

Kidderminster & Worcestershire Prostate Cancer Support Group



SUPPORTER

December 2023 issue 90

www.kwpcsg.co.uk

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EDITORIAL



Let me explain the front cover. Restricted space prevents me from paying respect to all those who have made 2023 an exceptional year for KWPCSG, but, if members remember, the September editorial named lots of those members and partners who helped the group expand its support range to members (e.g. PSA testing events, 3 additional Coffee & Chats in the north of the county).

The front cover seeks to remind members of the excellent speakers who have fronted our open meetings in Kidderminster and Pershore. If you attended those meetings or read our reports in the magazine, you may recognise **Aidan Adkins** (co-Chair, Tackle) and **Paul Rajjayabun** (Consultant Urologist). Also in the collage you will recognise KWPCSG Chair, **Mary Symons**, and two of her stalwarts over recent years, **Gordon Kingston** (SWPCSG Chair) and **Richard Langley** (Marketing Officer), both of whom are due to step down at the AGM in January.

Some of the remaining faces may not be so familiar to members yet, but my predictions are they will become increasingly important to us over the next few years. They include **Di Fox** (top right), who runs our still undersubscribed Zoom exercise sessions on Monday mornings, **Sharon Johnson** (bottom right), who, as Worcester City Cancer Care Coordinator, has promoted links between our group and primary care networks, and **Dan Cook**, whom we are extremely fortunate to have on board as our website manager and now committee member. The steady development of the website will, I feel certain, become so important to all our members.

Almost there, but still 2 faces I haven't mentioned. One is very well known to us all as BBC presenter and KWPCSG patron, **Nick Owen**, who joined the ranks of PC patients early in the year and bravely broadcasted his journey to millions. And, finally, there's **Mark Howard**, whose articles over the past 2 years charting his life and condition have earned the praise and respect of so many of our members.

December is a time to reflect and look back on our support for members in 2023. It is also, however, a time to look ahead and, at the risk of looking stupid 12 months from now, making a few predictions. Locally, I hope KWPCSG will succeed in establishing the Partner Group being spearheaded by our latest recruitment to the committee, **Alison Hanson** (see page 17) and in contributing to the formation of a PCSG in neighbouring Herefordshire. It may also become what I think may be the only PCSG in Britain with over 500 members by the end of next year. Nationally, I think 2024 will be a critical year for prostate cancer with the pressure from PCUK, Tackle and cancer research bodies driving all our major political parties towards a commitment regarding community PSA testing. Onwards and upwards, as they say.

Peter Corbishley / editor@kwpcsg.co.uk / Mob. 07876 556466

**Join us on the Zoom AGM on Monday January 22nd.
(for more details see page 3)**

FUTURE EVENTS



NEW PANEL DISCUSSION AT PERSHORE

In June 2022 Pershore hosted its first panel discussion with retired GP **Chris Perks** representing primary care, consultant oncologist **Lisa Capaldi** representing acute care and **Simeon Greene** from Wolverhampton acting as the voice of patients. 48 people attended the event, plus 30 others who watched the hybrid event live. This time there will be a new panel assembled at the Wychavon Civic Centre in Pershore on **Tuesday, March 19th. (18.30 for 19.00 start)**. More details will be available in the March 2024 magazine and in the Events section of the group's website (www.kwpcsg.co.uk).

DOUBLE TACKLE AT KIDDERMINSTER

The first Kidderminster open evening of 2024 will feature two guest speakers from Tackle, the federation representing the 120 UK prostate cancer support groups (PCSGs). Members may be familiar with **Sarah Gray**, who for more than 3 years has been the charity's **National Support and Development Manager**. Sarah was our guest speaker at our March 2021 meeting but, due to Covid restrictions, the event was via Zoom. Joining her will be Tackle's newly appointed **National Peer Support Coordinator, Mark Kelly**, who lives in Otley. Sarah will keep us updated with PC developments on the national stage, while Mark will inform us of the progress he is making at grassroots level with support groups, particularly in the north of England. The meeting – open to all members, their partners and non-members – will be at the **Harriers Social Club (19.00 for 19.30 start) on Monday, April 22nd**.

JOIN US ON THE ZOOM AGM IN JANUARY

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 **Monday, January 22nd. (19.00) via Zoom**, a platform which many of us mastered over the Covid period. **All the information and simple instructions are available on the group's website.**

According to our membership secretary, Derek Scully, we have just over 470 members. We'd be absolutely delighted if, say, 10% of you attended and perhaps a little disappointed if we attracted just 5% of the membership. The important treasurer's report will be revamped this year and, yes, there are 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 22nd.

MARY'S CORNER



We are lucky that we had a relatively mild October, with plenty of rain, and, now in November, crispy mornings and fog as the leaves fall off the trees. I love my walk every morning across the Snipes outside of my village with my dog Millie, where we meet the same walkers and dogs every day and have a nice chat.

We had our last open meeting at the Harriers Social Club on Monday 23rd October, when **Paul Rajjayabun (Consultant Urologist)** came to talk to us about robotically- assisted surgery at the Alexandra Hospital. It was put across so well by Paul who made it easy to understand, and the future for men in Worcestershire is now secure for surgery for prostate cancer. He mentioned that they still do open surgery when it is necessary, as not all men are able to have the operation done by the robot. I am extremely grateful to Paul, who came straight from working in a clinic to us and gave us so much of his time to answer questions.

We have three open meetings planned for next year at the Harriers Social Club, and I have arranged the speakers for the first on the 22nd April 2024 (see page 3 for more details). We have also had several coffee & chats events around the county, which have been very successful (see reports on page 8), including our most recent one at **Stourbridge FC social club**. We are planning some more for 2024 and the first one should be March (more information in the March magazine).

