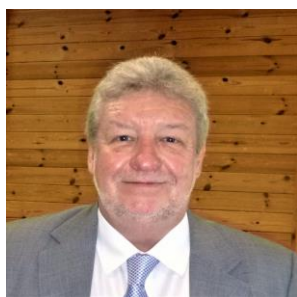


OUR NEWS

Huntingdonshire Branch

www.huntspds.org.uk

April 2024



Thoughts of Chairman Malcolm

On Monday 25th March we held our AGM via Zoom. Regrettably, it was badly attended though the necessary formalities were completed, the minutes will be circulated to everyone for comment.

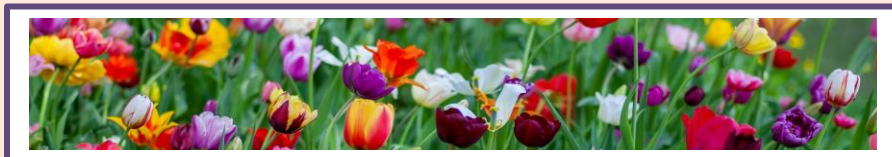
The success of the Café at The George in Huntingdon has meant that it has been

Repositioned to the MS Centre at a different day and time. Sarah's therapy class at the MS Centre has proven to be very popular, and she is going to start a second class, details for both in this Newsletter. We are hoping to start a Café in Ramsey soon, more details as it evolves.

The Chase Care Home in Huntingdon is going to have a cake stall in Huntingdon and a similar one in St. Neots on World Parkinson's day 11th April, please come along and support them.

Sunshine arrived in my village yesterday after a prolonged period of incessant rain, I hope the embryonic start to Spring along with the putting forward of the clocks will catapult us all into a revitalisation.

Malcolm



In Memorium

We are sorry to let you know that Philip Gibbs, one of our previous Chairs of the Huntingdon Branch, passed away peacefully on 19th March 2024. Many of you will recall this knowledgeable and kind man, who gave a lot of support to people in our branch. Philip attended a lot of our events, wrote some beautiful Poetry and had a fine voice if you were lucky enough to hear him sing.

You are invited to his Committal Thursday 11th April 2024 at 12.15 pm at Norse Road Crematorium, Bedford MK41 0RL, and/or his Memorial Service on Thursday 11th April 2024 at 1.45pm at United Reformed Church, High Street St Neots PE19 1BN.

Our condolences to his wife Jenny and his family at this sad time.

This Month and Next

Dates for your Diary...

St Neots Café

The Priory Centre PE19 2BH
16th April and 21st May

Huntingdon Café **New Venue**

MS Therapy Centre, PE29 1UL
2nd April, 7th May

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Parkinson's UK Activity Dates

(Please check with organiser if any changes)

Face to Face Activities

Date	Activities	Contact
16th April 21st May 2.00 – 4.00pm Coffee and Chat 3rd Tuesday of the month	St Neots Café The Priory Centre Priory Lane PE19 2BH	Malcolm Ryman Tel: 07720 080749 Email: malcolm.ryman1@btinternet.com
2nd April 7th May Coffee and Chat 10.30 am – 12.30 pm 1 st Tuesday of the Month	Huntingdon Café New Venue! Cambs Therapy Centre, Bradbury House, Huntingdon PE29 1UL	Suzanne Ford Tel: 07592 639374 Email: suzanneford346@gmail.com Or Malcolm Ryman as above
April and May 11.00 am – 12.00 pm Every Friday	St Ives Exercise Group with Becky Meets at the Crossways Church	Email beckyadamsrehab@gmail.com
April and May 11am – 12 pm Every Thursday	St Neots Exercise Group with Daniel United Reformed Church, High Street, St Neots, PE19 1BN.	Email danielgodward14@gmail.com
April and May 1.30 – 2.30 pm Every Tuesday (except Third Tuesday 11.30 – 12.30pm) Every Thursday Meets in the coffee bar first	Love to Move New Venue! New Dates! Cambs Therapy Centre, Bradbury House, Huntingdon PE29 1UL	Email sj-performing-arts@hotmail.co.uk Mob: 0771 265 8001
April and May Last Saturday in the month	Young and Active Parkinson's Group (YAPA) Various Venues	Julie Wilson Email jmwilson@parkinsons.org.uk Tel: 0300 123 3675

Parkinson's Nurse Team News

We are working closely with the Consultants as a Team, we have clinical supervision with 4 consultants per month online (TEAMS) for learning/development. This is with Physicians, Geriatricians and Neurologists in both Peterborough City Hospital and Addenbrookes.

