Kidderminster & Worcestershire Prostate Cancer Support Group



JOIN OUR CAMPAIGN (pages 12-16)

SUPPORTER

March 2023 issue 87

www.kwpcsg.co.uk Reg. Charity no. 1100718



EDITORIAL





In many ways 2023 could prove to be a landmark year for the KWPC support group. As I have stated time and again over the past couple of years, the group is one of the oldest PCSGs in the country (founded in 2000) and one of the largest in England (over 450 current members). By the time this issue returns from the printers and is delivered to your door, we may well have welcomed our 1000th. member to the group. Gaining 36 new members in 2022 was a remarkable achievement and reflects the efforts made to attract newly-diagnosed men to the group. Attracting an additional 50 members in 2023 could be a target, according to SWPCSG chair and KWPCSG trustee, Gordon Kingston

So, a suitable time to rest on our laurels? Absolutely not. The committee decided in November to expand the number of Coffee & Chat events from 3 to 6 to reach out to towns in the north of the county. Spurred on by the Worcestershire Ambassadors PSA Testing event in Worcester in March, we have organised 2 of our own (see Gordon Kingston's article on pages 14 and 15) in 2023. In total there are now 15 PC events in 2023 covering the county, all with dates and venues (see and save separate sheet).

Potentially more important than expanding our programme and involving different parts of the county is the aim to recruit non-committee members to run the Coffee & Chat events. 6 C&Cs @ 3 members = 18 willing members, all becoming involved in running our events. We hope very much that a number of these members will soon be ready to step up to join the committee and shape the future of the organisation. We have learnt that small PCSGs, whose committees have failed to recruit and renew, are likely to fold.

Not all our ambitions were successful. In December we were one of over 30 charities which applied to become the Worcestershire County Cricket Club's designated charity for 2023. We put forward a strong case, which centred on our Missing Men campaign highlighting the ongoing need for more men to have earlier and more regular PSA checks. Congratulations to Worcester Foodbank who were chosen as the WCCC charity for 2023, but we'll be back with a stronger bid next year.

I mention 'earlier' PSA checks because time and again I hear from members whose GPs sent them away without a test as (a) there was no history of PC in the family, (b) they were not from the African Caribbean community, and (c) they did not show any symptoms. Our good friend and columnist, Mark Howard, has compiled a spread sheet over the past 3 years with details of every appointment and procedure he has undergone since his diagnosis. That number is now beyond 160, all or most of which could have been prevented had his GPs in 2015 and 2017 erred on the side of caution and offered him a PSA test. (more about this in our June magazine).

We all know that treatment for prostate cancer can, in some cases, be devastating or debilitating, but outcomes improve every year. We want to share that good news with you and support you, so we look forward to seeing you at one (or more, or many more) of our events in 2023

FUTURE EVENTS

FIRST EVESHAM COFFEE & CHAT AT FOOTBALL CLUB

At our committee meeting In January we agreed to extend the Coffee & Chat programme from 3 in the year to 6, bringing in venues in new towns across the county as well as revisiting some old favourites. Early this month we pitch up in Evesham for the first time. Make a note in your diary for Thursday, March 9th. (N.B. one day earlier than printed in the December magazine) when all members and their partners are invited to join us at Evesham Football Club,



Cheltenham Road, Evesham WR11 2LZ. Our A5 laminated adverts have been on display in the Evesham, Broadway and Pershore area thanks to the actions of our team. Please contact Gordon on gkingston@btinternet.com if you require more information.

UROLOGIST SURGEON PAUL RAJJAYABUN TALKS ROBOT TO US



Paul Rajjayabun

The first open evening is scheduled for Tuesday, March 21st. (6.30 for 7.00) at the Wychavon Civic Centre, Pershore WR10 1PT. We are delighted to announce that our main speaker will be Paul Rajjayabun, one of the WAHT urological surgeons who are now using robotically-assisted surgery on patients requiring or opting for prostatectomies at the Alexandra Hospital in Redditch. Paul is one of the team on the front cover of the December magazine and he was interviewed for the RAS main feature on pages 12 and 13 of that issue. We are hoping for a great turn-out to hear more about the long journey to reach this historic point and to ask Paul about his hopes for PC surgery or radiotherapy in Worcestershire in the next few years.

KIDDERMINSTER HOSTS TACKLE'S AIDAN ADKINS IN APRIL

In last September's Supporter magazine our main feature centred upon Tackle, the umbrella organisation representing over 90 prostate cancer support groups (PCSGs) in England. Adorning the front cover in his hi-viz jacket as a volunteer at the Commonwealth Games in Birmingham was **Aidan Adkins**. Aidan is the chair of Solihull PCSG and a trustee on the national Tackle board. Those who attended will remember him for his talk at the Droitwich C&C in June. The date is **Monday, April 17th. (7.00 for 7.30 pm)**. Please remember that throughout 2023 the 3 Kidderminster evening meetings will not take place at the Town Hall (due to refurbishment) but at the **Harriers Social Club, Hoo Road, Kidderminster DY10 1NB**.



Aidan Adkins

MARY'S CORNER

Thank you to everyone who joined us for AGM on Tuesday 17th January. It is important that we have members of the group join us for this event. It was a very good AGM with our reports available online on our website.

We have vacancies on our committee for two co-opted members, and it was agreed at the AGM that Gordon Kingston and I arrange a meeting with three members of the group to discuss how they could help us with the workload, and they were all very keen to help where prof they could.

