# **Kidderminster & Worcestershire Prostate Cancer Support Group**



Mary Symons (centre) and Vincent Koo (Urology Consultant at Kidderminster) presenting the inaugural Mary Symons Award to Clinical Nurse Specialist Helen Worth at the Urology Trust Group Foundation Education Day in late August.

## MARY STEPPING DOWN AS CHAIR

## SUPPORTER

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### **EDITORIAL**





Any publication appearing in December feels duty-bound to review the past year, which could be a repetitive chore or an embarrassment if things had gone badly. Not for me, though, not for us in looking back over 2024. What a cracking year it has been! Part of me feels such a sentiment is, however, insensitive, given that a good number of members reading this will be receiving treatment which can be quite brutal, struggling to come to terms with serious and life-changing side-effects or, in the worst cases, realising their days on this earth can be counted in months, not years.

That said, let me qualify the remark. Our county support group is a force for good. It is there to support men and their

families in whatever way we can. We're not perfect and know we have to do better with, for example, our support contact and buddying systems. The tribute to **Mary's role as chair (pages 12-13)** takes us back to the dark days of 2020-21 when Covid 19 created enforced isolation, taking away from many of our members the fellowship, the bonhomie, the support they longed for. With this in mind, we can be proud of what we have achieved since those lockdowns, particularly in 2024.

The highlights? For me there have been so many, including the **panel event in Pershore** in March with an audience of 70 and all the **Coffee & Chats** across the county now attracting double the numbers that we had in 2022. Then there were the **PSA health check events in Kidderminster and Pershore**, plus the one financed by Wychavon District Council in October at the Naval Club in Pershore, which will save lives but also provide reassurance to 93% of those participating that all is well at present. With more events planned for 2025, where we will be working with other charities, local councils, primary care networks and individual benefactors, we can feel we are already having an impact in Worcestershire even before Sir Chris Hoy challenged the government to do more in testing earlier, more regularly and with the backing of all our GPs.

Thanks to the efforts of a handful of intrepid ladies we now have a **Partners' Group**, meeting every couple of months but communicating with each other regularly via a WhatsApp group. A **WhatsApp group for members** has also been set up, with over 50 now in the group and expansion expected in 2025, and **Dan Cook**, our IT and website manager and now a valuable member of the KWPCSG committee, is gearing up to create a new website to be launched early next year. With new officers (**Nicky Langford** as secretary, **Chris Marsh** as treasurer and Mary's successor to be announced) and new members such as **Alison Hanson**, **Colin Maisey and Phil Barrett**, the committee has been revamped and, my goodness, are they hard working and ambitious.

To end on a more sober note, all of you will know men, friends, maybe even family members, whose cancer, whether of the prostate or not, mean they are no longer with us at the end of this year. One who is much missed is **Mark Howard**, but we'll continue to remember him through his contributions to this magazine and the example he set for us all.

# FUTURE EVENTS

#### SUPPORT THE ZOOM AGM ON JANUARY 21st



Let's be honest. When many of us think of Annual General Meetings, we scramble to find an excuse why we cannot attend and are happy to leave it to the committed band of diehards to run the show. That way we can avoid going through the annual accounts with a toothcomb and – most importantly – we cannot be dragged kicking and screaming onto the committee.

This year we are again saving members the trouble of turning out on a cold January night to attend the AGM in Kidderminster, which may be a 50-mile round-trip away. The AGM will be on **Tuesday, January 21st.** (19.00) via **Zoom**, a platform which many of us mastered over the Covid period. All the information and simple instructions will be available on the group's website in January.

With about 500 members we'd be absolutely delighted if, say, 10% (50) of you attended and perhaps a little disappointed if we attracted just 5% of the membership (25). There will be vacancies on the committee, but don't press the 'Leave the meeting' button at this point. It's a great organisation doing so much for men and their families across the county, so please give serious thought to joining us. See you on the 21st.

#### **NEXT PARTNERS' MEETING**

The **Partners' group** meet every two months and our next event is on **Friday, January 31st. (11.00-12.00)**. Each session runs for an hour and is a very informal way for partners to meet up and share their experiences of living with a man with prostate cancer. We have laughed, we have cried and we have shared tips about how to prepare and cope with the different stages this disease throws at us.

We meet in the Perdiswell Young People's Leisure Club, Droitwich Road, Worcester WR3 7SN, iust round the corner from Perdiswell Leisure Centre.

If you'd like to join us, help me develop the group more or just find out a bit more before deciding whether it's for you, please email me at <u>alison.hanson@live.co.uk</u> or ring me on 07484 297405

#### GROUP'S FIRST PSA TESTING EVENT IN REDDITCH

One part of the county where we have very few members is **Redditch**. We are keen for this to change in 2025 and want to increase awareness of prostate cancer in the town. With a population

of over 82,000 Redditch is easily the county's second largest town after Worcester (101,000) and much larger than Kidderminster (57,000). We begin the process by attending their 'Tackling Mental Health Together' day at Redditch FC on Monday, January 20th. (10.00-16.00). If you are a member in the Redditch area, please drop by and have a chat with us on the KWPCSG stand. Our next commitment to the town is to run our first PSA testing event of 2025 there. The venue is Oakenshaw Community Centre (see Calendar on back cover for more details). It will be another first for the group in trialling a PSA event on a Saturday (March 8th., 09.30-12.30).



Oakenshaw Community Centre

#### MARYS CORNER

have written about the meeting on the 21st October at the Harriers Social Club, regarding incontinence and erectile dysfunction issues post-treatments. I was not too well, so Paul Markall stepped in and took over the running of the event, but I had to add at the end of the evening my concerns about some lack of follow-up for men who have had surgery for prostate cancer.

A nor I have recently had one incident when a man who had the operation in 2018 and was discharged two years later with no instructions about pror follow-up. When he mentioned that he no longer needed PSA tests because he no longer had a prostate, I explained that PSA testing is always necessary to continue with in case there is a change in the reading. As

many of you will know, some of our members have had to have salvage radiotherapy following surgery to the bed where the prostate was removed from. I have also been concerned that the Survivorship programme was not offered to him for telephone follow-up. I have spoken to another member's wife whose husband had his operation privately and was discharged. Unfortunately the reading started to rise without any action or a referral to a Consultant. It is most important that any man undergoing surgery for PC will be aware of follow-up for possible recurrence, and I have asked for help in showing how these readings should be acted on. I have, therefore, requested some help from Gary Mascall about the importance of the readings when the patient has had surgery, with guidelines from Best Clinical Practice which follows.