At the meeting at the Harriers Social Club **Alison Hanson**, the partner of a new member, Paul Hanson, went round the tables introducing herself to the ladies and explaining that she and her colleague, **Andrea Hingley**, were seeking to create a **Partners Group** which would offer support to partners of the men in our group. It is important that we offer this service for when men are undergoing treatment, so that experience of care following treatments can be shared appropriately. Please contact them if you feel this could benefit you (see details on page 15).

Our dates for meetings in the north of the county are:

- **Monday 22nd April 2024 at the Harriers Social Club, 7.00 for 7.30 p.m. start**
- **Speakers Sarah Gray and Mark Kelly (both representing Tackle). Discussion will include mental health issues. Alison and Andrea will give an update on the Partners Group**
- **Monday 15th July – Harriers Social Club - speaker to be arranged.**
- **Monday 21st October – Harriers Social Club – speaker to be arranged.**

Mary Symons (Chair, KWPCSG) / Mob. 07752 090697/ mandmsymons@talktalk.net

REMINDER

Annual subscriptions of £5 are due on 3rd January 2024

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 Support Group, please inform a committee member in order that we can amend our records.



RECENT EVENTS

INSPIRATIONAL TALK AT PERSHORE EVENT

The South Worcestershire PCSG's final event of 2023 on Thursday, September 14th, proved to be one of its finest over its 10-year history.

An audience of about 50 received short introductory talks from **Sharon Johnson (Worcester City Cancer Care Coordinator)** and **Branwen Bingle (Wychavon Communities Officers)** which exemplified the aim of both SWPCSG and its mother ship, KWPCSG, to work closely with **Primary Care Networks** such as Worcester City and **district councils** such as Wychavon in improving prostate cancer awareness across the county.



Tony and his wife, Tracey, at a Buckingham Palace Royal Garden Party

The main guest speaker was **Tony Collier BEM**, who travelled down from Altrincham (South Manchester) for the event. Tony, who is 66, is a **PCUK ambassador** and **vice chair**

and trustee of Tackle, the national federal body which represents the 120 PC support groups affiliated to it. Until recently, he was also joint owner of an accountancy company and had previously been both the Mayor of Altrincham and Chair of the Altrincham and Sale Chamber of Commerce. He was awarded the British Empire Medal in the Queen's 2019 Birthday Honours for his services to the community and charity in Cheshire.

When he was 45, Tony decided to take up running, steadily working his way through



5K Your Way meet-up at a park-run in Macclesfield

park runs to marathons. He was one of the first 30 people in the UK to have completed **all 6 World Marathon Majors (Berlin, Tokyo, Chicago, London, New York and Boston)** and was in training for his third **Comrades Ultra Marathon** in 2017 (100 km from Durban to Pietermaritzburg in South Africa) when, what he thought was a groin strain, led to a medical appointment, tests and, totally out of the blue, a diagnosis of stage 4 prostate cancer with a PSA level of 124. Tony's slide presentation included a bone scan, showing how widely the cancer has spread. A prognosis of just two years left Tony and his family devastated.

His talk centred on the need to keep running or, at least, keep active and keep fit. Few can aspire to becoming ultra marathon runners in their 60s or 70s, but many can participate in **Park Runs** (5 km running, jogging or walking or a mixture of all three), go to the gym a few times a week to build up muscles and core strength or just continue with golf, tennis, walking football (featured in the September issue) or go for regular walks or hikes, stepping up the pace a little where possible. He reminded his audience of the quote from **Chris Whitty, the UK Chief Medical Officer** one month into the Covid lockdown in April 2020. **'There is no situation, no age, no condition, where exercise is not a good thing.'**



RECENT EVENTS

With his considerable Facebook presence, Tony is no stranger to leading from the front when he perceives health inequalities. Frequently, he rails against NICE and its refusal to pass Abiraterone and Olaparib for general use, though the latter may soon be accepted. He campaigns vigorously about the post-code lottery when it comes to a patient being offered an mpMRI scan and leads the campaign in Tackle to get the government to commit to a PC screening programme.



Tony's display of all 6 World Marathon Major Medals

Over the past 6 years Tony has become a major fundraiser for PC research and awareness programmes, both through sponsored running and PCUK awareness speeches in the North-West.

Such fundraising can contribute towards the financial costs of earlier detection and screening, extending life expectancy, helping patients cope with side-effects, avoiding PC recurrence and, ultimately, in developing a cure for the cancer.

After Tony's diagnosis in 2017, running became even more essential to him. In 2018 he completed the London Marathon – not in the same, pre-diagnosis time but one which any 60 year-old would feel proud of. In 2022 he announced he would run 5 km every day of the year, a decision which gained great publicity for PC research and support and also raised thousands of pounds for his chosen charities.

One of the newly created initiatives he is passionate about is the **Prehab4Cancer and Recovery Programme** in the Greater Manchester area. Prehabilitation is all about the preparation for the physiological and psychological challenges of cancer treatment. The benefits of being well prepared for treatment include a shortened recovery period, improved quality of life and, hopefully, transition to a lifelong habit of physical activity.

One of the final slides in his 45-minute presentation involved the **5k Your Way** movement. The 5km walk, jog or run is important in itself in terms of fitness, but Tony emphasised the benefits relating to an active and fulfilling lifestyle in a supportive community. The coffee and chat afterwards



Tony and Tracey with their children and grandchildren

are so important, too, helping to develop new friendships, greater confidence and self-esteem. In some cases, this leads then to volunteering e.g. to raise funds, to join a PC support group or even to become a committee member.

