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The Park

Magazine

MAY 2020



GUILDFORD AREA BRANCH MEETINGS 2020

Meetings are held at Shalford Village UPPER Hall from 1.45 pm on the LAST Tuesday of the month

IMPORTANT NOTICE

Covid-19 pandemic

Due to the current situation it has been necessary to cancel all meetings and exercise classes including the summer Cream Tea in July. We hope we will be able to start again in September but to be confirmed.

STAY SAFE AT HOME AND CHECK OUR WEBSITE FOR UPDATES

www.guildfordparkinsons.org.uk

September 29th Bowling on the green—yet another year with Shirley. All equipment provided, wear flat shoes

October 27th

November 24th

Wednesday December 9th—Christmas Lunch

Cover photograph: Wisteria at Pyrford Court, Ripley.

A message from our Chair, Niki Tompkinson

Support for our members during the Coronavirus outbreak.

Dear All

First, I hope that you are keeping well during this very difficult period. Many of you will be practicing a degree of self-isolation, and all of us are having to practice social distancing and are physically separated from family and friends. But many measures have been put in place by government and other agencies to help those who need more support than friends, neighbours and family can provide. Here are a few numbers that might help you in case of special need:

Parkinson's UK helpline – 0808 800 0303

Surrey County Council new helpline (weekdays only) - 0300 200 1008

Waverley Adult Care – 01483 518990 Monday – Friday 9 am to 5 pm

Guildford Adult Care – 01483 517262 Monday – Friday 9 am to 5 pm

Out of hours number for both of the above – 01483 517898

Surrey and Borders Mental Health team – 0800 915 4644 24 hours

Exercise and social contact

All our regular meetings continue to be on hold and many of you will also be missing your attendance at your regular Parkinson's exercise class, Pilates, or the choir. It is so important to keep active and connected – more now than ever before – and I am delighted that our key providers have all managed to put something in place to replace the regular classes and gatherings, using modern online technology.

Those who were already participants will have heard from their provider and given an opportunity to take part in a different sort of activity.

Others of you might like to think whether there is something here for you too!

Parkinsong Voices Emily Bollon has very successfully trialled her choir session online using a live video link. Members can now join the choir live online from their PC or tablet and join in the singing. Want to join in? Contact Emily on 07807 504738 for more details.

Pilates Sue Buckland has set up a service to send regular PACET (Physical Activity and Cognitive Exercise Technique – based on Pilates) exercise videos to her existing class members and to also keep in touch with them by phone. These videos are for seated exercise, so is quite safe for anyone new to try. There will be at least one new exercise video each week. Interested? Contact Sue on 01483 285111 or 07914 512573. You can also look at her promotion video by clicking here <https://video.com/344836554>

Exercise by Surrey Hills Rehab Kim Wilson and her team are offering online video exercise sessions and are aiming to stream three sessions per week based on ability for existing clients.

PD Balance (mainly seated for those at risk of falls)

PD Fit (mainly standing)

Young PD Fit (people able to run/jump/hop) if you are new to exercise, it might be hard to carry out the necessary pre exercise assessment by telephone but do give Kim a call on 07976 849903 if you would like to be considered.

Exercise by Foundations Physio Adam Poulter and his team are developing online 30-minute exercise consultations for their existing members. These will be individual 'one to one' online sessions with one of their physios for those clients able to use such a service. They aim to run these 'one to one' sessions for each individual every 2 weeks. These will be for existing clients only because of the difficulty of carrying out pre exercise assessments remotely. As well as these 'one to one' exercise consultations, they are also preparing some general exercise videos for our members which will be for anyone to access online, and to do at their own risk.

For more details, please contact Adam on 07817 495791.

Member Payments towards Classes - Donations

In the past, participants have contributed to the cost of their classes but, during this difficult and unusual period, the Branch will be picking up the full costs of the above services that are being offered.

We would however be very grateful for any donations that anyone would like to make to Branch funds, which, added to the remaining Legacy money, should enable us to keep going for the rest of this year and maybe beyond.

There are two ways of making a donation –

1/ Make an on-line transfer direct to the Branch account HSBC, Sort Code 40-22-26, Account No. 71151746.