It has been a very successful year for us following the restrictions of the Covid lockdowns, and we have learnt a lot from changing our routines. The AGM was on Zoom, as have been our committee meetings in the winter, saving time and travelling costs to Kidderminster and restricting the potential spread of viruses.

We are advancing our events for the year by increasing Coffee & Chat meetings in other parts of the county. Our first one is in March in Evesham and the second one in April in Tenbury Wells (see page 11 and back cover for more details). Please contact us if you know of a suitable venue in your area for 2024.

We are also working hard to find the Missing Men due to Covid. You probably read Paul Rajjayabun's article in the December Supporter magazine when he informed us that, in 2018, 730 men were diagnosed with prostate cancer in Worcestershire. In 2021 that number had dropped to 420, which means that over 300 men are missing from our statistics for at least two years. We will, therefore, be resuming PSA testing in 2 locations in the county this year (see pages 14-15).

I am very sorry to report that, following a diagnosis of metastatic renal cancer in 2016, Jonathon Sullivan had died at home surrounded by his family on Friday 16th December, aged 57. I worked with him at Kidderminster for three years following the retirement of Mr. David Baxter-Smith. He was a good, caring consultant and a kind, considerate man and a pleasure to work with. Jon died peacefully at home with his family (Katy his wife and daughters Maddy, and Emilie) at his bedside.

I have sent a basket of flowers to the family from the group. Some of you may recall that he became our President from March 2012 and was with us until he moved to work at Cheltenham in 2013. There will be a private family service, but, for those of you who remember Jon, there will be a celebration of his life later in 2023. I will certainly attend with my colleagues from the Trust. Please contact me if you require more details.

I hope to see some of you at our open meetings throughout 2023 and also Coffee and Chat events. We are grateful when our members join us and offer to talk to any new potential members at them.

Mary Symons

RECENT EVENTS

2022 TRACTOR RUN - THE BEST EVER

On the morning of Boxing Day I was standing outside the Pavilion building on the sports ground at Callow Hill, watching a bright red sun rising into a clear blue sky. There were remnants of grey mist still clinging to the ground and then the smell of bacon and sausages being cooked in the kitchen filled the air. It was so quiet, almost surreal, but it didn't last for long as 120 tractors from many parts of the county started to descend onto the sports ground. Having parked up, the tractor drivers and their crews made their way to the Pavilion for registration and a breakfast snack.



Rod Stanczszyn (Mayor of Bewdley and tractor driver) with Paul Markall (right)

The Mayor of Bewdley, Cllr. Rod Stanczszyn, started the event at 10.00 am by activating two ex-lorry air horns that must have woken the entire locality. A gent in an old Model T Ford asked if he could join the convoy, but we did warn him that there was an off-road stage that we believed would not suit his vehicle.

At the end of the road-run at 12 noon, the tractors started arriving in Bewdley, coming over the bridge and parking on both sides, to be welcomed again by the Mayor and a crowd of approximately 2000 onlookers. Three thousand pounds was raised during

the event, and a big thank you must go to Ray & Tina Attwood, Tony Pain, the ladies in the kitchen, local land owners and Nicky Langford who managed the registration and cash on the day.

Val and I were ably supported by Nicky and committee members David Underhill, Dr. Dick Herbert and Mary Symons.

We have already started planning for next year but we could use more foot soldiers to help with the bucket collecting in Bewdley and Stourport. It would only be about two hours of your time on Boxing Day from 11.30am to 1.30pm and you will still be home for lunch!

The Model T Ford did make it to Bewdley - one way or another.

Paul Markall





AGM REPORT



WELL - ATTENDED ZOOM AGM

Charities organising AGMs in the depths of winter (in our case on a bitterly cold January 17th.) are on a hiding to nothing. Who but the odd intrepid committee member would wish, in their later years, to trail across the county to check on the state of the accounts and re-elect those same intrepid committee members? Which non-committee member would risk such a journey to find numbers so low that he or she would be at high risk of being dragooned onto the committee? And all of this in some poorly-heated, draughty village hall?

Not KWPCSG, though. Thanks to the IT wizardry of Daniel Cook and the advertising and reminders sent out by our marketing man, Richard Langley, and Mark Hall, our minuting secretary, the AGM was again organised via Zoom. Admittedly, Zoom is not for everyone, and access can depend on a number of factors, but it is being embraced by more members. On the night, according to Daniel, there were 28 subscribers – 8 committee members and 20 non-committee members from all over the county.

Mary Symons, our chairwoman and one of the founders of the support group more than 20 years ago, reported on the events of the year. These included talks given by Nick Owen (BBC news presenter), Adel Makar and Lisa Capaldi (Worcester AHT consultants), Dr. Steve Allen (chair of Tackle), Simon Adams (Healthwatch Worcestershire) and the June panel discussion in Pershore. These meetings were the first post-lockdowns, non-Zoom open evenings, and Mary noted how good it was to see numbers returning to pre-Covid levels.

We were reassured by treasurer Paul Markall that we had bounced back in 2022, registering a healthy profit of over £ 3000 on the year. Costs had risen e.g. for venues for meetings, for the Supporter magazine (now 24 pages per issue) and for advertising and postage, but Paul and others have established excellent relationships with groups, particularly in the north of the county, who continue to contribute generously to our cause.

The year ahead was set out by Gordon Kingston (chair of SWPCSG and KWPCSG trustee), who rounded off the evening with a vote of thanks to Mary for guiding us through difficult times. 88 minutes after the AGM was launched you could simply switch off your PC or laptop, turn on your TV, click onto the green button on part 2 of 'Silent Witness' and watch it from the start. No having to traipse across Kidderminster to find your car, de-ice the windscreen, hope that the battery is not flat and set off on a 45-minute journey home. Even I, as a confessed technophobe, can appreciate what works best for the support group and for me personally.