Also, as Parkinson's Nurses we are all working well within our own link roles of interests, which helps develop our service. This is within falls, admission avoidance, Parkinson's Plus, advanced therapies, dementia, research, palliative care, bowel and bladder management – which helps us develop our skills and knowledge, and offer more robust care planning to our patients.

Working with the Parkinson's Disease Nurse Specialists at Addenbrookes for admission avoidance is going to be so beneficial for both secondary and primary care services.

Becky Slimmon
Parkinson's Disease Specialist Nurse

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Huntingdonshire Branch AGM

This years AGM was held online by Zoom on 25th March. With a low turn out of members, we have circulated the draft minutes to our members so that you can query, clarify or challenge any decisions.

The minutes for the 2023 meeting were approved, as were the Chair's and Finance Report. Malcolm Ryman has been elected as Chair, Ildiko Drexler elected as Treasurer.

Lisa Lowe took the chair for the elections for Parkinson's UK, and talked through the various developments and support being provided by the charity. This included the numbers of calls to the Helpline, home visits made, help with benefits from the Welfare Team, Call Companions befriending scheme (see page 8) physical activities being funded, and research progress achieved this year. She also spoke about World Parkinson's Day, that will be 11th April this year.

More information will be circulated to you by email or post depending on your previous choices.

New Venues, New Opportunities!

There are changes over the next couple of months, Suzanne has let us know the Huntingdon group is moving to the Cambs Therapy Centre (MS Therapy Centre), the meetings will be the first Tuesday of the month starting from 2nd April. We have had links with the Therapy Centre over many years, having previously held our music and dance groups here. It is a welcoming and comfortable venue, and has good food and drink available.

Sarah has also changed her Huntingdon Exercise Group venue to the Cambs Therapy Centre, so we are building up more connections there! Sarah has is adding another class on a Tuesday in addition to her Thursday group, and this will start on Tuesday 9th April.

The St Neots Group needs to change from the Priory Centre due to refurbishments there, and we are also looking into the possibility of a Ramsey Group. We will keep you informed of any changes as soon as we know more.

Joy's Tip



You never know what you will learn at a Café meeting, and in the March St Neots meeting it was no exception!

Joy has been experiencing dystonia and cramps in her feet and toes, which are most uncomfortable. She was advised to try using one of these spiky massage balls, that she rolls around the arch in her foot when she has discomfort, and she advises it give her a lot of relief especially at night.

These balls are quite reasonably priced and you can find them online or at physiotherapy supplies. Have a chat with your Podiatrist, Parkinson's Nurse or other health provider, to find out if this would help you too.

Young and or Active Parkinson's Cambridgeshire Brunch

Julie Wilson our local Area Development Manager would like to invite you to the groups next meeting on 27th April. The Group meets monthly on the last Saturday of the month, at different locations each time.

The April meeting will be at the Visitor Centre, Ferry Meadows, Nene Park, Peterborough at 10.30 am. There will be a brunch session and if you want to have a walk afterwards, bring your trainers and have an amiable amble! There is a charge for parking that is about £2.80, and you can pay by card or cash.

For more information you can contact Julie by email on jmwilson@parkinsons.org.uk or by phone on 0300 123 3675

New Blood Test to Potentially Diagnose Parkinson's



There has been a new promising development in the potential diagnosis of Parkinson's. Research published in Science Translational Medicine has focussed on identifying DNA damage in mitochondria, the energy producing batteries within cells, that have been linked with Parkinson's. Their research indicates that the same mitochondrial DNA damage can be found in blood cells.

This discovery could potentially pave the way for a definitive diagnostic test, that currently does not exist.

