

UPDATES

The Newsletter of PCaSO Prostate Cancer Support Organisation

Dorset ● Hampshire ● Sussex ● and surrounding areas

ISSUE 75 *Winter 2024 - 2025*



Photograph by Lance Allen



Prostate Cancer
Support Organisation

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Dorset branch is Dormant. See below

Dorset Branch Committee

The Dorset Branch is currently Dormant, any members wishing to take up Dorset Committee roles please contact the Chairman chair@pcaso.org.

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NOTES FROM THE EDITOR

This issue is only available in digital format (PDF).

This is the second issue that I have produced as both editor and designer. One thing I have learned is it always takes longer than you thought to produce and it will never be finished but you have to publish it at some point.

So here it is, it will keep the same format as the previous version, being a mix of Men's stories, relevant articles and update from the branches .

This issue includes:

Five new members stories

Sarra Waite on the Cancer Care Co-Ordinators Role

News from the Branches

The minutes from the 2024 AGM

PCaSO testing results for 2024

As I said before, this is the second issue of Updates that I have edited and as with all things in life it is a learning curve and I am happy to learn.

So please send any comments or suggestions on this issue or for the next issue to:
editor@pcaso.org

Thank you for taking the time to read this issue and I wish you all good luck for the future.

Paul Bowler
Editor

Content for Updates

The opinions expressed in this newsletter are not necessarily those of PCaSO (Prostate Cancer Support Organisation).

All men and all cases are different and you should always discuss any changes to your treatments with your doctor and in the light of your own personal circumstances. PCaSO does not give advice, but shares experiences.

Chairman's Introduction



Good morning and welcome to the 75th edition of our digital magazine, 'Updates'.

Updates was started in 2014 as 'Updates 46', because a quarterly newsletter had been produced for 45 issues, before the change of name to 'Updates'.

Here are links to both first editions:

[Newsletter 1](#)
[Updates 46](#)

Updates 46 makes interesting reading, with many topics being similar to today although notably, and sadly, there is still no national screening programme.

However, PCaSO continue to offer free PSA testing at our many testing days around the branches. We are very grateful for the continued support of all our volunteers in making the testing days such a success, and running like clockwork. (A full summary is included.)

Our membership continues to increase, and we receive regular feedback from our members and their partners, thanking us for sharing our experiences and encouragement, especially when newly diagnosed. Over 80 members, and their partners, are participating in our WhatsApp groups for Active Surveillance, Partners and the general group.

On WhatsApp, we regularly hear from newly-diagnosed men who are trying to decide on their proposed treatment options. By talking about their diagnosis with over 80 other members, a variety of experiences are shared, which helps these men with their decision-making process, and even to learn about treatments which may not have been offered to them, such as HIFU or Retzius sparing surgery (both being described in detail on videos on our website). The WhatsApp approach is somewhat different from my own decision-making process eight years ago, when all I could do was make a couple of telephone calls to other members, notwithstanding the fact that the information I was given was excellent, and I have no regrets about my decision.

A subject that has been raised regularly over the last few months is that of health and familial links, highlighted in the sad case of Chris Hoy. From our own experiences, we have seen how those with prostate cancer may have had other male family members also with the disease, and should have been tested much earlier. In my own case, I

found out several years after diagnosis that my grandfather died from PCa. If I had known earlier, I could have insisted that my GP tested me, and maybe my cancer would have been found at an earlier, and less aggressive, stage. Because of my links, and the knowledge that my wife's father also died from prostate cancer, my son decided, at the age of 40, to get tested recently. His PSA is normal, and he now has a baseline to work from. Two of our members have written their stories for Updates, explaining that they have direct familial prostate cancer links, and the importance of getting tested early. Lastly, on this subject, we have recently had three men join us aged under 45, and we wish them well.

Familial links exist in many other illnesses, not just prostate cancer, and hence we have been promoting Our Future Health which is described more fully inside, by following the link in our AGM minutes.

This year, some of our members are retiring from key roles in running our charity. After many years' service, Peter Weir has stepped down from Chair of Hampshire Branch, but will remain as their PSA testing coordinator. Paul Bowler has stepped up to take on this role, as well as that of Vice Chair on the Executive committee. Roger Smith stepped down from being Hampshire Secretary, and we are pleased to say that Pete Strickland has taken over successfully. Brenda, our long-standing Treasurer at Sussex branch steps down at the end of the financial year, and I'm pleased to welcome Carol Isted who is taking on the role. Roger Bacon is reducing his role with Sussex PSA testing duties and, whilst we have an excellent group of 20 volunteers for 'on the day' roles, we still need new volunteers for pre-event organising. The Trustees and I thank all of those who are taking a deserved rest, as well as those taking up the challenge of helping to run our fantastic charity.

We hope you enjoy reading Updates.

Please feel free to copy to anyone who has an interest in, or has, prostate cancer concerns. As ever, we are here to help and share our experiences.

Stay fit, healthy and have a Happy New Year,

With very best wishes,

Brian and the team.

Edward Carter's Prostate Cancer Story

At my regular Masonic Lodge meeting in October 2023 the lodge secretary read a letter offering members PSA checks. I was curious enough to go along and find out my 'level', thinking I'd tick that box and carry on life as normal. Being 48 I'm too young to get an NHS invite or to even ask my GP for a test, unless I had the usual tell tale signs.

Well I didn't tick the box and life didn't carry on as normal, it started on this sideways pathway.

"I was curious enough to go along and find out my 'level', thinking I'd tick that box and carry on life as normal."

The Initial PSA test was conducted by [PCaSO](#) and my result came back via an email after a few weeks, it was 26.97. It should be between 0 and 2.5 for a man under 50.

I was directed by the email to contact my GP ASAP. They conducted a further PSA check, this time it was down slightly to 20.3. The GP referred to Eastbourne Urology. After a digital examination the Doctor wasn't overly concerned with the physical feel of my prostate, but was still worried about my high reading so sent me for an MRI scan. This led to a series of biopsies and it was finally confirmed in March this year, that I had Prostate Cancer.

This didn't come as too great a shock, after all the tests that had been carried out I was expecting them to confirm my thoughts.

"I know being tested has quite simply saved my life"

The shock came at how well developed within the prostate the cancer was, I have a T3 tumour. It had just breached the wall of the prostate, but was still within the membrane and had not spread to any other part of the surrounding area or more importantly the lymph nodes, this was confirmed by the PET scan.

I have been having Hormone Therapy since March and I'll be on it for 2 years. I definitely suffer with the hot flushes and complete lack of sex drive, not that its really been on my mind these last few months.

I was admitted into The Royal Sussex University Hospital Brighton for day surgery on the 15th of August to have a procedure called Brachytherapy. It's a very long day of surgery in the morning followed by an MRI and several CT scans over the day to plan for the temporary application of radioactive seeds direct to the prostate bed. This treatment is designed to work in conjunction with Radiotherapy and kill the deepest of the cancer cells in the prostate. I have been receiving Radiotherapy at Eastbourne General since the 5th of September Im due to finish 7th of October It's

mostly been Monday to Friday, I've have been a few breaks here and there during the weeks, one day being my birthday; but it hasn't affected or impacted on my treatments. I have nothing but admiration and respect for everyone I've come into contact with. The medical teams in all the various areas I've been. From the consultants, surgeons, nurses, radiographers, and the reception staff are all so kind warm and welcoming.

