UPDATES

The Newsletter of PCaSO Prostate Cancer Support Organisation

Dorset • Hampshire • Sussex • and surrounding areas

ISSUE 74 - *Spring 2024*

Terracotta Warriors, Buscot Park. Photograph by Paul Bowler

Prostate Cancer Support Organisation

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NOTES FROM THE EDITOR

This issue no. 74 is available in digital only format (PDF). This is also the first issue that I have produced as both editor and designer and I now know how much work goes into producing an issue of the Updates newsletter.

With that in mind I would like to thank both Tony Ball and Colin Woodman for all the hard work they must have put in to produce all the previous versions and for their assistance in this one. I can only hope my efforts will maintain the high standards they have set.

This issue includes:

Two new members stories and two updates to stories previously told.

An article on screening for Prostate Cancer.

News from the Branches

The minutes from the 2023 AGM

PCaSO testing results for 2023

As I said before, this is the first 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.

Chairman's Introduction

Good morning, and welcome to our latest Updates online magazine.
We are very glad to welcome nearly 150 new members to PCaSO, and hope that you are all benefitting from the support and sharing of experiences between members.

The last year has seen many changes within our charity, many of which have been shared with you in our various emails and newsletters.

I thought it would be interesting to share the following information about the running of the PCaSO charity with you. We now have three trustees from Dorset, three from Hampshire and two from Sussex, together with three officers – secretary, treasurer and chair - also from Sussex. This is almost a full complement of trustees, all of whom are executive committee members. We are supported additionally by our IT administrator, membership secretary and gift aid coordinator.

In our branch groups we have nine committee members. Ten members support our drop-in groups and chat rooms. Our PSA testing days are supported by another 20 additional volunteers.

So, in total, over 50 PCaSO volunteers make up the team who contribute to the success of our charity and give their support to our membership of about 800 men and their 600 partners by various means. Not forgetting, of course, the 7263 men who had a PCaSO PSA test during 2023.

If you would like to become more involved with our committees, local groups, testing days, or helping support members or newly diagnosed men in other ways, please get in touch. There's always room for new supporters and volunteers, and everyone has a skill we can put to good use.

Last year I said 'My commitment to PCaSO is to help ensure that men diagnosed with a raised PSA, who live within our catchment area (and sometimes beyond), are offered the friendly support of other prostate cancer patients, via an exchange of experiences and discussion of the ways of coping with the side-effects of treatments'.

One approach we tried out was to form a WhatsApp group for members. This has been a great success and has over 50 members sharing their experiences. One topic that has recently been raised is that of the higher prostate cancer risk for blood relatives. We urge you encourage such relatives to have a PSA test.

To join send a WhatsApp to 07879 903407.

We have had several Zoom presentations and face to face meetings, details are included.

I am really pleased to introduce Paul Bowler, our new Updates editor, and we hope that you enjoy reading the articles he has put together. We welcome your comments and contributions to our future online magazines. Paul can be contacted anytime at editor@pcaso.org

Stay fit, eat healthily, and we send you our very best wishes for the year ahead,

Brian and the team

Prostate Cancer Support Organisation

Charity No. 1170536

www.pcaso.org

PO Box 66,
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Hants PO107ZP

PCaSO Help Line:
07879 903407

Tim Swinton's Prostate Cancer Story

My prostate cancer story is much the same as anybody else's.
The principal reason I'm getting it out there to all of you is because of what might be a bit different - I'm gay.

Without going into the comic innuendos that verge into Carry On territory, I have to say straight away that almost any gay man will tell you what the prostate does for their sex life. Some rely on it. Straight men too I guess; although for me, that's only hearsay…

My cancer was diagnosed at the end of 2013 with a PSA of 25 and a Gleason score of 3:4. I was quickly given high-dose rate brachytherapy and fifteen localised radiotherapy treatments early in 2014. I was then on hormone treatment for about a year.

"Today, if I were newly diagnosed, I would definitely want to share my particular anxieties and concerns with a person familiar with my situation"

My PSA started to rise again in 2018-19 (the dates are uncertain as my PSA rose so slowly) as the cancer had metastasised so I have been having follow-up hormone treatment as quarterly injections for the last few years. Recently I found out that the prostate cancer has spread slightly further so I have just started on Enzolutamide.
Back when I was diagnosed, nobody prepared me for the sex-life-changing impacts of my treatments. One result is my sex drive has fallen to zero. Since I'm 70 this year that's not so important to me (my partner and I split up the year the cancer came back). However, if I get lucky and a sex life returns, I know there are several approaches I can take.

Today, if I were newly diagnosed, I would definitely want to share my particular anxieties and concerns with a person familiar with my situation. Until recently, I don't think any such help existed. However in the last few years, PCaSO (the Prostate Cancer Support Organisation) has established a support service so you can talk to a gay man like me. We're here to help; so get in touch - we can make a real difference.

The best of luck and health to you all,

Tim

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 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

We also have a ***WhatsApp group*** *to allow members to support each other, ask for and give advice on Prostate matters or anything else thought important,* Brian Holden runs the group.

WhatsApp a message to Brian on 07879 903407 to join the group.

Screening for Prostate Cancer

Although we are well into the 21st Century there is still no screening programme in the UK for prostate cancer, despite over 12,000 men passing away each year through this disease.
National statistics vary but at least 1 in 8 men will be diagnosed with prostate cancer in their lifetime, double that risk if there is family history of the disease (including breast or cervical cancer) or Black ethnicity. You may have seen Prostate Cancer UK's recent campaign including bus shelter posters, highlighting PCUK's useful Risk Checker.

