PCaSO Sussex Newsletter – Autumn 2026

Good morning members, guests and friends of PCaSO,

An early Autumn morning at glorious Sheffield Park

On 8th October 2026 it will be ten years since my first ever PSA test and my family and I are forever grateful to PCaSO volunteers who manned that small event in Burgess Hill.

We are pleased to welcome several new members who have joined Sussex Branch recently.

If any of you have any issues or concerns to discuss, please contact your group organiser, who is listed below or, alternatively, give Brian a call on 07778 065094.

Clive easternsussex@pcaso.org

Alf centralsussex@pcaso.org

Martin westernsussex@pcaso.org

Brian brighton@pcaso.org

Patient Story

As an experiment, I would like to introduce this as a regular feature, and to start it off here is my story.

Rather than repeat, here are the links from our website which cover the first two parts of my Lucky Journey.

updates-64.pdf

updates-69.pdf

2026 The Lucky Journey continues…

Unfortunately, my PSA has again continued to rise and, since I still have my prostate, I was advised by Dr Angus Robinson that when it reached 2, I would have a PSMA PET scan, which I did in 2023. This was inconclusive, and the doubling of PSA became the point at which another scan would take place, which I had in 2025, again inconclusive, but with signs something was happening.

In May 2026 my PSA was at 8, and a third scan was ordered, which showed, at last, that the cancer was again in my lymph nodes, but higher up. I started Bicalutamide and Tamoxifen on 1st September and had a CT planning scan at the end of September to determine whether I should have EBR or SABR. Either way, further radiotherapy is booked in for 20 sessions of EBR in November at Brighton Cancer Centre.

It would be helpful to other members if you would like to share your story in our next newsletter. Please email me chair.sussex@pcaso.org

We are writing to all PCaSO Sussex members to ask for your support to attend our monthly drop-in sessions. These informal sessions have proved to be really useful for those living with prostate cancer, to chat and discuss their treatment journeys. This can be very re-assuring, particularly for newly diagnosed men, who can be feeling overwhelmed or alone in their cancer situation.

We regularly post details of upcoming sessions on the WhatsApp groups, but this information is not seen by the many members and their partners who are not on WhatsApp.

As an experiment we are inviting all partners, not born with a prostate, to attend the Horizon Centre on Tuesday 13th October 10.30 to 12.30. This will be in a separate, private room to those born with a prostate, who will be meeting at 11.00 to 13.00. PLEASE pass this information on to your partner and ask them to email me chair.sussex@pcaso.org, or WhatsApp 07778 065094 if they would like to join in.

Many of you and your partners have been PCaSO members for several years and have good experience of how to deal with the effects of treatments and side effects. You are able to share this lived experience, which can be of particular value to newly diagnosed men and their partners.

There is absolutely no commitment to attend every month, but occasional support would be much appreciated by our volunteer organisers.

A reminder of the locations, days and times, follows. Please check the website for up-to-date information.

Going forward, we would love to see drop-in groups in all of Sussex's major towns, if we have enough willing volunteers.

All members and partners are welcome to attend the drop-in sessions, and we welcome non-members to drop in to discuss their prostate cancer issues – they may become members also.

Eastern Sussex group hold drop-ins at Tesco Store, 21 Lottbridge Drove, Eastbourne BN23 6QD. (Please note that parking is free for 3 hours, any longer and you'll have to register with Customer Services.) The meetings are held in the Community Room, at the back of the store, between 10.00 and 12.00, refreshments are provided. All meetings will be on first Tuesday of each month.

Brighton group hold drop-in sessions on the second Tuesday of each month, 11.00 to 13.00, at Brighton Macmillan Horizon Centre, 2 Bristol Gate, BN2 2BD. Numbers vary at our sessions, but have recently risen to 12 members, including newly diagnosed men.

Central Sussex group are holding sessions on the third Thursday of every month at the Triangle Leisure Centre, Burgess Hill, 10.30 to 12.30. Our first meeting in April had six members attending and was very well run by Alf, our new group organiser.

Western Sussex group meet at Haskins Roundstone Garden Centre's Roundstone meeting room, Angmering BN16 4BD (on the A259 eastbound side). These drop-ins will be on the first Tuesday of each month, 10.30 to 12.30. You'll be very welcome to come and chat! Plenty of free parking available.

Notices of drop-in sessions are regularly advised on our Website, WhatsApp groups and Facebook pages.

Working alongside the NHS — where PCaSO fits

Thanks to Martin for this timely article.

Prostate cancer care is delivered by highly trained clinical teams, and PCaSO is very clear about its role alongside them.