You should notify Steve that you have done this by emailing him on sheron@guildfordparkinsons.org.uk

2/ Send a cheque, payable to Parkinsons Disease Society Guildford and send it to Steve Heron, Branch Treasurer, 11 Merrow Woods, Guildford GU1 2LQ.

You can increase the value of any donation by completing a Gift Aid declaration, and it does not cost you anything extra.

Providing you are paying income tax, by using Gift Aid we can claim tax back at the rate of 25 p for every £1 you donate, and in these difficult times every penny counts!

You only need to complete the declaration once, then any future donations over the next 4 years will be covered for Gift Aid. The Gift Aid declaration form is included, and once completed should be sent by post to Steve Heron . (see pages 25-26)

If you have previously completed a Gift Aid declaration to Parkinson's please let Steve know when you make your donation so that he can ensure your donation is included in any Gift Aid tax back claim.

Finally, all the Branch committee are here to support you too.

Do not hesitate to let us know if you need anything else – even just a chat – and we will do our best for you.

Looking forward to happier times when we can all get back together again!

Niki Tompkinson

Chair's report to the AGM – 25 February 2020.

Overall, a busy year during which the Branch's programme of activities has continued to grow and, we hope, meet the needs of our members. Membership is around 300 and we have welcomed a steady trickle of new members.

Branch meetings and social events.

The Branch has continued to meet every month (now firmly booked for the last Tuesday of the month, to avoid any confusion over the fourth Tuesday!) Attendance is usually around 25 to 30 with a range of activities, speakers etc. Thanks are due to our Vice Chair Hilary who is energetic in her search for different attractions, and to Angela and others for their help and support in organizing the meetings and in the all-important provision of tea, cakes, raffle etc.

In addition, the Working Age Group has also continued to meet monthly on the 3rd Tuesday evening at the Withies pub in Compton. Attendance is of a similar level i.e. around 25. There have been some evenings with a speaker, or an activity, and some purely for socializing, plus some trips further afield. Thanks go to Keith and Val Black, Sharyn Bullen and others who organize these meetings.

We are fortunate to have a choice of meetings and events for our members to choose from – everyone is welcome at any or all, and there have been a number of joint occasions. Best attended of all was the Christmas lunch with a record attendance – 102 participants! Thanks to Margaret, Angela and Hilary for the huge effort required for making this occasion so popular and so memorable.

Activities.

As our Treasurer has reported, a great deal of effort and resources have gone into the various exercise and therapeutic activities which the Branch organizes and subsidizes, mostly from our legacy income. These continue to be well attended and are an important part of the committee's provision for members, bearing in mind that research continues to emphasise the importance of exercise in managing the symptoms of Parkinson's – as important as medication according to some. Our contracted providers currently offer weekly exercise classes in Cranleigh, Godalming and Haslemere, and Pilates in Clandon. There have had to be some changes to the timetable due to one of our longstanding providers (Sam Goodwin) leaving, but we were lucky to find an alternative (Foundations Physio) to take over without a gap. The Parkinson Voices, meeting weekly at Binscombe, has grown and is a popular and valuable way of getting some speech therapy alongside making excellent music.

The committee keeps all these activities under review to ensure that they offer good value for money and meet a real need. We also try to make information available to our members of alternative opportunities, as and when we hear of them.

Respite care.

Working with Crossroads Care, we have been able to support some of our members who have needed more respite care than the local authority has been able to provide. Take up has not however been as good as we had thought, and we would welcome other ideas to assist carers.

Communications with our members and beyond.

We have tried to keep members informed of events and activities, and of any other relevant information. The Park was published 3 times last year, and thanks go to Anne Folkes, our Editor, who has been so effective in building on what had been done before and producing such a high-quality magazine, full of interesting reports and information. In addition, we maintained our own website which is a good source of information for those of you happy to read things on-line. Our web manager, Mike Searl, is a (non-local) volunteer for us, and for other charities, and does the “techie stuff” swiftly and helpfully. Our own Membership Secretary, John Oldham, has been active in recent weeks in managing the content so that it is kept up-to-date and relevant, but we urgently need someone who can take on this task. The Working Age Group are also active communicators – Keith and others regularly pass on items of interest e.g. from research papers. Educating and informing others about Parkinson’s is an important task. Parkinson’s UK have a programme of work for this and one of our members, Valerie Box, has been active in giving talks to local groups. Several others helped at a recent highly successful event at a local school, where the children were encouraged to learn about the condition and to understand the real everyday effects of living with Parkinson’s. This awareness raising often leads to groups offering donations or to raise funds for us from their own activities. We have received offers of future funding from the Lions. And a welcome donation was made from the Cobham Brass Band’s Christmas performances. Just two examples.