Peter Corbishley



OBITUARY

JON SULLIVAN: FORMER PRESIDENT OF KWPCSG

It is with sadness that we report the passing of Jon Sullivan on December 16th. at the young age of 57. Jon was diagnosed with metastatic Renal Cell Carcinoma in 2016 and lived well on treatment for a further 6 years.

Jon studied medicine at King's College, London, qualifying in 1989. Following his basic surgical training, he undertook research in Bristol and was eventually appointed as a consultant in Worcestershire in 2006. He then moved to Cheltenham Hospital in August 2013, which was like a homecoming as he had spent time there during his training and first met his wife, Katy.

Jon accepted the role of President of KWPCSG in March 2012. He was always extremely caring, kind, considerate and popular with his patients and all his colleagues. He was extremely grateful for the treatment he had received at Cheltenham which helped him enjoy 6 years of retirement, allowing him to be there for his two daughters during their teenage years.

The family has indicated that they are happy to receive emails and cards:

Katyssullivan@aol.com

Brensham Lea, Dairy Lane, Dumbleton, WR11 7TP.



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
Peter Spencer	Co-opted Member	01562 914797

Please contact us if you need support or advice

FROM THE PERSPECTIVE OF A WIFE AND PARTNER

At the risk of sounding sexist, I have heard that it is often the case that the woman in the relationship is the driving force behind encouraging medical check-ups.

In our case, the initial appointment with the GP regarding prostate concerns was from my husband, so well done him! Out of the blue, he decided to book an appointment with the doctor, as he had been getting up in the night more often to wee.

I was pleased that he was going and that he had had the initiative to have a check-up, but my 'woman's intuition' said that all was OK and that we didn't need to be concerned.

The GP said he was referring him to a specialist as, during the examination that he had carried out on the prostate, he had felt something that may or may not be of significance but 'better to be safe than sorry'.



Andrea and Donovan Ferns at Tobermoray on Mull (Sept 2022)

As Donovan was going all through the tests, scans, etc, I still, somehow, did not think that the diagnosis would be cancer. It seems so odd now, looking back, that I was not worried at all and that I was still being guided by my totally dilapidated and shambolic 'woman's intuition' system which, evidently, has had a complete breakdown and needs a complete and radical overhau!

So when we were told that the prostate was, indeed, seriously cancerous, you could have knocked me down with a feather. Not so with Donovan, who said he was not surprised and was more prepared for the diagnosis than I was.



2 days after the operation (May 2022)

Not so long after that, he had a prostatectomy under Mr Makar – going into hospital feeling fine and 'normal', waking after surgery feeling not fine and not normal and coming home five days later feeling....still not fine and not normal!

My baptism of fire as a nurse had begun.

We are both lucky enough to have retired early and so we had the luxury of being able to concentrate on getting Donovan well. I was more than happy and quite determined to be the best nurse ever in the whole world, in order to provide my husband with the best care he could possibly imagine....and I know I succeeded. I am honoured to have been able to support him through a difficult time.

It was a steep learning-curve for both of us, but with guidance from The Spire Hospital we learned how to manage the tubes and bags and injections and medication and the wound and so on and so on, and we learned to deal with just one thing at a time, so that

we didn't get bogged down with 'what-ifs' and 'what comes next?' It is also about learning to deal with emotional issues and being able to listen and share and encourage and truly, truly give.



Donovan at the Tenbury Wells Show

For the first three weeks we often didn't sleep much at night as we had problems with bags and tubes and so on, as well as pain issues, and if I wasn't up and about sorting out those things, I was lying awake watching the bag to make sure it was draining properly, which was one of the problems we were having.

As a couple, we thought we were as close as close could be before prostate cancer, but going through what we have been through together puts a different slant on our already close relationship. We are often 'just a two', and the days and nights we spent after



Final night in Sicily (October 2022)

surgery we were most definitely just a two and we experienced a time together that nobody else could possibly imagine - blood, sweat, tears and all - and that added an extra bond to the relationship. Needless to say, there were also a lot of laughs here and there too, which always helps!

Although still living with the life-altering effects of the surgery, Donovan is very well, and we are looking forward to living as much life as we can get our hands on.



Andy's birthday (June 2022)

I have often thought about men living alone, without 24-hour care and how they manage to deal with all the things that I did on Donovan's behalf. I really don't know how they cope. That is why being a member of the support group is so important, so that everyone can share their experiences and feel comfortable to ask guestions of others.

Not one man with prostate cancer will go through the same experience as another and not one wife/partner will either, but, hopefully, the experiences we have had may one day help someone else to cope in their way.

Andrea Ferns

NEW PC DRUG OFFERS HOPE

In late November articles appeared in the national press about a new drug which should offer increased chances of survival to certain patients whose prostate cancer has spread to other parts of the body. Darolutamide, also known by the brand name Nubeqa, is already available to some NHS patients with localised (locally advanced?) prostate cancer. It will be made more widely available after the UK medicines regulator (MHRA) approved the treatment through Project Orbis, an international partnership involving the UK, US, Australia and other countries created to speed up the approval process for cancer treatments.

Professor Peter Johnson, NHS National Director for Cancer, said, 'This innovative treatment builds on the NHS ambition to improve cancer care and survival rates and will help thousands of men diagnosed with prostate cancer to live a better-quality life, decreasing their chance of dying by one third.'