Tony rounded off the evening with his hopes for the future. At the top of the list was a national screening programme, though he was only too aware of controversies around the PSA testing which prevented a decreasing number of GPs from supporting

these ambitions. He felt confident that there would be a steady improvement in early-stage outcomes and that soon a stage 4 diagnosis would not involve what he described as chemical castration. The future would be about targeted therapies suited to each individual patient. And, finally, providing that patient with a voice and listening to that voice.

Over 6½ years since his prognosis Tony is doing incredibly well, with an undetectable PSA level and still on his first course of medication. What he manages to pack into

every day is way beyond the rest of us, but we should be inspired by his dedication to attaining a high level of fitness, by his devoting so much of his time to achieving better outcomes for men with PC and by his inspiring talks and activities which made a huge impression on his appreciative audience.

Anyone who missed Tony's inspirational talk is strongly recommended to view it on the homepage of the website (www.kwpcsg.co.uk)

Peter Corbishley

ROOM WITH A VIEW AT WORCESTER C&C

Early in October KWPCSG returned to New Road, Worcester, for its latest Coffee & Chat. The venue was the Worcestershire County Cricket Club first visited in March 2022, but this time the event was staged in the Severn Suite just off the main entrance.

The room, which offered superb views across the cricket pitch towards the cathedral, was considered to be a great venue by those who attended. Unfortunately, the numbers of attendees was only 23 – a disappointing number, given that parking was free and the refreshments provided by the WCCC catering staff excellent.

We would like to extend our sincere thanks to WCCC, particularly its events manager, Debi Gross, for allowing us to hire the Severn Suite free of charge. Links with WCCC have strengthened this year through our sharing stands on 4 occasions at county cricket matches with Worcester City Primary Care Trust and PCUK.



STOURBRIDGE HOSTS FINAL C&C OF 2023

KWPCSG has a number of members in the Stourbridge area, so it was decided to run the sixth and final Coffee & Chat of 2023 at the Stourbridge United FC social club. This turned out to be a great decision, with no fewer than 27 attendees along with 4 committee members enjoying the early November morning there.

The venue – centrally located in Stourbridge with ample free parking – was an ideal choice and provided the opportunity for members in the far north of the county and over the border to chat over the refreshments. It attracted no fewer than 5 new members, taking the total to 44 this calendar year.

Special thanks is due to John Moss, his wife and daughter-in-law who baked the delicious cakes for the event and organised the publicity for the event in the Stourbridge area. These events, which are free to all who attend, have proved very popular this year. There have been 3 new venues (Evesham, Tenbury Wells and Stourbridge), plus returns to 3 visited in 2021-22 (Worcester, Malvern and Droitwich), as the group continues to cover much of the county.



RECENT EVENTS

WAHT SURGEON CHARTS THE PROGRESS OF ROBOTIC SURGERY IN THE COUNTY

In March those who attended his talk in Pershore (see June Supporter magazine) were given an insight into the first few months of robotically-assisted surgery (RAS). Seven months later, **WAHT Consultant Urological Surgeon, Paul Rajjayabun**, updated KWPCSG members and partners – this time at the Harriers Social club in Kidderminster – on the first year of treating men with prostate cancer requiring a radical prostatectomy at the Alexandra Hospital in Redditch.



Paul Rajjayabun speaking to the group in Kidderminster

Before his talk the audience of just over 80 listened to **Alison Hanson** outlining the creation of a partners' group for KWPCSG. The first planned

event exclusively for partners of members with prostate cancer was due to be held in late November at the Perdisswell Leisure Centre in Worcester. This is a very welcome development, and we wish Alison and her growing team every success with the venture.

Paul's talk started with a number of key statistics, including:

- **52,000 new diagnoses p.a. in England and Wales**
- **This figure is set to rise to 85,100 p.a. by 2038**
- **PC accounts for 14% of deaths among males and 7% of all cancer deaths**

One fact which surprised many of those present was that Worcestershire was one

of few trusts which would be routinely prepared to offer surgery to men over 70 depending on their biological rather than chronological age. This makes the county an outlier in the prostate cancer world, as does another fascinating revelation. **95% of radical prostatectomies undertaken in the UK involve RAS. Of the remaining 5% nationally, many have been undertaken as open procedures at the Alexandra Hospital.**

Paul went on to explain the need to continue to offer open surgery as well as surgery via the robot. In some cases, open surgery is the preferred - occasionally the only - option, depending on factors such as previous abdominal operations, large volume/high grade cancers etc. Having RAS has made a huge difference in terms of recruitment to the local Urology Department, including a recent collaboration with Wye Valley AHT surgeon **Mr Mehmood Akhtar** who has performed over 500 RAS operations in Cheltenham.

Already the team is pushing for further investment. Having a two-console system, as in Guildford, would make a huge difference to training, and a case can already be made for a second robotic system to expand into bladder/renal cancer surgery along with colorectal gynaecology procedures.

With the recent 100th RAS operation providing an early milestone since October 22nd last year, there has been a short learning curve. Excellent training in the UK and in Vienna meant that only one of the first 100 required a transfusion and 2 needed further hospital admission – all well within the expected parameters. The key problem, however, appears to be the size of the team, which needs to be doubled to cope with the increasing demands in Worcestershire.

