

UPDATES

The Newsletter of PCaSO Prostate Cancer Support Organisation
Dorset • Hampshire • Sussex • and surrounding areas

ISSUE 73 – Winter 2022-23



Worthing Pier, West Sussex. Photograph by Tony Ball



Prostate Cancer
Support Organisation

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FROM THE EDITOR

This issue no. 73 is digital only. PCaSO goes forward under a new Chairman in Brian Holden. Former chairman Roger Bacon remains as a Trustee and as a member of the Executive and Sussex Branch committees.

The PCaSO PSA testing teams, ably led by Peter Weir and Roger Bacon, have been active in Hampshire and Sussex. We include Statistics for 2022 and previous years, on page 5.


We include two new patient stories, from Andrew Somerville (pages 7 and 8) and Rob Stanley (page 13). An update from Mark Giddings describes his recent prostate cancer recurrence and subsequent treatment dilemma (pages 16 and 17). Thanks to all three for sharing.

On page 9 an article by Lance Allen on lobbying for National Screening.

(It is also noted the EU agreed on 9th December 2022 toevaluate the feasibility and effectiveness of organised prostate cancer screening for men, on the basis of prostate-specific antigen (PSA) testing in combination with magnetic resonance imaging (MRI) scanning as follow-up.....).

On the back page there is a HIFU addition to Videos, a list of PSA Testing Events for the first half of this year and, face-to-face Group meeting for Eastbourne and Otterbourne. Try not to miss the Zoom talk by Prof. Chris Parker on 2nd March 2023, details on back page.

Tony Ball



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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



I am very pleased to be writing this introduction as your new Chairman of PCaSO. Just over six years ago I was like most men - I didn't know what a prostate was, where it was or what it did. As described in December

2018 Updates 64, 'My Lucky Journey', this was all to change very quickly:-

<https://pcaso.org/patient-story-brian-holden/>

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. From my own experience after diagnosis, being able to talk with members of PCaSO helped me immensely in deciding which treatment path to take.

I am pleased to be able to share many of our members' prostate cancer stories in this edition, which broadly illustrate that, whilst we are all different in our approach to testing and decision-making after diagnosis, the outcomes are often similar.

Over the last year, since Updates 72, many developments have taken place for PCaSO and the world of PCa. New treatments are becoming available on the NHS such as HIFU, Enzalutamide, Abiraterone, Darolutamide, to name but a few. Some of our members have already been treated with these, and all are happy to talk with other men who are considering these treatments.

You will see in this edition that PCaSO has gone from strength to strength with PSA testing, resulting in our highest number of men tested in a year in 2022. All of this is down to our past chairman Roger Bacon, also Peter Weir and their

team of volunteers, in particular Cliff Carter our volunteer IT specialist, for his extensive work on the computerised system that we rely on to process record numbers of men. Using pre-booking and computerised systems, our mass testing events have been greatly streamlined, allowing hundreds more men to get tested quickly and efficiently.

More fine-tuning of PCaSO's systems means that all of the men who recently received results showing a raised PSA, following testing at one of our events, have been contacted by PCaSO with an offer of support. Some of their very positive feedback is summarised under 'Emails from Members and Guests'.

Recently PCaSO made a decision to form a new group based in central Sussex to cover those areas which aren't represented at the moment. The new Group Organiser is Rob Stanley who has extensive experience in Prostate Cancer support and has been volunteering at our PSA testing events. We wish Rob and the new Group members well (see the PCaSO website under 'Meetings' where you will find the 'Central Sussex Group')

Many of you will already know the benefits of keeping fit and eating healthily. During lockdown, and subsequently, PCaSO volunteers produced a booklet, 'Healthy Living', with the aim of encouraging all men to get into shape, and this makes excellent reading. We have had good feedback from clinicians, nutritionists and us men. The Healthy Living booklet is available to read on the website, or in paper format at our testing events.

Once again Updates has been professionally produced by our member Colin Woodman, with major input from former editor Tony Ball and some from myself. We are looking for someone to volunteer as Editor of Updates. Do you have the enthusiasm and motivation to help? Full training will be given.

Stay fit and healthy.

*Brian
Chairman*

Review of PSA testing in Sussex 2022

Photos show PCaSO, with their partners the East Grinstead Lions, in November 2022.

Reception

We have had a record year for the number of PSA tests carried out in Sussex. In the 10 years we have been organising these events, we have tested more men in 2022 than any other year. We held 9 events and tested 4130 men in total, 183 of those had a high red reading and a further 120 were borderline amber readings requiring a further check. Undoubtedly the two big events we held this year in Burgess Hill (1006) and recently East Grinstead (970) have helped swell those numbers, with 48 and 41 high results found respectively. We have had several really high readings, breaking any previous records we had, 922 (65 yr old), 899 (76 yr old) and 218 (58 yr old).



Registration and waiting to see phlebotomists

It is estimated that around a third of all the elevated readings recorded turn out to be prostate cancer following referral and further tests. We are following up on men who have had a high reading and

several of them do become PCaSO members, having been diagnosed with the cancer. An example is Andrew Somerville, who we tested at East Grinstead in 2021, he was only 42 then and had a PSA of 12.6, much

higher than the normal level for that age of less than 2.0 ng/ml. He has now joined PCaSO and organised a sponsored walk, raising over £3000, he has written his story, which you can read in this newsletter.



Review of PSA testing in Sussex 2022 continued from Page 4

Blood samples being taken by volunteer Phlebotomists

Since starting PSA testing, we have tested across our region a total of 26,478 and found an estimated 400 to 500 men with prostate cancer. We would like to thank our partner charities, all the PCaSO volunteers, and the phlebotomists who give up their Saturdays to test the men, that has enabled us to record such a figure. We are in the business of saving lives, and we do!