Being part of the PcaSO whatsApp support group is of great help, the members can offer their experiences and support. It makes the sometimes scary world of "cancer" just that bit easier; knowing you're not alone and that other guys have been there and done it. Being able to say to someone, "you'll be Okay, it's not as scary as you imagine it will be" is a great thing, passing on the help to the next man on the pathway.

I know being tested has quite simply saved my life, and It would be remiss of me not to shout it loud and clear if it's caught early prostate cancer is beatable..... I'm telling everyone I meet "Don't ignore the signs it's not going to get better by itself and it is definitely not going to go away!"

Sarrah Waite - The Cancer Care Co-Ordinator Role

My role as a Cancer Care Coordinator began in February 2024 working with 3 GP practices who form the Coastal Fareham and Gosport Primary Care Network.

With 15 years of clinical experience in many different cancer diagnosis and treatment pathways in the Royal Hampshire County Hospital, I loved the idea of moving into a more holistic role in my local community.

Primary Care Networks are unique in the way they build on existing primary care services and enable greater provision of proactive, personalised, coordinated and more integrated health and social care for people close to home.

The cancer care coordinator role is relatively new, extremely varied and is always evolving in response to the latest training and data from the Wessex Cancer Alliance and incredible support from our PCN clinical cancer lead Dr Marina Bartlett.

My working days are split between supporting the early cancer diagnosis and cancer care quality improvement work within our practices. Supporting newly diagnosed cancer patients with providing information, personalised care and most importantly, dedicated time to discuss areas most important to them.

One of our first projects was to implement a prostate health check which has ensured we have been able to contact our most high-risk groups to create easy access to PSA testing.

There is so much opportunity to make a positive difference to the community in this role and I feel very privileged to be a part of it.

Sarrah Waite
Cancer Care Coordinator

Contact PCaSO for Help, Support or just to Talk

When a man is diagnosed with prostate cancer his world stops. We know. We've been there. No matter how prepared you think you are when that word is mentioned you don't hear most of the rest of the interview. The doctor will probably give you choices of treatment or drugs and you have no idea of what they might involve or what side-effects there may or may not be. You probably don't even know the questions to ask.

PCaSO has a help line for men with Prostate Cancer, Call for a friendly chat on 07879 903407

PCaSO WhatsApp Groups

One of our core aims in PCaSO is support for members and their partners and so now in addition to our existing WhatsApp group we have launched two more groups.

One for those on "Active Surveillance" to enable them to talk to other men who are also on this treatment path.

The other is for the Partners of those who have prostate cancer, as they also need support and somewhere to discuss their particular experiences with other going through the same things.

To join any of our WhatsApp groups just WhatsApp a message to:

07879 903407 with the group you wish to join and your name or the name of the PCaSO member you are the partner of.

Remember you don't need to be alone in this

David Griffith's Story

Prostate cancer runs in my family.

My dad had it and lived with it until he was 86.

One of my brothers has had it for over twenty years with a variety of treatments and he is 82 now.

Another brother, now 85, was only diagnosed last year and has been successfully treated with Bicalutamide.

My brother Joss, seven years older than me, died of it fifteen years ago at 62.

It was therefore no surprise when I was diagnosed in 2013.

After Joss's diagnosis I started having six-monthly PSA tests. I was fortunate to have a sympathetic GP. My score had doubled to 4.5 in six months so my GP did some tests to rule out other causes and arranged for a further PSA test a month later.

By then it had risen to over five so after a negative digital rectal examination I was referred, on my request, to the Marsden Hospital in London.

The Marsden repeated all the tests and, when my PSA had risen further, arranged for me to have a biopsy. I found this the least pleasant aspect of my treatment to date, both the initial anaesthetic injection and the biopsy itself when 22 samples were taken.

This confirmed that I had local PCa with a Gleason score of 3+4. There followed several weeks of meetings to discuss treatment options.

I quickly narrowed this down to Brachytherapy or surgery although I was also offered SABR (Stereotactic Ablative Body Radiotherapy), a cutting-edge treatment then. I think it was being told that they used the same robot arm as in the old Citroën Picasso TV ads that put me off!

I had pretty much decided on some form of radiotherapy until I met my surgeon, Chris

Ogden, who instilled me with confidence that everything would be OK.

He had already performed over one thousand robotically assisted prostatectomies by then!

I left his office and decided to have surgery, which was scheduled for about six weeks later.

Those weeks were difficult, waiting and knowing that all the time my cancer could be spreading.

I was supported by my then wife and other members of my family, particularly my brother with PCa, which was invaluable.

“I had pretty much decided on some form of radiotherapy until I met my surgeon, Chris Ogden”

On the appointed day I was nervous but soon met the anaesthetist and the ever-reassuring Chris Ogden.

The surgery went well, and I left hospital the following day with a catheter in place and dressings over five small wounds in my abdomen.

Unfortunately, my recovery did not proceed as well as it might as I suffered a haemorrhage when one of the blood vessels that had been cauterised came away about ten days later. This resulted in a five-night stay in my local hospital.

All was then quiet with PSA tests reducing to annual until in January 2020 I woke up to the news that my PSA had risen to 8.29 - the highest it had ever been.

I was almost certain that my cancer had returned, and, after a PET/CT scan, this was confirmed.

I had metastases in lymph nodes and two vertebrae. To make things more complicated this was in March 2020 - right at the start of the first Covid lockdown.

I discussed treatment options with Dr Savage, my oncologist, and elected to start on Bicalutamide.

At the same time, I consulted a traditional Chinese medicine practitioner and a dietitian.

David Griffith's story continued from page 6

Whether this made any difference I will never know but it did give me a feeling of agency, that I was doing what I could.

My PSA soon went right down for about a year when it started rising again. I began three-monthly injections of ProStap 3, which I remain on to this day.

On its own this did not bring my PSA down as quickly as we hoped so it was supplemented with Abiraterone.

I took this daily, along with some supportive steroids. Things did not go to plan as a couple of months in I experienced a psychotic episode and had to stop taking it.

Ironically I was put on Abiraterone because the alternative, Enzalutamide, is considered more likely to cause mental health problems!

Six-months passed and my PSA started rising again and I started taking daily Enzalutamide which has reduced my PSA for almost two years.

At my most recent test it was 0.48.

The combination of these two drugs has unpleasant side effects - hot flushes, night sweats, loss of body hair and a complete loss of sexual urges.

On the plus side, I have never had a symptom of my cancer itself, the metastases have not spread, and I have been endlessly supported by the NHS, Macmillan, my friends and family and of course PCaSO!

Could MRI Scans Be Used to Screen for Prostate Cancer?

MRI scans could be used in prostate cancer screening according to results from the **ReIMAGINE** study, which found that MRI scans could potentially even detect prostate cancer that wouldn't be picked up by a PSA test.