Peter Corbishley



COMMUNITY



PSA TESTING SUCCESS IN PERSHORE

For the first time ever, Pershore hosted a prostate cancer (PC) PSA testing event at Wychavon Civic Centre. The event was organised by the Kidderminster & Worcestershire Prostate Cancer Support Group (www.kwpcsg.co.uk) in conjunction with the Graham Fulford Trust, who provided the online booking system, the phlebotomists, results to all participants within 48 hours and analytical data.

The event, which ran for almost 4 hours, was free to all men participating thanks to generous donations from the Pershore PC Support Fund (formerly Mayoral designated charity), the Friends of Pershore Hospital and KWPCSG (the county's PC support group and one of the largest in the UK with almost 500 members). We are also extremely grateful to Wychavon District Council for allowing us to use the Civic Centre, which worked so well for the GFT staff and men being tested.

One of the main features of the event was the gratitude shown by the participants in comments to the volunteers who ran the show and, in some cases, generous donations to the respective funds. The only disappointment was the no-show of 15 booked-in participants, reducing the number of those tested to 155. Of these the results were as follows:



Gordon Kingston (left, South Worcestershire PCSG chairman) with former Pershore Mayor, Chris Parsons

- **no fewer than 145 (93.55%) had results in the green zone i.e. they have normal PSA levels and no immediate action is needed**
- **there were 4 (2.58%) in the amber zone i.e. slightly raised PSA levels where further tests with GPs would be advised**
- **however, were recorded in the red zone (3.87%). Statistically, one out of 3 men with raised PSA levels will have cancer. Here GPs will arrange for these men to see a specialist for further tests**

It is hoped that the Primary Care Network will work together with the charities involved to make this an annual event. If so, this has the potential to offer an important contribution to men's health and wellbeing in South Worcestershire in the continued absence of a national screening programme.

Peter Corbishley



MEMBERS



PAUL HANSON: GETTING THE SUPPORT WE NEED

My husband Paul and I have been together for over 25 years and during that time his need to frequently pee has been a constant in our relationship; whether that's having to stop on a long journey or getting up frequently in the night. At times it's been funny, other times intensely frustrating.



Paul after his prostatectomy

In 2020 at the age of 62 he finally went to see the doctor. The GP did a blood test and concluded that his PSA level was low and therefore no action was needed.

In the following three years, I had gone through the menopause and had started to listen to mid-life podcasts! Gabby Logan (the sports reporter) did a really good one called the Mid Point, where she interviewed people in their midlife. One episode featured her husband, Kenny (ex-Scotland rugby international) who, through a general health check, had been told he had prostate cancer. Hearing Gabby and Kenny talking about this and them interviewing a very articulate surgeon resonated with me, and I thought that the next time Paul was in the car with me, I would 'by coincidence' play the podcast.

By this time Paul was getting up three or more times in the night, and his need to pee in the day was getting more frequent, too; although he was putting off seeing his GP (a typical male story). Anyway, thankfully the podcast resonated with him, too, and he went off for another appointment. This time the GP did an internal examination, and, whilst Paul's PSA levels remained low, the doctor could feel something. Fast forward to January 2022; Paul had been advised he needed a radical prostatectomy.

I started to research local support (even though I was uncertain about what I was looking for, I just knew that the next few months were going to be tough) and found the Kidderminster & Worcestershire Prostate Cancer Support Group website. What stood out to me initially was seeing Di Fox's photo on the website (Di provides exercise support to those recovering from cancer). We know Di through playing tennis and so I got in touch with her to see whether she had heard Paul's news. She invited us round the next day. Di was super helpful, empathetic and knowledgeable about cancer. During that conversation she offered to put me in touch with a couple she had recently met at her exercise class; Andrea and Donovan (dependant on them providing consent to be contacted, of course).

Donovan had had a radical prostatectomy 7 or 8 months previously. A couple of weeks later I drove over to Tenbury Wells to meet them. I wanted to understand how best



On the road to recovery

to support Paul practically when he went into hospital and through his rehabilitation, from a non- medical person who had experienced it.

Andrea gave me incredibly practical advice; from making sure that Paul took into hospital some loose-fitting shorts so that coping with the catheter was easier, to making sure that we had plenty of spare bedding when he



Paul and his wife, Alison, who is helping to set up the KWPCSG Partner Group

came out of hospital in case the night catheter leaked. This was information that isn't written down anywhere (or at least I couldn't find it). The thing that stuck with me was that Andrea and Donovan had been through it. And whilst our experience might have been different to theirs, they understood what we were experiencing.

Andrea and I have kept in touch since that day. Our common ground is the experience that our partners have gone through with their radical prostatectomies, I will never forget the friendship and support she gave me through WhatsApp messages, phone calls and face-to-face meet-ups.

Men going through prostate cancer are going through an emotional journey. Their partners are often trying to prepare and think ahead to support from a practical perspective; to make life more comfortable during their hospital stay and beyond (as well as coping with their own feelings)

This group does wonderful things for men; however, from my experience, there is a potential gap. That gap is the support that partners can provide to other partners via the offering of practical or emotional support and if I can help another person in the way that Andrea helped me, then I will be very happy.

PS Paul starts radiotherapy on the 10th. October, so we are going through the next stage of our journey shortly,

If anyone is interested in either one-to-one support or a group coffee morning activity specifically for partners, please get in touch with Andrea (hingleyandrea@gmail.com) or me (alison.hanson@live.co.uk).

Alison Hanson



MEMBERS



RICHARD LANGLEY BOWS OUT

'I can say that it's been an absolute privilege to work with KWPCSG for the past 10 years.'