PSA TESTING STATISTICS 2022

Date	Place	GREEN	AMBER	RED	Totals	% A & R	% RED	
HAMPSHIRE								
12.2.22	Petersfield	285	5	14	304	6.25%	4.6%	
23.4.22	Emsworth	289	6	25	320	9.7%	7.8%	
21.5.22	Gosport	355	17	12	384	7.6%	3.1%	
29.10.22	Eastleigh	292	11	17	320	8.8%	5.3%	
26.11.22	Waterlooville	316	14	20	350	9.7%	5.7%	
		1537	53	88	1678			
SUSSEX								
5.3.22	Uckfield	261	14	12	287	9.1%	4.2%	
2.4.22	Henfield	412	15	18	445	7.4%	4.0%	
14.5.22	Haywards Heath	91	1	8	100	9.0%	8.0%	
25.6.22	Seaford	131	2	7	140	6.4%	5.0%	
3.9.22	Worthing	620	15	27	662	6.3%	4.1%	
8.10.22	Burgess Hill	922	36	48	1006	8.3%	4.8%	
22.10.22	Copthorne GC	136	5	7	148	8.1%	4.7%	
5.11.22	Peacehaven	349	8	15	372	6.18%	4.03%	
26.11.22	East Grinstead	905	24	41	970	6.7%	4.2%	
		3827	120	183	4130			
DORSET								
		0	0	0	0			
ANNUAL TOTALS		5364	173	271	5808			
RUNNING TOTALS								
	2011	2013	2014	2015	2016	2017	2018	Totals
Hampshire		285	264		50	556	825	1980
Sussex	96	218	678	636	810	1277	2335	6050
Dorset		709	753	547	986	1067	1649	5711
							TOTAL	13741
C/F								
	RUNNING TOTALS	2019	2020	2021	2022	2023	2024	Totals
1980	Hampshire	1685	0	512	1678			5855
6050	Sussex	2941	0	641	4130			13762
5711	Dorset	1150	0	0	0			6861
	TOTALS	5776	0			GRAND TOTAL		26478

Emails from members and guests

Hi there Brian

I recently received an email which encouraged people to contact you with their prostate cancer stories. Mine falls under the banner "Alan Titchmarsh saved my life". You may find this a little strange so I will explain!

I enjoy his style of garden rescues, one in particular caught my attention. It centered on a gardener who was suffering with terminal prostate cancer. He only discovered that he had the cancer when it was too late to do anything about it. Since that time he encouraged all his mates at the golf club, the bowls club and his local pub to get a PSA test done. A number of his friends had raised PSA levels and were able to get treatment.

In late July 2018 I was due to have a blood test and requested that my GP included a PSA test in the light of the Alan Titchmarsh show. My GP voiced a little reluctance but I persisted and she agreed to include the test. Subsequently, I received a telephone request to make an urgent appointment with my GP as something appeared in the test results that needed some discussion. As you have already guessed my PSA was rather high, more investigation was required. To cut a long story short I had the dreaded C and quick action was required. My prostate was removed in November 2018 followed by a course of radiotherapy and by June 2019 my PSA level had dramatically fallen to acceptable levels and have remained so ever since. My experience proves the point that a regular PSA test can save lives as up until the original test I presented no traceable symptoms.

I hope my story adds weight to the call for regular PSA test should be undertaken as a matter of course.

Yours in much better health

Davis R Dodds (*member of the Eastbourne PCaSO group*)

Good afternoon

I would like to thank you all for the PSA Test, because I don't think I would have had another test for about a least a couple of years.

At the moment I am going down the route of an operation to remove my prostate.

I have spoken to Macmillan at Worthing Hospital, which again was very helpful.

I am okay at the moment, but when I get a date for the operation, I might well take you up on your offer of some support.

Again I thank you very much for that test.

Thank you for your follow up e-mail.

Following the elevated test result as advised by your team I contacted my GP via the e-consult service and arranged a repeat blood test. This confirmed the elevated level (~9) and triggered off a series of additional tests via the '2-week' rule.

Initially I had an internal examination with the GP and then an MRI scan to investigate some 'nodules'. The result of the MRI was positive in that nothing of concern was noted, but the NHS have suggested that I have a repeat blood test in January. If that shows the same level they will monitor me on a regular basis, if it has increased further they may schedule a biopsy and/or further tests.

I am thankful for the service that your group offers, since without it I would have been unaware of any issue.

Dear Brian,

Thank you for your message, I have been to my GP who sent me to the PRH to have further blood tests the results came back high, as a result I was sent for an MRI scan, I am awaiting results.

Thank you for your concern, without your organisation I would have been none the wiser.

Dear Brian,

Many thanks for getting in touch. I had a follow up which also showed a high reading and an MRI scan which led to being referred for a biopsy.

Obviously, the last few weeks have been a little unsettling as a result but the response from my NHS trust has been prompt and effective and I feel in good hands.

Whatever the outcome I know the testing your charity and your kind volunteers offered has been the starting point of the investigation and I'm hugely grateful to the service you provide.

Once I know what I am dealing with and feel able to share publicly with friends and family I will be encouraging every man I know to take up the offer of a free test and to support your charity.

Yours, with gratitude,

Andrew Somerville's story

An unexpected Birthday Present.

A couple of years ago, if you had asked me to guess what I'd be doing for my 43rd Birthday, facing a diagnosis of prostate cancer wouldn't have been in my top ten guesses. But there I was, after a short whirlwind of events, being given the news that my MRI scan showed an area of 'concern' that was highly likely to be prostate cancer.

Back in July 2021 I had seen a Facebook post by The East Grinstead Lions, advertising a free local PSA test, courtesy of PCaSO. Importantly, the ad stated for all men over the age of 40 and I was aware of what a PSA test was from working in the clinical diagnostic industry for some years. This, and the fact it was free(!) encouraged me to sign up. The PSA testing event came and went, and I thought no more about it; I assumed it would come back 'clear' given my relatively young age, lack of any symptoms whatsoever, and no known family history of the disease

I was however more than a little shocked when the result popped up in my inbox a week later; a 'red' result of 12.6 ng/ml – way above the healthy range for my age. I immediately contacted my GP surgery who, after considerable pestering, agreed to perform a second PSA test. This time the result came back as 10.5 ng/ml, further adding to my now increasing panic. After more phone calls attempting to contact the GP, they finally agreed for a doctor to actually examine me with a 'Digital Rectal Examination'. Not something I had experienced before, but not quite as bad as I imagined! The doctor did put my mind at ease a little, stating that everything felt fine in his opinion, he had never seen prostate cancer in a man of my age before, but he still referred me to East Surrey Hospital for an MRI to check if anything was showing on the prostate.