As part of the study, 303 men aged between 50 and 75 were given both an MRI and a PSA test at University College Hospital in London. Forty-eight men received a positive MRI and, following further assessment, it was found that 25 of those had clinically significant prostate cancer.

More than half of the patients diagnosed through MRI had PSA test results considered to be at normal levels and so their cancer may have been missed otherwise.

"Our results give an early indication that MRI could offer a more reliable method of detecting potentially serious cancers early, with the added benefit that less than one per cent of participants were 'over-diagnosed' with low-risk disease," explained Professor Caroline Moore, chief investigator of the study.

Larger studies are still needed to confirm the results, but this could have the potential to reduce prostate cancer deaths and over-treatment.

New PCaSO WhatsApp Groups

As mentioned on page 5 in addition to our existing WhatsApp group we have launched two more groups.

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The other is for the Partners of those who have prostate cancer, as they also need support and somewhere to discuss their particular experiences.

Both of these groups are run by those who have had or are going through these experiences.

To join either of these groups (or our existing general group) just WhatsApp a message to:

07879 903407 with the group you wish to join and your name or the name of the PCaSO member you are the partner of.

Remember you don't need to be alone in this

Ian Hallam's Family Journey with Prostate Cancer

This is our family journey of prostate cancer including my parents and six siblings, four of whom have experienced prostate cancer, one who had bladder cancer and the last who just has an enlarged prostate.

Ian (Me)

In 2005 at the age of 51 due to family circumstances I requested a PSA test from my GP who refused to do one saying they were unreliable and required an invasive digital rectal examination (DRE) foolishly I trusted her.

A few months later PCaSO were invited to Airbus where I worked at the time to do an educational talk on prostate cancer. Following that presentation where it had been impressed upon me my right to have the test due to my family history, I again approached my GP.

This time she gave me the blood test and did the DRE herself, at the time she said my prostate was enlarged and lumpy on one side. When the PSA result came back it was 2.9 which she said was normal for my age group and as I had no further symptoms she again said I needed no further treatment or monitoring.

In July of 2022 I had another PSA test due to frequency of urination the result of that PSA test was 14.6. I was then referred to a Consultant Urologist under my private health insurance, my Consultant repeated the DRE and said I required an MRI.

After the MRI I was sent for biopsies which confirmed I had prostate cancer which at the time was given a Gleason score of 3+4. I was offered radiotherapy or surgery as the possible treatment options.

I chose surgery as the most likely option to be rid of the disease, I had a keyhole robot assisted Prostatectomy in October 2022.

Following the surgery my prostate was sent for pathology where the Gleason score was upgraded to 4+3, I was also told 75% of the prostate was diseased or was showing pre-cancerous changes.

My PSA was checked two months after surgery when it was reported as 0.018 it was repeated 3 months later when it was 0.03. I was told the slight rise could be accounted for in tolerances of the equipment used to work out the PSA value and was subsequently

referred back to the NHS for future monitoring.

In May 2024 my latest NHS PSA test showed a rise from 0.1 to 0.2 as my NHS hospital only reports results to one decimal place. I was referred for a PSMA PET scan which I had in June the result did not detect any disease so I was referred to Oncology for salvage radiotherapy to my prostate bed. In August I was seen by an oncologist and told I would be prescribed hormone treatment for 2 years with 20 sessions of radiotherapy to the prostate bed.

At the time of writing I am about to start my final week of radiotherapy and have started taking Bicalutamide tablets which I will be taking till August 2026.

Genetics

Mervyn had a genetic blood test in XXXX the results showed no defective genes, Andrew and I have both filled in genetic questionnaires but have heard nothing since filling them in.

My Parents

Mother

My mother never experienced cancer in her lifetime nor did any of her siblings or parents as far as we know.

Father

In February 2000 my father who was 80 at the time was admitted to hospital with suspected fluid on his lung.

When it could not be found, further X-Rays and tests showed the shadow on his lung was not fluid but in fact incurable cancer.

This was thought to have metastasised from undiagnosed prostate cancer. He was admitted to a hospice and died shortly thereafter.

Ian Hallam's Family Journey with Prostate Cancer - Continued

My Siblings

Michael

In August 2005 Michael who was at the time 61 notified myself and other siblings that he had requested a PSA test which had come back high. After further investigation prostate cancer had been diagnosed and he had been given the choice of surgery or radiotherapy. He chose surgery as the best chance to be rid of the cancer and had his operation in Reading shortly thereafter. At the time it was open surgery as keyhole surgery was not being used at that time.

Following a successful surgery and recovery his PSA level has been routinely monitored, now he has one annually and so far is free of any reoccurrence his PSA level remaining at or below 0.01 for 19 years now.

Mervyn

In 2015 Mervyn who was 69 at the time was diagnosed with an enlarged prostate and prescribed Tamsulosin with annual PSA checks.

In 2020 Mervyn moved to Leicester where he continued to be monitored by his local hospital who also added Finasteride to his treatment plan.

In 2023 Mervyn's PSA test indicated a rise and he was sent for MRI followed by biopsies which confirmed he had prostate cancer. He was told he would be put on a course of hormone injections to shrink the tumour to be followed by radiotherapy to kill the cancer. He has been on the hormone injections for almost a year and has only just started his radiotherapy treatment in September 2024 which is still ongoing at the time of writing this article.

Peter

Unable to urinate Peter was admitted to hospital and had a TURP (Transurethral Resection of the Prostate) operation to relieve the pressure on his urethra to allow urine flow, he was told that a few cancer cells had been detected. He was monitored 3 monthly for a year then 6 monthly and finally annually the last we heard from him he was still clear.

Phillip

In 2016 at the age of 69 Phillip was diagnosed with an enlarged prostate and prescribed Finasteride with annual PSA checks.

His treatment has remained the same to the present date in 2024, at his latest PSA test he

was told it was slightly elevated but within the range for his age group.

Billy

In November 2023 Billy who was 61 at the time finally managed to see his GP after 3 or 4 weeks of having been passing blood in his urine. He was sent for tests which showed he had bladder cancer with the tumour on the inner wall of his bladder.

He had surgery to remove the tumour and the surgery appears to have been successful so far.

Andrew

In September 2022 due to my diagnosis, Andrew who was at the time 57, approached his GP for a PSA test.

The result was slightly elevated at 2.6 so he was referred for an MRI which came back clear, his PSA was then monitored every 3 months.

In October 2023 following a rise in his PSA results, Andrew had an MRI followed by biopsies which confirmed he had prostate cancer with a Gleason score of 7.

He was offered surgery or radiotherapy but as it was close to Christmas he was told to think it over and in the new year contact his nominated contact to give the hospital his decision.

In early February of 2024 Andrew finally managed to get in touch with his appointed hospital contact and after telling them he wished to have surgery to remove his prostate, was informed that they would need to carry out a second MRI to make sure nothing had changed.

The results showed the cancer had spread to his seminal vesicles so surgery was no longer an option.

At the end of April he received his CT & bone scan with the results being in May both scans were clear. He was given the option of surgery (although nerve sparing surgery was no longer possible) or radiotherapy, he was told to go home and phone his CSN when he had reached his decision.

