapy Group (with pets!)

2<sup>nd</sup> June 2023, 11:30 at Mannings Heath Village Hall, branch meeting, by popular demand Jeremy Collyer returns to talk more about his passion for photography.

7<sup>th</sup> July 2023, 11:30 at Mannings Heath Village Hall, branch meeting, with Rachael Fairs, physiotherapist in neurology.

### Working Age Group – open to all

Informal gathering of people with Parkinson's and their partners, second Thursday of the month, from 7pm, at the Lintot pub in Southwater.

For further details please contact Emma Brinton [emma.brinton@sky.com](mailto:emma.brinton@sky.com) or tel 07970 898 740.

### Discussion Groups

Cancelled until further notice! If you are keen for these groups to continue, please let us know.

### Argentine Tango

First Wednesday of the month, 7pm to 9pm, Mannings Heath Village Hall, ie next session is Wednesday 3<sup>rd</sup> May 2023.

All levels of dancers welcome, from complete beginners to experienced exponents. No booking required. No charge. Refreshments served midway through session.

For further details please contact Paul Dodd 01403 266 173, e-mail: [doddcp@yahoo.co.uk](mailto:doddcp@yahoo.co.uk)

## Weekly Activities

The following activities take place weekly at the following locations:

Mannings Heath Village Hall: Pilates, chair dancing, table tennis dance to live well and Qi Gong

Horsham Boxing Club in the park: Boxercise

Copsale Village Hall until 4<sup>th</sup> May then at the Laurie Apted Building, Church Lane, Southwater from 18<sup>th</sup> May: Yoga

Horsham Hospital Gym: Physio led exercise class

### Monday 2pm Pilates followed by tea, coffee and a chat

Please note this class has very limited capacity to accept anyone new. If you would like to attend, and have prior experience of Pilates, please contact Sue West (tel 01403 273 064) or Barbara Scarborough (tel 01403 891 218) and they will advise you if a place becomes available. Cost £4 per session.

Pilates is essentially a floor-based exercise class. Participants must be able to get to the floor and back up unaided.

**Please note: there will be no Pilates on the bank holidays ie 1<sup>st</sup>, 8<sup>th</sup> or 29<sup>th</sup> May 2023**

### Tuesday 11:30am Chair Dancing followed by tea, coffee and a chat

Cost £4 per session. No prior experience or booking necessary, just turn up! Chair dancing is open to all. It is excellent for people with Parkinson's (PWP) and anyone vertically challenged!

**Please note: there will be no chair dancing on 9<sup>th</sup> May 2023 (Barbara on holiday)**

### Tuesday 5pm Boxercise

Release some of that pent up frustration Parkinson's leaves you with.

Cost - £5 per session. Numbers at boxercise are strictly limited. To check on availability or express interest in attending please contact Emma Brinton [emma.brinton@sky.com](mailto:emma.brinton@sky.com). or tel 07970 898 740.

### Wednesday 10:30am – 12 midday, Table Tennis

All abilities welcome. Cost £5 per session. Please note this is open to all and is not exclusive to people with Parkinson's.

### Wednesday 3:30pm Dance to Live Well followed by tea, coffee and a chat

45 minutes ballet-based exercise followed by refreshments. Suitable for all, PWP and anyone with balance problems. Cost £5 per session, No prior booking or experience necessary.

### Friday 10:30am Qi Gong

Everyone welcome. Cost £3 per session. No prior experience or booking necessary, just turn up! May be enjoyed seated or standing.

## Wednesday 5pm and Thursday 5:30pm Physio led exercise classes at Horsham Hospital

Please note: booking is essential. Both sessions are currently full with a waiting list. Please contact Cath Stead for details on 01403 731 072 or 07789 778 094.

### Thursday 5:30pm Yoga

Everyone welcome. Cost to be advised. The number of participants is restricted by the size of the venue. To check on availability or express interest in attending please contact Emma Brinton [emma.brinton@sky.com](mailto:emma.brinton@sky.com). or tel 07970 898 740.