Mary Symons



#### **GUIDANCE FOLLOWING RADICAL PROSTATECTOMIES**

The following guidance is recognized as best clinical practice by the following organisations:

- Macmillan Cancer Support (2021)
- American Cancer Society (2023)
- Prostate Cancer UK (2024)
- National Institute for Clinical Excellence (2019)
- West Midlands Expert Advisory Group for Urological Cancer (2020) WMEAG

Two assays for Prostate Specific Antigen (PSA) are available in clinical practice, these being the PSA Generation 2 Assay (PSA) and the PSA Generation 3 Assay, which is the ultrasensitive PSA (uPSA) assay.

Current clinical consensus is the uPSA is best suited to research studies at the present time until it is more widely available to routine clinical laboratories.

Following radical surgery, the following levels 3 months post-surgery are considered as indicating complete removal of prostate tissue.

PSA <0.1  $\mu$ g/L (may be shown as ng/ml) uPSA <0.01  $\mu$ g/L (may be shown as ng/ml)

The WMEAG recommendations for follow-up and monitoring of patients after radical surgery are:

- 1. Follow up should be with the primary treatment team until the patient's condition is stable.
- Subsequent follow-up can be made with the primary treatment team, the referring team, or by GP according to the clinical situation and patient preference, according to personalised stratified follow up.
- Most patients require follow up as below; those with a high risk of recurrence may require more frequent monitoring:
  - · 3, 6 and 12 months for the first year
  - · 6 monthly for the second and third year
  - · annually thereafter in line with cancer network follow up guidelines.
- 4. Patients require the following at each follow-up review:
  - · clinical / symptomatic assessment
  - · serum PSA test
  - · assessment for erectile dysfunction and incontinence issues
- 5. The following should be observed for/actions should be taken:

After radical prostatectomy, a serum PSA level  $>0.1 \mu g/L$  or three consecutive rises with ultrasensitive PSA, should prompt referral for salvage radiotherapy, if appropriate.

G. C. Mascall (FRCPath)

Retired Consultant in Clinical Biochemistry Worcestershire Acute Hospitals NHS Trust

# FUTURE EVENTS

#### FORGE MILL VENUE FOR FIRST REDDITCH C&C

We are delighted to announce that our first Coffee & Chat of 2025 will be held for the first time in **Redditch**. Not only that, but we have booked for it to take place at the beautiful site where both the **Forge Mill Needle Museum** and the ruins of **Bordesley Abbey** are situated. We hope our relatively few members in the Redditch area will turn out in force and bring a few non-members with them, but we hope also that some of you will take the opportunity to stay on after the C&C to have a tour of the Needle Mill and Visitors' Centre (cost at time of writing: £ 6.80 per adult).



Bordesley Abbey Visitor Centre, café and the Woodward Room (left) on the Force Mill Needle Museum site

# RECENT EVENTS

#### FIRST 'WALK & TALK' EVENT FOR OUR GROUP



Worcester Woods

Thursday 31st October was the first "Walk & Talk" event to take place, an informal meeting for anyone to join Paul Hanson and Phil Goodall for a short walk around the beautiful woods at Worcestershire Countryside Centre. The event was organised initially via the KWPCSG WhatsApp group, followed by an email to all members. There was a good amount of interest with 14 walkers joining, some couples, some newcomers to KWPGSC, one person that had heard through his oncologist and a dog. Most were quite local and although this was not a stipulation, it was what we had expected.

The weather was kind, dry and not too cold. Phil walked up front, a veteran of the woods, while Paul brought up the rear. There was plenty of chat that could be heard during the 2km walk which took around 35 minutes, including people's personal stories and effects of treatment, but also plenty of random conversation ranging from parking to gardening. The walk was topped off by a coffee under the pergola at the **Orchard Café** where the chat continued, and the group was joined by one or two more members. The feedback was very positive, Paul and I were very pleased that everyone enjoyed the occasion, so much so that we have organised another date - **Thursday, November 28th.**, this time from **Perdiswell Leisure Centre**, at 10:30. We also hope that people in other areas might consider doing the same.

Phil Goodall

#### DR. STEVE ALLEN RETURNS TO PERSHORE

Back in September we welcomed Dr. Steve Allen back to Pershore for the first time since the Covid lockdowns. In recent months Steve has stepped down from his role as a Tackle trustee but continues to act as one of its patient representatives on national bodies such as NICE and the National Prostate Cancer Audit. I last met him at the annual Shedfest conference at the University of Worcester in July where he spent hours discussing prostate matters with the many men who engaged with him on the Tackle stand.

Steve, who is a former anaesthetist at the Royal Berkshire Hospital in Reading, talked of his own physical and emotional issues and major side-effects after his radical prostatectomy in 2008. His own experiences have crystallised into a passionate but expertly researched stance on matters such as early detection and the better use of PSA testing. He devoted

the final 30 minutes of his talk to the complex issues surrounding new drugs being accepted or rejected by NICE and to his risk-based promotion of PSA testing by GPs and in the community. As always there were many questions at the end of his talk which only concluded when the caretaker jangled his keys.

The evening has started with a short talk from Ian Butcher (one of the organisers of the hugely successful Wyre Men Sing project) and Adrian Evans, one of the choir members, followed by Jan Garratt talking about the role of the Friends of Pershore Hospital and being thanked for her charity's very generous contribution to the July 4th. PSA testing event at Pershore Medical Centre.



Dr. Steve Allen

#### SPECIAL NIGHT AT KIDDERMINSTER

The sixth and final open evening of KWPCSG's programme of open evenings took place at the Harriers' Social Club. It started with video extracts from the unforgettable Gala Concert with the Kidderminster Male Choir and the Wvre Men Sing Choir performing against the lovely background of St. George's Church.

lan Butcher talked about the 40 Wyre Men singing alongside KMC to raise money for our group. They attended to pass on a cheque of £10,200 for our group, some of which had gone towards our PSA tests in Kidderminster in September. The work that lan and his colleagues put into raising the highest donation we have ever received was appreciated by everybody in the room who thanked them with tumultuous applause.

