

Swindon & District Branch

Annual Report 2019



I am pleased to submit the Swindon & District Branch Annual Report for the year ending 31 December 2019, detailing highlights, issues and changes applicable for past 12 months. For those new to the Branch, our financial year is the calendar year.

Parkinson's Swindon will enter our 42nd year of providing services to those affected by Parkinson's in the wider Swindon area this March 2020.

I believe the main highlight was the great honour bestowed on the Branch of HM The Queens Award for Voluntary Service 2019, the equivalent of an MBE for charities. This was announced publicly by Buckingham Palace in the Honours List on the 2nd of June in the London Gazette, on the anniversary of HM The Queen's Coronation.

The story goes back to before Christmas 2018 when in last year's Chair's report, I advised that when we had been contacted by the Wiltshire Lord Lieutenancy's Office, advising of our short listing for the award. Also, of being interviewed by Mr. William Wyldbore-Smith, Vice Lord-Lieutenant of Wiltshire and Ms. Shirley Ludford, Deputy Lieutenant of Wiltshire, with the then hope of success and the wait to find out.

We had to wait until the 4th April when Tony Falkingham (Vice Chair) & Dawn Falkingham (Committee Member) were both in my house and an e-mail came through from Office of The Lord Chamberlin, with the good news that we had been successful.

Having all digested the content, particularly the warning that we could not tell anyone about the award until it was officially announced by Buckingham Palace on 2nd June. We were advised to do so would result in the Award being forfeited. We looked at each other and I said, "what do we do now". Tony immediately replied, "let's go to the pub for dinner to celebrate, and that is what the four of us did – our secret and rather surreal celebration.

What followed was an endless stream of communication, including logos, press release material and instructions. An invitation was also received stating "The Lord Chamberlin is commanded by Her Majesty to invite Mr. and Mrs, David Logan to a Garden Party at Buckingham on Wednesday 29th May 2019". We were both very honoured by attended the Garden Party representing our Swindon Branch. However, once again due to the rules, we were not able to tell anyone as it was prior to 2nd June official announcement.

- The 17th July saw the official presentation of a frames scroll signed by HM The Queen and the Crystal Award by Her Majesties Lord Lieutenant of Wiltshire, Mrs. Sarah Rose Troughton at the DoubleTree by Hilton Swindon. In attendance was the Vice Lord Lieutenants and Deputy Lieutenant of Wiltshire who initially interviewed us in 2018, also Jane Asher- President of Parkinson's UK, Gary Shaughnessy PUK Truster– now Chair of Parkinson's UK Board of Trustees and Councillor Kevin Parry, Mayor of Swindon. Others included:
 - Jane Henderson – PUK Volunteer Co-ordinator West
 - Nicola Hillier – Grant Officer of Wiltshire Community Foundation
 - Jane Boulton – Zurich Cares Community Involvement Programme, UK Manager
 - Rachel Gardner – Lead Parkinson's Nurse SPARKS

I would like to thank the following for their letters of support for the Queen's Award for Voluntary Service:

- Jane Asher – President of Parkinson's UK
- Steve Ford – Chief Executive of Parkinson's UK
- Jane Henderson – Parkinson's UK Volunteer Co-ordinator West
- Justin Tomlinson MP for North Swindon. Minister of State for Disabled People, Work and Health
- Robert Buckland QC MP for South Swindon. Lord Chancellor and Secretary of State for Justice
- Rachel Gardner – Lead Parkinson's Nurse GWH
- Gordon Hogg – Attorney Wills

Other Awards Received

Two Parkinson's UK Volunteer Awards 2019 of the Golden Parkinson's Brain were presented to Vincent Mobey (Branch Member and founder of the very successful Cricklade Monthly Coffee Morning and champion for better Parkinson's medical services for those living in North Wiltshire) and Dave Logan (Branch Chair).

The Citations Read:

For Vincent Mobey

Dear Vincent.

There were multiple nominations for you, both from volunteers and staff, meaning the list of how you have made a difference – both locally and nationally could more than fill this card!

What is timely to note is just what a role you have played in the recently secured nurse post for Wiltshire – your determination has made such a huge difference.