"over 30 men are dying every day in the UK from Prostate Cancer"

There is no simple direct test for prostate cancer, but the 'PSA' Test is a good indicator of the health of a persons prostate gland. A high PSA reading ("Prostate Specific Antigen" level in the blood) suggests that further tests or scans are needed to determine any underlying issues. As with many medical diagnostic procedures PSA can occasionally give some false readings, which is why not all professional clinicians support the test.
However, over 30 men are dying every day in the UK from Prostate Cancer.

"PCaSO started offering PSA tests back in 2011, since when we are proud to have carried out precisely 33,510 tests, across Sussex, Hampshire and Dorset"

PCaSO started offering PSA tests back in 2011, since when we are proud to have carried out precisely 33,510 tests, across Sussex, Hampshire and Dorset. In 2023 alone we ran 20 events, for 7,261 men of whom 578 were found to have raised PSA levels and then alert their GPs for further investigation. We achieved our 30,000th test at our Worthing event on 2nd September. BBC South East News came along and ran a good piece including an interview with our 'Man 30,000'.

The men who attend our testing events are often pleasantly surprised at how efficient the service is! All events are pre-booked online at www.pcaso.mypsatests.org.uk including our informative pre-test video, and the results are available from the same website within two weeks. Each man has his own ID and password. The actual analysis of the blood samples is conducted in hospital pathology departments, so can be regarded as robust.

We are always grateful for donations at our events, to help cover the necessary costs that PCaSO has to incur from suppliers. As a registered charity PCaSO can claim Gift Aid from the taxman, and this also helps.

The PSA Testing events are very much a matter of teamwork, for PCaSO's own volunteers, the local Lions or Masons who arrange the venue and act as marshals, and the professional phlebotomists who of course take the blood samples.

We'll have a range of events during 2024 across PCaSO's three counties, and details will be published on our website www.pcaso.org. If you are unable to attend a PCaSO event, remember that men aged 50+ have the right to ask their GP for a PSA test. It is worth highlighting that any person who has a prostate is at risk from prostate cancer, so we would urge trans women to consider getting checked also.

Finally, in Spring 2024 Prostate Cancer UK will publish details of their forthcoming "TRANSFORM" trial that will seek to identify the best screening tools for a national programme of Prostate Cancer screening.
This will enable many more cases of the disease to be identified in its early stages, with obvious benefits for men's health and longevity and for the NHS. Costed at some £42million, the trial will involve selected health authorities around the UK and involve 300,000 men.

Lance Allen,
PCaSO trustee and PSA event volunteer.

Andrew Somerville's Story - A Year On

It's been a year since I shared my cancer story and it's been a rather busy one.

To recap; I was diagnosed with pT3a Nx Mx (Gleeson 4+3=7) prostate cancer two years ago. In February 2022, I underwent a nerve-sparing, robotic radical prostatectomy by Prof Christopher Eden's incredible team at The Royal Surrey Hospital.

I was first alerted to potential prostate issues by attending one of PCaSO's PSA testing event, and at the tender age of 43, did not expect a "red notification" showing an elevated PSA level of 12.4ng/ml. As I had no symptoms and given the seriousness of my diagnosis, had it not been for PCaSO, things would certainly have turned out much worse for me.

So, to help say thank-you, I decided on doing some fundraising for the charity, which consisted of a 60-mile hike across Devon and Somerset (The Coleridge Way) with my brother in July 2022. We raised over £3K and I like to think helped raise awareness of the importance of PSA testing, particularly amongst younger men.

As the fundraising hike in 2022 went so well, we thought we'd do another one, this time hiking 10 peaks and 10 waterfalls of The Brecon Beacons. We did this in September 2023 over the course of 3 rather wet days. Although the hikes were fairly challenging, the rain didn't dampen our spirits and it did help to make the waterfalls all the more impressive. The excellent Welsh hospitality helped a lot and I highly recommend visiting this beautiful part of Wales for anyone wanting to get away from it all.

We raised £500 for PCaSO and I was delighted when Brian Holden advised me that the money we raised was spent on providing 500 water bottles for men undergoing radiotherapy for prostate cancer (before having radiotherapy treatment, men have to drink between 500ml and 1l of water, which helps to push the bladder away from the prostate to minimise radiation damage to the bladder). Plastic, single-use cups have previously been used and now the nice, branded PCaSO biodegradable bottles are used instead, saving thousands of cups from going to landfill.

"I've continued with my big 3 lifestyle changes, namely diet (now I'm mostly plant-based with very little processed sugar, alcohol, or any of the really fun stuff!), fitness (I train in martial arts and yoga fanatically) and finally trying to live as stress-free a life as possible (easier said than done!). "

I am pleased to say that after nearly two years post-surgery, no further treatment has been required to date and my PSA levels remain undetectable. My next PSA test is this Spring and if this comes back clear, I've been told that the chances of the cancer returning will drop significantly. Additionally, any side-effects because of the surgery are negligible and have little to-no effect on my daily life.

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Andrew Somerville's story continued from page 6

any of the really fun stuff!), fitness (I train in martial arts and yoga fanatically) and finally trying to live as stress-free a life as possible (easier said than done!). I certainly feel a lot better than I did before embarking on these quite dramatic lifestyle changes and I rarely seem to catch any of the colds and other grotty illnesses that my kids bring home from school; something must be working!