Paul Markall introduced then Caitlin Chris Marsh (KWPCSG treasurer, centre) receiving the cheque for O'Mallev from Worcestershire Hospitals NHS Trust. She is a physio who



£ 10.200 from Wyre Men Sing project leaders Ian Butcher (left) and Acute John Parkinson (right)

works with helping men to come to terms with incontinence issues. Her talk helped a great deal to get across the message that men have a pelvic floor as well as women and how to do this exercise, with great humour.



Guest speaker Mohit Mitra (iMedicare Ltd.)

Our main speaker was **Mohit Mitra**, an Area Manager for iMedicare Ltd., who has worked with PC patients for 7 years discussing erectile dysfunction and urinary incontinence preand post-treatment. He gave a wonderful presentation on the work of the human body affected by surgery, and radiotherapy for PC and focussed on penile rehabilitation.

After all the talks had finished, several members of our group and some new ones went to have a chat with Mohit and Caitlin. Altogether a very good evening for our members who need help, and I now have lots of flyers regarding the help that can be offered to anybody with erectile dysfunction or incontinence (please let me know if you require anything).

Mary Symons

#### SECOND EVESHAM COFFEE & CHAT

In October we returned to Evesham for a Coffee & Chat at Evesham FC Social Club. but organiser and KWPCSG committee member Colin Maisey was a little disappointed at the turn-out of 28 people. 'Despite having 50 posters displayed in the town and outlying villages and a good social media presence, we only managed to attract a couple of members from the Evesham area,' he said. Colin was keen to thank the football club for its generosity in not only waiving the fee for the hire of the room but also providing coffee free of charge. 'It's an ideal venue with ample free parking and a spacious social club.' Paul Hanson spoke about the newly-created KWPCSG WhatsApp platform, urging many more members to join. Phil Goodall also talked about his recent fundraising efforts through sponsorship for his recent Worcester 10k run.

#### PARTNERS' GROUP CELEBRATES FIRST ANNIVERSARY

12 months ago, Alison Hanson set up a group where partners of men who had recently been diagnosed or were living with prostate cancer could meet up and support each other through what can be a scary and difficult time.



lymphoedema. My friends and family have been a fantastic support. However, when we were going through this life-changing experience I felt quite lonely until I met some other partners who had been through the same as me. It made me realise that there is a lot of support for men but hardly any for their partners. So, 12 months ago, I decided to see whether any other partners wanted to meet up to chat about how they were coping with their partners' diagnoses. One year later, the meetings are going from strength to strength with a core group and new faces each time".

The group meets every two months at the Perdiswell Young People's Leisure Centre (just off Droitwich Road, Worcester) to share their experiences and support each other and regularly attracts about 12 partners from the local area who want to be supported away from the medical profession but in the company of others who have experienced the same as them.



Gwvn Scolari

Pat Booth, one of the attendees, said: "12 partners met to share the unspeakable and voice the unbearable in an atmosphere of care and support. These partners are grappling with a changed way of life and much uncertainty. We arrived as a group of strangers but who have ended up friends and confidantes".

Alison, the group leader said: "Paul my husband was diagnosed with prostate cancer in November 2022; he has had a radical prostatectomy, radiotherapy and is currently contending with the impacts of hormone therapy and chronic secondary

Gwyn Scolari and Anne Frazier joined the working group when the idea for the group was identified. They have both been a fantastic support, giving their time freely, coming up with ideas and helping to shape how the meetings are now run. Helping partners to connect with each other is a really important part of the support group and Gwyn and Anne both bring empathy and understanding to different members of the group.

Alison Hanson

#### UROLOGY INVESTIGATION DEPARTMENT NOW OPEN

Patients with bladder and prostate problems will benefit from a brand new 'one-stop' investigation unit that has opened at the Alexandra Hospital in Redditch. The Urology Investigation Unit (UIU) is a dedicated facility that will mean consultations, investigations and some treatments can be carried out in a single area.

The aim is to reduce the need for patients with urology, bladder and prostate issues, including cancer, who undertake multiple visits to the hospital. The £1.6million purpose-built UIU will provide investigational and treatment services, such as prostate biopsies, bladder endoscopic tests, urinary tract procedures, installation of bladder treatments, catheter changes and removals and stent removals.



Jan Garratt and Susan Stainton from the Friends of Pershore Hospital were invited to visit the Urology Department at The Alexandra Hospital following a donation from the Friends

Colleagues gathered at the UIU to officially open the centre. Mr. Vincent Koo, consultant surgical urologist at Worcester Acute Hospital Trust, said, "The UIU will increase capacity and allow more patients to be investigated in a shorter time frame. It has also enabled the establishment of a Urology Same-Day Emergency Care Unit (USDEC) to assess and treat patients with urological problems away from the busy Emergency Department. This is a more effective way for the correct specialist to treat problems in a shorter waiting time."

#### LINKS DEVELOPING WITH WAHT

Peter Corbishley and I had the pleasure of meeting Stephen Collman who is the Managing Director of the Worcester Acute Hospital Trust (WAHT) in October. We were introduced by Paul Rajjayabun the Consultant Urological Surgeon at WAHT. We had the opportunity to update Stephen on the good work that the KWPCSG does across the county. Stephen updated us on a number of initiatives they have ongoing including some of the data analysis that was taking place within the trust to identify and target the 'hard to reach' groups in Worcestershire. There is some significant disparity on health outcomes in certain areas



Stephen Collman, Chief Operating Officer of WAHT

of our county. This aligns with what we are trying to achieve when hosting our PSA events. We took the opportunity to ask for a quarterly meeting with the relevant NHS people at the hospital and within the community to continue to strengthen the great relationships already established. This would help us attract more members to the charity, target our events more specifically plus enable us to keep abreast with changes within the hospital setting and in the community so that we can continue to provide up to date information to our members.

Alison Hanson



## **FUNDRAISING**



#### NEW BIOPSY CHAIR FOR UROLOGY DEPARTMENT

Thanks to the generosity of the Kidderminster Male Choir in donating over £ 10,000 to KWPCSG from its Wyre Men Sing project, we have been able to complete the funding required for the biopsy chair at the Alexandra Hospital in Redditch, a campaign run by the Urology Department Charity at WAHT. Our donation of £ 6500 took the total to the required £ 25,000 mark.

The biopsy chair completes the creation of a new investigation unit (see page 9), with more detail supplied by Sophie Burt in the letter below.