After referral, the MRI came around very quickly and by now I was fairly certain that, given the GP's reassuring words, the scan wouldn't show anything too concerning; perhaps my prostate was inflamed



simply due to an infection? But, a week later I was sat discussing the result with a Urologist on my 43rd Birthday. This was my first experience of the terrifying use of the word "but" by medical professionals when discussing cancer diagnosis. He started by telling me that the MRI showed that I had "quite a small prostate actually" (phew!), then came the "but" – the MRI showed an area of concern in the form of a lesion on the left side of the prostate (PI-RADS 4 lesion) suggesting a high likelihood of prostate cancer.

At that point the room abruptly lurched to the side and all blood seemed to drain from me. Looking back, this was the single worst point in my journey to date, as I had convinced myself that this would not be anything serious.

After I had regained full awareness of where I was, we discussed the next stage of diagnosis: a biopsy which I opted for under general rather than local anaesthetic. All this was happening just a short while before Christmas, so after wishing me a Happy Birthday and telling me to enjoy Christmas and try not to worry, I was sent on my way.

The biopsy date was booked very quickly (6th January) as I was now on the Cancer Pathway. The after effects of the biopsy were rather uncomfortable, however, I discovered the luxury of a ring cushion for sitting on in the days following the procedure.

Within a matter of days, the result came through which I was now prepared for – cancer. The Urologist told me I had adenocarcinoma of the prostate, tumour grade T2a N0 M0, with a Gleason score of 4+3=7.

Even though I had now resigned myself to the fact I had cancer, I hadn't expected the required treatment to be as drastic as what the team now recommended – radical prostatectomy. The multi-disciplinary team stated that this was by the far the best treatment plan for me given my age and medium to high grade of cancer.

The PSA testing event came and went, and I thought no more about it; I assumed it would come back 'clear' given my relatively young age, lack of any symptoms whatsoever, and no known family history of the disease.

Andrew Somerville's story continued from Page 7

I needed to have a bone scan at the end of January to ensure the cancer had not spread there, prior to being confirmed for surgery. The result of this was the first bit of positive news I had heard in some time; the cancer had not spread to the bones, and I could now focus on my up-coming surgery.

The date of my surgery (robotic-assisted radical prostatectomy) was set for February 14th at The Royal Surrey County Hospital, under the care of Prof. Christopher Eden. I was told by the Urologist that Prof Eden was an extremely experienced surgeon, specialising in nerve-sparing surgery (which I was very keen on having, if at all possible, to reduce the long-term side effects of the procedure).

From the time of my diagnosis, I had decided to get myself in the best shape possible and had managed to drop a fair few pounds, so at least I felt physically fit and well going into theatre.

As this was all happening during the days of the COVID pandemic, I was having endless PCR tests performed before I could go anywhere near a hospital. Not to mention several visits to get my sperm frozen. However, on the day of surgery, the result of my pre-op PCR test had not been sent to RSCH so, I had to sit in a side room (pretty sure it was actually a cupboard!), whilst a hasty PCR test was performed. Fortunately, the result was negative so surgery could now go ahead.

When I came around from the anaesthetic (and sporting some very neat, small wounds), I was told I would be transferred to the Nuffield private hospital at the rear of RSCH, as all NHS beds were full. This turned out to be a pleasant surprise as I now had my own room, a nurse on-call and food that was better than many restaurants I have eaten in. And strangely, I had a pretty good appetite post-surgery.

After a remarkably pleasant overnight stay and visit from the surgeon and his team, I was sent home complete with a catheter in place. Again, not the most comfortable of experiences but the catheter was removed within 2 weeks. At this stage, I was having to wear pads around the clock but, as the surgeon had told me should happen, my "waterworks" started to improve fairly rapidly. This was good timing for me as I'm not great at sitting still for very long, so I was able to start getting much more active again.

The surgeon explained to me that full nerve-sparing had surgery had been conducted and that a good

level of continence and potency should return with time. A short while later, my histology results came through which revealed the cancer was more advanced than initially thought; it was re-diagnosed as pT3a Nx Mx. This meant that it was starting to break out of the prostate capsule BUT it had negative (albeit narrow) surgical margins; fingers crossed, they had got it all but literally in the nick of time.

Three months later, my first post-op PSA result came back undetectable and at 9 months, my latest PSA test has also come back undetectable.

My continence has returned to nearly pre-op levels and other performance 'down below' is pretty good too. I was told this should continue to improve and plateau at 3 years post-op.

I made some significant lifestyle changes concerning my fitness and diet. After some quite detailed research, I have changed my diet to a mostly plant-based one, reduced my alcohol consumption right down to a couple of glasses of wine a week and I train hard 5 days a week.

During recovery, I made some significant lifestyle changes concerning my fitness and diet. After some quite detailed research, I have changed my diet to a mostly plant-based one, reduced my alcohol consumption right down to a couple of glasses of wine a week and I train hard 5 days a week. I'm working now as a gardener and teaching martial arts again (I did this over 10 years ago).

I also made a number of changes to reduce stress in my life wherever possible as peer-reviewed research strongly suggests the hugely negative effect that this can have on ones' immune system and ability to fend-off disease.

With the great benefit of hindsight, I can see now that over the past 10 years or so my diet and lifestyle could have been quite a bit healthier than it was. But now, I have to say I feel fantastic and wouldn't have imagined this would be where I am nearly a year on from initial diagnosis. What a busy year 2022 has been for me!

In July, my brother and I did a 60 mile hike across Devon and Somerset (The Coleridge Way), by way of a thank-you to raise money for PCaSO. We raised over £3K which I hope would pay for a fair few PSA tests! I've also become rather vocal amongst my friends and (anyone else who will listen!) regarding my disease and treatment and how lucky I've been to have caught it when I did. As a result, many of them have now been tested and will continue to be tested regularly. And I shall continue to be rather vocal about the critical importance of PSA testing for men of all ages. I am very open to talk to any men about what I've been through; the ups and the downs.

Lobbying for National Screening

Each year some 50,000 men are diagnosed with prostate cancer in the UK, and nearly half of these patients will have advanced cancer, stages 3 or 4, at the time of diagnosis. Yet despite the fact that early diagnosis can significantly increase men's likelihood of successfully tackling the cancer, there is still no national screening programme. This places prostate cancer patients at a great disadvantage when compared to breast, cervical and bowel cancers that have long had screening programmes as standard.