**Please note: there will be no yoga on 11<sup>th</sup> May 2023**

## Argentine Tango

Report by Paul Dodd

Our first Argentine Tango evening for over three years, run by Carolyn and Paul at Mannings Heath Village Hall, was a great success, enjoyed by 16 of us. Nothing too serious but with the help of Julie, Malcolm and Carrissa everyone mastered some steps and enjoyed themselves.

Come and join in or watch at our next session on the first Wednesday of May (3rd) from 7 to 9 pm with a break for a drink and chat.

## New – Boxercise

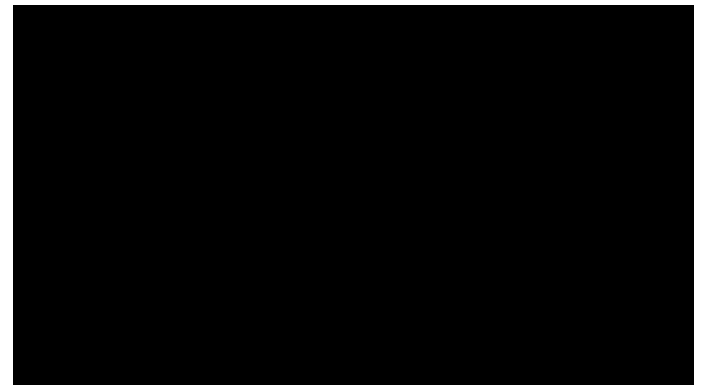
Report by Emma Brinton

We have successfully liaised with Horsham Boxing Club to set up a Boxercise class for PWP. Danny, the instructor, alongside his father, Jon, have specifically tailored a challenging but extremely rewarding class once a week on Tuesdays at 5 pm.

Boxercise challenges individuals on both a physical and mental level; it therefore can be an effective tool in delaying the progression of neurodegenerative diseases like Parkinson's. Boxercise centres around movement, balance, coordination and quick thinking.

A typical session includes warm up, cardio, learning boxing combinations, hitting pads with coach in ring (complete exhilaration!), stretching/cool down.

Feedback from this class has been exceptionally positive.



## New – Yoga

Report by Emma Brinton and Liz Collyer

A weekly yoga class has also just started currently at Copsale Village Hall on Thursdays at 5.30 pm, taught by Liz Collyer, trainee yoga teacher. (Venue will be relocating to Laurie Apted, Southwater from 18<sup>th</sup> May). Yoga offers many benefits including flexibility, strength, relaxation and mindfulness.

The first class was enjoyed by all who attended. We worked on connecting to our bodies through movement and breathing, focusing on the exhale to activate the rest & recuperate part of our systems (as opposed to the fight or flight). We did a range of postures including mountain pose, forward bend, warrior, cat, downward dog, bridge and upward leg raises. All the postures involved simple movements done in synch with our breathing, trying to notice how the movements felt and also where we felt the

movements. We finished with some seated breathing, again focusing on the exhale.

We had chairs on hand in case of needing a bit of steadying or a short rest, or to help us get up from the ground. The aim is always to keep things comfortable, and alternatives are available if something doesn't work for a participant. Liz demonstrates each posture clearly, encouraging all of us in a relaxed, calm manner.

The feedback again has been equally positive and it is clearly a class that is a definite benefit for PWP

## Working Age Group

Report by Emma Brinton

The working age group meet-ups in the pub have been a great addition to the Horsham Parkinson's branch. We have been regularly meeting on the second Thursday of each month from 7pm. We generally have a good turnout of approximately 12 people. The meet-ups have now been running since January this year.

I must admit that I was unsure initially but thought I'd give it a go as I had not met anyone else with Parkinson's before. From a personal viewpoint I have found it really beneficial and I definitely look forward to these social occasions. Everyone has been so positive and an amazing support for each other. We have a real mix of personalities and life experiences to share; it's just great to be able to relax and chat openly for a few hours with others who 'get it'.