Future plans

Our plan for the current year is to continue with the same programme of activities and events as before, while we have the funds available. We would like to do more for those needing more support for respite care and will be thinking of other ways we might be able to help our members. Looking ahead more widely, we will need to start planning for the post-legacy world.

Work of the Committee

Committee members, supported by a few other volunteers, take responsibility for the various events and activities which we offer. The committee meets every six weeks for two hours at Church House in Guildford. At each meeting we review the programme of events and activities, ensuring that everything is running smoothly, that we are doing what you, our members, find most valuable, and that the finances are in good order.

Our Treasurer, Sophie Cordice, resigned at the end of September due to work and family pressures. Myra Newnes Smith volunteered to “hold the fort” while we looked for a replacement so that we could continue to pay our providers and bank any donations. We are delighted now to have a new Treasurer, Steve Heron, who is getting to grips with our finances in good time to help us work out what to do for the coming year. Two other members of the committee are leaving at this meeting and need to be replaced. We are very sorry to have to say “au revoir” to Angela, who has been on the committee for many years and has been active for our Branch for longer than that, especially in helping to organize events such as the monthly meetings, summer cream tea, Christmas lunch, and many others. So, we have a vacancy for someone to take her place.

Val Black has been on the committee for the past year, improving our links with the Working Age Group and ensuring that our events and activities take their needs into account. Sharyn Black will be able to cover this role, but we would welcome an additional WAG member if possible

We also need someone to manage the content of our website.

Finally, as we are now in our last year of the legacy money, we need to do more to spread the word about the work of the Branch, to communicate with local groups and to coordinate fundraising for the future. Ideas and offers to help with this all-important task are urgently needed. If we cannot replace the legacy funding stream with other sources of funding, then we will either have to scale down our activities or they will have to become self-funding.

So – there are at least four more volunteers needed for a range of jobs. Please think about what you, or someone you know, might be able to offer.

Niki Tompkinson



Treasurer 's Financial Report for the AGM

Income and Expenditure for 2019

Introduction

Branch funds remain positive with a **bank balance of just under £21,000 as at 31st Dec 2019**. This is despite **spending almost £60,000 last year on membership support** activities such as exercise classes, the choir, Pilates and individual member support, as well as the regular social meetings and other gatherings. This positive financial status is primarily because of the substantial amounts of Legacy funds available.

Income

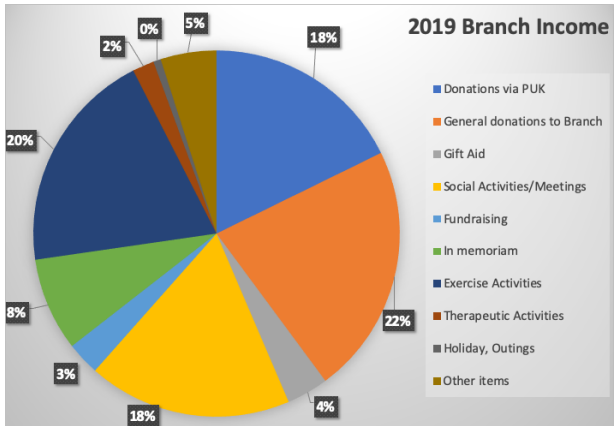
During the year our own Branch efforts **generated £25,420.84** (breakdown below). This is an increase of £5,000 compared to 2018. Almost 80% of Branch income came from 4 sources: Donations via PUK (18%), General Donations to Branch (22%), Social Activities (18%), and Exercise Activities (20%).

This was **supplemented with Legacy funds** of £14,300 in May (final amount from our 2018 Legacy budget) and almost £27,000 in September as the first tranche of our 2019 available budget.

It should be noted there is always a time delay in drawing down Legacy funds with some of the annual budget amount being delivered in the following calendar year. We are currently finalising the final drawdown amount (second tranche) for 2019, likely to be between £15,000 to £20,000. We will then draw down a first tranche of 2020 available legacy funds, with the final 2020 tranche potentially early 2021.