At the end of June he was finally able to contact his CSN and told her he wanted the radiotherapy, he was then referred to oncology who prescribed 3 monthly hormone injections which started on 1st July and a course of Radiotherapy to start in October.

Hampshire Branch News

Waterlooville Members meeting 2024

The meeting took place on the 3rd of December 2024 at our regular venue, in Waterlooville: Church of the Sacred Heart, London Road, Waterlooville, PO7 7SR.

This was a very well attended meeting and it was really good to see so many members turn out for the meeting.

Paul Bowler introduced the meeting and announced that he would be taking over the Hampshire chair for PCaSO from Peter Weir who would now be concentrating on running the PSA Testing Events.

Everyone thanked Peter for all the hard work he had put in over the years as Chair building up the Hampshire branch to where it is now.

Our speaker for this meeting was Jayne Willett, who is a Senior Care coordinator in the Urology Department of the Queen Alexandra Hospital, Portsmouth.

Jane and her colleague Nicola gave us an interesting talk on the work of the Urology Dept including a talk on **My Medical Record**. A new website that has been setup to allow patients to access online their health records. Then we had open questions for them about all things Urology.

This was followed by a general chat about PCaSO and Prostate Cancer.

The 2nd March for Men - Walk with Kev

The second Walk for Men was held in Petersfield on 15th September. It is held in memory of Kevin Birkett who died from Prostate Cancer and is run by his wife and friends.

There were over 200 participants at the well attended event and the total raised was about £14,000 which will be split between PCaSO and Prostate Cancer UK.

PCaSO participated and had a gazebo with several members handing out literature and talking to the public.



Several PCaSO members took part in the walk including my terrier Molly who raised £1000 and completed the 10k walk without trouble.



She was given her own medal and is the first dog to be interviewed on Petersfield Shine Radio even though I had to do most of the talking!

A very enjoyable event and a great fund raiser for Prostate charities.

The next walk is on **Sunday 14th September 2025**, with PCaSO holding a **PSA Testing event** in Petersfield on **Saturday 13th September 2025**.

Put the dates in your diaries

Tim Bonner

Nuffield Health Exercise Sessions



These are free instructor led exercise sessions tailored to our particular needs and are run by Leah Ilsley from Nuffield Health and are now at a new venue.

The new venue is:
Nuffield Health,
Portsmouth Fitness & Wellbeing Gym,
Alexandra Park,
Alex Way,
Northern Parade,
Portsmouth,
PO2 9PB

They are on Thursday Afternoons starting at 14:30 until 15:30, followed by Coffee and a Chat in the Nuffield Cafe.

In addition to this both members and their partners also have free use of all the facilities of the Gym including the Pool for that day.

This is made possible by funding from PCaSO and the assistance of Leah Ilsley from Nuffield Health in agreeing a new arrangement allowing use of the Nuffield Gym facilities.

I personally go to them and thoroughly enjoy them and would like to say a big THANK YOU to PCaSO and Leah from Nuffield Health for providing and running them.

PCaSO and Nuffield have put all this in place for PCaSO members and now need members to make good use of the facilities offered.

So if you are able to and want to get a bit fitter, meet and chat to fellow members and have free use of all these facilities for the day then please come along.

Just WhatsApp Leah using the link below to join the group and take part or send a WhatsApp to 07787 185791 and Leah will add you to the group.

[Nuffield WhatsApp Link](#)

Donations

Richard Kirkman Trust

Once again as they did last year the Richard Kirkman trust have donated £1000 to PCaSO and we would like to thank them very much for this.

Swanwick Lions Cheque Presentation

Following yet another successful PSA test event Swanwick Lions Club presented PCaSO with a cheque for £2,000.



This was presented by members of the Swanwick branch of the Lions and received by members of PCaSO.

The ceremony again took place at the Swanwick Green Community Centre, on a PSA testing day. We really appreciate all the help and support that the Lions Clubs International give us in running the PSA testing events.

King John's Morris Men

Just as they did last year the King John's Morris Men will be donating all the proceeds of their Christmas performances to PCaSO.

Peter Weir and I will be going to one of their performances to receive a cheque for the money raised. Last year they raised £1,500 for us and we are very grateful to them for making us their charity again this year.

Parker Foundation awards PCaSO \$7,333

Parker Hannafin each year award a Charitable grant amount to each Branch to award to local charities. Thanks to the staff at Parker Hannafin Fareham branch, PCaSO was put forward for part of the grant from the Parker Foundation.

Peter Weir filled in a proposal document and we were successful and were awarded \$7,333 (Approx. £6,000) on condition it was used as per the proposal. So we would like to thank the Parker Foundation and all those that helped to achieve the award.

Sussex Branch News

Findon Valley 5K Trail Run

Brian Holden (chair) and Lance Allen (secretary) gave a talk on PCaSO and prostate cancer to Findon Valley Residents' Association at the local Free Church on 9th November, including two PCaSO short videos.

With the recent media publicity around Sir Chris Hoy's diagnosis, this was timely.

We were delighted to be presented with a donation of £1,000 by Lorraine Taylor, chair of the Residents' Association, as PCaSO were the nominated charity for the inaugural Findon Valley 5K (3 mile) Trail Run in September.



Lance had recently retired as chair of the Residents' Association and said he

felt very honoured at this kind gesture in support of PCaSO, and also at being given entry Number 1 in the actual trail race (although he finished around 60th!).

Sussex Cancer Conference



The inaugural Sussex Cancer Conference took place in Worthing on Saturday 19th October, and we made sure that PCaSO was there! Lance Allen and Colin Woodman ran our stand, talking with many people and providing free copies of our Healthy Living and Knowledge Empowers books. A wide range of other support groups and complementary providers were at the event, and a range of talks and workshops were presented. Hopefully this will become an annual event, and more widely known, to help benefit a greater number of citizens.

Volunteer Vacancies -

Sussex PSA Testing Co-ordinator

As you know we organise up to a dozen PSA Testing events across the county each year, generally split between Spring and Autumn, and usually on Saturdays. Many readers of this Newsletter will have been introduced to PCaSO through a PSA Testing session and subsequent PCa early diagnosis.

Roger Bacon who has been planning and organising our PSA days for many years will be retiring from the role during 2025.

This creates an opportunity for volunteers to work alongside Roger at events already planned for early 2025, to 'learn the ropes' and organise future events.

Key features of the role include working with the local venue organisers such as the Lions or Masons, to ensure the site is suitable for the event and that local advertising is arranged by them. Liaising with the phlebotomists and PCaSO's team of over 15 event volunteers to ensure we have enough cover for the events. Also ensuring that PCaSO's equipment is available at each event.

At PCaSO we are proud of our work on PSA testing and have helped many men to obtain an early diagnosis. The events can be busy but enjoyable for our friendly and inclusive team of volunteers.



If you'd like to discuss the role above please contact Roger at westernsussex@pcaso.org or on 01903 775783.

Eastern Sussex Group

Drop in Sessions

We hold regular sessions, all members and partners are welcome to attend, and we welcome non-members to drop in to discuss their Prostate Cancer issues, and hopefully join PCaSO.

