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National Help Line: **0800 035 5302**

Support Organisation

www.pcaso.org

Charity No: 1170536

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.

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From the Editor

It has taken a long time and a great deal of work but the new version of our PCaSO **Knowledge Empowers Information Booklet** was finally published in January 2020. It is on the website and printed copies are available through Branches and Local Support Meetings.

The 'Stephen Fry and Bill Turnbull effect' has been beneficial in raising awareness and, together with PSA testing by numerous charities such as PCaSO, is thought to be a factor in the record levels of prostate cancer diagnosed in England in 2018. PCaSO tested 5776 men in 2019, raising the total since we started to 19,286.

We always like to include a 'Patient Story' in Updates so that people can learn from the experiences of other men in their prostate cancer 'journey'. We have a new twist on that from a woman's perspective, thanks to Nicky Annells 'standing by her man'! We have also started a healthy eating series with a soup recipe by Nicky, rich in lycopene.

It is some time away yet but the PCaSO AGM has been set for 1st July at Chichester, as last year. We have some enquiries out to enlist a senior medical person as speaker for that evening. So please make a note to attend if you can.

Note: Where we use the words 'man' or 'men' this refers to a person(s) with a prostate gland in their anatomy, irrespective of any gender choices they may make.

Further diagnosis and treatment after Surgery

A biopsy is a means to take tiny sample cores from the prostate to determine if it is cancerous. These cores will be examined in the pathology lab and their grading will contribute towards the diagnosis.

Those men who have their prostate removed by surgery (radical prostatectomy) will have the removed prostate gland also examined in the pathology lab. This provides a larger sample than the original biopsy and permits a more extensive assessment of the cancer. Sometimes this fuller knowledge may result in a regrading of the diagnosis.

Most men will not require any further treatment after prostate surgery and will be monitored regularly by PSA testing, etc, to ensure there is no recurrence of the cancer. (NICE Guideline 2019 clause 1.3.29 states immediate post-operative radiotherapy should only be used in context of a clinical trial).

In general, men only receive radiotherapy following surgery if their surgical pathology shows certain adverse features. Or if, usually some years later, their PSA level rises to an extent (usually above 0.2 ng/ml) that indicates recurrence of the cancer.

RADICALS Trial most men can safely avoid radiotherapy after surgery

In September last year the first results from the RADICALS-RT trial were presented at a major medical oncology conference in Spain. These results suggest that most men with prostate cancer can safely avoid radiotherapy after surgery.

The RADICALS-RT trial looked at 1396 men with prostate cancer who had recently had surgery to remove the cancer. They were allocated at random to receive either early radiotherapy or observation. Patients that were under observation (the standard care group) received deferred radiotherapy if their PSA level started to rise.

RADICALS-RT found that after five years, 15 out of 100 men in the early radiotherapy group and 12 out of 100 men in the deferred radiotherapy group had prostate cancer that had returned after treatment. The results suggest that radiotherapy can be safely

deferred, rather than given straight away after surgery.

Four in ten men in the observation group went on to need radiotherapy within five years of surgery. The other six in ten men avoided radiotherapy for at least five years after surgery, which means they also avoided the side-effects of radiotherapy.

These results have been submitted for publication in a medical journal.

The RADICALS-RT trial is continuing to follow-up the men taking part, to see what effect early radiotherapy might have in the longer term. Another part of the RADICALS trial is looking at the use of hormone therapy in men who are receiving radiotherapy after surgery. More results from both parts of the trial are expected within the next few years.

For more information about the RADICALS trial, visit http://bit.ly/RADICALS-RT

Knowledge Empowers Information Booklet

January 2020

Building on the work of the previous version from 2016 this new edition has been completely revised and updated with the latest information. It has been expanded to 76 pages and presented in a new and hopefully more user-friendly style. The information booklet sets out to provide a comprehensive guide, from a patient's perspective, to most aspects of prostate cancer. It aims to help men diagnosed with the disease (and their partners, friends and family) to understand about prostate cancer and its effects in order to have sufficient knowledge to give them confidence when talking to GPs, hospital consultants and specialist nurses. It is available to view or download at our website

www.pcaso.org



Printed copies are available to PCaSO members and non-members, at PCaSO Group meetings.

NPCA Annual Report 2019

The sixth National Prostate Cancer Audit annual report for England and Wales was published in January 2020 and its statistics cover men diagnosed with, or treated for, prostate cancer between 1st April 2017 and 31st March 2018.

The full Report is 50 pages and is mainly for health professionals, but contains some interesting statistics for patients, we show

a few statistics and findings here (note these do not cover the whole of the UK). To see the full report go to:

https://www.npca.org.uk/content/uploads/2020/01/NPCA-Annual-Report-2019_090120.pdf

In England 13% of newly diagnosed men were under 60, 32% between 60 and 70, 38% between 70 and 80 years of age, and 17% were 80 years and over.