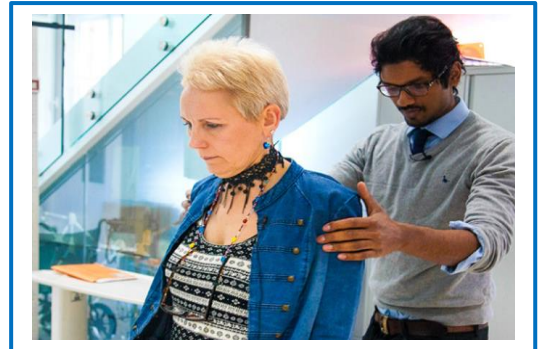
By being able to detect Parkinson's earlier, this will improve the opportunity to access timely support and treatment, and also early detection brings hope that there will be an opportunity to halt or prevent the condition's progression in the future when better treatments become available.

Parkinson's UK Clare Bale, Associate Director of Research, advises that further work is needed to develop the test, but is hopeful that biological tests for Parkinson's will be available in the next few years to provide an earlier and more accurate diagnosis.

New Treatment Available for Movement Related Symptoms

From 27th February this year, a new treatment will be available on the NHS in England. Foslevodopa-foscarbidopa also called Produodopa was approved last year by the National Institute of Health and Care Excellence (NICE), specifically for those who have movement related symptoms.

Initially helping around 900 people, hospitals will need to arrange the right training, resources and support. Each hospital is at different stages in setting these up, so therapy may not be available locally for a short while.



So how does this treatment work? The medication is delivered via a small pump, providing medication 24 hours a day from a syringe. The syringe is inserted under the skin, similar to another existing treatment called Apomorphine, that some people with Parkinson's use. It is also possible with this system to provide an additional dose, helping gain more control over your condition.

With this treatment, the medication will provide continuous symptom management, day and night. This may potentially help with those whose symptoms are not well controlled by oral medication, and who experience fluctuations and "off" periods. It may also help those not suitable for other treatments such as deep brain stimulation.

Laura Cockram, Head of Campaigns at Parkinson's UK advised this could have a big impact on families' lives, and enable people to better manage their symptoms.

Phil Hockey, who has had Parkinson's for 6 years and has experienced this treatment was positive about the results.

"When my oral medication stopped being as effective and my "off" periods were a significant part of my day, I signed up for a clinical trial of the drug.

"I was surprised at how effective it was at controlling my symptoms. Having the pump working 24 hours a day is a key benefit and it gave me back a degree of control in the management of my symptoms. It even means a return to my favourite sport – cycling!

"I'm happy that people with Parkinson's may be able to receive the benefits from this new therapy and, and I'm hoping this is the start of future developments that will help as many people with the condition as possible".

If you would like to find out more, please speak to your Consultant or Parkinson's nurse to discuss further, as this treatment is not suitable for everyone.

Huntingdonshire Consultation Questionnaire

We are aware we are seeing less people at our groups and events since Covid, and want to make sure that we are guided by our members so that we are offering the right activities in the future. Please help us by completing this confidential questionnaire so we can plan for the future together. Please tick all answers in the questionnaire that apply to you, or add any suggestions.

1. What is your primary reason for being part of Huntingdonshire Branch?
Friendship Keeping Active Entertainment Information
Other -
2. Would you find a Zoom Meeting helpful to you?
Yes No
3. Where are the best places to run our groups?
St Neots St Ives Huntingdon Ramsey
Other -
4. What kind of meetings would you prefer?
Group meeting Coffee Morning Pub Lunch/Dinner Walk and Coffee
Other -
5. What kind of content would you like in the meetings?
Guest speakers Quizzes Games Tea/Coffee
Other -
6. How often would you like the meetings?
Weekly Fortnightly Monthly
7. What days of the week would you like them to be? (Please tick any that apply)
Monday Tuesday Wednesday Thursday Friday
Saturday Sunday
8. What time of day suits you best?
Morning Afternoon Evening
9. What activities would you like the Branch to run?
Exercise Outdoor Walking Group Nordic Walking Group Dance
Singing Mindfulness
Other suggestions -
10. What other one-off activities would you like during the year?
Christmas Meal Cream Tea Boat Trip Coach Trip
Other -
11. Do you look at the Branch Website www.huntspsds.org.uk?
Yes No
If yes, is there anything you would like added to the website?
12. Do you have any other suggestions that you would like us to consider for the future of the Branch?