Total Income during 2019 = £66,418.38 [£25k Branch Generated + £41k Legacy (£14.3k +£26.7k)]

Branch generated income was 38% of our total income and in detail came from below sources:

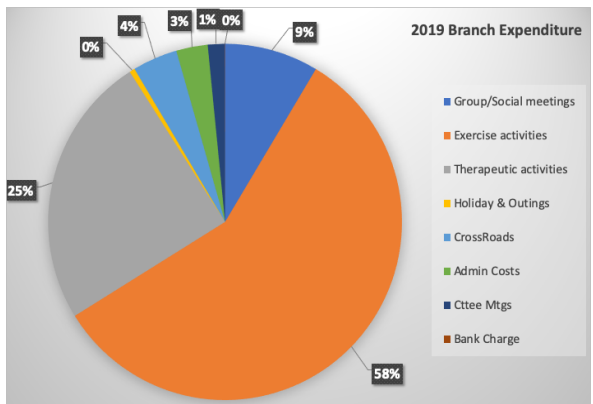


Expenditure.

Our Expenditure for 2019 was £59,758, up by approx. £5,000 compared to 2018.

Analysis of how this was spent is below:

58% of expenditure supported exercise activities and therapeutic activities comprised 25%. Social events totalled 9% of our spend, with then minor activity spending accounting for the final 8%



2020 Budget

Our provisional budget for 2020 is to spend similar amounts (allowing for inflation, etc) on these activities, although there will be some changes to providers, venues and member charges.

This expenditure will be funded through a combination of carried forward funds from 2019, accessing our 2020 Legacy budget and through our own branch generated income.

Final Notes

Although 2020 is the last year we benefit from the Legacy funds, we should go into 2021 in a relatively sound financial position. We will, however, need to ramp up our future fundraising activities to continue to be able to support our members at the same level as has occurred over recent years.

Your committee are actively working on this with some provisional planned events for early 2021. Your ideas and inputs are always welcome.

Steve Heron

Treasurer



GUILDFORD BRANCH AGM 2020

The Annual General Meeting of the Guildford and South Surrey Branch was held on Tuesday 25 February in Shalford Village Hall. A goodly turn out of 35 members and friends assembled and were welcomed by Niki Tompkinson, Chair, and Alastair Jack, Development Manager of Parkinson's UK.

The report on the year was very positive - and Niki outlined the progress made on securing contracts for exercise classes and the well-supported social events. However, with two Committee members standing down, members were urged to give serious thought to volunteering. There was still much to do.

The new Hon Treasurer, Steve Heron, who had literally been in post for only a few weeks, pulled the rabbit out of the hat by tabling a colourful and highly informative analysis of the financial position. The good news is that the Branch is financially secure for 2020- 2021

The business of the Meeting - the Election of Officers and Committee Members - was carried out expeditiously (see below) and Angela Campling, who has given many years of service to the Committee, was presented with a bouquet.

After the election Alastair Jack outlined the aims of the charity and its support of research seeking to find drugs that might slow the progress of the disease. He also stressed that social support for people with Parkinson's and their carers was equally important and congratulated the Branch on having an active and lively membership. The afternoon concluded with tea and delicious cakes - and a fair number of those present were lucky winners of raffle prizes.

Chair: Niki Tompkinson Vice Chair: Hilary Austin

Treasurer: Steve Heron Membership Secretary: John Oldham

Hon Secretary: Sharyn Bullen

Minutes Secretary: Margaret Westwood Editor, The Park: Anne Folkes

Committee members: Myra Newnes-Smith

(2 vacancies).

MW

PARKINSON'S AWARENESS FOR BARROW HILLS SCHOOL

Children at Barrow Hills School in Witley were learning about Parkinson's in January with the help of the local branch of Parkinson's UK. The awareness week was organised by the Head's wife, Mrs. Niki Oldroyd who was diagnosed with the condition at the age of 25 in 1992.

"My particular challenges with Parkinson's are in initiating movement (usually walking) and freezing, where my brain is saying go but my legs are saying no. This causes lack of balance, lack of coordination and often falls. I am very aware that the children see this when I am around the School and may be confused and worried."