It was typical of Richard to emphasise the power of the group and the ways it has helped him rather than dwell on the many ways he has been such an important part of the group in recent years. At the January AGM, however, Richard, who is now 79 and living in Rugby, will bow out after his 10 years as a committee member and marketing manager and he will be greatly missed.



Richard walking along the River Severn near Bewdley

When his wife, Elizabeth developed a rare and aggressive form of lung cancer 18 years ago, Richard virtually gave up his work to devote the next 2½ years to her palliative care. 'It was like getting married

again,' he told me when we had a long chat in Pershore in early November. His care and positivity must have contributed greatly to her living and enjoying life much longer than was her prognosis. It was here, however, that Richard realised that 'so many of us are lucky that we have family and friends to support us' but also that those who are alone and perhaps very lonely need others, such as a PCSG, to be there for them.

Following Liz's tragic passing Richard could address his own health issues. He had been diagnosed with prostate cancer (PSA 17, Gleason 3+4) and had opted for active surveillance. These 3 years were spent 'researching everything I could concerning prostate cancer.' He realised the worst countries for PC were the USA and New Zealand and the best China and South-East Asia, which led him to:

- **give up all dairy products**
- **remove red meat from his diet**
- **include lots of nutrients and meeting nutritionists**
- **follow a strict fitness regime**

Richard's 'guru' was an American doctor called Ben Ong who wrote 'All about Prostate Cancer : The definitive guide to healing your prostate gland.' The benefits for Richard were being able to come off Tamsulosin, which was affecting his bladder. His PSA level remained at 16 and the cancer was shrinking.

Towards the end of 2012 Richard moved to Worcestershire and at this time his PSA rose dramatically from 16 to 27. For him it was time to take action. It was just before Christmas when he was introduced to a friend of his partner whose husband had suffered from prostate cancer. Through this connection Richard attended the annual KWPCSG carol service where he met someone who mirrored his own journey. 'Resulting from this chat I changed my treatment and opted for a prostatectomy, a decision that probably saved my life.' Richard was also introduced to the Rev. Paul Brothwell, the co-founder of the support group, who invited him to join the committee.

In January 2013 Richard underwent a radical prostatectomy at the Priory, Edgbaston, followed by 3 months' convalescence. The next 3 years saw no detectable PSA level, then 0.2 moved up to 0.3, then 0.8. After a PET scan in Munich (do the research – it detected cancer in just one lymph node), Richard finally opted in 2018 for 32 sessions of radiotherapy at the QE in Birmingham. Since this treatment there has been no change in his PSA levels (undetectable), but there have been some serious side effects, notably lymphoedema and a debilitating 4-month period last year where he required a catheter.



Richard was responsible for the KWPCSG website for many years and for the advertising in county newspapers. He has championed the women who have contributed hugely to the success of the support group. 'In Mary Symons we have the most amazing chair,' he said, 'and as a committee we should do all we can to support her in her ambassadorial role.'

Finally, he praised the work done by many dedicated nurses and volunteers at the Myton Hospice in Warwickshire. Their day centres provide so much for the lonely and anxious, reaching out and providing security

and even happiness and joy in difficult times.

'We (KWPCSG) are stronger now than we have ever been. We are reaching out to all corners of the county. We now need to concentrate on reaching out to the lonely in our community.' This would be Richard's rallying cry for the next few years. Let's all work harder at identifying those on their own with PC and ensure they do not fight their battles alone.

Peter Corbishley



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MEMBERS



FROM HERE TO THERE - MOVING FORWARD

In 2006, his Yorkshire consultant suggested that a 10-year horizon for those whose PC had spread beyond the capsule (T3) was reasonable! Ok, but here we are!

Anyway, a good diet, exercise, and plenty of social connectivity has probably helped, (plus latterly, the critical treatments from his consultants). After a move to Worcestershire, a certain Mary Symons arranged for Gordon to join her Prostate Cancer Support Group.

Gordon believes passionately in the work and aspirations of our Prostate Cancer Support Group.

It has achieved huge success over its 23 years of support to men & families in Worcestershire and we think that it can become even more helpful in the coming years but to do so it needs more of our member ideas and guidance.

So, as he leaves the main KWPCSG committee, Gordon reflects on where the group has come from and ponders its future direction. Perhaps you could share your thoughts – just follow the timeline of the group with Gordon and then please give us your own views ahead of next year's January AGM.

Gordon Kingston

A HIGHWAY TOWARDS THE FUTURE -

Past Success & Developments

A Patient Focus – Mary & Friends – Birth of a Support Group – 2000.

Support – Meetings, telephone contacts & fund-raising events.

Later - Spreading our wings! Towards the south!

Is SWPCSG a satellite – or a branch – or a sub-group? No - we are part of one group.

Success in raising funds - Harnessing support for Rory the Robot.

Current state of play.

A strong financial position.

Growth of group events. Always developing and moving the goalposts! A Wives / Partners Group.

We now hold more public meetings – up from 3 to 6; We trialled Coffee & Chats – up from 2 in 2022 to 6 in 2023; After many years, a resumption of PSA Testing with 330 men tested via GFT.



Gordon Kingston

And we have a home - In the Leapgate Activities Centre where our committee meets.

Yet more Awareness: 1. Plum Fayre 2. More Golf Club Links! 3. Regular Boxing Day Bewdley Tractor Runs 4. Attendance at Charity events such as Choir Concerts 5. Mayoral Charities. 6. Partnerships with Health Organisations. 7. Partners with PCUK & Tackle, local health authorities and many others.

More Volunteers – Their Energy & Enthusiasm in 2023 has been a key part of 2023 success.

Plenty to Play for - - - Where to next - - - our Future Direction ?