The popularity of the Cricklade Café is also surely a testament to the support you have made available and the impact it has on those who before may not have been connected to the charity.

Thank you, Vincent, you are obviously valued by all who meet you and by all who are part of Parkinson's UK.

The Volunteer Awards Panel

Tim and Freda (PUK Trustees).

Elaine (Volunteer)

Lucy (PUK Staff)

For Dave Logan

Dear Dave,

Both volunteers and staff at Parkinson's UK recognised how dedicated you are in running the Swindon Branch.

Uniting the local community, being an ambassador for Parkinson's UK and championing the needs of people with Parkinson's are all evident in the nomination received for you.

Thank you for going above and beyond to improve the lives of many.

With thanks,

The Volunteer Award Panel

Tin and Freda (PUK Trustees)

Anna & Elaine (Volunteers)

Lucy (PUK Staff)

Putting things to Right

Our Branch Membership comes from mainly two Health Authorities. I have mentioned in past Annual Reports that the majority of Branch Members come under the Swindon & Shrivenham NHS CCG area and the other 12.8% of Branch Member come under North Wilts Health Authority. There are many more people with Parkinson's in North Wilts we do not know about. This resulted in the Parkinson's medical service they receive being vastly different, virtually non-existent, it's a post code lottery. North Wilts has one Nurse Specialist to look after all the Neurological conditions including Nursing Homes, an impossible task. In fact, North Wilts does not even advise their patients of the existence of the Specialist Nurse. People only find out when they are referred to her. They can see the Parkinson's Consultants at GWH but do not have access to Swindon Parkinson's Services (SPARKS), physiotherapists, Speech and Language (SALT), Occupational Health and the Parkinson's Nurses.

This is not something that has been neglected and an issue continually raised by me at meetings of the BARTS, North Wilts and the Swindon & Shrivenham NHS CCG Trust amalgamation meetings. More recently with a little support and advice Branch Member Vince Mobey, Parkinson's UK Volunteer and Cricklade Café Coordinator, has been campaigning relentlessly to rectify this situation and success is now hopefully very close. Vince has advised the following:

That he has engaged with the following key members of the forthcoming revised 'Parkinson's Care for North Wiltshire' project, resultant from his persistent campaigning:

Parkinson's UK's Sally Wood, Area Development Manager, West. Sally's PUK colleague Katherine French, Service Improvement Programme Manager, has reconfirmed that PUK will provide the initial funding for one full time Parkinson's nurse post for North Wilts. With regards to any linked costs, she will be seeking confirmation from the CCG about what they will be provide. Sally has flagged up to Katherine the issue about people from North Wilts wanting access to a service like that of the GWH SPARKS team, which Ted Wilson had previously given Vince an assurance about.

Ted Wilson, Director of Wiltshire CCG

Ted has advised Vince of the following: Clare O'Farrell has taken over his Commissioning Director role and is progressing this service improvement on behalf of him and the CCG. Ted has passed Vince's contact details and role in this campaign onto Clare and Vince shall make a formal introduction in due course.

Ted has confirmed that Parkinson's UK have agreed the funding of one full time Parkinson's Disease Specialist Nurse (PDSN) to be operating from within the existing SPARKS Team at GWH. The Wilts CCG are going to fund the additional costs of further nursing and administration costs now and to take on all of the costs once the Parkinson's UK funding ceases after an agreed period. Ted has also confirmed that Clare is committed to taking over his work regarding the improvements to Parkinson's Care in North Wiltshire and to providing an equitable service to that in neighbouring areas.

Ted also said that Parkinson's Lead Nurse, Rachel Gardner at SPARKS, GWH is excited and highly motivated to make this new service successful. Ted added that Rachel is conscious that people might be concerned that the existing SPARKS facility in GWH might not be able to cope with additional patients being seen there.

Rachel is currently meeting with all stakeholders regarding the new service to make sure that it is well prepared, properly staffed and ready to go. Rachel is also keen to dispel any concerns that Swindon Parkinson's patients may have regarding this new service and recently advised Dave Logan that the current service for Swindon & Shrivenham NHS CCG patients will not be affected by the North Wilts improved service.