Note from Editor

Although initially started by the working age group the informal pub meet is open to all.

## Movers and Shakers

Movers and Shakers is a new podcast. It finds six friends – Rory Cellan-Jones, Gillian Lacey-Solymar, Mark Mardell, Paul Mayhew-Archer, Sir Nicholas Mostyn, and Jeremy Paxman – gathered in a Notting Hill pub to discuss the realities of life with Parkinson's. And maybe find a few silver linings.

<https://open.spotify.com/show/4dipKcMG0locnGsdRmB2n>

## Neuro Heroes

Liz Roberts reports

This is a commercial operation run by neuro physiotherapists who run online exercise classes at different levels for people with Parkinson's and other neurological conditions. They are a Community Interest Company with a Community Interest Fund which hopes to attract funding so that those who are unable to afford the cost of the classes could be subsidised. Its aim is to attract people with Parkinson's who are unable to attend live exercise sessions. There are different levels of classes and participants would need to complete an online assessment so they can be allocated to a suitable class. The physios will interact with participants, correct movements where necessary, and give advice.

Details of classes and costs can be found at [www.neuroheroes.co.uk](http://www.neuroheroes.co.uk)

## CUE1 Review

By Denise Baldwin

I was diagnosed with Parkinson's in February 2014 although I had symptoms for a year before that.

When I had a chance to try the CUE1 I jumped at the idea. Thank you Sue for letting me try and buy your CUE1, last time I looked I was 1900 on the waiting list for one.

Although sceptical at first I believe in trying anything to improve life.

Life has been tough the past year with endless falls, resulting in many trips to A&E with broken bones or the latest four stitches to the side of my head.



For a while I was unable to walk at all; freezing constantly I ended up using a wheelchair indoors as well as outside. Things improved after a visit to Dr Kimber who increased by meds drastically (he has a horrible job after all he can only do so much). But still I had no confidence walking unaided and used a frame indoors.

Then I tried CUE1. I couldn't believe the difference. I was amazed. I was sitting at the table and got up and walked without reaching for my frame. I now walk most of the time indoors unaided, from one end of our bungalow to the other, even outside to the car and back indoors.

I still have off days when freezing rears its ugly head again but I just relax and it passes without a drama.

I know CUE1 is no miracle cure and not suitable for everyone, but if you have problems with mobility its worth a try.

It hasn't reduced my tremor or dribbling. I still can't write or dance but my mood is lighter.

Looking at the results I think stress has an enormous affect on symptoms whether good, bad, happy, exciting or sad things.

Days when I have an appointment eg dentist my freezing worsened,

I hope one day to be walking outside again but for now I am grateful for what I have and can do.

## **CUE1 trialled at Addenbooke Hosptital**

The CUE1 is being trialled within a hospital setting for the first time.

Alistair Mackett, who specialises in Parkinson's disease at Cambridge University Hospitals Trust, said: "I felt that it was exciting to trial the CUE1 devices as they have been shown to be safe with almost no side-effects, yet potentially helpful with mobility and a reduction in falls."

"In the UK almost 1,000 people already use the device. We are the first hospital in the world to use them with inpatients."

"The pilot will allow us to collect data and understand how best to use the CUE1 device in people with Parkinson's who have been admitted to hospital."

He said: "Addenbrooke's Hospital usually had between 20 and 30 inpatients with the disease at any one time".

"My hypothesis is that we might be able to see an improvement in mobility, allowing patients to better participate in therapy and hopefully go home quicker," he added.