“Coming together is a beginning; keeping together is progress; working together is success.”

Henry Ford.

How can we work smarter together is the key question for KWPCSG in the future – do you agree?

We need your help and suggestions to take the Support Group Forward. We welcome comments on all the outrageous ideas below which could provide the basis for development over coming years. Some will be rejected, some need a lot of further discussion and work, others we might try to implement next year.

1. **Simplify our structure. A County-Wide Committee Group (Governance and Management), with subgroups to deliver services to members, PR & awareness, and fund-raising events.**
2. **A Volunteers group to harness ideas, energy, enthusiasm and helping with our events.**
3. **Agreed priority events and fund raising for the year ahead.**

Have your say. We shall harvest your ideas via the website and coming meetings. If you want your say – please use: contact@kwpcsg.co.uk

Or look on the website for our short survey. www.kwpcsg.co.uk

Gordon Kingston

ANNUAL SUBSCRIPTIONS REMINDER

Annual subscriptions of £5 are due on 3rd January 2024

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.

In order that we can claim **Gift Aid**, it is essential that the donor must have paid enough annual UK income or Capital Gains Tax to cover all of their annual charitable donations and not just the donation made to us. Other taxes such as Council Tax and VAT do not qualify. If you have in the past completed a Gift Aid declaration to our Group and you now no longer meet the above requirements, please contact the Treasurer, Paul Markall Tel: 01562 751355



FUNDRAISING



PERSHORE BRASS SUPPORTING OUR CHARITY

As our name suggests, we are a six-piece brass ensemble from Pershore, a small market town eight miles south-east of Worcester on the banks of the River Avon. We are a family-oriented group, with Ann and Adrian White playing Bb Cornets, Helen and Marshall Faizey playing Eb Tenor Horn and Trombone, Ken and Eleanor Smith (father & daughter) playing Eb Bass and Bb Baritone. Between us we represent five different brass bands in the area - the Alcester Victoria Band, the Badsey Players, Bretforton Silver Band, Shipston Town Band and the West Midlands Fellowship Band. Although most of us are now retired, in the past we have been firemen, postmen, teachers, soldiers, forensic scientists, pharmacists, electronic communications engineers, integrated logistics support engineers, librarians, fingerprint specialists, Bikeability instructors and National Trust volunteers.

Since we formed, over 15 years ago, we have played in Normandy for Pershore Twinning Society, at several of the park bandstands in the area, for several village fetes, the Pershore Plum Fair, the Severn Valley Railway and every Christmas we raise money for charities, a different one each year. This year we have chosen the county Kidderminster & Worcestershire Prostate Cancer Support Group. Over the years we think we have raised over £17,000.

Marshall Faizey



SETTING UP A NEW PARTNERS GROUP

The Kidderminster and Worcestershire Prostate Cancer Support Group do a fantastic job of supporting men in the local community when they are diagnosed or are living with Prostate Cancer. This horrid disease doesn't just impact men, it affects everyone around them, especially their partners. So, we feel it's important that partners can talk and share their experiences with others who have supported their loved ones.



Alison with her husband, Paul

We are in the process of setting up the group; the first meeting will have taken place on the 24th November. We are planning on organising bi-monthly coffee and chat sessions (probably to align with the main KWPCSG programme) and to organise some speakers who can help partners work through the specific impacts that Prostate Cancer has on us. In addition, we would love to set up a Buddy system like the men have. I had that support when my husband went through his prostatectomy, and it was invaluable to me. Andrea was introduced to me via a mutual friend, and we have stayed in touch and become friends because of our shared experience (in fact we feel so strongly about the benefit of peer to peer support we are both involved in setting up this group along with four others).

If you are interested in attending the sessions please look out for the dates on the website, in the magazine and on the Facebook site. If you are interested in helping us shape the group, please get in touch with alison.hanson@live.co.uk; we would love to hear from you.

Alison Hanson

KWPCSG COMMITTEE 2023

Mary Symons	Acting Chair / Secretary	01299 823166
Paul Markall	Treasurer	01562 751355
Dick Langley	Publicity / Website	07861 233930
Derek Scully	Support Contact Co-ordinator	01886 833236
David Underhill	Tackle Representative	07817 518201
Mark Hall	Minute Secretary	01299 879953
Peter Corbishley	Editor Supporter Magazine	01386 554650
Dick Herbert	Trustee	01299 250598
Val Markall	Co-opted Member	01562 751355
Nicky Langford	WAHT Fund Raiser	07590 624426
Dan Cook	Website Manager	01299 887277

Please contact us if you need support or advice



I NEVER SAW THAT COMING!

THE NEWS I DREADED



Mark Howard

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 (this was the last option available to me, though there is talk of clinical trials at the Royal Marsden or a 10% chance of being suitable for Olaparib).

In all honesty, I knew I was now on the final treatment available to me. I am not going to hold out on the hope that people constantly tell me there are new procedures and medications appearing all the time. Any new treatments we hear about in the newspapers are years away from general use in the NHS.

Back in October 2019, I started my treatment in the Rowan Suite with Docetaxel chemotherapy, I had six cycles, and they all came with the standard side effects, most involving the toilet and fatigue. Anybody who has had chemo may understand that I was not looking forward to another course, this time 10 cycles of Cabazitaxel. I suspect, however, that my clinical team were dropping some hints about moving on from Abiraterone, but, like most men, I do not respond well to hints! In August 2023 my PSA had reached 42, rising from 2.0 in December 2021. Although I had spent months considering more chemo, the choice was not obvious. How much time would I gain was the obvious question. For the answer, talk to your clinician. The situation was marginal, and everyone must make their own choice.