Darolutamide is usually taken as a tablet with food and in combination with androgen-deprivation therapy and docetaxel chemotherapy. After completing chemotherapy, patients will continue to have their original hormone therapy alongside darolutamide in order to keep testosterone levels low and help the treatment work.

The main group of people in the trial quoted (ARASENS) had a high proportion of patients with newly diagnosed metastatic PCa, which is deemed to be hormone sensitive, rather than those patients who had disease that was initially treated successfully and went on to have recurrences that were deemed to be hormone sensitive. These are often fitter than those whose disease has progressed

after initial ADT alone and then going on to chemotherapy.

We approached Dr. Steve Allen (Chair of Tackle) for his reaction to the news. 'Darolutamide,' he said, 'has a good side-effect profile, and there was little increase in overall side effects by adding darolutamide to the existing treatment of ADT / chemotherapy. It should be noted, however, that all patients in the trial were relatively fit and thus able to potentially tolerate side effects better than less fit people.'

He added that the triple therapy is to be appraised officially soon by both NICE and the Scottish Medicines Consortium. 'It will be interesting to see how many clinicians take up this opportunity for early aggressive treatment before a decision is made by NICE,' Steve said – 'but of course this is something that we may never know unless patients tell us about their treatments.'

Roger Downes, who took part in the trial at Colchester Hospital, had been diagnosed with metastatic prostate cancer, but he was declared cancer free about four years ago. 'It was an extremely positive experience, and the outcome has been amazing,' he said. 'I had no adverse effects from the drug and still take it now.'

His consultant medical oncologist, Dr. Dakshinamoorthy Muthukumar, said, 'The drug is proven to have real benefits for patients and I have seen first-hand how it has saved lives, giving our patients in trials, who have had limited success with other treatments, complete and long-lasting remission from cancer and hope of a future that is cancer-free.'

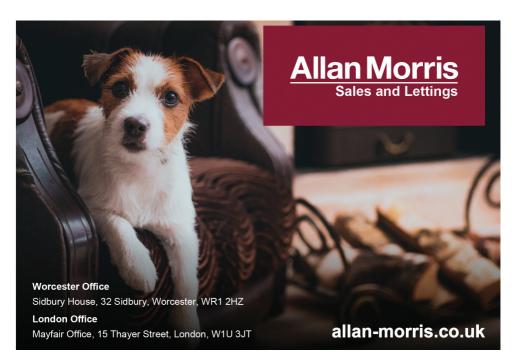
GENTLE REMINDER TO SOME MEMBERS

Annual subscriptions of £5 are due now

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 wish to send a cheque directly to our treasurer, Paul Markall, please make it payable to 'Kidderminster & Worcestershire PCSG' and send it to Paul's home address (13 Coningsby Drive, Kidderminster DY11 5LU).

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 phone the Treasurer, Paul Markall on: 01562 751355.

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.





MISSING MEN 2023 CAMPAIGN

This all happened accidentally. Back in November an invitation was sent to me – just as a lapsed season ticket holder, I think – from Worcestershire County Cricket Club to apply on behalf of an organisation to become their designated charity of 2023. What's to lose, I thought, so, with the support of Mary and Gordon, we set about putting in a submission for KWPCSG.

It occurred to me, though, that it would be better to link the application to a campaign covering and specific to 2023. This thought process lasted seconds, not days or weeks, because the answer was in the December Supporter magazine. The last paragraph of the article written about consultant urological surgeon, Paul Rajjayabun, held the key. Paul had spoken about the drop in numbers of men in Worcestershire who had been diagnosed with PC, from a 2019 pre-Covid annual figure of 740 to just 420 in 2021. These are our own Missing Men.

The NHS invited Prostate Cancer UK to partner it in its 6-week Missing Men campaign in February 2022. This was a unique collaboration between the two organisations to raise awareness of the fact that an estimated 14,000 undetected in 2020 and 2021. On a single day the campaign reached through social media an incredible 2.9 million hits and Prostate Cancer UK reported 100,000 visitors to its website in just one morning.

In late January I spoke to Kate Feeney, PCUK's Awareness & Engagement Manager UK. What impressed me hugely was her willingness to discuss the PCUK campaign for 45 minutes just hours before she was due to fly out to Mexico for a 2-week holiday. Kate hails from the West Coast of Scotland and a quick glance at her Twitter feed elicited this

maxim: 'A wise woman knows her limits. A smart woman knows she has none.' She has been in post for 6 years, having previously worked as an oncology nurse.

Kate spoke about the Risk Checker which is easy to locate on the PCUK website. Launched in 2021, 30,000 people had clicked onto it by the end of the year. These numbers indicate just a modest success, but it was worrying to discover that only 1% had been from the African Caribbean community, the most at-risk group in the UK.

In January 2022 data was available to show that, after 2 years of Covid and lockdowns, numbers being treated in all other areas of cancer had recovered to pre-Covid levels with just 2 exceptions – lung cancer and prostate cancer. These statistics underlined the urgency for the Missing Men campaign. Within the first 3 weeks of its launch in February 2022 no fewer than 750,000 had been on the Risk Checker, including a significantly higher proportion from the black community.

The 6-week campaign is at an end, but, when asked if it had been a success, Kate responded, 'Absolutely! And we're not done yet,' indicating that there is a determination to get figures to a pre-Covid level and that systematic searches should be made, particularly in deprived communities or ones with a higher density of men from African Caribbean heritage.

Returning to the KWPCSG's own Missing Men campaign, a call through to our wonderful printers, Vernon Print (formerly of Droitwich, now of Birmingham), elicited a draft of 4 potential logos and straplines, all of which we loved and which you will find dotted around this feature. So we had a

I in 8 men will get prostate cancer

We think you're worth saving.