The venue for EasternSussex branch is:
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 will be held in the Community Room, at the back of the store, between 10:30 and 12:00 and refreshments are provided.

Future drop-in dates are as follows:

All dates 2025, February 4th, April 1st, June 3rd, August 5th, October 7th, December 2nd

Brighton Group

Drop in Sessions

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

Other News

Early in 2025 We are working towards a large campaign to mark Prostate Cancer Awareness Month in the Brighton area with another charity ACT, further details to follow.

In conjunction with MacMillan, we have been invited to take part in testing a new app for people with incurable illness. This is part of a wider project about using technology to empower those people.

The app will be a portal that provides access to all the different services people might use, including GP, oncologist, radio/chemo-therapy, pharmacist, physiotherapy, mental wellbeing and palliative care. It is intended to simplify access to these services.

If you'd like to participate and have a smartphone please contact
David Griffiths by email

We are seeking to find out if the app can also be accessed via a laptop or tablet.

AGM Minutes 2024

Minutes of the PCaSO AGM

Held on Zoom on Thursday 12th September 2024 at 7pm.

The meeting was quorate throughout (20 members are required, 35 were present).

1) Welcome & Introduction

Brian Holden, Chair, welcomed the attendees and noted it was good to see some of the faces behind WhatsApp group participants. Apologies had been received from Roger Bacon, Cliff Carter, Debbie Hatfield, Allan Higgin, John Keane, Rob Stanley, Peter Weir and Robin Weldon. One proxy form was received.

2) Approval of 2023 AGM Minutes

The minutes from the previous AGM 5 October 2023 were approved as a true record. Proposed by Barry Taylor, seconded by Geoff Williams. No abstentions or votes against.

3) Chair's Report

Brian Holden's (BH) report had been circulated with the agenda and included the three county branch reports. See Appendix 1 below.

BH stated that a new WhatsApp group was being set up for the partners of men living with prostate cancer, run by Eastern Sussex Group member Lorna Earl who is a MacMillan Counselling Service Lead. Partners can often want to talk to others in a similar situation, so do make your partners aware of this, and contact Brian to be added to the new WhatsApp group.

BH responded to a question about PSA testing events, where there was none planned within 30 minutes of one member's home. Another support group holds testing events in that general area but both they and PCaSO are subject to volunteer availability for events that are quite time-consuming to plan and conduct. Future PSA events in Sussex will be subject to volunteers coming forward for planning and logistics, when Roger Bacon retires.

The Report was approved with no abstentions or votes against.

4) Approval of Accounts for year to 31 March 2024

Group Treasurer Kevin Simons (KS) had provided the Consolidated Accounts and Treasurer's Report for circulation with the agenda. The accounts had received independent verification, as required by the Charity Commission.

KS noted that donations, including corporate donations, had significantly exceeded expenditure

In the year, as reflected in the increase in funds held. Expenditure related primarily to PSA testing events, plus publication printing and IT costs. KS highlighted the responsibility of using charity funds wisely, and that the trustees had confirmed that the funds were adequate for PCaSO to pursue its charitable objectives.

BH stated that our volunteers work hard at PSA events on receiving donations, with Gift Aid where appropriate. PSA costs are however likely to increase into next year.

The Accounts were approved, with one proxy abstention and no votes against.

5. Election/ Re-election of PCaSO Trustees.

All Trustees are standing down. Those offering themselves for re-election are Lance Allen, Roger Bacon, Brian Holden, Kevin Simons and Peter Weir. Those offering themselves for a first term as trustee are Tim Bonner, John Keane, Rob Stanley and Mike Tompsett.

The elections were approved *en bloc* with no abstentions or votes against.

The roles of the elected Trustees will be determined by Executive Committee meeting.

BH thanked the retiring Dorset trustees Allan Higgin, Derek Pilling and Barry Taylor for all their hard work and dedication over many years and wished them well into the future.

6. The need for new volunteers.

Lance Allen, Secretary (LA) highlighted that PCaSO is run by volunteers and we do have specific need for new team members, including new trustees for our Dorset branch, and individuals to take on the planning and logistics for PSA testing events in Sussex. LA would be pleased to discuss volunteering roles with interested persons, without commitment (secretary@pcaso.org).

7) Any Questions

The geographic distance of West Dorset was raised, where Weymouth has a local 'New-Man Prostate Support Group' with some 100 members, PSA test events locally and meetings with invited speakers. They could support PSA testing around the county.

The zoom AGM closed at 7.35pm and was followed by guest speaker Iain Turnbull from the "Our Future Health" project, which is building a large database of citizens and health outcomes, with the three objectives of 1) Better Prevention, 2) Earlier diagnosis/detection and 3) Earlier Intervention. For further details of this exciting project, which is being run in partnership with the NHS, see

<https://ourfuturehealth.org.uk>

Dr. Turnbull's presentation was recorded and is available as a video on PCaSO's website via this link <https://pcaso.org/videos-2/>

AGM Minutes 2024 - Continued

Appendix 1 – Chair’s Report and Branch Reports (as circulated with the agenda on 29th August 2024)

Good evening, and welcome to our AGM.

This has been a very active year for PCaSO, with several changes including four new Trustees. A big thank you to all of our amazing volunteers who keep PCaSO running smoothly - as I have mentioned previously, there are over fifty of us.

Our membership numbers have been increasing, and many have joined the WhatsApp group of over sixty members, all sharing their experiences and helping each other. Subjects range from the many treatment options to side effects. The WhatsApp group is open to all members who were born with a prostate. Since March, we now also have a second WhatsApp group, formed specifically for those members who are on Active Surveillance, which currently has half a dozen members. Do let us know if you are also on Active Surveillance, not having received treatment for prostate cancer, and would like to join this group.

PSA (prostate specific antigen) testing remains a key activity for PCaSO, and is detailed in our county branch reports below. At the time of writing the grand total number of tests conducted by PCaSO stands at 37,651, a figure we are particularly proud of.

Our three long-serving Dorset trustees, Allan Higgin, Barry Taylor and Derek Pilling are standing down as trustees and from the Executive Committee, for well-earned retirement from their volunteer roles. I thank them for all their hard work over the years and wish them well into the future. We are placing PCaSO’s Dorset branch into ‘dormancy’ until new volunteers can be found to run the group and its local events. Details are in the Dorset report below.

After many years of dedicated work Cliff, our IT Administrator, has asked that we share the workload that he has been carrying out. At the request of the Executive Committee we have set up a small group to review our website and its management, using an outside company. This will have a one-off cost of several thousand pounds, and ongoing maintenance costs. Similarly, our new Membership Secretary and Trustee, Mike Tompsett, is reviewing a new membership administration system, which will integrate the collected data more efficiently and reduce time needed to carry out the task. At all times we are very conscious of GDPR and protecting membership personal data.

Substantial donations have been made to our Charity, as mentioned in the group reports below, and the monies are being wisely used by the groups.

Gift Aid received on donations contributes over £10,000 each year. I’m glad that Tim Bonner, a new Trustee and Executive Committee member, has taken on the important role of Gift Aid Coordinator.