The organisation that controls and recommends a wide range of screening programmes (to the Government and the NHS) is the National Screening Committee (NSC) whose members have tended to focus on the risk of over-diagnosis and over-treatment, rather than catching the cancer early. Most readers will be very much aware that in its early stages, prostate cancer presents no symptoms, so by the time a man is suffering pain or discomfort, the cancer can sadly be well established.

There is no simple test for prostate cancer excepting the Prostate Specific Antigen (PSA) test that is a 'marker' for the health of the prostate gland, and is used regularly by the NHS – but usually only when men show symptoms and decide to see their GP. The PSA test has a good accuracy rate when tested by hospital pathology labs, whereas in the past the old 'fingerprick' test was rather more hit & miss. Positive PSA test outcomes are now followed up by hospital MRI scans,

which further reduce the risk of over-diagnosis.

The NSC have recently put out a call (albeit very low-profile!) seeking recommendations for new screening programmes for various medical conditions, and thus providing an opportunity to get prostate cancer back on the agenda. PCaSO has supported a submission by a consortium of support groups, and I have taken the opportunity to send a recommendation in my own name in the context of the "Patient's Voice", and offering my cancer journey as a prime example. I was luckily diagnosed early through attending a PCaSO PSA blood test event back in 2016, although I was asymptomatic at the time.

Screening could easily be arranged and at relatively low cost to the taxpayer, on the basis, for example of 3-yearly test for most men aged (say) 45 to 75, but annual for higher risk groups. Such groups would include close family history of prostate cancer, African-Caribbean heritage, or to monitor slightly elevated PSA readings.

Perhaps this time the NSC will re-consider, and accept that prostate cancer screening is long overdue, to reduce the 12,000 deaths each year through this insidious disease? If the NSC politely declines, I may be asking PCaSO members to sign a petition, or join me with placards in Westminster! However on a positive note, we could in 2023 find we have something magnificent to celebrate....

Lance Allen

Our 1,000th member joins PCaSO

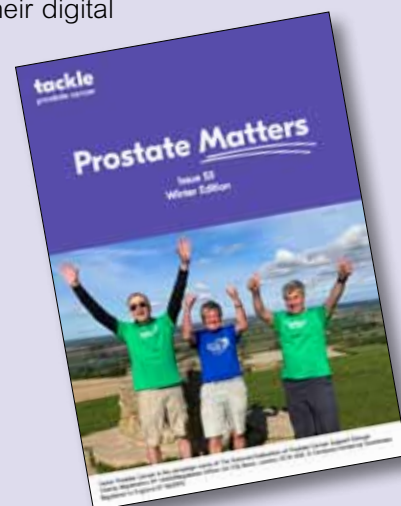
I am very pleased to announce that Rob Stanley recently became our 1,000th member.

Rob has been a friend and an active volunteer with me over the last two years with our previous support group, and about a year ago he also volunteered to help at PCaSO PSA testing days. He has not missed one event, and now works hard with Lauren on our donations desk. Together they make a formidable team, encouraging men to donate and to fill in the Gift Aid forms. This has resulted in total donations to Sussex Branch of over £10,000 and additional gift aid tax refunds of over £3,000 – an excellent job, well done!

Brian Holden

Tackle Newsletter

Tackle have issued their digital version of their newsletter Prostate Matters.



<https://pcaso.org/forms-leaflets/Prostate-Matters-Winter-2022-23.pdf>



PSA Testing

Hampshire Branch held five PSA testing events during the year at Eastleigh, Emsworth, Gosport, Petersfield, and Waterlooville, testing a total of 1678 men, with 88 men having a raised 'red' PSA result and 55 'amber' results.

Events in 2023 are planned for:

Swanwick	18th February
Alton	18th March
Petersfield	15th April
Basingstoke	13th May
Fareham	17th June

Also, events are planned in the autumn for **Cosham**, **Eastleigh** and **Havant** details to follow on www.pcaso.org/psa-testing

Member's Meeting at Waterlooville and Otterbourne

In Dec 2021 we resumed our branch meetings, with the attendance of two Prostate Diagnosis Nurse Practitioners from University Hospital Southampton, namely Ellyse Webb and Sam Oxford.

Their aim was to give us an insight into the prostate diagnostic processes they have adopted at UHS. A key part of this innovative approach is the use of the new biopsy chair, which our Hampshire branch funded in 2020. The chair facilitates the biopsy procedure called 'PrecisionPoint' which gives a more accurate and speedier diagnosis. Earlier in 2021 we funded a second chair.

2022

March **Steve Bond**, Head of Programme – Cancer Patient and Public Involvement gave a talk

on the role and the work of the Wessex Cancer Alliance.

June **Richard Roope**, a Portfolio GP working in Primary Care and Cancer Management, gave an informal talk on the early diagnosis of cancer together with delivery of cancer care.

Sept **Dr. Steve Allen** gave an interesting and first-hand account of some of the side effects of PCa treatment including incontinence and ED. Steve is the acting chairman of Tackle.

Dec **Sarah Gray**, National Support and Development Manager, gave an insight into the role of 'Tackle Prostate Cancer'

Awareness Events

In July several PCaSO members were present at a charity awareness event organised by One Community, held in West St, Fareham.

In November two of our members manned a display stand at Portsmouth's first International Men's Day organised by Dadzclub. Awards were presented by the Lord Mayor of Portsmouth and Stephen Morgan MP for Portsmouth South to local



men and boys for outstanding achievements in the community.

Donations

In March Guildford Phoenix Ice Hockey Team raised nearly £700 for PCaSO.

Ellyse and Sam, and six other members of University Hospital Southampton Urology Dept (*Right*) raised over £2000 for PCaSO by walking from Eastleigh FC to Havant & Waterlooville FC, a distance of 24miles.

Sarah Woolley, the daughter of one of our members, raised over £100 for us by doing a 37.5-mile wheelchair marathon as part of the PCUK 'Run the Month' challenge.

New Members

We welcomed 22 new members up to Nov 2022. Andrew Bloxham, former executive and Hampshire treasurer sadly died.

Peter Weir



Dorset Branch news

Dorset Branch has struggled for a long while to attract volunteers to take on committee roles and PSA testing events, etc., this severely limits activities. Also existing committee members and Trustee representatives have been in post for many years, and feel the need to hand over to new members.