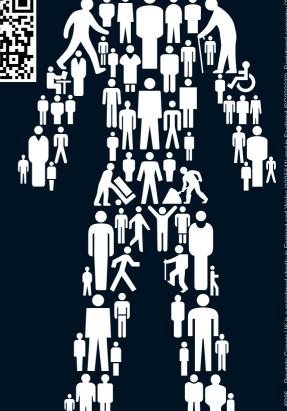
Check your risk of prostate cancer in 30 seconds.



prostatecanceruk.org/v-risk8

PROSTATE CANCER UK





campaign theme and logos. Now we needed a programme of events.

No problem in identifying the 6 open meetings (3 in Kidderminster, 3 in Pershore) and in extending the Coffee & Chat events from 3 in the south of the county to 6 across the whole county, but the clincher for such a campaign was surely going to be PSA testing events. Fortunately, the Worcestershire Ambassadors had already got that particular ball rolling, having booked the Graham Fulford Foundation to run a testing session for them on Monday, March 6th. at the Worcester Golf & Country Club at Boughton Park, Worcester (see pages 14-15 for more details).

The first in July, which will be in Kidderminster. will be fully financed by KWPCSG, while the second in Pershore in September will be underwritten by the Pershore Mayoral Prostate Cancer Fund.

Now we have a programme of 15 events over 2023, reaching out into parts of the county where we will be holding events for the first time, such as Evesham and Tenbury Wells. The success nationally of the NHS-PCUK campaign has galvanised us into looking at the year as a whole and seeing how we can do what we can at a local level to find our own missing man and hope we will have reached them in time.

We now turn to our 470 members and ask every one of them to At a support group committee meeting in January, we decided to run our own free summer and autumn testing events. bringing to an end a long and troubled few years when there were divisions in our charity and also nationally about whether we should be involved in such commercial events and whether there could be a risk of false positives. Happily, however, the committee put its full

friends and family to sign up for one of our 2 PSA testing events in this county in 2023.We also turn to them to support our nontestina events. to interact with other members and to help to increase awareness of PC across the county

and beyond.

put the word out among

Peter Corbishley

HOW YOU CAN HELP

support behind the two events.

- Volunteer to support the Missing Men campaign (phone me on 01386 554650 or 07876 556466)
- Help organise just one of our 6 Coffee & Chat events in 2023
- Be willing to distribute Missing Men mini posters in your area (local pubs, clubs, supermarkets, etc.
- Take any opportunity to tell friends and families about the Missing Men
- Get those eligible to sign up for one of our free PSA testing events in Kidderminster and Pershore
- Do some or all of this and you will be saving lives



Early diagnosis saves lives.

Check your risk of prostate cancer in 30 seconds.

prostatecanceruk.org/v-risk4







TESTING TIMES

Where are they? According to our next Pershore Civic Centre speaker, Dr Paul Rajjayabun, we are missing over 300 men in Worcestershire in 2020 alone!

As many members will be aware, Prostate Cancer UK ran a successful "Missing Men" Campaign last year seeking to identify and connect with the 14,000 unidentified men across the country. Whilst some in the county used the PCUK "Prostate Checker", we clearly failed to raise sufficient awareness in our own county.

The KWPCSG committee agreed the need to try harder in 2023, and we are set to launch our own "Missing Men Campaign" (see pages 2, 12 and 14). We shall step up our efforts with Open Meetings and Coffee & Chat events sprinkled across the county.

But how better to help reach those hundreds who have yet to be diagnosed? It is believed that, by offering free PSA testing, as has been developed elsewhere across England, we should attract many more men to come forward.

To check the possibilities, I visited one of the many "My-PSA Tests" events in Warwick recently and was hugely impressed. These are run by the Graham Fulford Trust (GFT).

The whole process is extremely professional and well organised, with the 180 attendees on the night having gone through 4 short steps to have their PSA test:

- · First, the participants registered online
- Next, they explored the events in their area and booked a test
- Thirdly, they took a printed booking form to the Warwick venue where their blood test was taken
- Finally, they were notified, usually within 48hrs, when their test results are available online.

Three very experienced phlebotomists needed less than 3 hours to carry out this exercise with men arriving every 5 minutes for their pre-arranged appointments throughout the evening. A maximum of a dozen chairs provided the only facilities required (apart from the men's toilets!).

We shall therefore trial two events in the county – in Kidderminster and Pershore – (see calendar for details), and these will follow a similar event sponsored by the Worcestershire Ambassadors in early March at the Worcester Golf and Country Club. We aim to publicise these events with articles and media coverage and also provide the resources to ensure our 2 events can be free.

We will be using PCUK publicity which concentrates attention on those aged over 50 (in the case of those with African Caribbean ethnicity this would be over 45), with any familial connections to prostate cancer. We shall arrange a few of our trained "Buddies" to attend these events to chat to attendees.

Raising awareness has never been so important. If you feel you can help us at any of our events – please get in touch.



WOULD YOU CONSIDER BEING A BUDDY?

One of the main reasons we received the Queen's Award in 2017 was the fact that this support group from the very start offered a Buddy to any newly diagnosed man immediately. It was started by myself, after our registration as a charity, and was supported by the Consultant Urologist at Kidderminster Hospital. It was much easier for me in my role, as Clinical Nurse Specialist, to be able to match men with a Buddy because I had full knowledge of the diagnostic results and could ensure the match would be very close in grading.