During the year, Roger Bacon completed the review, together with our medical advisors, of our publication "Knowledge Empowers". This is now available on our website, and hard copies are distributed when required. Many copies have been posted to other support groups around the country (paid for by them, of course!).

Tony Ball is currently revising our "Healthy Living" booklet, for publication later this year. Several thousands of the first edition have been handed out to men or their partners at our PSA testing days.

Our latest, online version of "Updates" magazine was compiled and published by Hampshire member Paul Bowler. This was well received, and the next edition is in the course of preparation. Contributions of your stories and experiences would be most welcome.

During the autumn 2023 and spring we had several video presentations on various relevant subjects, some of which have been added to our website, and others are awaiting editing and uploading.

This year Tackle (a National umbrella organisation for local groups) decided, with no notice to us, to stop their national helpline. This has not hugely affected us, since we already had in place our own PCaSO helpline on 07879 903407. However, we are now in the process of updating the PCaSO banners used at our PSA testing and other events with our own helpline number, and taking the opportunity to have a general update. Similarly, our leaflets will be updated when new stock is needed.

Brian Holden
Chair

AGM Minutes 2024 - Continued

Dorset Branch Annual Report 2024 (Allan Higgin)

It is with sadness that I have to report that since the COVID lockdown, there has been no enthusiasm to revive the Dorset Branch. No one has come forward to take on the major management roles of Chairman, Treasurer and Secretary, and no member has requested the revival of regular meetings or any other activity. The decision has therefore been made to place the Branch into a dormant state; please see the proposed process below. As proposed, this dormant state would last for a period of four years, unless the group again becomes active.

Allan Higgin
Interim Chair, Dorset Branch

Process for placing PCaSO Dorset branch into dormant status, as agreed by Trustees, pending the identification of new local volunteers who could build up a new active Dorset group:

1. *Executive Committee Chair, Secretary and Treasurer to hold the equivalent Dorset roles, in dormancy.*
2. *Dorset bank account at HSBC to be closed and the funds held for benefit of Dorset men, ring-fenced within the Executive account, although sharing pro-rata with other counties, any relevant, ongoing PCaSO central costs.*
3. *Any donations received during the period of dormancy that are annotated as being for PCaSO Dorset will be applied to the ring-fenced fund.*
4. *An advisory email to go to all Dorset members (or by post if no email address held). NB this is pending further discussion with Membership Secretary regarding Dorset actual member numbers.*
5. *There is no requirement for a Dorset members' meeting, as the branch is not being woundup.*
6. *If no new Dorset Branch activity commences within four years of the start of the dormancy, any residual funds will be applied for the general charitable purposes of PCaSO.*
7. *If an active new Dorset group is formed, that group will be invited to provide up to three trustees, as per PCaSO rules.*
8. *An active new Dorset group will, when formed, adopt and adhere to PCaSO's charitable objectives and rules.*
9. *An active new Dorset group will, when formed, be able to open a Branch bank account on the same basis as the other county groups. Any ring-fenced funds will be transferred from the Executive account to the new branch account.*
10. *During the period of dormancy, Dorset members will remain as full members of PCaSO and be able to*

take part in general meetings, Zoom talks, WhatsApp etc, and receive enewsletters, "Updates" etc. Any new members of PCaSO resident in Dorset will be regarded as Dorset members unless they wish otherwise.

11. This dormancy process is written in good faith and is 'original' in having no practical precedent.

Hampshire Branch Annual Report 2024 (Peter Weir)

We have held eight PSA Testing Events so far, since last AGM:

- Cosham 9th Sept 2023 (269 men tested)
- Eastleigh 21st Oct 2023 (309)
- Havant 18th Nov 2023 (366)
- Hayling Island Feb 10th 2024 (444)
- Portsmouth FC Mar 17th 2024 (384)
- Gosport Apr 26th 2024 (500)
- Comserv Havant, 21st May 2024 (40)
- Fareham, 15th Jun 2024 (449)

2761 men tested, of which 98 were 'amber' (elevated PSA level), and 157 'red' (high PSA level).

Future Events:

- Alton, 21st Sep 2024
- Petersfield, 12th Oct 2024
- Swanwick, 26th Oct 2024
- Basingstoke, 16th Nov 2024
- Comserv Havant Dec 2024 (TBA)

Follow-up emails have been sent to all men found to have a raised PSA level at our testing events. An increase in the Graham Fulford Charitable Trust administration fees and laboratory costs, meant an increase of approx £3 per man tested. However, donations from attendees and partner charities were still in excess of costs. A donation of over 3,000 blood collection devices was received from Greiner Bio-One, which offset some of the above increased costs.

In Sept 2023, a "Walk with Men with Kev" event in Petersfield took place in memory of Kevin Birkitt, who died earlier that year. The walk was organised by his family and Hampshire Media Group. The event was a great success, over 300 walkers raising over £10,000, which was split between PCaSO and PCUK. The PCaSO side of the event was organised by Tim Bonner, with a PCaSO display stand present in the Town Square. The event will be repeated on Sunday, 15th Sept 2024 with, hopefully, a bigger turnout.

We continue with face-to-face meetings at Otterbourne and Waterlooville, including three talks - on the BK ultrasound equipment which Hampshire Branch are to purchase for Winchester Hospital; a talk on exercise and health from Nuffield Health; and Prostate Cancer Investigations and Treatment at Southampton Hospitals.

John Keane is currently negotiating supermarket collections with Asda in the area. Collections have been carried out at Havant ASDA Sat December 3rd, Fareham Asda 21st June, Portsmouth Asda August 16th, Eastleigh Asda August 23rd. Asda are keen to help PCaSO in awareness, fundraising and PSA testing.

Purchase of an ultrasound scanning machine specifically for use in the diagnosis and treatment of prostate cancer for the Royal Hampshire Hospital, Winchester, is now ordered and awaiting delivery in August. This will allow men to be treated and investigated in Winchester, and not have to travel to Basingstoke.

Nuffield Health Portsmouth continue to offer keep fit classes for PCaSO, having now moved from Titchfield to Fareham, with a regular attendance of nine or ten men.

Roger Smith has stepped down as Hampshire Branch Secretary, and Peter Strickland has taken over the role.

Apart from PSA partner charities, donations have been received from King John's Morris Men of Southampton, The Charitable Baker UK, Comserv Ltd, The Brewers Golf Club, and the Richard Kirkman Trust.

Peter Weir,
Chair, Hampshire Branch

Sussex Branch Annual Report 2024

We are very fortunate in Sussex group to have a proactive group of volunteers that ensure its smooth running. As their Chairman, I am encouraged by their commitment to help others with their prostate problems.

After 20 years at the helm of our Eastbourne group, Debbie Hatfield retired, along with her longterm colleague, Christina Cutting. The Trustees thanked them for their invaluable contribution over many years, and wished them well for the future. Our new team in the re-named Eastern Sussex Group - Lorna, Lisa and Clive - have so far held two presentations, with two more planned for this year.