Kidderminster and Worcestershire Prostate Cancer Support Group C/o: paul.markall@yahoo.co.uk

18 November 2024

Thank you for supporting the Worcestershire Urology Appeal



Dear Kidderminster and Worcestershire Prostate Cancer Support Group

Thank you for supporting the Worcestershire Urology Appeal and helping to provide the finishing touches to the new Urology Investigations Unit and Urology Same-Day Emergency Care facility at the Alexandra Hospital, Redditch.

Every year our specialist urology service performs around 2,500 surgical procedures, sees more than 22,000 patients in clinic and treats 1,500 emergencies. As a Charity we aim to enhance our patients' experience of care, and we can only do this with your support.

Thanks to your generosity we will work alongside the Trust to deliver those additional added extras to make the development the best it can be for patients across our county.

Thank you for your support.

With best wishes

Sophie Burt Head of Fundraising and Community Development

#### PROSTATE CANCER RESEARCH REPORT UNVEILED

A potentially game-changing report unveiled by **Prostate Cancer Research (PCR)** at the **House of Commons** on November 14<sup>th</sup>. has for the first time, concluded that universal screening for prostate cancer would be cost-effective and save lives. It stated that routinely offering PSA tests to men over 50 could save £ 204 million per year by catching cancers earlier, saving lives and reducing the cost of treatment.

Under present NHS guidelines GPs are barred from offering PSA tests, although men can request one from the age of 50 or 45 if they are black or have a family history of the disease.

The PCR event was co-hosted by David Lammy (Foreign Secretary). **James** Cleverly (former Conservative Foreign and MP Secretary) Liberal Josh Babarinde, who all urged the NHS to launch a screening programme. In a speech the Oscar-winning film director, Sir Steve revealed he had received a prostate cancer diagnosis in 2022 and had surgery to remove a tumour. He said, 'My father had died of prostate cancer, so I was aware of my chances of a positive diagnosis as a black man. For a number of years, I have been proactive in getting tested. In some ways, my father saved my life, because if he hadn't died of prostate cancer, I wouldn't have been proactive.'

Tackle trustee, **Tony Collier**, wrote in a WhatsApp that morning, 'Just left a brilliant session at Parliament where Prostate Cancer Research launched their report into the socio-economic impact of screening. There was cross-party support to do something with speeches from Wes Streeting, James Cleverly and David Lammy, but the best speech was from our own **Aidan Adkins** (former co-Chair of Tackle and Solihull **PCSG chair**) representing the patients' view which was incredibly powerful and heartwrenching.... lots of celebs there, including **Gary Lineker**, **Frank Lampard and John Bishop**.'

Health Minister Wes Streeting had previously stated that health officials were reviewing guidelines on screening, with final recommendations due by the end of the year. Although the much-vaunted TRANSFORM trial, financed mainly by the NHS and Prostate Cancer UK, is due to be launched in 2025 – later than originally intended and due to take at least 10 years to report back, new research shows that a targeted screening programme for highrisk groups is set to outweigh the harm of overdiagnosis.



From left: Aidan Adkins (Tackle patient Representative), Rt Hon James Cleverly MP, Rt Hon. David Lammy MP, Josh Babarinde MP, Oliver Kemp (PCR CEO), Sir Steve McQueen.

### MARY SYMONS: STEPPING DOWN AS CHAIR

At the KWPCSG October meeting Mary Symons, the Chair of the charity since 2020, announced that she would be stepping down for health reasons as Chair at the AGM in January 2025 but that she would continue to support the group as a committee member.



Adel Makar (President of KWPCSG), Mary and Lisa Capaldi (President of SWPCSG)

For the few of you in our 500-strong charity who may not know Mary, she was one of the founders of what was originally the Kidderminster & District Prostate Cancer Support Group. Mary had become the Clinical Nurse Specialist (CNS) in Urology at Kidderminster Hospital in 1999 and was soon setting up a Patient Participation Group. What started as a coffee morning for 8 men and their partners in the Millbrook Suite on a Saturday morning was, 24 years later, to become a county-wide charity with 500 members, one of the largest of the 135 PCSGs affiliated to Tackle Prostate Cancer in the UK.

An early appointment to the group included Rev. Paul Brothwell as Chairman. Paul remained in this role of what later became the registered charity Kidderminster & Worcestershire PCSG for 20 years until his death in 2020. In April 2000 no fewer than 100 men attended the inaugural formal meeting, with 60 paying  $\pounds$  5 and signing up as members. 2001 saw the creation of the Supporter Magazine under the editorship of John Poole, a Widows' Group (later to be renamed the Ladies' Group) and PSA testing at Kidderminster Town Hall. More details of the formative years of the group will be published in the March magazine when we celebrate 25 years of the existence of a PC support group in Worcestershire.

Mary was the founder of the group, but also its medical advisor whilst still working at the hospital as a nurse. After retiring completely and being removed from the

register, she was no longer able to act as adviser in medical knowledge, so she became the Secretary to the group in 2016. In 2017 our group was put forward for the Queen's Award for Voluntary Services, and both Paul and Mary were asked to fill in paperwork and explain our work with our group as well as being interviewed. The work for our Buddies and Support Contacts were major factors in achieving this award. If we fast forward to 2020, we find Mary taking over the role of Chair after the death of Paul Brothwell at a time when the group was struggling on several fronts. The unresolved saga of 8 years of fundraising for the Rory



Mary and Rev. Paul Brothwell at a Buckingham Palace Garden Party after receiving the group's Queen's Award for Voluntary Services in 2017

the Robot campaign to provide robotic surgery at the Alexandra Hospital in Redditch was weighing heavily on the group when Covid 19 struck and we were all told on March 23rd. to stay at home and shield the vulnerable, which would include many of our members. As Paul Brothwell wrote in what proved to be his final Chairman's Letter in May 2020, 'We are a group of older people, and many of us, like me, are not all that good with modern technology.....I try to grapple with all the modern jargon Zoom, Facetime, YouTube, Mary with former South Worcestershire PCSG chair, Gordon Kingston



WhatsApp. This is all mind-blowing to me.'