PSA testing:

Hampshire Branch and Sussex Branch managed to restart PSA testing following the period of absence due to Covid-19, but Dorset Branch were unable to do so due to lack of volunteers. However, Dorset Branch are exploring an alternative approach for 2023, using another charity, GFCT, to handle PSA tests for Dorset, this would be more expensive but

possible. These would be PCaSO events handled by the Dorset Branch, together with helpers from local groups/Masons/Lions etc. There could be a practice event in March 2023 to prove the system.

PCaSO-funded 'biopsy chair' now in place:

In Updates No. 71, Spring/Summer 2021 we explained that Dorset Branch had decided to fund the Royal Bournemouth Hospital purchase of a 'biopsy chair' and why. The biopsy chair is now in place and the article below from NHS University Hospitals Dorset describes this purchase and the expected benefits. The associated photo shows Dorset Branch Chairman Allan Higgin handing over a 'cheque' from PCaSo for £14,353.

Prostate cancer patients benefit from new equipment

University Hospital Dorset NHS Charity has funded a new 'biopsy chair' to improve treatment and care for patients with prostate cancer.

The biopsy chair is designed so patients can sit in a more comfortable position while they are having a biopsy taken. It manually moves the patient into position, meaning staff at the Royal Bournemouth Hospital can focus on other elements of care, and is height adjustable making it easier for patients who struggle with their mobility to sit on.

The design also enables a more thorough examination of the prostate, giving more accurate

results and a higher likelihood of detecting cancer in harder to reach areas.

The technology can improve recovery for patients, including reduced risk of infection and readmission, and reducing the need for repeat procedures. The procedure does not require general anaesthetic resulting in a shorter stay in hospital for patients and a positive effect on waiting times.

Dr Christopher Watts, consultant interventional radiologist, said: "The purchase of this chair has made a huge difference to the team and our patients. The chair is a really good way for the patient to

maintain contact with staff while receiving their treatment. Patients are more comfortable and can watch part of the procedure; this hopefully takes away some of the stress from their visit.”

Lindsey Sturman, fundraising manager, said: “The purchase of this equipment will make a massive improvement to the treatment of patients with prostate cancer. This would not have been possible without the incredibly generous donations University Hospitals Dorset NHS Charity received from the Prostate Cancer Support Organisation (Dorset). It has been a privilege to work with them and to hear from the urology team the real difference the equipment will make.”

Right: Representatives from University Hospitals Dorset NHS Charity, PCaSO (Prostate Cancer Support Organisation) and the urology team at University Hospitals Dorset.



Eastbourne Group celebrate 20 Years

The full 20-year story was posted by Debbie Hatfield on Jan 18, 2023

The link is:

<https://www.pcasoeastbourne.org.uk/blog/20-years-and-more>

A few extracts from the Eastbourne Group story are shown below:

“ Brother and sister Graham and Debbie Hatfield started the group in September 2002 following the death of their father with prostate cancer the year before.

Debbie is a nurse by background and at the time was a senior lecturer in nursing. She explained the motivation for starting up the group in her PhD which was about involving patients and the public in the buying and leading of health and care services for communities.

Christina Cutting got involved with the Eastbourne group in 2009. Sadly, her husband Bob died from prostate cancer having been diagnosed with advanced disease. Bob and Christina (aka Chris) attended the group briefly soon after his diagnosis. After Bob died, she returned in February 2009 with Dawn, one of his daughters and presented a very generous fundraising cheque.

In September 2008 we asked Roger Bacon from PCaSO to come and tell us about the federation (later known as Tackle Prostate Cancer) and how we could join PCaSO. The rest is history as they say because in May 2009, we transitioned to PCaSO as our new parent charity.

The Eastbourne group was one of the first to meet face to face again and started up in September 2021. We were aware that not everyone was able to embrace the digital interface. We held five meetings in 2022 but have reduced that to a once a quarter in 2023. We think it is time to move the meetings out of the hospital environment so that we can truly embrace living with and beyond cancer. ‘Survivorship’ and living well has always been our raison d’etre for 20 years and now there is much greater interest in fully embracing the concept with plenty of evidence-based practice.”



Christina Cutting

Debbie Hatfield

Rob Stanley's story

Firstly, I have to stress that everyone is different, and despite what you read here and in the other members' stories, your journey will almost certainly differ from ours.

My PSA was at 4.2 when my GP first thought that I might have an issue with my prostate. He just did a blood test and included PSA in the list. He decided to put me on Tamsulosin (muscle relaxant for sufferers of enlarged prostate, to help with passing water). He also decided to refer me to the urology specialists because my Dad had died from prostate cancer. I asked if I could be referred to the Princess Royal Hospital (PRH) at Haywards Heath, which is part of the Brighton and Sussex University Hospital Trust.

March 2015 – I had my first urology consultation, where they undertook a digital rectal examination (DRE – finger up the back-end) to check the prostate by feeling for irregularities. Nothing was found, but they said to come back in three months. I then had three subsequent appointments with the urology specialists over the next twelve months. My PSA was gradually rising over that period and reached 6.8.

April 2016 – the urology team sent me for an MRI scan, which showed a dark area on the left side of my prostate. That was followed by a guided biopsy in May 2016, where they took about 20 samples based on the MRI findings.

June 2016 – I was told that the dark area in my prostate was cancer, and they also told me that it was still within the gland ('capsule' as they call it). They also said that it wasn't too aggressive – that's the Gleason score – mine was 4 / 3. I was given the usual three options of removal of the prostate, brachytherapy or hormone treatment. I opted for removal of the prostate, a radical prostatectomy.

June 2016 – I went into Eastbourne Hospital for the surgery under Steven Garnett and was released home the next day with a catheter and five small wounds on my tummy area. The catheter was in for ten days.

July 2016 – I attended PRH for a TWOC (Trial Without Catheter), basically to check that when the catheter is taken out you can still pass water OK. I was fine – in fact when the catheter came out I couldn't hold myself at all. I was incontinent, and they gave me some large nappy-like underwear to get home.



I was very depressed about the incontinence, and it took me about two months to get to the point where I was able to do normal things without passing water all the time. Pelvic floor exercises are what help to regain control of the bladder, and I got the hang of it eventually after asking many different professionals how to do them properly – nobody really knew the answer!

August 2016 – I had my first post-op meeting with Steven Garnett, where he told me that everything went well and the cancer had been

removed with the prostate. He asked me to come back in eight weeks and have a PSA test beforehand. During this time, I had got control of the incontinence and everything was good.