It is not possible to have the same knowledge while dealing with offering a Buddy to a new member now I am retired, but I have to work with the knowledge men give me when we talk about speaking to a new member. It is, therefore, important that men see this role being a friendly support, where they can tell another man what their experience, but being aware that it may not be the same for every man. We know the value of this support is more important to newly diagnosed men, and their partners, to have the chance to talk to their Buddy, and many men go on to offer their service to other men after their recovery and become close friends.

I need new Buddies for surgery, especially robotic surgery, who have had the surgery in the past three years. It would be wonderful if any member has had their surgery in Worcestershire. It doesn't matter if it has been done at another Hospital Trust. What matters is that you are happy to talk about it.

N.B. A Buddy has a different role to play compared to a Support Contact.

We still need men who undergo open surgery to talk to other men also and men who have gone through radiotherapy.

It has to have been in the past three years, because the treatments vary frequently. Please contact me on my mobile 07752 09697 if you would like more information.

I am not able to keep records of all members' treatment details on our database, so the information when we talk is important for me to be aware of.

I will be arranging a class for Buddies some time shortly.

Mary Symons



4 new volunteers who met KWPCSG chair, Mary Symons (right) and Gordon Kingston at the Checketts in Ombersley in January to discuss ways of supporting the group. L-R: Eric Scrannage, Gez Kenney, Maureen Kenney and Phil Rudd.

COFFEE & CHATS EXPANDING ACROSS THE COUNTY

As we emerged from the second Covid lockdown in 2021 the South Worcestershire PCSG decided that it was time to do more than simply rely on the resumption of open evening events in Pershore to entice wary members back into the community. We thought a simple coffee morning in carefully chosen venues (plenty of space, good ventilation, adequate parking, access to seating outside and – most importantly – good quality cakes!) could begin that process.



Malvern Cube, the venue twice in 2021 and again this June

Our aim was to set up the events in different towns in the south of the county and to make them free of charge. We agreed on the name Coffee & Chat for the events and launched the venture on Friday, July 16th. at The Cube in Malvern. It was a lovely summer's morning, but numbers were a little disappointing — just 17, if you include a few of the committee members.

Nothing daunted, we proceeded with our second C&C, this time in late September at the Angel Hotel in the middle of Pershore. With schools reopening and, inevitably, another wave of Covid threatening, numbers were still disappointing, as they were when we returned to Malvern on November 12th.

So far, so underwhelming in terms of numbers, but we had noticed how keen those who had attended were to discuss PC and non-PC matters with other attendees. It brought people together from the same town who could talk through their concerns, their fears and even their triumphs. The outlay for each event was still relatively modest, so we decided to try 3 new venues in 2022. We found an ideal location to launch our programme in 2023 – the New Road Café at the Worcestershire County Cricket ground. It proved to be a memorable, early April morning where members could enjoy the iconic view across the ground towards the cathedral.

At last, we had pushed the numbers up into the low 20s – encouraging, but not conclusive proof we had cracked it. What was surprising, though, was that there were only a couple of members there who actually lived in Worcester. On the plus side there were a good number of new faces and their partners. Where to next? Step forward Chris Marsh, one of the newcomers at Worcester and keen to help set up a C&C in Droitwich



County cricket ground venue for a 2022 C&C

Friday, July 15th. was, in many ways, a turning point. 35 people turned up, enjoying not only the excellent refreshments but also the panoramic views across the Gaudet Luce Golf Course, our generous hosts. We also had, for the first time, a guest speaker. Tackle trustee and Solihull PCSG chairman, Aidan Adkins, joined us and told us about his own journey and the work that Tackle were doing for PC sufferers.

Our final event of 2022 was also something different. On November 8th. we linked up with the South Warwickshire PCSG on their patch at the Studley Village Hall in the Main Street. Again over 20 attended, and it was really interesting to find out what our neighbours were able to offer their members. We promised to keep in touch and to run a similar event in the future.

As I wrote about in the December 2022 Supporter magazine, we reviewed the success or otherwise of the 6 C&C events over the two-year period at committee level and concluded not only to continue with them but for KWPCSG to organise their own 3 C&Cs across the north of the county in 2023. If you look at the separate 2023 programme of events, you will see that the 3 SWPCSG C&Cs take us to Evesham, Malvern and Droitwich, while the 3 KWPCSG coffee mornings sees us pitching up in Tenbury Wells, Alveley (just over the border in Shropshire) and Hagley.

Not only are we making a concerted effort to spread ourselves across the county but also to involve more of our members in the running of the events. We are looking for teams of at least 3 members and / or partners to run each of the 6 events. All that is required is to help distribute the laminated A5 posters 2-3 weeks before each C&C, to inform members in those areas by email and to run the show on the day, helping serve the coffee and cakes, to take details of all those present and to make newcomers feel particularly welcome.

If anyone feels he or she could become a helper-organiser at one of the C&Cs, please contact Gordon Kingston (SWPCSG) or Mary Symons (KWPCSG) as soon as possible.

Peter Corbishley



Evesham United FC will host our first C&C in 2023

I NEVER SAW THAT COMING!

I'M NOT THE SAME PERSON NOW



AR3D radar. Ecuador 1986.

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. Television was in Malay or Indonesian. Every so often the local hotel

where I stayed found me an old copy of The Straits Times from Singapore, I read every page - even the adverts - about what was happening in Singapore. I would turn on my small HF radio every night and wait for the music that proceeded the announcer saying, "This is the BBC World Service." The radio reception was terrible, but for ten minutes I felt was back at home. I spent over two years commuting to and from Indonesia. Four months on site, travel home to the office, two- or three-weeks' holiday, return to the office, pick up my ticket, then back to Jakarta and onwards.