Communication with members continued to be severely disrupted in 2020. Much depended on our support contacts to keep lines open to our members. Mary organised Zoom meetings later in the year with speakers such as Dr. Steve Allen, but by the end of the year numbers attending the Zoom meetings were very low and only 5 new members joined the group that year. Another lockdown had meant things would not improve anytime soon, creating real problems for Mary and her committee, but she was always able to call on the support and guidance of another key figure in the development and progress of the group, Gordon Kingston, the chair of the South Worcestershire satellite group.

With the vaccine roll-out and the end of lockdown in Spring 2021 the first live meetings could take place. It was decided to expand the reach of the group into other parts of the county, so the Coffee & Chat was invented and piloted in Malvern as the first of 3 in the southern part of the county in that year. Three years later the number of C&Cs has doubled, with groups meeting this year in Cleobury Mortimer, Ledbury, Worcester, Stourbridge, Evesham and Bromsgrove. Also this year numbers attending these events have almost doubled.

Mary can look back at her 4 years at the helm of KWPCSG with great satisfaction. She has supported Alison Hanson's initiative in developing a Partners' Group and allowed the Supporter Magazine to expand from 12 pages to 24. Links with our key donors are stronger than ever, and the group was able to donate £ 6000 in 2022 towards the purchase of abdominal compression devices for SABR radiotherapy and £ 6500 in October 2024 to complete the acquisition of a biopsy chair for the Urology Department Charity.

Although she will be stepping down as chair, Mary will continue to play an active role as a committee member, helping the group celebrate its 25th. anniversary in 2025 in very good shape financially, with a vastly expanded programme and, critically, a number of new faces both on the committee and as key volunteers to continue the development of the group into a truly countywide organisation. The group is very different from the one she was instrumental in setting up in Kidderminster 25 years ago, but she can be proud of what it has achieved over the years in its primary objective - giving vital support to men and their families affected by prostate cancer.

#### PHIL BARRETT: MAN ON A MISSION

I first met Phil and his wife, Lyn, when they attended the first Coffee & Chat of the year in Cleobury Mortimer in late March. We shared a table and were soon in discussion about a wide range of issues. I was surprised to learn that the couple lived in Bournville but, sadly, not so surprised for Phil to confirm that there were no prostate cancer support groups (PCSGs) in South Birmingham or indeed anywhere in the city.

Why choose KWPCSG? Phil had attended a number of excellent monthly meetings run by the Solihull PCSG but he felt he needed to become part of a group which offered its members more get-togethers and more support. After trawling the net and comparing PCSG groups, he opted for KWPCSG. In October he was co-opted onto the committee, the same month that he was invited to become a Patient Advocate for Early Diagnosis, Health Inequalities and Skin Cancer on the West Midlands Cancer Alliance. Phil is clearly a man in a hurry, a man on a mission.

Born in Slough in 1960, Phil and his family moved to Abergavenny when he was 10. After completing his secondary education at the King Henry VIII School, he moved



Phil and Lyn enjoying the sun in the Algarve

back across the border to Worcester to work for NatWest Bank, the company he remained with throughout his career. He looked back with fondness at his two years in Worcester, living in digs on Cannon Street in Redhill and walking to work each day down the London Road to the Cross.

In the 1980s there were moves back to Abergavenny, then Hereford and finally up to Birmingham where he met Lyn. House moves saw him in Great Barr, then Halesowen and finally, in 1989, to Bournville where they still live. Their three children are dotted around the country in Cheltenham (Adam), Merthyr (Matthew) and Bedford (Lauren).

After the broadly-based banking training in his earlier years. Phil was able to specialise in financial crime in his later career until retirement in May 2023. But before that, he was diagnosed in November 2020 with prostate cancer. Although his PSA level was only 4 and he had no symptoms. this was not a good time to receive such news as Covid 19 was at its height and no one was answering phones at hospitals. Nevertheless, still having medical cover through work, he underwent an open radical prostatectomy just before Christmas and recovered quickly with few side effects. Now he only requires an annual PSA test to monitor his recovery. Being a great believer in men becoming more aware of their condition, he said, "I find it helpful to keep a diary and share details to help you help yourself."

Having attended a number of meetings organised by the Solihull PCSG, Phil soon became aware of the possibilities available to him to show his gratitude for his

medical treatment and to raise awareness of the disease or support others already diagnosed with prostate cancer. Through his involvement with Prostate Cancer UK. he has volunteered at two British Masters golf tournaments at the Belfry, as well as with the Bob Willis Fund, and given a Zoom talk to no fewer than 1700 staff members at NatWest. He has also been involved in round table discussions for the Prostate Cancer Research charity and is just waiting to see if he has been accepted onto the Patient Representative Network at Prostate Cancer UK. The day after Nick Owen's disclosure of his condition on the BBC Breakfast programme. Phil was interviewed on Midlands Today for his reactions.

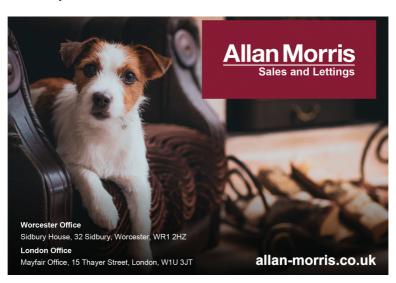
If Phil appears to be a serial volunteer, I'm sure he would go along with that assessment. In his words, 'It's not easy for men to talk about their health, so when I can, I try and start the conversation.' His volunteering and opportunity to talk to more people take him, however, beyond the prostate cancer world to the Edgbaston Stadium and the world of top-class cricket where Phil volunteers to help out in one of the two sensory rooms for children and young autistic adults, a choice linked to the condition of a family member.



Phil at The Belfry volunteering during the British Masters

KWPCSG is fortunate to have acquired the skills and services of someone whose experience gained over just the past 3 years of so many prostate-related organisations and charities makes him such a valuable recruit to the committee. We wish him well and also look forward to seeing Lyn return to our meetings after her recent operation.

Peter Corbishley



#### FITNESS AND RUNNING WHILST LIVING WITH PROSTATE CANCER

I started running in 2017 after my wife and I decided to lose weight and get fit to see us into our later years. By late 2018 we'd got the running bug, I achieved a Parkrun PB of 22:57 and we both entered the Worcester City Half Marathon.