I continue to be extremely vocal amongst friends and acquaintances of all ages regarding the importance of PSA testing and a fair few of my friends have attended PSA testing events organised by PCaSO. I did bump into some of them at the recent testing event in East Grinstead in November last year when Brian invited me to drop by for a chat and "thank you" for the fundraising and to give me a bottle of my own. This was quite a poignant moment for me, as it was the test event at this location two years prior (nearly to the day) that alerted me to having cancer.

I am pleased to say that none of my friends who were tested received a "red" PSA result. However, my father, who at my insistence had his first ever PSA test at the age of 79, was shown to have an elevated result and has subsequently been diagnosed with prostate cancer. His cancer is much slower growing and less aggressive than mine was, and he is following a programme of "active surveillance". Over the past year, his PSA levels remain stable which is good news.

Because of the known risk of prostate cancer running in families, I was invited by the Thames Genetic service to be involved in a genetic testing trial (the PMPRC study) conducted by The Royal Marsden Hospital. The aim of this trial was to eventually produce a test for men to determine their likelihood of developing prostate cancer based on genetic risk factors, and if they fall into the top 10% of the risk distribution, regular screening be applied. The benefit for me (as well as helping to develop another potentially life-saving test) was that they would see if I carried any of the "high risk" genes associated with prostate and other cancers. I was extremely pleased when the result came back to say that I did not carry any of these genes. As I have children, one of my initial thoughts back at diagnosis was the fear of them having an increased risk of cancer from any genes passed on by me.

So, like I said, it's been a busy year for me and I'm looking forward to another fundraiser this year, probably something heading a little further North; watch this space!

Andrew Somerville

Could MRI Scans Be Used to Screen for Prostate Cancer?

MRI scans could be used in prostate cancer screening according to results from the **RelMAGINE** 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.

Hampshire Branch News

Swanwick Lions Cheque Presentation

Following a successful PSA test Event in February 2023 Swanwick Lions presented PCaSO with a cheque for £2,000.

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

Who were, from right to left:
Peter Weir, Roger Smith and me (Paul Bowler).

The ceremony took place at the Swanwick Green Community Centre, fortunately the actual cheque wasn't this size! We really appreciate all the help and support that the Lions Clubs International give us in running the PSA testing.

Otterbourne Members meeting

The meeting took place at our regular venue, Otterbourne Village Hall at 7:30pm on 5th September 2023.

Unfortunately, our guest speaker for the evening (from BK Medical) was unable to attend. They make the bkSpecto Ultrasound System that we are looking to help provide. However, our Chairman Peter Weir stepped in and gave a great 'off the cuff' presentation of this equipment.

Tim Bonner then spoke about the upcoming 'Walk with Kev" (see next item for details), both talks were well received.

Following this we covered our fund raising, current funds and what we use them for. Focusing on testing events and provision of equipment to help local hospitals. Including our current goal of providing at least one bkSpecto Ultrasound System (as above).

Then we had very good Q&A and general chats over refreshments. New members were able to chat to one other about what they been through or were about to go through. This was very successful and something we will look to provide more time for in future meetings.

March for Men - Walk with Kev

On September 17th 2023 a sponsored walk took place in Petersfield, Hampshire in aid of raising awareness of prostate cancer. Kevan Birkett, a popular manager of Petersfield Town Junior football team, sadly lost his fight with the disease in May that year.

Organised by his widow and friends in conjunction with Hampshire Media Group, they brought the London March for Men to Petersfield in his honour.

Over 300 people took part in the walk, the longest being of 10K and an amazing £10,000 was raised to be donated equally between PCaSO and Prostate Cancer UK.

Several PCaSO members marched including Hampshire Branch committee members Peter Johnson and Tim Bonner. A PCaSO gazebo was also manned by members distributing information and raising awareness of prostate cancer and PCaSO.

Tim Bonner was very proud of his dog Molly who

not only raised £500 but completed the course in one of the biggest thunderstorms of the year. Most walkers returned soaked but happy to have contributed.

The event will be held again next year on September 15th 2024, it is also planned to hold a PCaSO PSA testing event in Petersfield a month later.

Greiner Bio-One donation to PCaSO

Greiner Bio-One, an Austrian company with a UK division based in Gloucester are a major supplier of laboratory equipment including specimen collection systems for blood and urine.

Greiner Bio-One have kindly donated to the Hampshire Branch of PCaSO 3000 units of their Vacuette® blood collection system to be used for blood taking at PSA events.

The Vacuette® Quickshield safety tube holder system is an innovative blood taking device with a protective safety feature to cover the exposed needle and thus reduce the risk of needle stick injury to the phlebotomist.

PCaSO are extremely grateful for this donation, it will be much appreciated and put to good use in helping to save mens lives.

Richard Kirkman Trust Donation

We have received another donation of £1000 from the Richard Kirkman Trust to be used for the benefit of people in the local area. This is an annual donation for which we are very grateful to the trust.

The King John Morris Men

We also received a donation from the King John Morris men for £1500.

Roger Smith (Hampshire Secretary) went to one of their Pub performances to collect the cheque from them.

They chose us to be their charity as several of their members are unfortunately dealing with Prostate Cancer.

Nuffield Health Exercise Sessions

Nuffield Health are offering free exercise classes for all PCaSO members in the Hampshire area (all members anywhere welcome but sessions are only in Hampshire).