The week's events started with an exciting Monday Assembly, led by Mrs. Oldroyd and Parkinson's UK volunteer speaker Valerie Box. Throughout the week the children attended interactive sessions, designed to give them an understanding of the main symptoms of Parkinson's - slowness, stiffness and tremor. As much as possible the symptoms were simulated, allowing the children a glimpse into the world of the 145,000 people in the UK who have the disease (1.2% of people with a diagnosis of Parkinson's are under the age of 50).

"We practiced drinking from a cup, realizing if we had the shakes, we would find drinking without spilling it very difficult," said Aria, age 7. We also found it hard to open a purse and take money out while wearing gloves to feel what it is like to have clumsy fingers". Luke, also 7, commented " we have all enjoyed an amazingly interesting week"

The week culminated on Friday 24th January in a Use Your Head for Parkinson's event to raise funds for Parkinson's UK. Children and teachers were encouraged to donate £2 and wore something silly on their head. From wonderful wigs to silly hats and crazy hair bands, the whole school community supported the event, raising over £500



“Our children learnt about Parkinson's at a level suited to their age, understood the key symptoms and the best way to help, while also having a fantastic day of fundraising fun. There was some spectacular headwear. Events such as this allow our children to demonstrate their compassion towards others, both in school and the wider world" said Mr. Oldroyd, Head of Barrow Hills. “This week has been a great success and the children now have an insight into what it is like to live with a condition such as Parkinson’s”.

Any other school, club or organization wants to learn more about Parkinson's should contact the local speaker, vbox@parkinsons.org.uk”

Parkinson’s awareness week at Barrow Hills: a volunteer’s perspective

“Hello, I love Parkinson’s!” was the unlikely greeting I got from a 7-year-old boy a couple of days after we held a school assembly and took over the PHSE (Personal Health and Sex Education) lesson for his class. I couldn’t share his sentiment but was pleased he was enjoying learning about PD and preparing for the assembly his class was going to hold at the end of the week, sharing what they had learnt.

An older boy had really taken onboard that Parkinson’s can affect how you feel. “How is your mental state today?” and “how is your Parkinson’s today? Are you managing alright?” were his questions when he saw Niki Oldroyd.

It was a great pleasure to help with the Parkinson’s awareness week at Barrow Hills, watching the pupils’ enthusiasm as they experienced simulations of our symptoms. “This is impossible” was a common refrain as they tried to get a small coin from a purse, wearing thick gloves. Others struggled to balance on a wobble board with their ankles tied together with resistance bands, but enjoyed the challenge of reaching for an imaginary item on an imaginary top shelf. Some landed on the floor just as we can!



A volunteer's perspective continued:-

Volunteers from the branch helped in every class, answering questions about their own PD experiences and explaining the challenges the children were going to try. Whilst one would tie legs together, another would make sure that suitably thick gloves were being worn for attempts to undo buttons, tie a tie or remove a credit card from its slot in a purse. We made impatient noises when they struggled with coins, just like in a real shop queue. The pupils loved it all but did see that what is fun for a few minutes would not be fun all the time. Sharyn and I joined some of the parents at a bacon butty stall on Friday morning to see how much they had heard of the week's events. Most gratifying was the report from the parent of a child with special needs who never normally says anything about what happened at school but said "we learnt about Parkinson's today". Result! - and it wasn't only him who learnt about Parkinson's. Judging by the buzz in the school all week and the enthusiastic adoption of amazing head gear for 'use your head' day by pupils and staff, there are many more people who are now aware of Parkinson's. Thank you to all the volunteers: we couldn't have done it without you.

Valerie Box



It was a dank and stormy night but the intrepid Anne Folkes and Margaret Westwood set forth to represent the Branch at the 5th *Florence Pite Lecture* held at the prestigious **Francis Crick Institute** in London.

The event was chaired by Gary Shaughnessy Chairman of the Parkinson's Board of Trustees (himself a person with Parkinson's) and the evening included a stimulating lecture by Dr Heather Mortiboys, a researcher in neurodegenerative diseases, and a presentation by Nicola Cooper, who since being diagnosed with Parkinson's has volunteered herself for numerous tests, trials and genetic analyses.

Dr Mortiboys has studied mitochondria in skin cells for decades - she described mitochondria as *the batteries* that produce the energy that makes cells work. They come in all shapes and sizes and can be readily identified. Her research team found that treating skin cells with a particular drug stimulated these *batteries* back into action. This led her to pose the question "Could energy be the key to stopping Parkinson's?" Her research group of ten scientists is hopeful that within a decade a drug may be developed that, whilst not offering a cure, could slow down the degenerative process.