Face-to-face drop-in sessions regularly take place in Eastern Sussex, Central Sussex, Western Sussex and Brighton.

Rob Stanley produces a monthly newsletter for Sussex members, which is also sent to various clinicians and contacts within the local NHS. Gregg McMellon regularly updates our Facebook page with local events and activities.

PSA testing continues, and two new venues were successfully tried this year, Tonbridge in Kent and Bexhill, East Sussex.

We are exploring ways of continuing our PSA testing events after our current organiser Roger Bacon steps down from the role next year.

Our Sussex group have held four successful events in Spring 2024, testing 477 men at Uckfield, 465 at Billingshurst, 818 at Tonbridge (a very busy day!) and 373 at Bexhill. Of that total 2,133 men, 40 had elevated levels and 91 had high levels of the prostate specific antigen in their blood.

Our next round of PSA testing events in Sussex will begin with Worthing on 14 September, East Grinstead on 19 October, Burgess Hill on 16 November and Peacehaven on 30 November 2024.

Two substantial donations were gratefully received - £22,500 from a golf society called The Breeze Club, and £5,000 from the staff at Tclarke Contacting Ltd, a Breeze Club affiliate. These have been ring-fenced in the Sussex accounts for the sole use of PSA testing.

Brian Holden,
Chair Sussex Branch, and Executive Committee

Robert Talbert's Story



My original 2016 PSA reading pre-prostatectomy was 4.9, Gleason score was 4 + 4, T3a (stage 4 cancer).

I also had an ileostomy bag (reversed after 6 months), as I had ulcerative colitis, and therefore could not have radiotherapy.

In 2018 I started hormone therapy, PSA level 3.99 reducing to 0.08 within 2 years.

Aug-Nov 2023 - 6 x 3 weekly chemos Docetaxel, not much hair loss.

Feb-July 2024 - 6 x3 weekly chemos Cabazitaxel, no hair loss and hair growing this time.

Current chemo reduced PSA from 15.6 in Feb 2024 to 3.81 September 2024, with lymph nodes reducing too.

I'm 71 years old, and I'm married with three adult daughters and two grandchildren. I have several close friends and some good acquaintances. I play tennis, table tennis and golf and have just rejoined the gym.

In 1974 I travelled overland through Asia, reaching Nepal and India. I was away for over a year, and I found the whole experience exciting and character-building, meeting so many diverse people and situations.

In 1980, I went to a Kibbutz, being at a crossroads in my life, working in the City of

London in finance. Whilst there, I visited Bethlehem, where I bought the beautiful, unique, hand-carved mother-of-pearl jewellery as presents. Thereafter, I started importing it for the next three years, after which diversifying to importing from Asia. The business lasted 40 years, until 2020 when Covid struck, the manager took over, and I retired aged 67.

Sadly, my brother Anthony died eleven years ago with pancreatic cancer, and I was fortunate to be with him when he died.

Eight years ago, I noticed that I had started to pee in the night a couple of times. Literally, within three days, I had a scan, and they saw that my prostate had a lot of cancer in it that needed to be taken out immediately. Three months prior, I had a hernia removed, and there was still a mesh there to help it heal. When they did the prostatectomy, the risk was that they might perforate my bowel because of the mesh, and sadly that's exactly what happened.

“Eight years ago, I noticed that I had started to pee in the night a couple of times”

I was on life support, and they put in an ileostomy bag for six months, happily then reversed. I was in the

hospital for six weeks, and then I lived a normal life until the cancer returned a few years ago. Then I was on a medication called Enzalutamide, which brought the PSA levels down.

When I got the news, I felt a fear, a dread, that my life was going to end sooner rather than later. My life was on hold until I saw the efficacy of the drugs and that they were doing what they needed to do. Once that happened, I let go of the dread. I trusted that something bad could happen in the future, but that I was okay right now in the moment, remembering my mother saying, “don't worry about things till they happen”.

My family were worried, especially my wife. Throughout the last eight years, they've seen

the changes in how I look and how I am day-to-day. That can be difficult for them. I have regular CT scans every three months, and that can also cause anxiety for all of us. They've got different ways of dealing with things.

I'm very proactive at utilising what support is on offer, and that's what led me to Penny Brohn UK. I found it online, as it's near where my sister lives. I rang them up, and they sent me all the info about how I could participate. I thought, "Right, I don't know if it's going to work, but if it makes me feel better, that's important to me." I promptly booked onto the residential retreat that took place earlier this year, February 2024, and I'm planning to go to the Men's Day in October.

There were twelve people on the retreat, including myself, and it was eye-opening. What I got from the retreat was a connection with other people and a real sense of camaraderie. I felt more grounded with where I am in my life health-wise. I gained a better perspective of my situation, and I left feeling reassured about my life.

One of the things we did on the last day was to share a piece of music and to say what it meant to us and why. When my twin brother died ten years ago from pancreatic cancer, this song by Rihanna called "Diamonds" kept playing on the radio. It would make me burst into tears. I played this track and, at one point, the lady next to me held my hand for what felt like twenty seconds. Eight of the ten people were holding handkerchiefs afterwards. It's good to share emotion, especially us men. We don't take care of our emotions enough.

That place, I felt so much from it. It gave me hope. I felt gifted by the universe, which sounds lah-di-dah, but I just felt looked after. I felt like I was letting go of a cloak of armour

that we have, to protect ourselves in this fear of death. I can now say that I feel more positive, more able to consolidate and run my life in a better, calmer and more proactive way.

At the end, all of us felt like a family. There was a connection. When I came back home, we kept in touch with each other via WhatsApp. Since I've been there, I feel like I'm being guided and looked after.

I've subsequently taken up services that the charity offers, like the lymphoedema support group, mindfulness classes, healthy eating advice, and treatment support programme. I also had a one-to-one with Dr Catherine

Zollman, who was there on the retreat.

Everyone who has, or is affected by cancer, has their own way of dealing with it, but I feel strongly that it doesn't define who we are. We all need purpose in our lives, and finding out ways to enrich our lives through others' experiences and healing, which is at the core of the ethos of Penny Brohn, has helped me in so many ways.

Penny Brohn UK is making a difference to people's lives, certainly mine, and helps to put one's situation into perspective.

I'm so grateful to have found and explored what Penny Brohn have to offer in a such a caring way.

Note:

PCaSO has previously worked with Penny Brohn UK.

See <https://pennybrohn.org.uk> for information on their excellent cancer wellbeing work.

"I'm very proactive at utilising what support is on offer, and that's what led me to Penny Brohn UK"

Peter Barton's Story

This is an article first published 10 years ago in Prostate Cancer UK.

Sorry its long but if you are incontinent you might find it helpful

As a fit farmer aged 65 I could not have foreseen that chasing Grand Children on a Mountain Bike could have resulted in a calamitous sequence of events that lead first to emergency admission to A&E and thence to Surgery for Prostate Cancer. The Prostate is located in close proximity to the saddle and this had damaged the tissue causing and obstruction. Fortunately my Urologist undertook further tests to determine its cause and a PSA of 8 ng/ml lead to a Biopsy showing a high risk of Malignancy.