We are not a substitute for the NHS, and we do not give medical advice. Diagnosis, treatment decisions, medication, symptoms and clinical follow-up must always remain with the appropriate GP, consultant, Clinical Nurse Specialist or other healthcare professional.

What PCaSO can provide is the support around that clinical care.

For many men, a prostate cancer diagnosis brings a flood of information in a relatively short period of time. Even after a good consultation, it is quite common to come away remembering only part of what was discussed, or to think of additional questions later.

That is where peer support can make a real difference.

PCaSO volunteers can listen, share their own experiences where appropriate, explain how they personally found treatment and recovery, and help men and their partners think about what questions they may want to raise with their medical team.

Just as importantly, we can provide support outside the hospital environment. Our drop-in meetings offer an informal setting where people can talk without the pressure of a clinical appointment. Sometimes that means discussing treatment experiences; sometimes it means talking about practical concerns, relationships, confidence, work, travel or simply how life has changed since diagnosis.

Partners are an important part of that support. They often have concerns of their own and may find it helpful to speak to others who have faced similar situations.

There is also scope for PCaSO to work more closely with hospital teams by making sure patients know that this type of support exists. A simple referral or introduction to PCaSO can give a newly diagnosed man somewhere to turn between appointments, without adding to the workload of the clinical team.

The relationship works best when the boundaries are clear:-

The NHS provides diagnosis, treatment and clinical judgement.

PCaSO provides lived experience, peer support, information, listening and signposting.

If a discussion raises a medical concern, we direct the individual back to the appropriate healthcare professional.

PCaSO can also support prostate cancer services in practical ways. As a charity, we are able to consider funding equipment and other initiatives connected with the diagnosis and treatment of prostate cancer patients, where these can make a genuine difference.

Our aim is simple: to complement, not compete with, the excellent work already being done by NHS teams.

When clinical care and peer support work side by side, men and their partners can feel better informed, better supported and less alone.

Martin

PCaSO Western Sussex Coordinator

Martin Hickey
Western Sussex Group Organiser
Tel: 07805 458041

Central Sussex Update

Big Bash Brighton - July

Joseph and Alf represented PCaSO at the Big Bash, Brighton & Hove's celebration of Black culture. The free family event is organised each year by Brighton & Hove Black Anti-Racism Community Organisation CIC.

We had many conversations about prostate cancer and the importance of PSA testing with many black men over the age of 40. Few had had a PSA test in the last two years and were not aware that they were at greater risk of prostate cancer at some point in their lifetime. Many partners of these men were keen to follow up and ensure the men were tested soon. It was clear there is a need for more awareness raising and for PCaSO to regularly hold testing events in Brighton.

Our drop-in sessions at the Triangle, Burgess Hill, continue to attract more attendees, which is encouraging and helpful for them.

Eastern Sussex Update

Tuesday 15th December 4pm-6pm
Steff Collins, Macmillan Information & Support Manager - Radiotherapy referral process and radiotherapy side effects.

Please make your best efforts to attend and support these sessions that have been organised for members, with time not only given freely by volunteers, but also employees giving up their own valuable time.

Western Sussex updates

From diagnosis to the Haskins Drop-In — why peer support matters

Being diagnosed with prostate cancer inevitably brings questions, uncertainty and a great deal of information to absorb. In my own case, diagnosis was followed by treatment, and like many men I quickly discovered that the clinical side is only part of the experience.

The medical teams provide the essential diagnosis, treatment and follow-up. But there is also enormous value in being able to talk informally with someone who has already been through something similar.

That is one of the reasons I became involved with PCaSO.

PCaSO is run entirely by unpaid volunteers, many of whom have personal experience of prostate cancer themselves. Across the charity we have more than 1,000 members, bringing together a considerable amount of lived experience. That does not make us medical experts, and we are very careful not to present ourselves as such. Clinical questions are always

referred back to the appropriate GP, consultant or Clinical Nurse Specialist.

What we can offer is something different: time to listen, personal experience, practical support and reassurance that others have faced many of the same concerns.

That is very much the idea behind our monthly drop-in meeting at Haskins Garden Centre in Angmering.

There is no formal agenda and no appointment is needed. Men can simply come along for a coffee and a chat. Some have recently been diagnosed, some are undergoing treatment, some are many years beyond treatment, and others simply want to understand more about prostate cancer.

Partners are equally welcome. Prostate cancer affects couples and families as well as the individual who receives the diagnosis, and sometimes partners find it just as useful to talk to others who understand what they are experiencing.

Nobody has to arrive with a particular question. Sometimes the most valuable part of a drop-in meeting is simply discovering that somebody else has been through the same thing.