A Q &A session followed with Dr Mortiboys, Professor David Dexter, who established the Parkinson's Brain Bank at Imperial College, Dr Rimona Weil who is a neurological specialist in cognitive and movement disorders, and Alison Leake, a Parkinson's Specialist Nurse. A wide variety of questions drew some fascinating observations and raised issues which many went on to discuss at the Reception afterwards. One point became abundantly clear: the complexity and huge range of malfunctioning mechanisms that leads to Parkinson's makes the experience of the Special Nurse invaluable. Close observation of an individual's problems fed back to researchers can lead to the examination of different mechanisms that cause nerve cells to die - and thus bring a step closer personalised treatments.

Margaret Westwood

FUNDRAISING

ALL SPONSORED FUNDRAISING EVENTS ARE POSTPONED UNTIL
FURTHER NOTICE

BUT

IT IS HOPED THE SURREY HILLS WALK WILL BE ABLE TO TAKE
PLACE

Date, Sunday 12 July 2020

Start and finish:: Denbies Wine Estate, London Road, Dorking, RH5 6AA

Routes: 3 miles and 6 miles

Registration opens: 09:30 am

Sign up on www.parkinsons.org.uk

at

Walk for Parkinsons –Surrey Hills

You can also volunteer to help on the day.

Any questions—phone 0800 138 6573 or email fundraising@parkinsons.org.uk



WAG NEWS

Important Contacts

Email: guildfordwag@googlegroups.com

Guildford Parkinson's Branch

Info@guildfordparkinsons.org.uk

WAGS

Keith Black:

kblack@guildfordparkinsons.org.uk

Val Black: vblack@guildfordparkinsons.org.uk

Sharyn Bullen: sbullen@guildfordparkinsons.org.uk

Darren Dunkley: ddunkley@guildfordparkinsons.org.uk

Join us on [Facebook @ Guildford Working Age Group](#) to get all the up to date news

Where: The Withies Inn, Compton, GU3 1JB

When: 3rd Tuesday of the month

Time: 7.00pm



PARKINSON'S^{UK}
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Working Age Group Calendar 2020

IMPORTANT NOTICE

All meetings are cancelled.

KEEP IN TOUCH VIA OUR FACEBOOK PAGE

We hope to be able to start again in September but this will be confirmed,

15 September

Withies - No Speaker – Social Evening

20 October

Withies - Quiz + “Fish & Chips”

17 November

Venue tbc - Emily – Parkinsongs – 7.30pm

09 December **Guildford Group Christmas Dinner. Details to follow**

15 December

Withies - Christmas meal

Items in **RED** are extra activities to our normal monthly meetings at The Withies Inn.

An interesting story from Val and Keith Black

Radio Parkies is an online radio station run by people with Parkinson's.

www.radioparkies.com

I am sure many of you will enjoy listening to these radio programs.

Radio Parkies is an online radio station that gives a voice to people having to deal with Parkinson's Disease. There are now DJs in nine different countries, reaching out to all countries via the internet. I am writing about DJ Scazza on the UK team.

<https://www.radioparkies.com/dj-scazza.html>



Ian, aka DJ Scazza, was diagnosed with Parkinson's in 2014, aged only 53. He decided to reach out to other people with Parkinson's, playing a mix of music together with information that may be useful to them.

Three years after his diagnosis, Ian retired from work on ill-health grounds. He wanted to find people with Parkinson's in his age bracket, and was looking for something to do.

" I always loved music and decided to sort out my CDs and records as I have a large collection, but I wanted to do something more. My Parkinson's Nurse told me of a local meeting to find potential roles for young-onset Parkinson's Disease people in the area. At this meeting I met Martin and Shamsa. We talked about how we could get people involved and mention was made of using radio. It took some time to work out how we could get into radio. It looked quite expensive and I thought it was too big for me to do.