These are instructor led sessions tailored to our particular needs and are led by Leah Ilsley from Nuffield Health.

Currently the venue is:
Titchfield Community Centre,
Titchfield,
PO14 4AB.

But from April will be moving to a new venue:

Wallington Village Hall,
Wallington,
Hampshire,
PO16 8ST.

They are on Monday mornings starting at 09:45 until 11.

The attendance for these is increasing and the feedback is that they are excellent as well as being a good place to meet other members and have a chat. Most of us will also be going for Tea/Coffee and chat afterwards.
I personally go to them and thoroughly enjoy them and would like to say a big THANK YOU to Nuffield Health and Leah for providing these free of charge.

So if you are able to and want to get a bit fitter and meet fellow members 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.

WhatsApp Link

Sussex Branch News

Breeze Club Donation

PCaSO are delighted to have received a donation of £22,500 from the Breeze Club, this being the charitable arm of a group of London property development companies.

From left to right, Dean Manning, Roger Bacon & Lance Allen

Also a further £5,000 from the staff at TClarke Contracting, a Breeze Club member.

From left to right, Lance Allen, Lee Crozier and Roger Bacon

This all started at a PCaSO PSA Testing event at Copthorne Golf Club, when Roger Bacon was approached by the club captain about donations. This led to PCaSO being nominated as one of three charities supported by the Breeze Club for 2023. Roger, together with Lance Allen and Rob Stanley, set up a PCaSO stand at the Breeze Club's pro-celebrity golf event in the luxurious surroundings of Kingswood Golf Club. Lance found out at short notice that he was the after-lunch speaker!

The year-end presentation to nominated charities took place in London on 17 January, attended by Roger and Lance, who spoke of PCaSO's work and our appreciation for the Breeze Club's generosity. We are looking in 2024 to arrange a PSA testing session for the Breeze Club members and guests, possibly at one of their golf events.

The funds donated to PCaSO by the Breeze Club have been ring-fenced to go towards the cost of running our PSA events. Breeze are aware that PCaSO's PSA testing sessions are provided free of charge, and although many men do make donations, we are determined not to exclude those with limited financial circumstances, who might otherwise miss out on this essential health check.

Dry January

Our Sussex member Gregg has just finished his sponsored 'Dry January' and raised £640 for PCaSO. We are all most grateful to Gregg for undertaking this challenge.

Royal Support

Lance our Secretary has sent a letter to King Charles offering our support with his prostate journey together with copies of KE and HL.

Chat room

We held our first Zoom Chat Room for members on 19th January, it was well supported by 9 members all sharing their experiences.

Following good feedback from attendees we are held another Zoom chat room on 15th February at 1630 until 1800.

Fourteen members joined in and have agreed that it is very useful to see each other and future Zoom chat rooms will be held.

Eastern Sussex Group

We are pleased to say that Clive Hancocks, an Eastern Sussex member, has also joined the team to liaise with Lorna and Lisa, particularly when new members join.

Clive is the go-to member for all new and existing members wishing to chat about their concerns.
Clive is preparing to organise a drop-in session for Eastbourne and Bexhill area.
Clive easternsussex@pcaso.org

Eastern Sussex Group Meetings

East Sussex will be holding several group meetings over the next year and have some very interesting speakers for you.

These meetings are physical NOT Zoom and will be at:
Tesco Community Room
Tesco Extra
Lottidge Drove
Eastbourne
BN23 6QD

Tuesday 26th March 24
Speakers Ed Calleja, Speciality Doctor, Nicola Milton, Urology/ERAS Specialist Survivorship Nurse and Gabby Sullivan, Lead ERAS Nurse, talk on 'ESHT Urology discuss enhanced recovery, robotic prostatectomy procedure and living with and beyond cancer (survivorship)'

Tuesday 25th June 24
Speaker Sam Bentley, Engagement Officer, One You East Sussex, talk on Support in East Sussex for physical activity and wellbeing.

Tuesday 24th September 24
Speaker Sally Sawyer, Lead Uro-Oncology Clinical Nurse Specialist, talk on Prostate cancer treatments in general including managing side effects.

Tuesday 17th December 24
Speaker Rebecca Rushton, Specialist Urology Diagnostic Nurse talk on Managing the diagnostic pathways.

Brighton Group

On 17th January we held an informal 'Meet the PCaSO team' at the Horizon Centre in Brighton at 18:00. We had a good turnout despite the wintery weather.

Two members shared their situation being on Active Surveillance, two more with HDR Brachytherapy with EBR, two more having had RARP and two more with advanced PCa and chemotherapy.
One member's wife also came along and was welcomed by the group.

Feedback from those that attended was very positive and we plan to hold the next one in a few months' time, wives and partners will be very welcome to come along and chat together as well.

Drop-in Sessions

Our next drop-in sessions are scheduled for the following dates:

12th March and 9th April
At the Brighton Horizon Centre.

All members are welcome to attend between 11:00 and 13:00, plus we hope that non-members will 'drop-in' to discuss Prostate Cancer issues.

The Horizon Centre is in Brighton, across the road from the Sussex Cancer Centre in Bristol Gate. The facilities are brilliant and there's plenty of complementary therapies for you to book if you want e.g. acupuncture for hot sweats, massage for the aches and pains, a full list is available on the Horizon website.