On completion, please email a scanned copy back to huntsbranchnews@gmail.com, or send by post to Malcolm Ryman, 6 Manor Close, Brampton, Cambs, PE28 4UF

Many thanks for taking the time to complete this questionnaire

HiVis Event



For those that have difficulties with their sight, you may be interested in this event that is being held in Huntingdon Library. The event will be held 10am – 12 noon on Friday 14th June.

The aim of the event is part of an annual campaign, HiVis Fortnight, bringing together public libraries and blind and partially sighted people in an effort to improve access to books and information.

There will be an opportunity to try out devices, and find out what services are available in Cambridgeshire Libraries.

Turn up on the day or, to find out more, please contact Rebecca Iddon Rebecca@huntsblind.co.uk or 01480 453438 (option 6)

Grief Café at Pinnies Godmanchester

Pinnies tea rooms in Godmanchester have launched a 'Grief Café' on Mondays twice a month. This is a support group for anyone who has experienced bereavement and wants to have a chat and share thoughts and feelings over complimentary tea, coffee, and pastries.

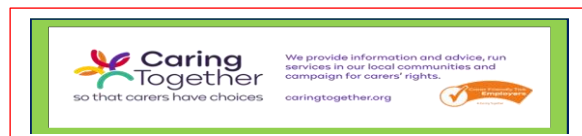
The café is open from 10.30am – 12.00pm twice a month on Mondays and all are welcome. Their address is 18d Causeway, Godmanchester, Huntingdon PE29 2HA telephone 01480 453555.

For more information contact Karen Berkley at email karen.berkley@cambridgeshire.gov.uk or telephone 07341 881073.



Carers Update from Caring Together

Huntingdon Carers Hub
9th April, 10.30am – 12.30pm
Coneygear Centre, Huntingdon PE29 1PE
2nd Tuesday of the month



Meet with other carers, have a chat, and get support from one of the Caring Together Advisors, join in relaxing activities or learn from local speakers. Please contact Caring Together on details below if you would like to join them, and you can find out more about the Carers Hubs [here](#).

If you would like more details on carer support locally or their activities, please contact one of Caring Together's care advisers for help and advice, by emailing them at hello@caringtogether.org, or by phone on 0345 241 0954. They can help with

- Emergency Planning – the What If? Plan
- FREE Caring Magazine
- Email newsletter for carers, those who support carers, and everyone that has an interest in ensuring that carers are recognised and supported
- Help to attend your own medical appointments, or in time of crisis through the Family Carers' Prescription
- Carers Hubs
- Carers Card
- Education and Social Sessions
- Homecare and helping you enjoy activities in the community
- Information on Carers' Assessments

Please contact them to find out more, to gain valuable support for yourself if you are a carer.

A Recollection of David Rudd

I was bored. I don't often say that, but the evening shift in a British Rail booking office could be too quiet on a Sunday in 1954. In summer there were sometimes excursion trains to liven the day, mostly to Skegness. Families with excited children and a measure of chaos during the early shift, then the return during the late shift, the children fractious or sleeping draped across a parent and inevitably one family with parents one side of the barrier, children on the other.

But this was winter: few trains and few passengers on Sundays. So, by about nine o'clock I had nothing to do but wait until ten. No sign of the porter. I cashed up then. Not much, just 17/6d for a period return to London, taken by John after he had cashed up on the early shift. That was in the safe with the previous two days' takings, the only cash in the old till was the float to start with in the morning. The till probably dated from 1850 when the station opened. It was a drawer fitted under the counter with sections for copper, tanners, bobs, larger silver and a clip to keep paper money in place. It once had a lock but that had disappeared long ago and nobody bothered.

The office as you will have gathered was old-fashioned and inconvenient. The counter was L shaped, a door in the corner giving the public access to the leg of the L we didn't use: it was for people who brought a parcel to go by passenger train – or sometimes a Railway Letter; remember those?

Suddenly I had visitors. Three men. It didn't feel good. They wore black overcoats and black trilby hats. I'd seen the like in films and they were never up to anything good. There wasn't one smile between them. They were sinister. Cold. Frightening. I can't say my blood ran cold because obviously, it didn't: it just felt like it. I realised I had no escape route and was alone. They arranged themselves in formation: the one who could speak at the front, the other two behind his shoulders.