I was also one of the 20% of men who have Surgery for both Benign and Malignant Prostate Cancer to be left with "Incontinence"

This came as a great shock unsurprisingly and we examined all options for treatment and opted for Robotic Assisted Surgery at The Royal Marsden which was still then in its early development in the UK.

The Surgery went well and I was out of hospital in 2 days but had to wear a Catheter for 2 weeks which is distressing for most patients.

I was also one of the 20% of men who have Surgery for both Benign and Malignant Prostate Cancer to be left with "Incontinence"

At first it was horrific, for the first 2 months it required 2-3 Tena Size 2 Pads however this reduced to just one later unless trying to get back on The Bike which proved hopeless. A radical new saddle specially designed for Prostate sufferers however proved most valuable.

My excellent Urologist confirmed the pathology and said that we had just got the tumour before it had broken out of the Prostate.

My family were much relieved as he confirmed it was unlikely to return.

For the next 9 years life was good though my Incontinence slowly worsened to the point that I sought the advice of a Specialist in Male and Female Incontinence and one taking part in The Master Trial.

The MASTER trial is the first randomised controlled trial comparing the artificial urinary sphincter and the male sling – both treatments for urinary incontinence in men who have had prostate Surgery.

We discussed the two options at great length and as a Private Patient I was free to choose which option was suitable for me.

He was careful to compare the known risks of the AUS against the less known long term success of The Advance XP Male Sling procedure.

After painstaking online research, I opted for the Sling and underwent Surgery and had a Spinal Block instead of normal Anaesthetic which led to a swift recovery.

I was about to leave the next morning but found after the removal of the overnight Catheter that I could not urinate. I was one of the 10% of Patients who had this problem due to extreme irritation of the surgery site!

I had very little pain just discomfort and after a week the Catheter was removed and to my great joy I was fully continent and able, with some difficulty to urinate.

The MASTER trial is the first randomised controlled trial comparing the artificial urinary sphincter and the male sling

This difficulty persisted for nearly a month but after 9 weeks I was completely continent using no protection and able to pass urine without difficulty.

A word of caution, this is still early days and I am conscious that not all Sling Procedures are so successful and that about 50% of men may require a Pad if only for protection when coughing or laughing.

This was written for Prostate Cancer UK nearly 10 years ago and I am still happy with my decision.

Peter Barton

PCaSO Testing Results for 2024

RECORD NUMBER OF MEN TESTED IN 2024

The Sussex and Hampshire Branches of PCaSO organised 9,014 PSA tests at 18 different locations over the 2 counties during 2024, a record number of men tested during the year.

393 men were found to have a red result requiring further investigation and 224 with an amber result who need a further follow up.

Since we started PSA testing in 2011, we have now arranged over 42,500 PSA tests in Hampshire, Sussex and Dorset.

2024 PCaSO PSA results										
2024		Total	Green	%	Amber	%	Red	%	A+R %	Rejects
Sussex										
Uckfield	3/11/23	477	452	94.8	8	1.7	17	3.6	5.2	
Billingshurst	4/13/24	465	436	93.8	9	1.9	20	4.3	6.2	
Tonbridge	5/18/24	816	771	94.5	10	1.2	34	4.2	5.4	1
Bexhill-On-Sea	6/8/24	373	340	91.2	13	3.5	20	5.4	8.8	1
Worthing	9/14/24	750	704	93.9	19	2.5	27	3.6	6.1	
Copthorne	9/28/24	141	125	88.7	2	1.4	4	2.8	4.3	
East Grinstead	10/19/24	1000	952	95.2	21	2.1	27	2.7	4.8	
Burgess Hill	11/16/24	1136	1050	92.4	35	3.1	51	4.5	7.6	
Peacehaven	11/30/24	438	414	94.5	11	2.5	13	3.0	5.5	
Total		5596	5244	93.7	128	2.3	213	3.8	6.1	
Hampshire										
Hayling Island	2/10/24	444	400	90.1	16	3.6	27	6.1	9.7	1
Portsmouth	3/17/24	384	347	90.4	12	3.1	25	6.5	9.6	
Gosport	4/20/24	500	463	92.6	17	3.4	20	4.0	7.4	
Comserv	5/21/24	40	38	95.0	0	0.0	2	5.0	5.0	
Fareham	6/15/24	449	404	90.0	21	4.7	24	5.3	10.0	
Alton	9/21/24	335	314	93.7	6	1.8	15	4.5	6.3	
Petersfield	10/12/24	426	401	94.1	11	2.6	14	3.3	5.9	
Swanwick	10/26/24	475	431	90.7	7	1.5	37	7.8	9.3	
Basingstoke	11/16/24	340	320	94.1	6	1.8	14	4.1	5.9	
Comserv	12/4/24	24	22	91.7	0	0.0	2	8.3	8.3	
Total		3417	3140	91.9	96	2.8	180	5.3	8.1	
Overall Total		9013	8384	93.0	224	2.5	393	4.4	14.2	
TOTAL SINCE 2011										
Hampshire	12008									
Sussex	23533									
Dorset	6983									
Combined	42524									

Many thanks to all the PCaSO volunteers, phlebotomists, and volunteers from partner charities who helped with the smooth running of these events. We could not do them without you all.

PCaSO Testing Events for 2025

Dorset

The Dorset Branch is not currently planning to run any 2025 testing events due to lack of PCaSO members in Dorset willing to be on the Dorset committee or volunteer for events.

If you would like to volunteer to be on the Dorset PCaSO Committee and help to restart testing in Dorset then please contact the Chair of PCaSO Brian Holden by emailing chair@pcaso.org

Full assistance would be provided to anyone willing to help resume the Dorset branch of PCaSO.

Hampshire

Portsmouth	-	Saturday 1 st February 2025 (Private Event)
Havant	-	Saturday 15 th February 2025
Eastleigh	-	Saturday 15 th March 2025
Ringwood	-	Saturday 12 th April 2025
Southampton	-	(May/June/July) To be Confirmed
Gosport	-	Saturday 28 th June 2025
Petersfield	-	Saturday 13 th September 2025
Fareham	-	(October 2025) To be Confirmed
Basingstoke	-	Saturday 15 th November 2025

Sussex

Horsham	-	Saturday 5 th April 2025
Crawley	-	Saturday 17 th May 2025
Angmering	-	Saturday 7 th June 2025
Worthing	-	Saturday 13 th September 2025
Burgess Hill	-	To be Confirmed
East Grinstead	-	18 th October 2025
Peacehaven	-	29 th November 2025

To book a test go to the PCaSO website, choose **PSA testing** then scroll down and choose a venue by clicking on the highlighted **Here** in the details for the venue.

Please read the instructions for making a booking carefully and you will be taken to the booking page where you will need to make an account if you do not already have one.

PCaSO Zoom / Videos Archive

You may not be aware but there is a whole library of archived Videos and Zoom meetings on the PCaSO web site, so if you missed a presentation or a Zoom meeting it should be there for you to watch later.

Simply click on the link below or in a browser type <https://pcaso.org/videos-2/> to view the library page.

[PCaSO Video Link](#)