Following a PSA test, MRI and biopsy in January 2019, I received a Prostate Cancer diagnosis and had a Prostatectomy in March. Although the operation went well one of 24 lymph nodes removed was found to have cancerous cells. Over the next 4 years my PSA slowly increased again needing 2 separate rounds of SABR treatment but by November 2023 the cancer had started to spread more widely, Phil Goodall running his first needing chemotherapy and ongoing hormone treatment. There were 6 sessions of chemo, finishing in March 2024.



race after chemotherapy at the Worcester City 10 km event in September

I continued running during the first 3 sessions but eventually fatigue got the better of me. I also continued sessions with my Personal Trainer (Luke Evans), doing as much as I could with weights and other tailored exercises. A month or two after the chemo had finished, I started to do some gentle runs of a shortish distance, listening to my body and not pushing myself too hard. After a few runs I found the fatigue starting to fade.

It was about this time that my wife entered the Worcester City 10k and suggested I enter as a nod to that first race that we did together. I agreed saying I'd just take it easy and trot round. Well Luke, who is also a runner, asked me what my training plan was. "Just going to wing it" was my reply. However, something clicked, and I started to do some training for the race.

As the days and weeks went by, I found myself getting stronger and able to cope with the fatigue, in fact the more I did the less fatigued I was. I found myself wanting to run faster. With a week or two to go I was feeling confident and decided that I would raise money for KWPCSG and I am glad I did as with the generosity of many of my friends, members of the KWPCSG and others that were strangers, donations reached £780.



Phil and wife Donna having completed the Worcester City 10 km.

On the day the weather was perfect, there were large crowds giving lots of support and encouragement and great atmosphere. The race went pretty much to plan, finishing with an official time of 55:29. I also saw runners from Southco Manufacturing who were raising money for the charity too.

I owe thanks to Donna for persuading me to enter and to Luke for his expertise and encouragement. Training for the race gave me focus with a great sense of achievement in finishing in a decent time and not least, raising a good sum for the charity. It has been a very positive experience indeed.

Phil Goodall



#### JOIN THE KWPCSG WHATSAPP COMMUNITY

More than 2 billion people in over 180 countries use WhatsApp to stay in touch with friends and family. A lot of us started to use WhatsApp more during the pandemic to stay in touch.

The KWPCSG started to use WhatsApp over 12 months ago when Alison Hanson set up the Partner group. The group was used to communicate meeting dates and share experiences and tips. After the success of the Partner Group, it was decided that a 'Community' be formed on WhatsApp for all members and their partners to join.

The 'Community' is a safe space to share information, meeting dates, ask questions and provide tips. The Community was set up by Phil Goodall and Paul Hanson.

Currently we have 52 members in the main discussion group, with more people joining every week as word spreads. Recent topics of conversation have been reminders of events, information about Sir Chris Hoy and a discussion about the benefits of PSA testing. (So far we haven't found that participants have gone off topic which is the worry that lots of people have of communicating in this way).

We understand that WhatsApp isn't for everyone, but if you are worried about your phone continually pinging with new messages, don't forget you can mute the conversation and read it at your leisure if that suits you more.

If you would like to join the KWPCSG WhatsApp Group, scan the QR code below or if reading online, click on the link https://chat.whatsapp.com/GQM3C4jQlucEoFIGMm8UZ7.



#### **SCAN TO JOIN**

If you have any questions, please contact Phil Goodall, WhatsApp or Text +44 7845 559981 or email phil.g.goodall@gmail.com

#### REMINDER

Join us via Zoom for the Annual General Meeting on Tuesday January 21st. at 7 pm. More details on the website in January.

#### SUPPORTING PSA HEALTH CHECKS

To our knowledge over 660 men have attended community prostate cancer PSA tests or, more accurately, **PSA health checks** over four events in Worcestershire in 2024.



The admin team – seated: Hilary Brothwell and Mary Symons. Standing: Maryon Harrington, Alison Hanson, Martin Harrington

The first took place in March in Worcester and was organised by the Worcestershire Ambassadors. Next was the Pershore PSA event, organised by KWPCSG, held at Pershore Medical Centre and attended by 168 men (sadly, there were 12 noshows) on Election Day in July. This was free of charge to those registered thanks to the generous donations of the Friends of Pershore Hospital, the Pershore Prostate Cancer Support Fund and Southco Manufacturing (Worcester). In September attention switched to Kidderminster where 197 men received PSA tests at the Kidderminster Harriers' Social Club thanks to the generous donations from the Worcestershire Ambassadors and the Kidderminster Male Choir. KWPCSG raised £ 1200 through donations from the men tested, every penny of which will go towards the next PSA event in Redditch (see page 3).

Unexpectedly, however, a fourth event was arranged for October 19<sup>th</sup>. The event was organised and funded by the **Wychavon** 



Jon Gaskell (Rainbow founder) having a PSA test

District Collaborative, with 100 places being offered for tests at Pershore Naval Club. Efforts were made to involve hard-to-reach communities in the Pershore area, and all the slots were taken over a 3-week period. Wychavon Wellbeing Officer Hayley Corbett was delighted with the response. KWPCSG provided 7 experienced members on the night to support the Wychavon officers. Once again donations totalling over £ 600 were received which will be returned to Wychavon for PSA testing in 2025.



Peter Corbishley (left) and Dave Lambert outside the Naval Club



## **FUNDRAISING**



#### MAJOR CONTRIBUTIONS TO GROUP'S FINANCES

As referred to in the Editorial, this has been an exceptional year financially for KWPCSG. We are, once again, hugely grateful to **Jon Gaskell** and his team for donating £ 5000 to our group as part of the funds raised by the **Rainbow Cancer Care Foundation** at the Rainbow Day at **Cleobury Mortimer Golf Club**. It's great to see Jon on page 18 apparently enjoying his PSA test (for more about Rainbow, go to the March 2024 magazine on the website).

The largest-ever single donation to the group is acknowledged on page 5 and at length in the September Supporter Magazine. Having had several KWPCSG members and other men with family histories of prostate cancer taking part in the **Wyre Men Sing project** would have been the highlight of 2024 even if not a penny had been raised. As it was, a magnificent sum of  $\mathfrak L$  10,200 was handed over to our treasurer at the October open evening in Kidderminster.

There were many other smaller but still significant contributions from all around the county from groups linked closely with KWPCSG over many years (see Fundraising feature in March magazine), but the most important new donor was **Southco Manufacturing** (**Worcester**) who donated money towards the Pershore PSA testing event earlier in the year and through the Worcester 10 km in September (see photos).