Tim Burns Commissioning Manager Wiltshire Clinical Commissioning Group, has advised Vince of the following

He has spoken at length with Tim regarding the huge disparity of services between Swindon and North Wiltshire. In particular they have covered issues concerning the fact that there is no central phone number for Wiltshire Parkinson's Patients to call for help or advice. If the new service as proposed is going to offer an equitable service, then this matter needs to be reviewed so that, upon launch everybody knows how the system should work and who and where to call.

Tim is currently discussing with the North Wiltshire Team of Physiotherapists, Occupational Therapists and SALT, how they can be more accessible to patients and if they can attend forthcoming Parkinson's UK – Café events in North Wilts to introduce themselves to the community.

Vince's summary is that, everything is moving along in the right direction.

The plan is to have the new service, up and running and to commence from week one of April 2020. This is a tight timescale and there is a possibility that this might overrun.

Vince said he will keep in touch with all parties concerned to help keep the matter on the table. Where necessary, he intends to point out any potential problems should they arise to ensure the new service hits the ground running from day one. – Thank you Vince.

At our AGM on 13th March, it is intended to give an update on the improved Parkinson's services for North Wilts.

The Branch Respite Programme

Our free Respite Programme with subsidised transport where needed continues to support of our carers. If you are new to the Branch and do not know much about our Respite Programme. It offers four hours free respite in a secure environment on Mondays to give Carers some 'Me Time'. This year we allowed some people who were now in nursing homes but missed the companionship of friend they had made in our Respite Centre, Hop, Skip & Jump, to attend twice monthly which was very much appreciated and beneficial to them and their Carers as I am sure some of the users will vouch for.

Dance for Parkinson's

Our Dance for Parkinson's class which is followed by tea, coffee and biscuits and a chat is encouraged globally, continues to be very popular and successful here in Swindon, so if you have not already tried it, why not give it a go. Rachel Gardner, Lead Parkinson's Nurse often sends trainees to this and other classes.

Our Wednesday Double Balance & Exercise Class

This class has had an overhaul this year by our Swindon Parkinson's Services physiotherapists who have re-designed the circuits. We now have four sets of circuits with ten stations. These are rotated every 4 weeks. We also have a new instructor, Linda Barret who has proved very Popular with everyone.

Exercise Instructor Training

We paid the expenses for Linda Barret and Jean Harvest our Tuesday instructor for the Seated and Tai Chi Classes to attend a free Parkinson's UK training course in Reading for instructors of exercise classes for people with Parkinson's. Unfortunately, Andy our Thursday Tai Chi instructor was on holiday at the time.

Our Walking Football and our annual Match against SPARKS

This year the Swindon Parkinson's Services team came back for revenge after losing 6-0 to our team, their patients the previous year. Alas, they took the trophy back to GWH after beating us 8 - 6. Our excuse, some of our star players dared to go on holiday instead of defending the honour of their team. Also, SPARKS brought Joe, their giant physiotherapist. We intend to get the trophy back in 2020 – challenge! I heard from Rachel Gardner our Lead Parkinson's Nurse very recently, the SPARKS team captain, with excuses already. To quote Rachel "two footballers have gone to Australia for a year. I have asked them to come back for the match, but they will only do it if I pay the air fare!!

Due breaches of contract and other issue at the PlayFootball venue we had to give them written notice of leaving prior to the Christmas break. Arrangements were made to move to Supermarine Sports Club's SwindonDome with three 4G pitches at the start of 2020. New Parkinson's Local Contracts have been signed and a Risk Assessment completed for the new venue.

Thank you for your support

We would like to thank all who have supported the Branch financially or otherwise. This includes but is not inclusive of:

- Family members taking up sponsored events.
- Members and Branch supporters holding their own fundraising events, particularly Sharon Fulcher second Barn Dance held in this financial year.
- Making, selling or donating handy craft items and our own Crafty Parkers group who raised £500 on the second day of the Swindon Steam Museum Christmas Fair this year.
- Steam Museum Christmas Fair. On Day 1- The volunteers on our Tombola Stall which raised £595. So generous were the donated items that Tony & Dawn Falkingham were running out of space to store the prizes. A very successful weekend.
- All those who supported our Bucket Collections.
- Couples celebrating milestone anniversaries and individuals' birthdays and asking for Branch donations rather than gifts.
- Organisations and companies who have awarded us grants. For example:
 - Stratton St. Margaret Parish Council £1,000
 - St. Barnabas Church £500
 - Fish Brothers Lexus (Through Vice Chair Tony Falkingham) £1,600
 - Nationwide Building Society who advised of a further grant of £500 due to our Branch after Christmas
- All those who at times of bereavement have requested donations go to the Branch.
- The Swindon Male Voice Choir concert, accompanied by A Splash of Red Fairford Ladies Choir.
- And finally, not forgetting grants and funds raised by our own Branch Committee fundraiser, Roger Youldon such as the one from Stratton St. Margaret Parish Council and generous donations from our Hugh Meredith. Roger also organised the second Penalty Shoot Out fundraiser with Swindon Town and Manchester United ex goalkeeper Fraser Digby. This also created a great deal of media coverage on Swindon 105.5 and the

Advertiser. Facebook and a vast amount on Twitter. He with help from Teresa also has a knack of obtaining quite a few prize donations. Roger also spends a lot of time completing grant application forms.

- Ray & Kirsty Matthews for their time spent getting information printing, stuffing enveloped and posting to members not on e-mail. It is very much appreciated. Thank you both.

The 300Plus Club Lottery Launch

We launched the 300 Plus Club Lotters at our Christmas Lunch on Sunday 15 December following the last draw of the 100Plus Club Lottery also at that event. The 300Plus Club Lottery launch is intended to make our lottery more attractive and encourage participation. I can report that it most certainly has succeeded in this.

The 300Plus Club monthly lottery income will still be split as follows, **Branch 50%, 1st prize 35% and 2nd prize 15%**. As membership continued to grow, the two monetary prizes will also continue to increase.

With the introduction of the 300Plus Club Draw, a third Bonus Prize is being added. All the members numbers included the two monetary winners' numbers will go into this draw. This prize will differ monthly and be things like meal vouchers, cinema tickets, shopping vouchers and are being generously donated by Gordon & Bill from Attorney Wills as is the Launch Bonus Prize today of this lovely hamper.

The 300Plus Club Launch at our Christmas Lunch was for a fabulous hamper donated by Bill and Gordon Hogg of Attorney Wills. The winners were Mr & Mrs Robinson.

Branch Activities This Financial Year

Monthly Coffee Mornings at the office of Justin Tomlinson, MP, Minister for Disabled