I would return to this idea. I was like a child in the beginning. I was trawling the internet and I noticed a message on Parkinson's UK site about a radio station called *Radio Parkies*. I have no history of doing anything in the music industry. It was very unlike me but I contacted the Belgium *Radio Parkies* station, asking if they wanted the help of an unqualified music fan. I just thought I could help. I had a conversation with JP, the boss, and he said he thought I could be a DJ. That was such a big surprise! It was thumbs up! I realised that role was perfect for me as I love music and would just learn to do the other stuff. "

"When I started my voluntary work at the radio station, I put out my own Parkinson's story to try and help anybody who might relate to my story. This was broadcast on 30 January 2018 and it is my second most listened to show. My problem then was how to bring useful Parkinson's information into the show. Fortunately I have a very friendly group in my town, Birmingham, who are very happy to be involved.

Through the last two or three years I've been able to speak to many ordinary people doing extraordinary things. I have talked to the CEO of Parkinson's UK, to Emma Lawton, to people raising money for Parkinson's, and to poets, writers and dancers.

I love talking to people and playing music so this really suits me. I'm happy to speak to anybody and to do shows around their story. I have worked with Keith Black (Guildford Group) on a couple of occasions. I met him on an online training course and I'm sure he's enjoyed the shows when he's been on my radio station.

As this is an internet station, people can listen from all over the world. Currently my show is live on the internet on Friday mornings 10:00 - 12:00 (UK)."

On the *Radio Parkies* website, Ian says:

"If you are involved in something that is Parkinson's related, like research, official groups or non medicinal related, and that you think others might be interested in, please get in touch. If you just want me to play your favourite track, then ask me. But there is more chance of me playing your request if you can give me your Parkinson's related story."

Ian also wanted me to add that if anybody wants to have a go at dj'ing to get in touch and he can talk through what you need to do and he'll put you in touch with his boss.

Ian's email address is

scazzmundo@gmail.com

All shows are held on mixcloud

For example:

https://www.mixcloud.com/RadioParkies_uk/djscazza-talks-on-2822020-with-pat-from-fighting-fit-songs-with-sax-new-order-psb-keith/

Facebook page:

<https://www.facebook.com/djscazza/>

A poem by John Dench

THE BAD NEWS

It started with a subtle throb.
A funny sort of feeling,
As though I had spent yesterday
Painting the dining room ceiling.
I went to the doctor and told him my news,
About this peculiar feeling,
That this twinge interfered
With my darts and my snooker
And the cards if it's my turn for dealing
He said an expert you really ought to see,
An appointment with one I will book you.
He will sort all your problems out
Your darts your cards and your snooker
I went along the consultant to see
If an answer he could find
He was a very patient man,
And really very kind.

We sat and had a talk together.
We had a lovely chat,
And then he said you've got Parkinson's
I'm afraid there is no cure for that,
Try exercises and take these pills,
To alleviate the progression
But Parkinsons is in one of those ills
That creates its own transgression
At first it may not bother you,
Your hands may shake a bit,
But then you start to freeze in doorways
That makes you feel a proper twit
And then there is constipation,
Another of natures jokes.

You can't go far from a toilet
Unlike the ordinary folk,
You rush to the nearest public loo
Hoping it's not occupied,
And what relief sweeps over you,
There is no- one waiting outside.

You go inside thanking your lucky charms
You made it just in time
Only to find it's a false alarm,
And you're sitting there wasting your time

I loved singing in the local church choir,
I was blessed with a reasonable voice,
But now the notes come out sounding so queer,
With no hope of a tuneful rejoice,
My poems I can still produce
I can write the occasional sonnet
But if Mr Parkinson has his way
Don't put your money on it,
Food used to be a great delight,
Now a challenge it has become,
Some dishes we can manage alright
With that shaky hand you know it's a cert
You find there is gravy spilt down that clean shirt
Or else a lap full of crumbs

I have not mentioned the appointments
That govern your everyday life
I would hardly call it a trial
But sometimes it can lead to strife
Whether it is the Royal Surrey
Or maybe Frimley Park
They have their own procedures
That keep you in the dark
You juggle with the transport
Spend ages on the 'phone
And hope you've given the details right
Or you will be left all alone
Waiting in a wheelchair
In a draughty corridor
Cursing you had not checked the details
Asked the man to repeat them once more
You learn it is foolish to hurry
Parkinson will take his own time
No matter how much you may worry
Over problems I could list here in rhyme.

THE BAD NEWS (CONT.)