## **Singing is great therapy for People with Parkinson's.**

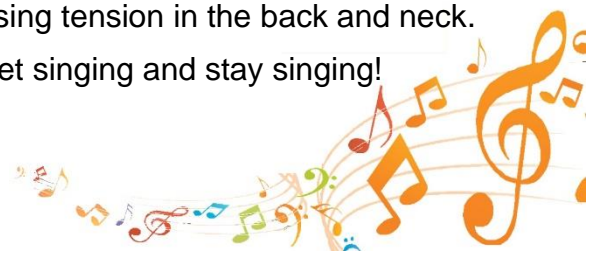
Report by Sue West

Speech impairment is not one of the symptoms people immediately associate with Parkinson's. However, it affects about 75% of people with the condition. The voices of sufferers typically become quieter, more monotone with less variety in volume, intensity and pitch. This can cause people to become increasingly socially isolated with an associated drop in quality of life.

Singing can help to counter this. It strengthens the muscles which control rhythm, tempo and tonal changes. Since these are the same muscles that control swallowing and breathing, singing can also help to reduce problems associated with these vital aspects of life.

Singing in a group is fun. It gives you that feel good factor, lowering stress hormones and increasing endorphins. Research has shown that singing can also relieve other symptoms of Parkinson's such as tremor and issues with walking and posture by relaxing muscles and releasing tension in the back and neck.

So, get singing and stay singing!

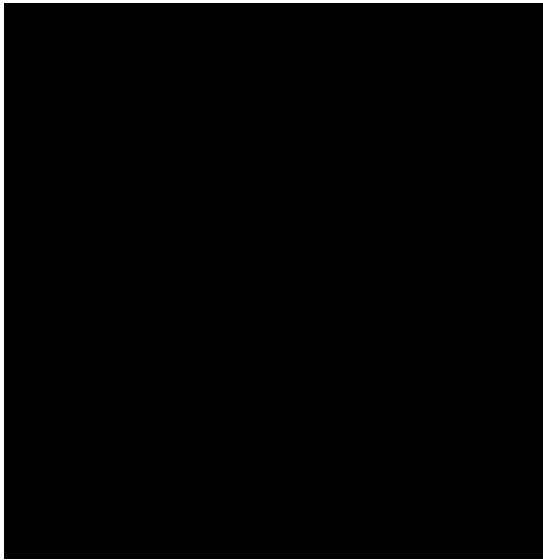


### **Campaign News**

## **New Ambassador**

Northern Irish broadcaster and journalist, Claire McCollum, has joined Parkinson's UK as an ambassador.

Best known for presenting Songs of Praise, Claire has joined Parkinson's UK to help promote the work we do and encourage others to get involved. Claire's dad, Sam, lived with Parkinson's for over 12 years, and sadly died in March 2021.



## PUK gains award for health information

Parkinson's UK has been recognised for providing reliable, accurate and trustworthy health information.

The charity are excited to say that we've been awarded the Patient Information Forum (PIF) TICK. It is the UK's only quality mark for print and digital health information.

Having the PIF TICK means that the charity's production processes have been reviewed by an independent body, ensuring the charity's health information is high-quality and developed in line with best practice.

To be successful, Parkinson's UK were assessed against certain criteria. This included:

- Using reliable, up-to-date evidence to produce our information.
- Writing and designing our print and digital content in a way that is clear, easy to understand and in plain English.
- Developing and testing all of our information with both users (people living with or supporting someone with Parkinson's) and subject matter experts (health and social care professionals).

Research has found that 80% of the public would look for a quality mark on health information. It's important that we're providing reliable, accurate and trustworthy health information about Parkinson's to those who need it most.



## Research Roundup

By Mike Onley

Parkinson's UK organise, fund and publicise a comprehensive research program. The charity publish a periodic document titled "Our Research Projects" the most recent of which details their focus for the years 2022/2023. There is a link to the document below for those of you who would like more information.

Research projects have been divided into two groups:

- Cure projects, work towards treatments to slow, stop or reverse Parkinson's, and include new treatments and improving diagnosis and monitoring of the disease.
- Life projects, work towards treatments to improve the symptoms and general quality of life for PWP. They include therapies and apps to help with issues such as falls, gait freeze, anxiety and memory problems.

Projects are also classified according to the stage of research.