'Can I help you?' He asked for train connections to somewhere I'd never heard of. I asked where it was. He said it was south of London. Southern Region then. I didn't like the SR timetable at any time; it was twice as thick as the other regions' and more complicated. I was struggling with the unwieldy book; he was looking round. The other two were staring at me! Expressionless faces glaring. He stretched upwards with his hands on the counter. What was he doing? What had he seen? (It's surprising how much you can see in peripheral vision when necessary). I had left the till open! He was peering into it estimating how much was there. 'Never mind' he said. They left. I relaxed.

We never left the till open when we moved away from it, but their appearance just as I had counted the float into it took me off guard. Never have I been so grateful for an error! Only a handful of silver. If the till had been closed it might have been.... who knows?

The porter and a smell of beer came in. 'You awright? Didn't like the look o' that lot. Creepy. They 'ad a car outside. Didn't turn the lights on 'til they got to the main road. As long as you're awright.' 'Yes thanks Ted. You can lock up now, it's only half past nine but I'm going home.

I have not mentioned this to anyone until now.



Parkinson's Virtual Biotech

Do you know about Parkinson's Virtual Biotech, and how this is working towards life-changing new treatments in years, not decades?

Parkinson's UK have a strategic partnership with the Parkinson's Foundation, to enable them to invest in the Parkinson's Virtual Biotech, that is a research driven investment fund. Parkinson's UK already fund research grants and are involved in a global genetics study, but the aim of the Biotech is to invest in drug discovery and investment so that people do not have to rely on a therapy that is more than 50 years old.

The aim is to –

- Develop new therapies or approaches, towards greater understanding of the disease
- Increase resources for research and development
- Partner with a range of industry organisations, with a view to lead and direct resource
- Develop a people first approach for new discoveries and development.

Some current studies in developing treatments are [Project Galaxy](#) - looking at how to target inflammation in Parkinson's, [Project EndLyz](#), - finding ways to boost cell recycling in Parkinson's, [Project Sheffield](#) - looking at ways to restore the power plants of brain cells, Project NRG – targeting brain cells to slow Parkinson's progression and [Project Eurofins](#) – creating new drugs to improve symptoms and slow Parkinson's.

Current clinical trials are [Project Neurolix](#) - a phase 2 trial for treating dyskinesia, [Project Top Hat](#) a phase 2 clinical trial looking at the potential of ondansetron for treating hallucinations, [Project CBD](#) – a trial to investigate CBD and Parkinson's related psychosis, [Project Enterin](#) – looking at a new treatment for Parkinson's related dementia, [Project Pharmaxis](#) a phase 2 clinical trial – to relieve symptoms and target inflammation to slow the onset of the condition, [Project GDNF](#) and [Project ASPro-PD](#) – a phase 3 trial looking at the potential of Ambroxol to slow down Parkinson's progression.

Find out more by calling the Helpline on 0808 800 0303 or by clicking the link [here](#).

Call Companions – A Regular Friendly Phone Call

Parkinson's UK are working with Re-engage to offer a new telephone befriending service to older people over 60 with Parkinson's and with their carers.

Re-engage is a national charity that provides a call companion service across the UK.

This is a free service, and you can refer yourself. Once you have referred, you will be matched with a friendly volunteer that has similar interests who will then be able to call you every 1-2 weeks.

It can be a general chat, or about anything you like. The volunteers are fully trained and know about Parkinson's but you don't have to talk about Parkinson's if you don't want to.

To use the service, you must be

- A person with Parkinson's, and or a carer of someone who has Parkinson's
- Age 60 or over
- Confident Using the telephone

To refer, use the online link [here](#) or alternatively call the Helpline on 0808 800 0303.

Useful Contact Numbers

BRANCH CHAIR

Malcolm Ryman

07720 080749

VICE CHAIR

Vacant

PARKINSON'S UK CONFIDENTIAL HELPLINE

0808 800 0303

(Also access to Parkinson's Local Adviser)

Email: enquiries@parkinsons.org.uk

PARKINSON'S DISEASE SPECIALIST NURSES

0330 726 0077

BRANCH MOBILE

07724 400527

FACEBOOK PAGE

Parkinson's UK Huntingdonshire

BRANCH EMAIL

Huntsbranchnews@gmail.com

PARKINSON'S UK WEBSITE

www.parkinsons.org.uk

This Newsletter is compiled to the best of our knowledge from information available at the time of publication.