September 2016 – I had my second post-op meeting, where my PSA was undetectable (less than 0.01) – that was good news.

For the next three years I was having regular PSA tests and consultations with the urology team in PRH. Everything seemed fine and I was just getting on with life.

May 2019 – I had one of my regular urology visits to PRH, but my PSA had gone to 0.1 which was a really big blow to my confidence. I couldn't understand why that had happened, but they told me it can happen and often does. Having the prostate removed is no guarantee that the cancer won't come back – now they tell me!!!

I was in a very low place mentally after that meeting and I really retreated from the world and let everything slide. I had no thoughts other than "I'm going to die", and that's all I could think about every day. I was put onto anti-depressants (which I have had many times before) and Valium to calm me down. I was losing weight rapidly, and despite needing to eat I just didn't bother.

September 2019 – I was referred to Angus Robinson at the Sussex Cancer Centre with a PSA of 0.25. Angus was very kind to me – he knew that I was suffering from GAD (Generalised Anxiety Disorder) so he explained my options in a simple way – do nothing, have hormone treatment or take radiotherapy. I opted for radiotherapy.

October 2019 – I had my planning CT scan – where they make sure you're fully prepared for the radiotherapy (empty bowel, full bladder), then they put you into the CT machine and then tattoo three permanent dots on your abdomen to help alignment for the radiotherapy. Also

Rob Stanley's story continued from Page 13

at this meeting I was given my dates and times for the radiotherapy – 33 sessions over six and a half weeks.

By this time my mood was lifting somewhat, because at least I was being dealt with and I knew from Internet research that radiotherapy was very effective.

November 2019 – I attended the Radiotherapy Centre in Preston Park, Brighton. They were wonderful, kind people, and I was among fellow sufferers, a lot of whom were far worse-off than I was. After a few weeks the daily routine became a simple thing and I knew all the names of all the staff at the Centre so it was like a little family. Luckily for me, I also met Brian Holden, who was undergoing 23 sessions and was scheduled just after me each day, so we met and talked every morning. Meeting Brian was a revelation to me – here's someone who's going through this ordeal for the second time but he's so motivated and doing many normal things including cycling, going on holiday, sailing, walking, etc...

I was ashamed of myself and determined that I should try to have the same attitude as Brian. I started walking the dog again and I went back to my normal hobbies and pastimes. I felt so much better about things generally – it's called Living Well with Cancer.

December 2019 – My last radiotherapy session finished on Christmas Eve, and I was so pleased to be able to have time to recover. The radiotherapy does give some side-effects – apart from the daily enemas which we have to give ourselves (these cause back passage spasms and are quite uncomfortable), there are known effects from the radio-beam itself, but it wasn't too long before I was able to get back to normal and I was feeling great about everything.

February 2020 – I had a PSA test and a follow-up consultation with Angus Robinson – my PSA was still going up!! That was unexpected, but by now I was fully into the Living Well with Cancer lifestyle and I took the news very well. The plan was to send me for a Choline PET scan to see what was going on.

May 2020 – the PET scan showed that I had two secondary cancers, but they were small and easily controllable with treatment. Angus Robinson recommended that I go straight onto hormone therapy, which I did through my GP. I started with a month of Bicalutamide and after one week of that I was given an injection of Zoladex concurrently, which lasts for three months.

September 2020 – I had a PSA test and a follow-up call from Angus Robinson – my PSA was down to 0.03

which was fantastic. I had a PSA test at my GP just beforehand, and that said less than 0.01 – both results were good news.

Dec 2020 – My PSA reading was 0.01, which I was assured was as low as could be expected, so I was happy. There are some side effects from the Zoladex, but they're not really a big problem.

Dec 2020 – I joined the Mid Sussex Prostate Cancer Support Group. I was invited to join the committee in Jan 2021 and was then responsible for organizing the group walks, the weekly group update emails and the 2-weekly zoom chat room sessions. I really enjoyed meeting all the other members and hearing their stories as well as providing them with support and advice.

Nov 2022 – Now over two years on the Zoladex and my PSA and testosterone have been undetectable for the last two years.

Since I met Brian Holden, and another guy called Brian who was also undergoing radiotherapy at the same time as us, we have formed a friendship based on our mutual experience of cancer and our love of cycling. We go out on our bikes regularly, weather and other commitments permitting. We usually meet somewhere convenient to us all and have a great time just talking to each other and have something to eat and a good laugh. I have also taken up indoors rowing again and am trying to do that every day, but I don't always feel like doing it – so I don't.

What have I learnt through this 6-year period?

Don't let a diagnosis of cancer get you down – the first time I was diagnosed I took it well, but the second time wasn't so good for me mentally. Big mistake.

Whatever happens during your treatment, remember that the professionals are trying their best to make you better – they are dedicated and caring.

Join a support group if you like that sort of thing, because when you meet people in a similar situation to yourself it's like belonging to a club – everyone has the same interest and all want the same outcome.

Don't wallow in self-pity, because those negative emotions will have a detrimental effect on your condition and on those people around you. I've tried it and it doesn't do any good!!

More to come in the future I suspect...

Rob Stanley

Healthy Living may reduce the risk of cancer developing or recurring

During 2019 I assisted Roger Bacon in updating the PCaSO Knowledge Empowers Information Booklet (known as KE for short). KE is very informative on medical aspects of prostate cancer diagnosis and treatments and has been developed and updated regularly by our past and present members over many years. The 72-page KE booklet is currently at Version 8 (published January 2020, in print and on the PCaSO website). Our KE booklet was also adopted by 'Tackle', the National Federation of Prostate Cancer Groups, and made available to other groups nationally, under a Tackle cover. (Dr. Steve Allen of Tackle had helped review KE drafts).

There are only a few pages in KE specifically about healthy living aspects, so we recognised the opportunity to create and publish a 'sister' booklet to KE that was dedicated to expanded information on healthy living. A team was formed of Lance Allen, Brian Holden, Mark Giddings and Tony Ball, with Roger Bacon as team reviewer. In 2021 Brian organised a talk to members on Diet and Nutrition by Nicky Robinson of cancer charity Penny Brohn UK and a talk on Exercise by Peter Williamson. You can view or download these talks, as videos on:

<https://pcaso.org/videos/>

Some of the healthy living content was released in previous editions of Updates, then after a great deal of further work, some with our own Designer, Colin Woodman, the new PCaSO Healthy Living booklet was completed and published, at Version 1, in October 2022. At 64-pages it turned out longer than we anticipated, but it is such a broad and developing topic it needed proper consideration.