If you have never been to one of our drop-ins, why not come along?

Those born with a prostate, partners and family members are all welcome.

Sometimes the most useful conversation after a prostate cancer diagnosis isn’t another medical consultation. It is sitting over a coffee with someone who has already travelled the same road.

Martin
PCaSO Western Sussex Coordinator

WhatsApp Support

We have three active groups, for PCaSO members only:-

Our Main group and Active Surveillance group have over 100 members who are living with prostate cancer, and who support each other by comparing notes and sharing details of their experiences and treatment pathways.

Our Partners' group is run by volunteer Macmillan nurses.

Prostate cancer news is updated and shared much more quickly on WhatsApp than via our newsletters.

The only way to join the WhatsApp groups is to send a send a WhatsApp to 07879 903407, stating your name and current treatment situation.

Brighton News

Subject: Charity Art Auction in support of The Macmillan Horizon Centre Brighton

Hi, I'm Chris, a PCaSO member,

I write with the consent of PCaSO and Macmillan, to introduce the following in the hope it is of interest and you may be willing/able to support the initiative?

In November (25.11.26) I am planning a Charity Art Auction in support of Macmillan Cancer Charity in Brighton (The Horizon Centre) with a view to raising £10,000+

The sale will include the following:

Original artworks donated by artists/galleries

Limited Edition prints donated by artists/galleries

Original artworks donated by cancer patients/families

Legacy Portrait commissions

AOH Merchandise

An Art Draw (Lottery for Art Prizes)

Please share this e mail with anyone you know affected by cancer – Family, Friends, Artists who may be interested in supporting this initiative in any way possible and in particular –

1 Donations of Art

2 Offers to buy/sell Art Draw Tickets - £5 each with 5 Art Prizes

3 Tickets for the Event - £10 each (including first drink free/pay bar thereafter) NB DJ

4 Jazz Quartet – to play before auction

5 Sponsorship

6 Venue

7 Bar

8 Volunteers to help on the night

9 PA Hire – mike/dj mixer

10 Sharing Hope

Many thanks

Chris Roche / Prostate Cancer Patient

Macmillan Horizon Centre Brighton schedule, digital version

OCTOBER Schedule PRINTABLE (1).pdf

Mike please insert latest Horizon newsletter link.

Sussex PSA Testing report

For this Autumn we have our three regular big events in the diary, these being Worthing on 19 September, East Grinstead on 10 October, and Burgess Hill on 14 November.

Hi everyone,

I just wanted to add my own huge thank you to everyone who helped make Saturday's Worthing event such an incredible success.

1,206 PSA tests completed — absolutely amazing! 🎉 What a fantastic achievement, and such a great result for PCaSO. It was a real team effort, and I'm so grateful to all of you for giving up your time and working so hard throughout the day.

It's particularly encouraging to see that 782 men were attending PCaSO for the first time, which shows just how much awareness these events are creating and how many new men we're reaching.

Cliff has analysed the results, so you might be interested in a few key stats:

- RED (out of range) = 58 (4.8%)
- AMBER (Borderline) = 32 (2.7%)
- GREEN (Normal) = 1,115 (92.5%)

782 men were 'first timers' to PCaSO and 195 had attended Worthing last year.

Age range of attendees:

- 40-49 174
- 50-59 335
- 60-69 420
- 70-79 270
- 80 7

And what a fantastic fundraising result too — £16,107.98 raised, with Gift Aid hopefully taking that to around £20,000. A huge well done to the Donations Team! 👏 Bearing in mind the event will have cost PCaSO around £15k overall, these events aren't cheap. But thanks to the Charmandean Centre for free use of the venue.

Thank you again to all the phlebotomists, volunteers and everyone behind the scenes who helped make the day run so smoothly. I know it was a long day for everyone, so I hope you've all had a chance to recover!

It was lovely working alongside you all, and I'm looking forward to seeing many of you again at East Grinstead on 10 October.

Thanks again for everything you do for PCaSO. +

All the best,

Lance and team

PCaSO will be represented at the Crawley K2 Leisure Centre Health Awareness event on Thursday 8th October. Do drop by if you are in the area.

Your committee would appreciate feedback via email, with your thoughts on the support we are giving and how we can help further. Remember that we are all simple volunteers, sharing our own experiences of prostate cancer.

Enjoy the Autumn weather and make great efforts to stay fit, active and healthy. Our Healthy Living Booklet is a must-read and should inspire you!!

Brian and your Sussex Committee

Please contact Brian on email chair.sussex@pcaso.org with any questions or ideas for future newsletters, phone 07778 065094.