Someone that I have been talking to regularly over the last year was surprised when I told them that I was going to try chemo again, but I would do it cycle by cycle, making the decision whether to continue after each cycle. I did not want to be lying in a bed somewhere in the future, thinking, 'If only I had tried chemo again.' It is hard to put into words, but it was one of those, "What if," moments. I had to try.

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.

There were no problems with the infusion, I was disconnected from the pump, given anti-sickness pills and Filgrastim injections (for use on days 5 to 9), then I left the hospital.

I did not know that this was the lull before the storm. For 4 days everything carried on as normal as far as eating and sleeping were concerned, then on day 5 it started. First vomiting, then the filgrastim injection. I had requested one of the district nurses to attend and give me some moral support. The injection went in without problem, and the nurse left. The following day I felt terrible, just no capacity to do anything, no appetite, curled up on the sofa, dozing whilst watching a movie channel. A nurse appeared for the second injection and left happy



The Oncology centre in Worcester where Mark had radiotherapy in March-April 2020

that I would manage the remaining injections by myself. The following days saw diarrhoea and constipation before all settled down after the last Filgrastim injection.

On 6th October I felt comfortable enough to visit my younger brother in 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.

On the morning of 10th October, I woke up feeling terrible. Using the thermometer that the nurses recommend you buy before chemo, I checked my temperature - it was above 38 degrees. An LFT showed that I was positive for Covid. I rang up the chemotherapy helpline to ask their advice. Shortly after, I was in an ambulance, (without blue flashing lights) on my way to the Acute Oncology Assessment area in the Worcestershire Royal Hospital. As my high temperature could have resulted from chemo problems or Covid, the team at the hospital had to assume that chemo was the problem. Shortly after arrival they asked for my emergency sepsis antibiotic prescription, the form supplied when you have your first chemo cycle (you should always carry this with you).

Blood samples were taken after a few problems finding a vein. Shortly after, the emergency antibiotics appeared and were connected to the canula in my hand. Next was the highlight of the day – lunch! I am not sure what Gordon Ramsay would have had to say, but I was hungry and both plates were soon empty.



Worcestershire Royal Hospital's main entrance

Shortly after lunch, the nurse practitioner gave me the good news that my blood test results were all okay and I could leave. The high temperature was Covid-related. A false alarm, but it was a great relief to see that the hospital has the procedures in place to look after chemo patients. I was discharged and travelled home, with a replacement emergency prescription form, to enjoy the rest of the day thinking how fortunate I was. It was only on 27th October that I started to get negative LFT test results, so the chemo scheduled for 17th October was delayed.

Mark Howard



MISSING MEN

PROSTATE AWARENESS



MISSING MEN AND PUB POSTERS CAMPAIGN

Back in March we had hoped to run our own Missing Men campaign to back up the NHS-PCUK national campaign at a local level. The aim was to get men who had failed to engage with their GPs over the Covid period and be checked out for prostate cancer to do so.

Originally, we discussed creating our own poster but, finally, we looked to Prostate Cancer UK with their excellent publications and posters, chose the '1 in 8 Men' one, had them laminated and drummed up some support at the October meeting in Kidderminster. So far, thanks to our band of 10 volunteers, the posters are now displayed at the pubs listed below, namely:

Mug House, Claines, Worcester
Alma Tavern, Droitwich Road, Worcester
Angel Hotel, High Street, Pershore
New Inn, Ombersley Road, Worcester
Pickled Plum, High Street, Pershore
Swan Inn, Barbourne Road, Worcester
Courtyard, St. Nicholas Street, Worcester
Ounce, Main Street, Bishampton
Wheelbarrow Castle, Radford
Boot, Flyford Flavell
Lenches Club, Church Lench
Oak, Worcester Road, Upton Snodsbury
Flyford, Old Hill, Flyford Flavell
Talbot, New Street, Ledbury
Toby Inn, St. Peter's, Worcester
Harvester, St. Peter's, Worcester
Ale Hub, St. Peter's, Worcester
The Retreat, Norton, Worcester
Chequers Inn, Fladbury, Pershore
Anchor Inn, Fladbury, Pershore
Vale Golf Club, Bishampton, Evesham

Anchor Inn, Kidderminster
Cavalier, Kidderminster
Hare & Hounds Inn, Kidderminster
Park Gate Inn, Kidderminster
Plough Inn, Shenstone
Westlands Community Centre, Droitwich
Droitwich Spa Football Club
Droitwich Rugby Club
Droitwich Working Men's Club
Vines Park Bowling Club, Droitwich
Land Oak, Kidderminster
Swan, Kidderminster
Bear & Wolf, Kidderminster
Pillar of Salt, Droitwich
Star & Garter, Droitwich
Red Lion, Droitwich
Talbot, Droitwich
Hop Pole, Droitwich
Miller's Arms, Pershore
Galton Arms, Himbleton
The Chequers, Crowle



Galton Arms, Himbleton



Boot, Flyford Flavell

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

You can enter and pay ahead of the event.

Prizes for the best dressed seasonal tractor and occupants

Contact:

Ray Attwood

07973 790214

attwoodraymond@gmail.com



RAINBOW'S HUGE CONTRIBUTION TO KWPCSG FUNDS



Mary Symons receiving the cheque from the Rainbow Cancer Care Foundation. John Gaskell is standing far right

Back in 2010 John Gaskell was due to celebrate his 60th. birthday at Cleobury Mortimer Golf Club. Sadly, a few weeks before the event, John's wife, Ange, lost her mother to cancer. The event went ahead with 40 guests and £475 was raised for charity. The golfers decided they would like to make this an annual event and over the next few years this figure grew to £1200, then £1800.