The address is:

Brighton Horizon Centre
2 Bristol Gate,
Brighton BN2 5BD

Final Meeting of Eastbourne Prostate Cancer Support Group

Eastbourne Prostate Cancer Support Group are part of PCaSO and following the 20th anniversary article in Updates 73 updates_73.pdf (pcaso.org) here are the notes taken from that meeting held on 14 December 2023 at Eastbourne District General Hospital.

This meeting was the very last one to be held under the leadership of Debbie Hatfield and Chris Cutting at which Debbie's brother Graham, the other founder member of the group in 2001, was introduced to those present.

Debbie also introduced Trustees Brian Holden, and Lance Allen, Chair and Hon Secretary of PCaSO respectively; Brenda Pearson-Woodd, Sussex group treasurer as well as Lorna Earl and Lisa Hollands, both of Macmillan and working within Eastbourne DGH to support cancer patients. Last, but by no means least, a substantial number of members of Eastbourne Support Group were welcomed, both recent and long-standing.

Debbie has recently taken a donation to the Sarah Lee Trust in Sidley, and PCaSO now has a good link with them for support for cancer patients in the Bexhill and Rother area. The Group still had a balance of over £3,500 so, with some additional funds from Sussex Branch of PCaSO, the DGH Urology department has been funded for three new recovery chairs, TVs for staff training and fitness watches for recovering patients.

Chris organised a very successful raffle during the evening, raising funds to pay for the refreshments which were enjoyed by all.

Lorna and Lisa were introduced to those present as the new organisers of Eastern Sussex Group. Both work in EDGH, supporting cancer patients in Eastbourne. Lorna leads the Macmillan Counselling Service, a team of 30 counsellors, and Lisa is Lung Macmillan Cancer Support Worker. Lorna and Lisa are very keen to continue to support prostate cancer patients, and asked the Group members to put forward any ideas they have for future meetings. They have a lot of links within the NHS, Macmillan and the community, and are committed to helping the members, as volunteers. Subsequent to this meeting Clive Hancocks has taken on the liaison role with PCaSO members.

Brian asked members to ensure that they had given permission for PCaSO to use their contact details, so that they could be kept informed of PCaSO and Eastbourne activities in the future. He suggested that Eastbourne members should join PCaSO, free of charge.

In future, PCaSO member Rob Stanley, as Sussex Newsletter Editor, will produce an email newsletter for the whole of Sussex, thereby allowing all members to know about events within all of Sussex, which it is hoped will be particularly helpful for those members who live outside Eastbourne itself.

PCaSO also now has a new editor of the Updates magazine, who will be bringing some fresh ideas to the publication.

Lorna said that their first meeting will be held around March time, possibly at the Sarah Lee Centre, but more likely in the Community Room at Tesco Extra in Eastbourne, which is well equipped and convenient for most Eastern Sussex members, with free parking.

PSA testing has been continuing apace over the last twelve months, and around 34,000 men have now been tested by PCaSO. Roger Bacon, testing coordinator, and Clive Hancocks, have been looking into setting up new venues and links with Lions for testing in towns further east in Sussex. New volunteers to help at these testing days will be most welcome, since many of the current team of PCaSO testing volunteers live to the west of the county.

A discussion about testing followed, with several members agreeing that PCaSO are providing a much-requested service for men unable to obtain PSA tests through regular channels. However one of our members sadly does not agree with our PSA testing.

Brian is very pleased that Lorna and Lisa have agreed to take up the reins of Eastbourne Support Group. Debbie and Chris have done a wonderful job for over 20 years. It is important to continue holding face-to-face meetings for the members wherever possible, to enable men to share experiences. The newly-revised 'Knowledge Empowers' publication by PCaSO is now available, and has been found very beneficial, especially for newly-diagnosed men.

A member suggested that PCaSO leaflets and posters should be available in places locally for the public to see. Brian pointed out that PCaSO would be most grateful if members of the Group could volunteer to distribute publicity material to such places – after all, PCaSO is a charity run solely by volunteers, and new volunteers and their ideas are always greatly appreciated.

Chris gave a final heartfelt plea about the importance of men getting tested before they get any symptoms. As in many families, her own husband and male family members never spoke about 'men's problems' and, sadly, she lost her own husband to late-diagnosed prostate cancer. She requested that all members should discuss their prostate cancer journey with family and friends, so that more men know they should get PSA-tested before they get symptoms.

Gifts and cards of thanks were presented to Debbie and Chris by Brian, and Debbie also gave presents to Lorna and Lisa.

Photo: from left, Lorna, Debbie, Chris and Brian.

AGM Minutes 2023

Minutes of the Annual General Meeting
PCaSO Prostate Cancer Support Organisation
Held on Zoom on Thursday 5th October 2023 at 7pm.
Reg'd Charity No. 1170536

The meeting was quorate throughout (20 members are required, 29 were present inc. 8 trustees), and commenced at 7.04pm.

Welcome & Introduction
Brian Holden (Chair) welcomed the attendees. One apology for absence had been received, Mike Tompsett who joined part-way.

Approval of 2022 AGM Minutes
The minutes from the previous AGM, 25 July 2022, were approved as a true record. Proposed by Lance Allen, seconded by Derek Pilling.

Chair's Comments on the year to date
Brian Holden reported with much sadness that membership secretary Andrew Collett passed away last week, our condolences have been sent to his family and Brian, with other members, will be attending Andrew's funeral. Andrew did a brilliant job for PCaSO and left our new membership secretary Mike Tompsett with an excellent database system to carry on the good work.