But Parkinson's tends to make you slow
And blunts your good ideas
And takes away your get up and go
It simply just disappears
Then with shaky hand
And querulous voice
We inhabit this land
Without having a choice
So if you should see Mr Parkinson,
Tell him there are things I still lack
I really don't want his rotten disease
I'll be quite pleased to give it him back.

The author John Dench has always been interested in poetry but after being diagnosed with Parkinson's 11 years ago he has found it an outlet for his frustrations. His book *A Touching Place* was published in 2019. John and his wife Greeta are dedicated members of the Parkinson's Group at Loseley Christian Healing



An explanation of Gift Aid - a message from our Treasurer

Remember to Gift Aid any donations to us.

Donating through Gift Aid means we can claim an extra 25p for every £1 you give, and it does not cost you any extra.

Every penny we receive helps pay for the various exercise and therapeutic activities we provide across our Branch.

So, when you send a cheque to us as a donation please don't forget to Gift Aid!

What you need to do

When you make a donation to us you need to complete a Gift Aid declaration (enclosed) and send that to the Treasurer along with your cheque. Cheques should be made payable to 'Parkinsons Disease Society Guildford'. You only need to complete the declaration once, then any future donations over the next 4 years will be covered for Gift Aid.

If you make your donation by bank transfer directly into our Branch bank account, remember to also complete a declaration form and send that to the Treasurer along with a note saying how much you have donated.

If you have already completed a Gift Aid declaration for us within the last 4 years, then please let the Treasurer know so we can continue to claim gift aid on any donations you make.

(Treasurer email: sheron@guildfordparkinsons.org.uk)

If your declaration is more than 4 years old, please complete a new declaration.

This then enables us to claim the tax back (25p for every £1!) from HMRC

An explanation of gift aid - a message from our Treasurer

Paying enough tax to qualify for Gift Aid

Your donation will qualify as long as you are paying tax, and the total of your annual donations is not more than 4 times what you have paid in tax in that tax year (6 April to 5 April).The tax could have been paid on income or capital gains.

Note: You must tell us if you stop paying enough tax.

For more details please visit:

<https://www.gov.uk/donating-to-charity/gift-aid>

Please complete the enclosed gift aid form with your full forename and surname, sign, and then send with your donation to:

Mr S Heron

Treasurer

Parkinsons Disease Society Guildford

11 Merrow Woods

Guildford

GU1 2LQ

Committee Members

PLEASE NOTE CHANGE IN EMAIL ADDRESSES

Chair

Niki Tompkinson

ntompkinson@guildfordparkinsons.org.uk

Vice Chair (and Referrals and Activities)

Hilary Austin hillawrie@googlemail.com

Treasurer

Steve Heron sheron@guildfordparkinsons.org.uk

Membership Secretary

John Oldham joldham@guildfordparkinsons.org.uk

Secretary

Sharyn Bullen sbullen@guildfordparkinsons.org.uk

Committee members

Myra Newnes-Smith (Carers' issues)

mnsmith@guildfordparkinsons.org.uk

Margaret Westwood (Minutes secretary)

westwood.m@talktalk.net

Anne Folkes (Editor of The Park)

afolkes@guildfordparkinsons.org.uk

Useful Information

Parkinson's Local Advisers

Guildford, Runnymede, Surrey Heath, Waverley and Woking

Jackie Wingrave 0344 225 3669

Reigate, North Tandridge and East Surrey

Nicky Lawrence-Gravestock 0334 225 3743

Mole Valley, Dorking, Kingston, Spelthorne, Elmbridge, Epsom
and Ewell

Emma Southwell 0334 225 3772

Mid Sussex, Tandridge, Horsham, Crawley and East Grinstead

Carol Coupe 0334 2253686

Parkinson's Nurse Specialists (NHS)

Milford Hospital Assessment Unit

Amanda Dodson 01483 782750

Email: rsch.gw.ms.parks@nhs.net

North Surrey. Farnham Hospital Outpatients

Rose McKinley 01483 783481

Email: rsch.gw.ms.parks@nhs.net

Parkinson's UK Helpline Service 0808 800 0303

Lines open: Monday to Friday 9.00 am–8.00 pm

National Website

www.parkinsons.org.uk

Local website

www.guildfordparkinsons.org.uk

Don't forget to stay informed of classes, events, meetings and much more on our own Guildford website..