This was just the start of the incredible fundraising for local charities in the north of Worcestershire and Shropshire that we will cover in a special article in the March 2024 Supporter Magazine. This year a total of £30,015 was raised by what became the Rainbow Cancer Care Trust. Tragically, Ange was diagnosed with cancer in 2018 and passed away just nine months later at the age of just 60.

This year's recipients were Macmillans, West Midlands Air Ambulance, Guts UK (stomach cancer charity), Milbrook Suite (Kidderminster), Acorns and KWPCSG, all of whom received £5,000. We are so, so grateful to John and his team and will chart the development of this extraordinary charity next time.

PUMPKIN FEVER AT LEAPGATE



In an earlier edition of the Supporter magazine, Fred Penn, our Allotment Co-ordinator, had challenged the management team at the farm to see who could grow the heaviest pumpkin. If Fred lost the challenge, he promised to make a donation to the farm's charity.

On the day of the weigh-in, Fred proudly appeared with his pumpkin which weighed 21lbs. The rival team from Leapgate then weighed their contender, which was a massive 45 lbs. Fred, true to his word, donated a cash sum to the Leapgate Treasurer.

Not down-hearted, Fred immediately challenged the Leapgate team to a further contest in 2024. Fred has a cunning plan, as he has acquired some zombie pumpkin seeds from across the pond which he believes will result in a win in 2024. I think the answer lies in the soil!

Paul Markall



BOYS NEED BINS CAMPAIGN REACHES WESTMINSTER

In September our 'Boys Need Bins' campaign reached Westminster. It was a great event with several MPs in attendance. The event was supported by Stuart Andrews, MP for Pudsey, who is also the Minister for Sport, Civic Society and Minister for Inequalities.

I caught up with Stuart Andrews after the event and told him of the man I met at the Metro Walnut group picnic in July 2022 and how his story made me start asking more men about their incontinence experiences. Discovering the glaring inequalities, a chance conversation at PCUK got us thinking about a campaign on male bladder and bowel continence care.



Ken Mastris (far left, Tackle trustee) and Sarah Gray represented Tackle as the campaign reached Westminster

This campaign has helped us raise awareness of the importance of our support groups.. Working alongside PCUK and other stakeholders is a great example of the benefits of partnership work for a small charity like ours. I am super proud to have been a part of this campaign and know we can make a difference if we all stick at it and work together.

Sarah Gray (Tackle)

QUIZ NIGHT RAISES FUNDS FOR PCUK

Another event at the County Cricket Ground, but this time it was an annual quiz evening for 150 staff and associates of Worcester accountancy company, Bishop Fleming. The beneficiaries of the fundraising were PCUK, but, as a sign of the closer relationship between the UK's major PC fundraising charity and county support groups, KWPCSG was invited to raise PC awareness at the event. Supporter editor Peter Corbishley gave a talk about the support group and its goal of increasing PSA testing locally and nationally.

PERSHORE PLUM FESTIVAL DELIVERS FOR THE GROUP

Once again a team of volunteers from the group assembled by SWPCSG chairman, Gordon Kingston, ran a tombola stall as part of the town's annual Plum Festival in late August. Despite the cost of living crisis, visitors were in a generous mood and £650 was raised.

The good weather helped the event attract thousands to the town. The KWPCSG stall, centrally positioned in Broad Street, was also visited by people seeking more information about prostate cancer and, in particular, accessing PSA tests.

Our thanks to the Pershore PC Support Fund (formerly the Mayoral Fund) which kindly provided Funding for the stand / Funding without capital. Most of the prizes had been kindly donated by members and well-wishers.



Stephen Branchett, Gordon Kingston and Derek Scully manning the SWPCSG stand

CALENDAR OF EVENTS 2024

KWPCSG ANNUAL GENERAL MEETING

Monday, January 22nd. (19.00)

The group's AGM will be held, as it has been for the past 3 years, via Zoom.

To access the AGM, please go to the support group's website:

www.kwpcsg.co.uk

In January you will find more details of the event, including the agenda and the treasurer's report

SOUTH WORCESTERSHIRE PCSG

Tuesday, March 19th. (doors open at 6.30 pm for a 7.00 pm start)

Wychavon Civic Centre, Queen Elizabeth Drive, Pershore WR10 1PT

DISCUSSION PANEL

Following the success of the panel event in June 2022 (see page 3 for more detail), we are pleased to announce that 3 more guests representing different strands of PC detection, treatment, care and patient feedback will form our panel.

More information will be available in the Events section of the website and in the March 2024 magazine. For the moment, just make a note of this date.

KIDDERMINSTER & WORCESTERSHIRE PCSG

Monday, April 22nd. (doors open at 7.00 pm for a 7.30 start)

Harriers' Social Club, Stadium Close, Hoo Road, Kidderminster DY10 1NB

SPEAKERS : SARAH GRAY & MARK KELLY

(Sarah is now in her 4th. year as the National Support & Development Officer of Tackle.

For those who do not know, Tackle is the name of the National Federation of Prostate Cancer Support Groups. Sarah has managed the transfer of almost 30 groups in recent months from PCUK to Tackle. Mark is the group's newly-appointed National Peer Support Coordinator and his main task is to support the 120 groups such as ours in all corners of the UK)

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

Keep in touch with us via: Tel. 01299 832166 /

www.kwpcsg.co.uk / contact@kwpcsg.co.uk