Our long-standing treasurer and Gift Aid coordinator Andrew Bloxham passed away last October. Brian had previously met Andrew B to take on the well run Gift Aid claiming system, on which we have since claimed several thousand pounds from HMRC.

Since our last AGM Brian had taken on the Chair role and and other roles previously carried out by Roger Bacon. Brian's clear focus is on PCa support, before, during and after treatment.

We have instigated a system whereby all men found to have a raised PSA result at our testing events have been contacted by email offering the support of PCaSO. Our membership fee has been dropped completely. Directly or indirectly these changes have resulted in nearly ninety new members joining us.

Successful face to face meetings restarted in Hampshire and Eastbourne after the Covid problems, with good numbers attending and excellent speakers. There are plans to also restart face to face meetings in Brighton in January 2024.

We have also held several zoom presentations by our medical advisors and guest speakers. These can be viewed on our website.

WhatsApp Group

We now have a WhatsApp group currently with 35 members from across the three county branches of PCaSO. Many on the group are actively involved in wide ranging discussions covering various treatment options right through to the side effects of our treatment paths. The group have no inhibitions in discussing problems such as ED, incontinence, psychological issues and much more.

We have started what Brian hopes is a pilot scheme for others to follow, by going into a partnership agreement with Macmillan and their Horizon Centre in Brighton. A team of seven PCaSO volunteers have been DBS checked and trained by Macmillan via a listening and responding course to support men with PCa . We hold a monthly morning drop-in session which is open to all including their partners. Private rooms are made available to us , but normally we hold group chats, once again very open and frank discussions take place.

PSA Testing 2023
Our PSA testing is running extremely smoothly under the guidance of Roger Bacon in Sussex, Peter Weir in Hampshire and Alan Higgin in Dorset, together with numerous volunteers. We receive many letters of thanks from the men being tested as usually they don't often have symptoms! Our thanks to the professional phlebotomists who are essential to our testing events.

This year we tested our 30,000th man and received excellent media coverage via TV and radio, some of which can be viewed on our website.

We have provided radiotherapy units in three local hospitals with 500ml biodegradable drinking water bottles for those patients having treatment for prostate cancer. As many of you will know, each patient has to drink half a litre of water before radiotherapy to the prostate and the PCaSO-branded bottles replace single-use plastic cups. One radiologist in charge has thanked us and said the bottles provide a good introduction for men to talk about getting support.

Although Dorset branch are currently dormant due to lack of volunteers coming forward, we are hoping that more testing events will be held next year which may encourage new volunteers to step forward.

Brian stated he must thank Cliff Carter for all of his work maintaining PCaSO's website together with the many other IT support activities managed by Cliff, necessary for our efficient running in this digital world.

Roger Bacon and Colin Woodman, our designer, have been updating our booklet 'Knowledge Empowers' which has been a major task given the many changing treatment options. It is also being changed in size to match our Healthy Living booklet. The online version will be available in the next few weeks.

Our thanks as always to our medical advisors for their help in checking documentation, and the various presentations they have given to us over the year.

AGM Minutes 2023 - Continued

Brian also thanked our enthusiastic volunteers, since without their tremendous support running the various committees and events our charity could not function as well as it does now.

We need more volunteers in various roles that are not too onerous, please email to Brian chair@pcaso.org if you want to become involved with our fantastic charity.

Finally Brian offered grateful thanks to David Hurst for his dedication over the last ten years as Secretary. Brian had first spoken with David early on in his treatment decision process and is extremely grateful for the benefit of David's experience. Once more PCaSO working at its best. Many of you will know Lance Allen who is taking on the role of Secretary and Brian was really pleased that he has volunteered to take up where David leaves off.

Approval of the Accounts for year to 31 March 2023
Group Treasurer Kevin Simons had taken on the role during the last year, and expressed his thanks to David Hurst and Roger Bacon for their support. Kevin presented the accounts and highlighted key elements.

Total income was £106k (2022 = £38k) due largely to the resumption of PSA testing events. Costs for PSA events at £68k (£15k) had risen due to both volume and inflation. PCaSO had made one large donation, £14k for a specialist biopsy chair at the Royal Bournemouth Hospital.

The year end funds at £148k (£145k) were slightly up on the previous year.

It was noted that payments for newsletters and support to members were each shown as £579. Kevin stated this was just co-incidence.

The account were duly approved. Proposed by Barry Mitchell, seconded by Peter Johnson.

Election/ Re-election of PCaSO Trustees.All Trustees are standing down. Those offering themselves for re-election are Lance Allen, Roger Bacon, Allan Higgins, Brian Holden, Derek Pilling, Kevin Simons, Barry Taylor and Peter Weir but *excepting* David Hurst who is retiring as a Trustee. The roles of the re-elected Trustees will be determined at the first Executive Committee meeting after this AGM.

Any questions
There was brief discussion on Intensive Radiotherapy Therapy (recently highlighted in the National news). Professor Emberton (see below) advised that the PACE trial had shown the benefits of 5 strong Radio fractions rather than the more usual 30 'regular' doses, often avoiding the need for Hormone Therapy also. The long-term benefits were yet to be assessed but longer-term harm is believed unlikely.

Stereotactic Therapy was also discussed, being experienced by one member for smaller tumours.

The formal meeting closed at 7.29pm.

Presentation on Photodynamic Therapy by Prof. Mark Emberton

Professor Emberton continued the zoom session to give a very interesting presentation on **Photodynamic Therapy** (PT).