Monthly Committee Meetings at Tesco, Ocotal Way, Community Room

21 Jan – Parkinson's awareness on-line Video presentation to Rotary

25 Jan – Race Night with Buffet at Churchways Bowls Club

4 Feb – A Parkinsons Awareness to our Branch Respite provider new staff,

8 Mar – Branch AGM

19 Mar – Lunch at Fabios Italian Restaurant

22 Mar – Pub Lunch at Village Inn

4 Apr – Pre- recordings at Swindon 105.5 for Parkinson's Awareness Week (PAW) broadcast

6 Apr – Swindon Male Voice Choir Concert accompanied by The Fairford Ladies Choir

11 Apr – PAW and World Parkinson's Day at Gorse Hill Liddle

12 Apr – PAW at ASDA Haydon Wick#

13 Apr – PAW – Cake Sale in Barclays Swindon

15 Apr – PAW – Annual Walking Football Match against SPARKS

16 Apr – PAW – Invitation to Mayor's Parlour for all Committee

26 April - Skittles Evening with Buffet

29 Apr – Committee meal at Village Inn

1 May - Rondo Theatre, Bath to see Paul Mayhew-Archer

9 May - Wilts PUK Get Together Event with Dave Logan & Margaret Kennedy attending

11 May – Sharon Fulcher's fundraising Barn Dance

29 May – Queen's Award for Voluntary Service (QAVS) - Queen's Garden Party

31 May – Quiz Night with Buffet

7 June – Age UK Talk

10 June – BBC Wiltshire interview with Victoria Edwards and Dave Logan

Jun – Our Crafty Parkers Group formed

22 June – Parkies Pals Afternoon Tea fundraiser at Shrivenham

5 June – Participated at PUK's sParksFest (Celebrating the creativity of people with Parkinson's) at Devizes

7 June – Parkies Pals Choir Evening Fundraiser at Watchfield

10 July – Ceders Care Home PD Awareness & Abuse Talk on request Wilts CC

12 July – Walking Treasure Hunt at Coate Water

13 July – Wroughton Silver Band Concert for Branch & Prospect 50/50 Fundraiser.

17 July - QAVS Awards Presentation at Doubletree by Hilton, Swindon

20 July – Fraser Digby Penalty Shoot Out Fundraiser (Press & Radio in attendance)

24 July – Broad Town Coffee Morning in aid of the Branch

9 Aug – Pub Lunch 1 at Village Inn, Wanborough

13 Aug – Pub Lunch 2 at Village Inn, Wanborough

6 Sep – Crafty Parkers at Volunteer Centre 25th Anniversary Pop Up.

14Sep – Cake Sale & Coffee Morning at Highworth Methodist Church

20 Sep – Skittles Evening with Buffet

8 Oct – Voluntary Action Swindon AGM

24 Oct – Wilts PUK Get Together Devizes – Ian Davey and Anna Newman attended

25 Oct – Quiz Night with Buffet

29 Oct – Dave L & Roger invited to Zurich Meeting re Grants. Roger sat with Zurich at QAVS

7 Nov – Talk at Oxford Brookes University for Royal College of Nursing Frailty Study. Speakers included Dr Debesh Mukherjee on frailty, Rachel Gardner Lead on PD Symptoms and Dave Logan Swindon on Branch & importance of Exercise.

28 Nov - Christmas Shopping Coach Trip to The Valley Evesham

30 Nov/1 Dec - Steam Museum Christmas Fair, Day 1 - Branch Tombola. Day 2 -Crafty Parkers

10 Dec – Parkinson's Awareness Talk at Marlborough Nursing Home

15 Dec – A very successful Branch Christmas Lunch at DoubleTree by Hilton with Zurich Community Trust Volunteers providing free Disco, including equipment. Christmas Quiz questions were placed on the tables to help people get to know others sitting with them.

Dec –. To finish 2019, Phil Webb planned and organised the Branch's first short break holiday in some 30 year or over. Thirty-two people travelled to the Berkeley Hotel in Weymouth for the four-day break. The package included breakfast, full evening meal and free entertainment each evening cost just £169 per head including the coach transport. Despite the weather all enjoyed their holiday break.

It gave me great pleasure to welcome Wendy Matthews, a Zurich Community Trust Volunteer, accompanied by Ian Sutton from Zurich who for want of better words is Wendy's 'Roddie'. And not forgetting young Fraser Matthews, Wendy's assistant. All are giving their time freely at our Annual Christmas Lunch to entertain you with a selection of music. It was pleasing to see people take to the dance floor and show their moves. Zurich Community Trust, through Roger, has supported our Branch with grants for which we are very grateful.

Other Activities included:

Supporting new coffee mornings in Cricklade and Marlborough.

Supported Vince Moby's campaign for improved PD medical services in North Wilts.

Supported SPARKS Speech & Language with refurbished laptops for new therapies (refurbished free by Richard Kennedy).

Change of Bank to Barclays for internet Banking. PUK Finance was updated with account details.

Branch Committee

Anna Newman. Anna has taken over the Branch Secretary Role from Lynne Culling and settled into the role very well.

Margaret Kennedy. Margaret is now our Branch Treasurer, taking over from Emma Lucey as we were going through the process of changing bank accounts from RBS to Barclays and starting to use internet banking. This was not without a few difficulties. Compensation was paid into our accounts by both banks.

Phil Webb. Phil has joined your Committee in the welfare role, including helping complete Assistance Allowance forms and has organised our first short and successful holiday break.

Ian Davey. Ian continues as Branch Membership Secretary. Ian's role has expanded greatly with the introduction of new Data Protection Legislation involving annual reviews.

Roger Youldon. Roger continues to do a great job in his fundraising role and a lot of time is spent completing Grant Applications.

Ruth Panting. Ruth continues as our Newsletter Editor and also does a great job.

Tony Falkingham. Tony is Branch Vice Chair and has been very supportive to me this year, for which I am very grateful. He was also succeeded in persuading Fish Brother's Lexus to give us a £1,500 grant.