#### .....AND WHERE THE MONEY GOES

The money raised by the Kidderminster Male Choir has allowed us to donate  $\mathfrak L$  6500 to the **Urology Department Cha**rity towards a biopsy chair at the Alexandra Hospital. This donation, together with a similar sum from the Friends of Pershore Hospital, accounted for just over 50% of the total amount needed.

Part of the Rainbow contribution is funding a new website which will be launched in the New Year. The rest goes towards the Supporter Magazine. Importantly, the group's total expenditure has reduced this year due to the cancellation of newspaper advertising with the Newsquest series of publications.

Thanks to the generosity of donors, we could offer both PSA testing events in 2024 free to all participants. All the funds we raised at these events are going towards similar events in 2025, starting in Redditch in March.

KWP	CSG	COMM	IITTEE	2024
LANDL		COIVIIA		LULT

Mary Symons	Chair	01299 823166
Nicky Langford	Secretary	07590 624426
Chris Marsh	Treasurer	07734 581830
Derek Scully	Support Contact Co-ordinator	01886 833236
Paul Markall	Trustee, Shed Organiser, Fundraiser	01562 751355
Peter Corbishley	Trustee, Supporter Editor	07876 556466
Dan Cook	Trustee, Website Manager	01299 887277
Alison Hanson	Trustee, Tackle rep., Partners	07484 297405
Phil Barrett	Co-opted Member	07745 010394
Colin Maisey	SWPCSG representative	07949 723359
Val Markall	Co-opted Member	01562 751355

Please contact us if you need support or advice

# MARK HOWARD; LOOKING BACK TO 2023

I have been trawling back through the 10 articles that Mark Howard, who died on July 13th., wrote for the Supporter Magazine. These are all available on the www.kwpcsg. co.uk website (go to Menu, click onto Blog and scroll down). Here are a few extracts from 2023 which best illustrate his contribution to our group and his view of life after his Stage 4 diagnosis.



I was always a solitary individual. My nature ultimately served me well working in Borneo and Sulawesi in Indonesia. A team of engineers would install a radar, then one of the team stayed for a period, usually four months, to help train and offer advice on the maintenance and operation. This would be the Resident Maintenance Engineer. Being the only westerner for hundreds of miles around was a strange experience. When I went for a walk, everyone stared at me, quite often shouting "Hello, mister." I would normally respond with a "Hello", and they would all continue on their way, giggling with the occasional backwards glance. (March 2023)

In 2012 just as the world was watching the Olympic Games, I accepted redundancy, the old radar being replaced with a newer, more reliable system. I decided to move to the Midlands. Nothing scientific about the selection, just somewhere someone was building new houses, so I settled in Evesham. Here I continued by myself. Walking down into the town centre, enjoying a coffee and muffin, walking home and just keeping to myself. I started volunteering for the National Trust at Hanbury Hall and the Gloucestershire Warwickshire Steam Railway, but every day I got home and locked the front door behind me. (March 2023)

Then in 2019 everything changed, I received my diagnosis of metastatic PC. For three months I was on basic hormone therapy, then chemotherapy was offered. I didn't even talk to anyone about it. Dr Capaldi offered the treatment, I accepted. It started the gradual change in my approach to life. I found that I needed to talk to people and tell them how I was doing. Some friends were very supportive, others turned and walked away, "too much information." My CNS...referred me to the Oncology Psychology Service. Two weeks later I was chatting to someone. During the first session was when the floodgates opened. It was the first time I had cried or shown anyone else my true feelings. As we entered the first lockdown in March 2020, I knew that I needed to do something, but, being placed in the extremely vulnerable group due to the chemo and radiotherapy, I was advised to stay at home and not venture out. (March 2023)

It may seem strange to hear from an individual who is well into his '3-5 years prognosis' - but I have enjoyed the last 18 months. Even ignoring some health scares, one involving putting a camera where adults really should not put cameras. The pandemic was a challenge, to find myself with a life-limiting illness and advised to become a hermit was not what I expected when I got my prognosis in 2019. Once the country opened again, I dusted off my suitcase, relocated my Senior Railcard and was off on my travels. (June 2023)



At times I have not been the most cooperative of patients. When things go wrong, I tend to overreact and need time to get myself together. My medical team has looked after me, but it has taken a while for me to let go and just follow their advice. Since January 2022 my PSA has been increasing. It's now up to 27 (last blood test on April 19th.), on average going up 2-3 every month. Tumours (lymph nodes) are now over 5 cm. in length. It is difficult being aware that something rather unpleasant is growing inside me. Chemotherapy will hopefully shrink the tumours, but once I have had chemo again, under current guidelines there is nothing else in the cupboard. Delaying chemo till I become symptomatic is the sensible thing to do. (June 2023)

I think the biggest change of my life is due to 4 years on hormone therapy – or, more accurately, treatment to prevent the production of testosterone. It would have been curious to have done some baseline tests on my physical and cognitive functions before I started treatment. Without a doubt, there has been a lot of change – fatigue, stamina, loss of strength to mention just a few - but the biggest and most notable changes centre on emotion and cognitive function. (September 2023)

I have frequently mentioned my constant battle with emotions and indicated the help I am receiving. My problems occur when I am blind-sided. On the anniversary of the start of my journey, a PCUK spokesperson appeared on BBC Breakfast to advise all men in the at-risk group to go for a PSA test. This triggered a stream of insults and swearing hurled at the television. "Thanks for the f..... advice, just 5 or 6 years too

f...... late for me!" (September 2023)

Back in October 2019, when I first came under the care of the wonderful Oncology team at Worcester, I knew that my future was the palliative pathway. I would undergo a series of delaying treatments, but eventually I would exhaust the options and that would be it. So it was in September 2023 that I found myself in the chemo section of the Rowan Suite, undergoing the first cycle of Cabazitaxel chemotherapy. (December 2023)

The fateful day was 26th September 2023, 1568 days since I boarded the train and started my journey. I attended the Rowan Suite and soon found myself being prepared for the infusion, the heating pad, the insertion of the canula, the anti-sickness medication and, 30 minutes later, the Cabazitaxel, placed inside a red cover to show that it was cytotoxic and hazardous. (December 2023)

On 6th October I felt comfortable enough to visit mν younger brother Blackpool. I had a very enjoyable time. but. unfortunately. I returned on the 9th with Covid. As a friend put it,



most people return home from Blackpool with a stick of rock. (December 2023)

### ANNUAL SUBSCRIPTIONS REMINDER

Annual subscriptions of £5 are due on 3rd January 2025

If you have not completed a standing order with your bank, payments can be made either by cheque or cash to any member of the committee. If you no longer wish to remain as a member of the Group, please inform a committee member in order that we can amend our records.