The talk has been recorded and can be viewed on PCaSO's website at

https://pcaso.org/videos-2/ .

In summary, PT uses tiny needles of diffused laser light to directly target and destroy the cancer cells, after the patient is first injected with a seaweed-derived 'sensitiser' that makes the skin and organs extremely sensitive to light. Healthy cells including the prostate wall are unaffected by the laser. A randomised study saw around 200 men trialled, with a further 200 just on Active Surveillance. The outcome was described as clinically significant, even 'magical'. Sadly the procedure is not approved in the USA or UK and there are no funds available to fully prove the concept.

In response to questions, Prof. Emberton stated that the Photodynamic study had not made any comparison with HIFU, which was seen as 'novel' at the time the PT investigation began.

Mp-MRI scanning had been highlighted in the National news as a potential screening tool. The 're-imagine' study had established that 10-minute scans were far more effective than PSA testing. However many hospitals' scanners were old, and new ones would need investment of £1.5m each plus annual running costs £0.5m. Screening by MRI could be available within 10 years, perhaps as stand-alone diagnostic hubs, even in shopping centres.

Roger Bacon gave thanks to Professor Emberton for his talk, and for explaining the treatments very clearly.

The zoom meeting closed at 8.32pm.

Gregg McKella's Story - A Year On

This is really an update to my full story following my prostatectomy that I had on 12th January 2023.

My full story can be found on the PCaSO website under the patients' stories section.

https://pcaso.org/patient-stories/

I have also made a few YouTube videos telling folks my journey, with a hope to raising awareness, and helping newly diagnosed patients get some insight, just as I had discovered a few videos that I had found helpful.

I will be doing another one shortly, a "one year after" episode.

https://youtu.be/DFUOzUe1g-s

I really can't believe a whole year has gone since I had my operation. I have now had four 3-monthly PSA blood tests, all coming back 0.01ng which is a massive relief.

My journey started in Spring of 2022, when my GP suggested I have a PSA blood test. I did not know what this was, but was happy to have this stuck on the growing list of blood tests along with the cholesterol, blood sugar levels etc. It came as a great shock to find that I had a raised PSA level of 5.95 and I was told it might be cancer. In August 2022 it was confirmed.

I was introduced to the PCaSO support group by Clive Hancocks, and the advice I received from the PCaSO members at that time was invaluable in helping me decide which treatment I should go for. I have since become an active member, being part of the Horizon Centre team that hold the monthly drop-ins, and am part of the dynamic dream team on the donation table at the PSA blood testing events.

So after this first year, overall I feel quite fit, am not as fatigued as I was following the first few months post operation and feel very positive about life in general. My continence has been pretty good, now I use the lightest continence pads, and only when going out. On the E/D front, I still have issues but things are moving positively, although I realise this can be a slow process.

So, following my operation last year, I decided to do a Dry January, and managed to raise just short of £1700.

The funds raised went to getting 1500 water bottles for men undergoing radiotherapy for prostate cancer (before having radiotherapy treatment, men have to drink between 500ml and 1l of water, which helps to push the bladder away from the prostate to minimise radiation damage to the bladder). Plastic, single-use cups have previously been used and now the nice, branded PCaSO biodegradable bottles are used instead, saving thousands of cups from going to landfill.

This year I have done another Dry January, and no alcohol has passed my lips. I will be going out for a beer or two in February mind!

So if anyone fancies chipping in to my Dry January fundraiser here's my Just Giving page

Greggs Just Giving Page

Gregg McKella

Chaloner Chute's Story

As I sat down as chairman of our local PCaSO men's lunch back in 2015, I didn't appreciate how lucky some of us would have to be to survive another 10 years, some, sadly, did not.

It has however been heartwarming to read and hear about other men's stories – and especially the humour that shines through.

I was 66 then, and now I am a healthy 75 years senior.

This is my story, it is only a brief outline of what I have been through as most of it is covered in a documentary film I made to share with men and their partners, showing many of the issues they may face on their journey.

At the time I knew nothing about PSA and I was told by the GP that "we will monitor that and call you back in". No-one did.

For me it almost began at an annual general medical check up that showed a PSA of 5ng/ml. At the time I knew nothing about PSA and I was told by the GP that "we will monitor that and call you back in". No-one did.

Mea culpa, as I didn't chase it up either and it was only after a routine checkup a year later was I diagnosed, rather too late, with a now PSA of 13.5 ng/ml, and following a DRE and the usual biopsy & scans, at Stage 3a.

I then made it my job, as others have, to learn about the disease and how to manage things. My partner didn't really understand – so it's important to sit down and have a good talk with them and explain. Here I found the support & friendship of charities like Macmillan, PCaSO and CancerWise was massive.

I followed a conventional treatment programme balanced with natural healing and complementary therapies; yoga, Mindfulness, therapeutic massages and Gym. Also most importantly gentle sailing in a small boat was mandatory therapy, and being outdoors.

For me, there was no more trips up to London, nights out, and Ronnie Scotts! Just driving with my film crew to interviews was a huge effort.

There followed an extraordinary journey as described in my film.

The next 5 years of my rather eventful life was filled with superb care & treatment by my team at St Richards, wonderful support from the specialist nurses, love, amazement, surprise from friends & family.

All this was tinged with sadness and the realisation that perhaps this was the end of the road, and the awful tiredness and other side effects.

Above all though I learnt that while many things change and some parts of the old body will not perhaps function as they used to, cancer need not define one's life and that there were some surprising benefits.