Most people are aware that cancer is best dealt with when diagnosed early, as curative treatments may be still possible, or in the case of low-grade prostate cancer, possibly just 'Active Surveillance'. However by the time actual symptoms arise prostate cancer may have developed further and the range of treatment options becomes more limited. PCaSO believes that any man over 40 should become aware of the increasing prostate cancer risk as they age. Following an unhealthy lifestyle may further



increase this risk, whereas adopting a healthier lifestyle may reduce it.

As well as 'survivors' of prostate cancer treatment, for whom healthy living might guard against or slow any cancer progression or recurrence in later years, the new Healthy Living booklet has been broadened in scope to be an awareness tool for (un-diagnosed) men, such as those who voluntarily attend our PSA testing events. Commencing with the Burgess Hill, Sussex event on 8th October 2022, held in conjunction with the local Lions charity, PCaSO have been offering a printed copy of the Healthy Living booklet to all men who come for a PSA test at our events (about 3000 copies taken so far since October by attendees at PSA events, etc).

The Healthy Living booklet can be viewed on the website under 'Information' then 'Publications', or via the link below:

<https://pcaso.org/publications/>

We welcome any feedback on how we might improve this new Healthy Living booklet in future.

Tony Ball



Mark Giddings – Story update

Prostate Cancer recurrence and resulting HIFU treatment

This article is a follow up to my original 'Patient Story' (published in PCaSO's "Updates" issue 63, Summer 2018) where I discussed receiving a 'Trial' triple course of Radiotherapy (RT) following 3 years of ADT Hormone treatment (Zoladex/ Bicalutamide). This in turn was initial treatment following a routine PCaSO Test in 2014 when, at age 59, a PSA of 126 was discovered.

Since the RT, I continued on routine surveillance PSA checks at The Royal Marsden. These had been fairly consistent at 0.04 for 4 years, but in late 2021 had started doubling every 6 months – time for action again!

An MRI and a PET scan were duly actioned to investigate. The tests confirmed the cancer was active again, though it appeared still confined within the prostate.

The Marsden commenced further checks with a view of determining which options they considered 'best' suited. It transpired that any future treatment is now termed "salvage ", not exactly the most pleasant terminology (I do hope they change it sometime!).

It was now I heard for the first time that the original RT would have left substantially damaged "tissue, tubes and ducts" in and around the prostate. This invariably brings complications for any subsequent surgery due to the difficulty when trying to connect such tissue (including urethra, etc.). In addition, because I had received fairly high doses of RT, there was only a limited extra dose of RT they could administer, if surgery proved impractical.

It was therefore suggested I explore these two options in more detail and then make a choice, once armed with the pro's and con's of each as regards effect on lifestyle, urination frequency and longevity, etc. These two options were:

OPTION 1 – Brachytherapy

They invited me to attend Royal Surrey County Hospital at Guildford for a Template Biopsy and Urinary Flow Tests. These would determine exactly where the cancer was and where it was spreading to, as brachytherapy was deemed a possible choice. The



upside was that physical surgery would be minimised, but there was a risk the brachytherapy rods might need to be positioned too close to the Prostate Wall. They also needed to assess if my body could handle the extra RT to this area.

OPTION 2 – Radical Prostatectomy and possibly Bladder removal too

A meeting was arranged at London's Chelsea and Westminster Hospital so I could similarly be appraised for this surgical option.

On a personal note, I found this all quite traumatising for myself and family as I had optimistically thought the 2017 RT had worked

it's wonder. So much so, I actually consider doing "Nothing" (choosing "quality vs quantity") For, as being someone who loved his sports (walking, cycling, sailing and kitesurfing) I was aware how these would most likely be impacted. However, family discussions ultimately convinced me otherwise. Once again, I wore my 'positive' hat and acknowledged that whilst some eventualities might not be desirable, there was a bigger family dynamic to consider.

Several months passed in arranging these meetings into July 2022. Eventually, brachytherapy was ruled out (a Gleason rated 4+4 Tumour was deemed too close to the Bladder) so the only option was Prostate / Bladder removal. This needed 5 – 7 days in hospital, with a recovery period circa 3 months – not exactly my 1st choice! A decision was now pressing as I was advised time was becoming critical if any treatment was to have success, but something was causing me to hesitate.

At this time my wife and a close friend recommended having a 'second opinion' – "Just in case "!

Long story short, a London-based contact recommended seeing Professor Mark Emberton, a consultant Urologist and Oncologist at King Edward VII's Hospital. Professor Emberton specialises in "HIFU" (High-intensity Focused Ultrasound) I had no knowledge of this, though recalled seeing it mentioned in PCaSO's 'Knowledge Empowers' booklet.

At an initial meeting Professor Emberton explained exactly what HIFU was, together with benefits

Mark Giddings's story continued from Page 16

and risks. It was dependant though on having an immediate MRI to determine the tumour location. Reason being if it had spread outside the prostate, then it wouldn't be suitable.

This was not an NHS option, so costs were evaluated, impact vs Lifestyle and success rate. A huge benefit was just one day in hospital, with a short recovery period of a few weeks. So we chose HIFU.

Three days later I travelled to London for the pre-treatment MRI and PET scan. The result was good and gave Professor Emberton sufficient margin to conduct the treatment. I visited Professor Emberton again for final preparations and was offered a slot only 2 weeks later. On the day of the treatment at King Edward VII, everyone was kind and caring and professional – I had never had 'private' before. I arrived at midday, was wheeled away for anaesthetic at 3pm and "came to" in my room, only 4 hrs later. My wife joined me and we had dinner in my hospital room. The nurse explained all the 'do's and dont's and Professor Emberton swung by to say all had gone well. I walked out of hospital at 8.30 pm, returning on the train to Angmering that same evening.

I was fitted with a Catheter (removed 1 week later). I did find this uncomfortable, for sure. I was also given muscle exercises to religiously do daily, but all in all

quite miraculous that I was out walking (gently) 2 days later, gentle cycling 3 weeks later and back kitesurfing 5 weeks later.