There were some very enjoyable benefits. Half way through every four-month trip I got to fly to Bali for a long weekend. There I could sit in the restaurant of a 5-star western-style hotel and have a burger and chips along with a cold beer, just absorbing the atmosphere as the tourists around me talked away in English. The food where I stayed near the radar was all local, typically nasi goreng (fried rice), with everything. There was the occasional mistake as I attempted to translate the menu in the shack that passed as my local restaurant. One evening I had ordered a particularly spicy meal, but it soon became obvious it was far hotter in spice terms than I thought. Seeing the expression on my face, one of the staff brought out a bowl of sugar and teaspoon, indicating that I should eat a spoonful of sugar. It did the trick and soothed my mouth. I never tried that dish again, but there was always a bowl of sugar on my table after that night.



Indonesia 1992 - 1994, with air force maintenance technicians. Age 34 - 36

I spent time in some wonderful places, spending six months on Crete, trips to Cyprus, Accra, Gibraltar, the Falkland Islands, Majorca and many more. In just over 13 years I had flown nearly half a million miles. Many of my tasks were carried out by myself, sometimes as part of a team. Occasionally, the customer was responsible for the problems they were experiencing, not connecting a unit correctly or not checking that a circuit board was configured correctly. At times like these I found myself having to be very diplomatic, particularly in the Middle or Far

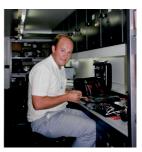


Indonesia, Supervising maintenance technicians training to replace the display CRT, cathode ray tube.

East, where "loss of face" was a big problem. In 1998 I was told by my manager that I was going back to Saudi Arabia for another two years. I resigned and walked straight into a job with the Civil Aviation Authority looking after the radars at Heathrow, Gatwick and Stansted airports. Ultimately I managed my own radar stations at Claxby, just outside Market Rasen, and Great Dun Fell, just outside Penrith.

In 2012 just as the world was watching the Olympic Games, I accepted redundancy, the old radar was replaced with a newer reliable system. I decided to move to the Midlands. Nothing scientific about the selection, just somewhere someone was building new houses, 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. Twice a year I flew to the States

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." I contacted the local community health trust and, after assessment, was told that I would benefit from some talking therapy. There was, however, a 3- to 4-month waiting list. I mentioned this to my CNS, who then 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



Sat in the workshop cabin of the AR3D radar, repairing a circuit board from one of the radar displays. 1988 aged 30.

we entered the first lockdown in March 2020, I Knew that I needed to do something. Being placed in the extremely vulnerable group due to the chemo and radiotherapy, I was advised to stay at home and not venture out.

Previously I would speak to my brothers 3 or 4 times a year. Once a year we would all meet somewhere, but after that it was an exchange of Christmas and birthday cards. After my diagnosis we set up a system where one brother would ring me every day at eight o'clock



Sitting on top of Mount Pleasant, the site of the RAF airfield. Falkland Islands 1986.

in the evening, check that I was okay and have a chat. One brother listened to me tell him about how I was doing and interacted with the gruesome medical details. Another would always divert the conversation away from my medical problems. "Let's talk about something cheerful," he would say. My younger brother spent 30 minutes telling me about his problems. For the first time in my life, I looked forward to the daily chats with my brothers. As I learnt what my nephews and niece were up to, I realised we had become a family again. I joined their WhatsApp group - something I had resisted for a long time - exchanging messages every morning.

IMPORTANT YEAR FOR SUPPORT CONTACTS

One of the difficulties facing the support group is to find replacements for those members who have generously given of their time over many years as support contacts. Typically, a support contact would have between 12-15 members whom he is encouraged to contact 2-3 times a year to find out how things are. More calls may be desirable in some cases where a member is requiring more emotional or practical support. Having such support contacts has made a difference to the lives of many KWPCSG members over the years.

If the Missing Men campaign in 2023 is to produce results in Worcestershire and beyond, word must get down to the grassroots. This magazine, open meetings, C&Cs, adverts and a higher media profile will all be vital cogs in this process, but our support contacts can play a critical role, too. If word extends down the grapevine through them to our members, those members may know of someone who just needs a little more encouragement to visit his GP or to attend our 2 free PSA testing events in

Kidderminster and Pershore respectively in 2023.

First, however, we must ensure we have new support contacts to add to the team organised by Derek Scully, the group's Support Contact Co-ordinator. Derek does a sterling job of allocating new members (a record number of 36 in 2022) to support Contacts, but the retirement of a number of SCs has created an urgent need for replacements. Anyone interested in finding out more should contact Derek as soon as possible on 01886 833236 or write to him at derekscully@btinternet.com

Next month there is a meeting of all Support Contacts and anyone interested in joining the group. The venue is Ombersley Golf Club (WR9 0LE) and the date set is Saturday, April 15th. at 10.00. The meeting is set to finish no later than 12.30. Again please contact Derek if you would like to attend or just turn up on the day

FIGHTING FIT – DI FOR A NEW LEASE OF LIFE

The facts of life have been spelt out clearly in many recent "Healthy Living" supplements to most of our newspapers and programmes on the TV.

If you want to have a healthy life into older age, it pays to follow the three-pronged mantra of Michael Moseley and other gurus:

A Mediterranean diet, good social connections and appropriate exercise.