Many on here speak of the benefits change to a healthy exercise routine and definitely a change to a healthy diet, such a changes will help with overcoming and preventing a host of other health issues too.

Chaloner Chute

Chaloner's film that was mentioned earlier in the story can be watched using the link below.

Prostate Cancer – One Man's Journey - PCaSO

In the film we follow the whole process from diagnosis to treatments, talking to many experts in their field, consultants, nurses, scientists and of course patients.

The film partners include the Royal Marsden, St Richards Hospital, Addenbrookes, PSCUK, PCaSO, Macmillan, CancerWise, Southampton University Immunology centre and others.

It gives lots of practical advice and he hopes it will help to remove some the fear and uncertainty of going through the Diagnosis and Treatment of Prostate Cancer.

PCaSO Testing Results for 2023

RECORD NUMBER OF MEN TESTED IN 2023

The Sussex, Hampshire and Dorset Branches of PCaSO organised 7,238 PSA tests at 20 different venues throughout the 3 counties during 2023, a record number of men tested during the year.
355 men were found to have a red raised result requiring further investigation and 222 amber borderline results who need a further follow up.
Since PCaSO started PSA testing in 2011, we have now arranged over 33,500 PSA tests in Hampshire, Sussex and Dorset.

2023 PCaSO PSA results

2023		Total	Green	%	Amber	%	Red	%	A+R %	Rejects
Dorset										
Chickerell	25/03/2023	190	178	93.7	3	1.6	9	4.7	6.3	
Portland	22/07/2023	163	147	90.2	4	2.5	12	7.4	9.8	
Total		**353**	**325**	**92.1**	**7**	**2.0**	**21**	**5.9**	**7.9**	
Sussex										
Uckfield	11/03/2023	302	271	89.7	10	3.3	21	7.0	10.3	
Hove	01/04/2023	272	245	90.1	9	3.3	18	6.6	9.9	
Henfield	22/04/2023	260	240	92.3	8	3.1	12	4.6	7.7	
Seaford	20/05/2023	242	225	93.0	6	2.5	11	4.5	7.0	
Horsham	03/06/2023	149	135	90.6	3	2.0	11	7.4	9.4	
Worthing	02/06/2023	635	609	95.9	8	1.3	18	2.8	4.1	
Copthorne	30/09/2023	146	140	95.9	3	2.1	3	2.1	4.1	
Burgess Hill	21/10/2023	802	766	95.5	15	1.9	21	2.6	4.5	
East Grinstead	11/11/2023	993	928	93.5	30	3.0	32	3.2	6.2	
Peacehaven	25/11/2023	374	346	92.5	11	2.9	16	4.3	7.2	1
Total		**4175**	**3905**	**93.5**	**103**	**2.5**	**163**	**3.9**	**6.4**	
Hampshire										
Swanwick	18/02/2023	410	373	91.0	10	2.4	27	6.6	9.0	
Alton	18/03/2023	360	313	86.9	20	5.6	27	7.5	13.1	
Petersfield	15/04/2023	340	301	88.5	16	4.7	23	6.8	11.5	
Basingstoke	13/05/2023	327	293	89.6	17	5.2	16	4.9	10.1	1
Fareham	17/06/2023	352	315	89.5	17	4.8	20	5.7	10.5	
Cosham	09/09/2023	269	245	91.1	7	2.6	17	6.3	8.9	
Eastleigh	21/10/2023	309	279	90.3	10	3.2	20	6.5	9.7	
Havant	18/11/2023	366	328	89.6	15	4.1	22	6.0	10.1	
Total		**2733**	2447	89.5	112	4.1	172	6.3	10.4	
Overall Total		**7261**	**6677**	92.0	**222**	3.1	**356**	4.9	8.0	

Running Totals

	2011	2013	2014	2015	2016	2017	2018	2019
Hampshire		285	264	0	50	556	825	1685
Sussex	96	218	678	636	810	1277	2335	2941
Dorset		709	753	547	986	832	1653	1150
Yearly Totals	**96**	**1212**	**1695**	**1183**	**1846**	**2665**	**4813**	**5776**

	2020	2021	2022	2023	TOTAL
Hampshire	0	513	1680	2733	**8591**
Sussex	0	641	4129	4175	**17936**
Dorset	0	0	0	353	**6983**
Yearly Totals	**0**	**1154**	**5809**	**7261**	**33510**

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 2024

Dorset
TBA

Hampshire

Portsmouth -	Sunday 17th March 2024
Gosport -	Saturday 20th April 2024
Fareham -	Saturday 15th June 2024
Alton (TBC) -	Saturday 21st September 2024
Petersfield -	Saturday 12th October 2024
Swanwick -	Saturday 26th October 2024
Basingstoke -	Saturday 16th November 2024

Sussex

Uckfield -	Saturday 9th March 2024
Billingshurst -	Saturday 13th April 2024
Tonbridge -	Saturday 18th May 2024
Bexhill on Sea -	Saturday 8th June 2024

To book a test go to the PCaSO website and choose **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 Presentations 2024

These are the dates and details of the current 2024 Zoom presentations from PcaSO.

20th March 19.00 - Zoom Presentation by Dr Steve Allen.

Discussing Incontinence.

1st May 19.00 - Zoom Presentation by Professor Mark Emberton

Discussing Irreversible Electroporation (more details can be found on page 32 of Knowledge Empowers).

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