Dawn Falkingham. Dawn is our Procurement Guru and is responsible for our local re-branding of our Parkinson's clothing and finding local suppliers. Dawn also orders and stocks Parkinson's information documents amongst other things.

John Mead. John despite poor health continues in his role of designing and producing our flyers, business cards etc. Thank you John.

David Cragg. David looks after our Respite Programme and main contact. He took over from Keith Cooper following Keith's serious illness last Christmas which prevented him from standing in for me at our last Christmas Lunch. It was great to see Keith with us at our Christmas Lunch after his very long convalescence.

Katherine Arnell. Katherine who has recently joined the committee is proving a helpful asset.

I would like to thank all our committee for their support and hard work this year. They are all stars including the Parkinson's UK registered volunteers who support our monthly coffee mornings on the first Tuesday of each month and Bill Hogg who manages our 100Plus Club Lottery, now re-launched as the 300Plus Club.

Also not forgetting my wife Daphne for her support.

As you can probably guess, with most Committee Members having Parkinson's themselves or being a carer of someone with PD, commitment can be affected by personal difficulties. This year has been very difficult for some committee members, who have had to resign to take care of their loved ones.

I would like to express my and our committee's condolences for the passing of three ex-committee members and to their families who have lost their loved ones. This year we have lost:

Jeff Culling - Husband of Lynne our previous Branch Secretary.

Ian Duthie (Ex committee member) – Husband of Linda Duthie. Linda was Branch Chair prior to me, both having long terms on the committee, close to 10 years I believe.

Colin Freegard (Ex Membership Secretary) – Husband of Anne, both were very committed Committee members.

Also not forgetting all the Branch members who have also passed this year. Our thoughts and condolences go out to all their families.

A toast was made for all those who have gone at our Christmas Lunch.

Here's to the ones that we got.

Cheers to the wish you were here.

But you're not.

The drinks bring back the memories of everything we've been through.

Toast to the ones here today.

Toast to the ones we lost on the way.

This toast was sent to me by Linda Duthie and comes from a song by Maroon 5.

Looking forward to 2020

What do you want your committee to do? Please do tell us. A lot of effort and money is put into organising events and support. We would prefer providing what you really want.

Event organised and proposals for 2020 are:

- **Friday 24 January.** We start with another popular Race Night hosted again by the Stratton Churchways Bowls Club, beside Grange Leisure Centre. Thank you, Diane and David Humphreys for funding the buffet again this year.
- **Saturday 1 Feb.** Bucket Collection at the County Ground for STFC home game.
- **Friday 28 Feb.** Prize Bingo at Grange Leisure.
- **Friday 13 Mar.** Branch AGM at Supermarine Sports Club.
- **Friday 20 Mar..** Skittles Evening with Buffet at Grange Leisure.
- **Friday 10th Apr to Thursday 16th Apr.** Parkinson's awareness Week 2020. Parkinson's Awareness Week aims to raise awareness about this potentially devastating condition.
- **Saturday 11 Apr** is World Parkinson's Day
Funding events are needed for vital research work into the causes and treatments of Parkinson's Disease and to support those living day to day with this condition.
- **Fri 17 Apr.** Bucket collection at Tesco, Ocotal way
- **Sat 28 Apr.** Charity Concert in aid of our Branch by the Swindon Male Voice Choir, accompanied by the Thamesdown Ladies Choir.

Event Programme proposals for consideration

- Pub Lunches
- A member's suggestion of a 60's evening with buffet.
- A talk on 'A Year in The Life of a Mayor' by Ex- Mayor of Swindon Teresa Page. A lady from Bantry, Co, Cork with a lot of funny and amusing stories.
- Another Coate Water walking treasure hunt.
- A Steam Train Trip with Cream Tea – postponed from this year due to bridge work.
- Another popular Quiz Evening with buffets.
- Are you interested in a visit to an NGS Garden.
- A coach mystery tour.
- Another short holiday.
- Disco & Dance.

Your suggestions always welcome,

Disappointments

There was no mention of the Branch being awarded HM The Queen's Award for Voluntary Service in PUK publications, The Parkinson's or Network News.

Dave Logan

Dave Logan

Branch Chair