- 1. So, are you still on your New Year diet with the help of Michael? If not, he is on the radio regularly with simple tips about how to improve your health. Go For It It Works.
- 2. Why not try to speak with another relative, neighbour, or friend tomorrow? It is proven through countless studies that more social connections keep us mentally & physically well into our later years.
- 3. And why are you still on the couch? A return to the strolls we all enjoyed during the pandemic can be a life saver. **Or better still!** Start a new lease of life through a little GENTLE exercise. But how to start?

KWPCSG has been encouraging members to join the Monday morning hour-long sessions with **Di Fox** over the past year. **Zoom in to the website** – and just watch **every Monday at 9:30am**. These gentle friendly exercises help your joints to stay supple and increase your appetite for life.

Go on – you know it works. Join at www.kwpcsg.co.uk every Monday at 9:30

NO, IT'S NOT A TYPO

'PROSTrATE CANCER' BOOK COULD TACKLE (sic) YOUR FANCY

Want to send a fellow PC sufferer a book to cheer him up? Here's a suggestion. Why not order a copy of 'Prostrate Cancer: The Misunderstood Male Killer' (Graham Sharpe / Oldcastle Books)? This is a generally light-hearted and humorous look at the author's own journey.

Before you write in to point out my typing error, let me explain. The word 'Prostrate' is deliberate. It reflects Sharpe's dedication: 'This book is dedicated to anyone who believes that there are two 'R's' in PROSTATE – I hope you don't have to learn the hard way how to tell your 'R's' from your elbow!'

In a letter to the Metro in June 2021 Ben Mundy (Wells, Somerset) wrote: 'I have lost count of the number of friends I know who have complained of 'prostrate' problems. I have stopped bothering to correct them.'

Now, I thought at first it was just me who knew of people who mispronounced the word. One that always baffles me is a very dear friend from schoolboy days who got a first in Chemistry at Cambridge and worked all his life for AstraZeneca, yet still adds that second 'R'.

Maybe it is just me, Graham Sharpe and Ben Mundy, but if you are one of us, let me know (editor@kwpcsg.co.uk) and suggest what we ought to do to solve the issue. Is it too late for me to apply to write a thesis on the issue?

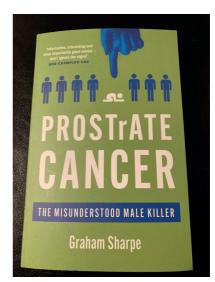
The book is autobiographical and devotes the first 120 pages to 39 visits to the oncology department at Mount Vernon Hospital in 2018 for radiotherapy. Much revolves around the camaraderie that developed between him and his fellow male and female patients, all given names such as Forty-Mile-Each-Way Family, Crutch Lady, Mr. and Mrs. Umpire, Very Tall Posh Man and Not-Quite-Luton Man. His daily trek to hospital via 3 buses,

the minutiae of the journeys, the best stopoff points to pop or dash to the loo on the journey home.....yes, been there, done that, some of us may concur.

Interspersed in the humdrum of the daily journeys and waits are lots of anecdotes about music, football and horse-racing (the author has written a number of books on the subject), plenty of gallows humour but no shortage of positivity and lots of information about such topics as PSA testing and how to interpret Gleason scores.

In the final hundred pages the author resorts to a lot of cut-and-paste, with many pages devoted to articles on prostate cancer culled from daily newspapers. I'm not sure if the author is running out of ideas, but I certainly feel a book of between 200-250 pages could have been more punchy. Credit to him, however, for shining a light on the highs and lows of prostate cancer treatment from our perspective.

Peter Corbishley



CALENDAR OF EVENTS 2023

EVESHAM COFFEE & CHAT

Thursday, March 9th. 2023 (10.30 – 12.30)

N.B. new date / one day earlier than printed in the December magazine Evesham Football Club, Cheltenham Road, Evesham WR11 2LZ

Free coffee and cake for every member and partner!!!

The perfect opportunity to get to know others who are being treated for or who have recovered from prostate cancer

SOUTH WORCESTERSHIRE PCSG

Wychavon Civic Centre, Queen Elizabeth Drive, Pershore WR10 1PT Tuesday, March 21st. (doors open at 6.30 pm for a 7.00 pm start)

SPEAKER: DR. PAUL RAJJAYABUN

(Consultant Urological Surgeon for Worcestershire Acute Health Trust who will be talking about Robotic-Assisted Surgery at the Alexandra Hospital, Redditch)

TENBURY WELLS COFFEE & CHAT

Friday, April 14th. 2023 (10.30 – 12.00) Fountain Inn, Oldwood Road, Oldwood, Tenbury Wells WR15 8TB

Free coffee and cake for every member and partner!!!

The perfect opportunity to get to know others who are being treated for or who have recovered from prostate cancer

KIDDERMINSTER & WORCESTERSHIRE PCSG

Harriers' Social Club, Stadium Close, Hoo Road, Kidderminster, DY10 1NB Monday April 17th. 2023 (doors open at 7.00 pm for a 7.30 pm start)

SPEAKER: AIDAN ADKINS

(Chair of Solihull PCSG and Trustee of Tackle, the representative body of 93 PCSGs in the UK, Aidan will be talking about his own PC journey and what PC patients can do to improve their chances of surviving cancer)

Free and ample parking in the club's own car park

DROITWICH COFFEE & CHAT

Tues. May 30th. 2023 (10.30 – 12.00)

Gaudet Luce Golf Club, Middle Lane, Hadzor, Droitwich Spa WR9 7JR

Free coffee and cake for every member and partner!!!

The perfect opportunity to get to know others who are being treated for or who have recovered from prostate cancer

Keep in touch with us via: / Tel. 01299 832166 www.kwpcsg.co.uk / contact@kwpcsg.co.uk