One week after the operation I returned for a post-treatment MRI – this showed an excellent result, with all 'visible' traces of cancer eliminated.

Two months after HIFU, all seems good, family are happy and I'm soon due a 3-month review and further MRI to check. Only issue is that any remnants of sexual drive have gone to zero! Though this was forewarned.

Statistically, I understand HIFU yields similar 3 and 5 year 'success' rates to that of prostatectomy. Another HIFU advantage is that In most cases a second 'dose' of HIFU can be administered if the cancer does return some years later.

All in all, I consider myself fortunate to have been able to have this option.

'We' as a family unit have embraced "Healthy Living" again as we too must share responsibility for ensuring our bodies receive optimum conditions for survival. Indeed PCaSO's new booklet on Exercise, Healthy Eating and Lifestyle is a highly recommended read for everyone.

For those interested, the PCaSO website now hosts a video transcript of a recent PCaSO talk by Prof Mark Emberton, which contains a wealth of information.

Phases and timeline

Initial Diagnosis – 2014 Age 60

PCaSO PSA test – result PSA = 126

Personal decision – intensive healthy living self-care commenced. NHS offered Radiotherapy as an option.

Hormone treatment (ADT)

Remission and ongoing PSA monitoring

PCaSO Penny Brohn course (self and wife) and continuation of intensive healthy living

Had ADT for 3 yrs (Zoladex Injections, plus Bicalutamide tablets)

2017 – Marsden suggestion of Radiotherapy Trial (PSA @ 0.04)

Salvage Radiotherapy (EBRT) – to prostate, but also to both lower abdomen and upper abdomen. Reason; research suggested after 3 yrs of ADT it became ineffective and also, that the cancer was deemed 'likely' to slowly be spreading into these three areas.

Remission and ongoing PSA monitoring

1st Recurrence – late 2020 (Rising PSA past 18mths, levels; 0.07, 0.14. 0.27

New PET scan & MRI; series of 5 tumours found WITHIN prostate; 4x 4/3 & 1x 4/4

Two NHS treatment options offered via Royal Marsden Hospital, Sutton. Advised to consider & evaluate +/- of each.

Treatments difficult because of previous radiotherapy, advised potential for severe side-effects

Salvage Brachytherapy tests and review Royal Surrey Hospital, Guildford

Salvage Prostatectomy review at Chelsea and Westminster Hospital, London

July 2022 – brachytherapy ruled out, so only NHS option offered was salvage radiotherapy

Aug 2022 – Chelsea advised Bladder removal too, due to proximity of 4/4 Tumour

Personal decision made, with wife Angela, to have a '2nd opinion', to explore any other options as a tricky surgical operation, with likely severe ongoing side effects, particularly potential loss of bladder & effects on lifestyle/sports etc

Consultant Urologist/Oncologist specialising in HIFU consulted at King Edward VII Hospital, London; +/- explained about HIFU

Proceeded to MRI and PET scan, to assess if HIFU suitable.

Salvage HIFU treatment at King Edward VII Hospital (private patient) 30 sep 2022

MRI a week later, all visible traces of cancer eliminated

Remission but with ongoing assessment (King Edward/NHS)

PSA Testing Events 2023

Feb	18th	Swanwick	(Hants)
March	11th	Uckfield	(Sussex)
	18th	Alton	(Hants)
April	1st	Hove	(Sussex)
	15th	Petersfield	(Hants)
	22nd	Henfield	(Sussex)
May	13th	Basingstoke	(Hants)
	20th	Seaford	(Sussex)
June	3rd	Horsham	(Sussex)
	17th	Fareham	(Hants)

PCaSO Zoom Events**Thursday 2nd March, 7pm.**

With our Medical Advisor, **Professor Chris Parker, Consultant in Clinical Oncology at Royal Marsden Hospital**, who will present the results of RADICALS-HD. RADICALS is a clinical trial protocol including a number of randomised comparisons. The research is taking place in the UK, Canada, Denmark and the Republic of Ireland.

To attend this event please email chair@pcaso.org to ensure that you receive the Zoom link a few days before the meeting.

Local Support Meetings**Eastbourne:**

Our meetings are open to anyone who has an interest in prostate cancer. This includes men with prostate cancer, their partners, family members, carers and friends. We meet four times in the year, usually on a Thursday, at 7.00 pm in the Education Centre, Eastbourne District General Hospital. Subject to COVID safe arrangements, including restricted numbers. Please book a place by emailing:

contactus@pcasoeastbourne.org.uk

2023**9 March** (7.00pm)

Management and treatment of advanced metastatic prostate cancer talk by Dr A Soultati, Consultant Medical Oncologist in East Sussex.

8 June tba**14 September** tba**14 December** tba**Hampshire:****March 28th** (7.30pm) Otterbourne

Radiotherapy and Prostate Cancer talk by Clare Murphy, Trainee Urology Consultant Radiographer, Queen Alexandra Hospital, Portsmouth

Video presentations available now on PCaSO website

www.pcaso.org (click top RH menu then 'Information')

HIFU (High Intensity Focused Ultrasound)	14 Nov 2022	81 min
Retzius - sparing robotic radical prostatectomy	26 Aug 2021	52min
Developments in Immunotherapy	19 May 2021	76 min
Diet and Nutrition	22 April 2021	123 min
Chaloner Chute: Prostate Cancer – One Man's Journey	2 March 2021	58 min
Healthy Living - Exercise	18 Feb 2021	91 min
Keeping Active through & beyond Prostate Cancer	14 Jan 2021	56 min
HDR Brachytherapy	26 Nov 2020	24 min
Radicals RT Randomised Controlled Trial	26 Nov 2020	34 min
Erectile Dysfunction	14 Oct 2020	63 min
PCaSO & Prostate Cancer	2020	4 min
PCaSO - what happens at a PSA Test event	2020	5 min

The Surrey and Sussex NHS Cancer Alliance (search for [surrey-and-sussex-cancer-alliance/news-and-events/](https://www.surrey-and-sussex-cancer-alliance/news-and-events/)) is promoting prostate cancer awareness and early diagnosis. It has also released a video presentation

starring PCaSO members Lance Allen and Brian Holden. This video can be found on YouTube at:

<https://www.youtube.com/watch?v=ehUVo7RTPU8>