Scientific discoveries make up the initial stage, in which researchers try to find out what is causing Parkinson's and how we can fix it.

Developing treatments make up the second stage, where dedicated teams look at the most promising scientific discoveries and try to develop potential new treatments.

Clinical trials can then be carried out once new treatments have been proven safe and effective and ready to be trialled in volunteers.

Parkinson's UK use charity funding to make active research grants to approved projects. Your committee at the Horsham Parkinson's group regularly give monies to selected projects after reviewing them with the information available from Parkinson's UK. What we have tended to do in the past is fund a variety of Cure and Life projects. We try to include both early scientific discovery, research and later clinical trial projects which we think could have benefit to you all.

which may be effective against Parkinson's disease.

Finally, for now, there are several projects looking at helping mechanisms for the physical symptoms of Parkinson's disease. These include gait freezing, drooling, speech therapy and physio.

There is a huge amount of information available so take a look at the PUK research, handout or visit [parkinsons.org.uk/rsn](http://parkinsons.org.uk/rsn) if you are interested in taking part.

I also recommend visiting the Charco Neurotech website for a look at their CUE1 gadget, more on that in the next edition.

## Contacts

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[johnandcarolmatthews@hotmail.com](mailto:johnandcarolmatthews@hotmail.com).

Cathy Stead: exercise groups Horsham Hospital, landline 01403 731072 Mobile: 07789 778094 e-mail [cathstead@yahoo.co.uk](mailto:cathstead@yahoo.co.uk).

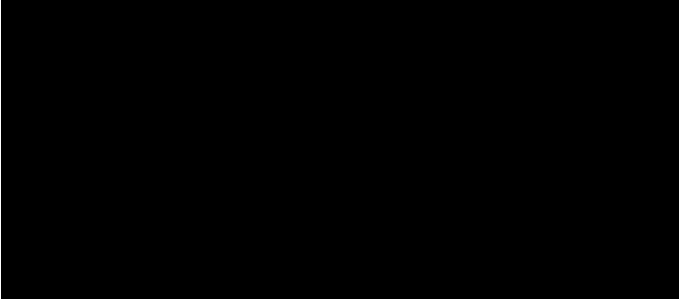
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Stevie Lewis, Horsham Parkinson's Nurse tel 01403 620 437 or e-mail [sc-tr.parkinsonsdiseasenurse@nhs.net](mailto:sc-tr.parkinsonsdiseasenurse@nhs.net)



Research into Parkinson's disease concentrates on several specific areas. The biggest area of funding is currently the Parkinson's brain bank at Imperial College, London. This facility provides data and tissue samples for many other research projects.

There is much emphasis on how the brain cell recycling system works, and on how to improve it. Scientists accept that formation of clumps of poisonous alpha-synuclein protein in the dopamine producing cells of the brain can damage these cells. This impedes the body's ability to produce dopamine which is directly linked to Parkinson's disease. There is much speculation that alpha-synuclein is actually produced in the gut and then transferred to the brain. With this in mind, researchers are looking at the effectiveness of probiotics to improve gut health.

Another area of interest is growing brain cells using skin tissue to provide research opportunities. The ability to mass-produce stem cells from skin tissue is also becoming a reality. Scientists think that direct injections of dopamine producing stem cells into damaged areas of the brain may be beneficial in the future.

Early diagnosis of Parkinson's disease is also an area of interest. The sooner Parkinson's is diagnosed the better in terms of treatment. Once symptoms become obvious, it is thought that over 80% of dopamine producing cells have already died. Genetic links are a big area of research, Gene mutations are also thought to be relevant to the onset of Parkinson's disease. Blood markers are also being investigated. in the future, a simple blood test may be used for early diagnosis.

Another area of research is into the inflammation of brain cells. It is thought that there may be a link between the body's immune response system and this inflammation in PWP.

The relevance and effectiveness of drugs for other conditions are also being considered. Examples include probiotics and epilepsy drugs,