For more details, please contact the Treasurer, Chris Marsh mob. 07734 581830

#### THE SHED AT LEAPGATE FARM

The Shed at Leapgate Farm (Wilden) is not a wooden structure, as you might expect, but a concept, a venue to pursue practical interests and designed as an extension to our group's support role where guys undergoing treatment for prostate cancer or post-treatment can meet socially and their partners are also welcome.

The Allotment: It's been a difficult year for our outdoor activities with the unpredictable weather. In the past, we have welcomed the rain, but the volume of water dumped on the patch this year has not only made working the plot more difficult but has affected the vegetable yield, particularly potatoes. We still have a regular team of guys who turn up every Monday, and the main topic of conversation is putting the troubles of the world to right! We also welcome members who just come along for a coffee/cake and a chat.

**Annual quiz**: This was organised for members and their partners earlier in the year. Wendy Wild, the resident chef at Leapgate did us proud with an assortment of delicious cakes all homemade on site. A barbecue had been planned but due to the unpredictable weather it never happened.

**Envirosort**: A group of our members and their partners visited the Envirosort complex at Norton (near Worcester). I was aware at the time that this activity would not be an event that would be everyone's cup of tea for an afternoon's entertainment. However, the feedback from the group that attended was very positive. The group spent 2 hours on site, mainly in the Training Room where practical demonstrations, which the group were encouraged to take part in, were conducted.

Towards the end of the session, we did have an opportunity to see the recycling plant in operation from an overhead platform. Envirosort are well aware that educating the general public into what you can and can't recycle is in their interest. Free training programmes are offered to community groups and schools throughout the year.

Just before the visit ended the Training Officer said that you would be surprised as to what some people believe they can put in a recycling bin. On one occasion part of the plant was stopped by the operators as a six-foot boa constrictor snake appeared on a conveyor which fortunately had passed away.



Fred Penn, our Gardening Co-ordinator, and one of the youngsters from Leapgate at the Annual Pumpkin competition.

Canal Boat Trip: A group of members and their partners embarked on another canal boat trip, this time from Alvechurch to Tardebigge. Trevor and Wendy Albutt, who crewed the craft for us, are members of our group and also the Worcester-Birmingham & Droitwich Canal Society. We ended the cruise with a meal at the Red Lion in Alvechurch.

**Previous Visits** - In the past we have visited local breweries, RAF Cosford, Blenheim Palace, National War Memorial and Slimbridge Wildlife Park.

If any member or partner wishing to join our activities, please contact me.

Paul Markall - Tel: 01562 7513555

# BOXING DAY TRACTOR RUN



£10\*
Minimum entry fee for each tractor

(additional donations optional)

\*In aid of the Kidderminster and Worcestershire Prostate Cancer Support Group & Worcestershire Acute Hospitals Charity





# Leaving from Far Forest Showground (DY14 9DA) Callow Hill, at 10am prompt.



All welcome at Far Forest Showground from 8am for registration, breakfast rolls and hot and cold drinks.

Route: Available a few days prior, and may change on the day subject to weather conditions. The route will include Stourport Town Centre and will end in Bewdley Town Centre on Severnside South around 12 noon. The event is supported by the Mayors of Bewdley and Stourport.

#### **FANCY DRESS ENCOURAGED**

Prizes for the best dressed seasonal tractor and occupants

You can enter and pay ahead of the event.

Contact:
Ray Attwood
07973 790214
attwoodraymond@gmail.com

To book online please contact <u>nicky.langford@nhs.ne</u>t



## **CALENDAR OF EVENTS 2025**

#### **KWPCSG ANNUAL GENERAL MEETING (ZOOM)**

Tuesday, January 21st. (7 pm)

The group's AGM will be held, as it has been for the past 4 years, via Zoom
To access the AGM, please go to: www.kwpcsg.co.uk
In January you will find more details of the event on the website, including the agenda
and the treasurer's annual accounts

#### **PARTNERS' GROUP MEETINGS**

Friday, January 31st. / Friday, March 28th. (11.00-12.00)

N.B. New venue near Perdiswell Leisure Centre

Perdiswell Young People's Leisure Club, Droitwich Road, Worcester WR3 7SN

All partners of members and non-members are very welcome
to attend these meetings of a group formed only a year ago

#### REDDITCH PSA TESTING EVENT

Saturday. March 8th. (09.30-12.30)

Oakenshaw Community Centre, Castle Ditch Lane, Oakenshaw, Redditch B98 7YB

This is an opportunity for men to sign up for a FREE PSA TEST

Registration only online via the GFCT website (www.mypsatests.org.uk)

#### SOUTH WORCESTERSHIRE PCSG (WORCESTER)

Tuesday, March 18th. (doors open at 7.00 for a 7.30 start)
The View, WCCC, New Road, Worcester, WR2 4QQ
Free parking in WCCC car park immediately after cafe.

PLEASE NOTE LATER STARTING TIME AND NEW VENUE

PLEASE NOTE LATER STARTING TIME AND NEW VENUE GUEST SPEAKER: TO BE ANNOUNCED

#### **REDDITCH COFFEE & CHAT**

Wednesday, March 26th. (10.30-12.30)

Woodward Room, Forge Mill, Needle Mill Lane, Riverside, Redditch B98 8HY Free onsite parking at the top of the lane and by the Woodward Room Free coffee and cake for every member, non-member and partner!!!

#### **KIDDERMINSTER & WORCESTERSHIRE PCSG**

Monday, April 14th. (doors open at 7.00 for a 7.30 start) Harriers' Social Club, Stadium Close, Hoo Lane, Kidderminster DY10 1NB

#### **DISCUSSION PANEL**

Following the successful Discussion Panel in March 2024 in Pershore, a new set of panellists including GPs and WAHT consultants will answer your questions.

For the latest updates on and directions to these events, go to www.kwpcsg.co.uk/our-events

> Keep in touch with us via: Tel. 01299 823166 / contact@kwpcsg.co.uk