Use of mpMRI continues to increase. 87% of men in England having multiparametric MRI had it carried out before biopsy.

TRUS biopsies are still dominant, but 17% of men had a transperineal (template) biopsy (up from 12% in 2016/17)

Docetaxel is now advised as a treatment option for men with high-risk nonmetastatic prostate cancer and recommended for metastatic prostate cancer. 27% of men newly presenting with metastatic disease received primary docetaxel.

The proportion of men presenting with metastatic disease was 16% (no change from 2016/17)

Potential 'over-treatment' of men with low-risk disease was 4% (no change from 2016/17)

32% of men with high-risk / locally-advanced prostate cancer did not

have radical treatment and were potentially 'under-treated'. (33% in 2016-17)

Men with a family history of prostate, breast or ovarian cancer should seek advice from their GP.

Active Surveillance should continue to be advocated in the first instance for men with low-risk prostate cancer.

Brachytherapy Boost was used in 5% of high risk/locally advanced cases

14% of men were readmitted within 3 months following surgery.

Within 2 years of treatment:

1 in 10 men experienced severe genito-urinary complications after surgery

1 in 10 men experienced gastrointestinal complications after radical radiotherapy

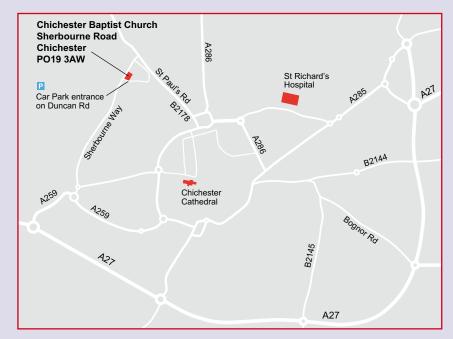
PCaSO Annual General Meeting

NOTICE is hereby given that the Annual General Meeting of PCaSO Prostate Cancer Support Organisation will be held at the Chichester Baptist Church, Sherbourne Road, Chichester, PO19 3AW on Wednesday 1st July 2020 at 7.00 pm for the following purpose:

- **1.** Approve minutes of the AGM held on 3rd July 2019
- **2.** Trustees report for the past year.
- **3.** Accounts report for the year ending 31st March 2020
- **4.** Election of the PCaSO Trustees
- **5.** Any other business.

It is requested that nominations for PCaSO Trustees are with the Secretary 14 days prior to the AGM, i.e. by 17th June 2020. The Secretary, PCaSO, 4 Skeyne Drive, Pulborough RH20 2BB.

email: secretary@pcaso.org

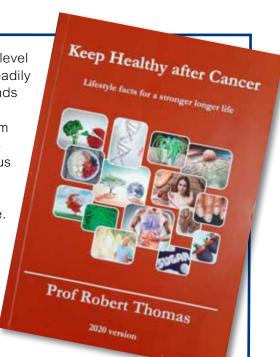


'Keep Healthy after Cancer'

Sussex Branch have purchased a number of copies of **Professor Robert Thomas's** updated book and are making them available to members through the Groups in Sussex, a donation of at least £5 per copy would be appreciated. Professor Thomas is well respected and gave a fascinating talk to a large audience at PCaSO Chichester Group several years ago.

His book is over 300 pages long and covers an amazing number

of topics, some of them in a level of detail that one does not readily find elsewhere. This book lends itself to selecting sections to read, rather than reading from cover to cover. Not all of it is applicable as it covers various types of cancer, but it can be very useful and there is something there for everyone. For those of us who have had cancer we need to be more aware of looking after our general health and this book deals with that as well as side-effect of treatment.



Special Note as to 2020 PSA testing events

At the time of writing there is an unusual level of uncertainty surrounding the PSA testing events. Firstly, over how the implementation of the latest online booking and results system is deployed across events for all three of our PCaSO branches. Secondly how the coronavirus (Covid-19) and its containment measures might impact our events. So, whereas in previous newsletters there was in practice little change to the listed events,

you should now always check that an event is to proceed, any change of circumstance as to how the event is to be booked and any special measures that may be required for public safety reasons (including all our volunteers).

Anyway subject to the above, below is what we currently plan as far as June 2020 (other events are planned for the autumn but are not shown yet)

PSA Testing Events:

Check our website www.pcaso.org for the latest details

PSA testing is by booked appointment only.

To register online go to **www.psatesting.org** and follow the links to the event you are interested in. If you do not have a computer ask a family member or friend to help you complete the process'.

Mar	Sat 21st	Copthorne (Sussex)	12.50pm – 3pm	
April	Sat 4th	Littlehampton (Sussex)	CANCELLED	
April	Sat 25th	Uckfield (Sussex)	CANCELLED	
May	Sat 16th	Seaford (Sussex)	10am –1pm	
May	Sat 16th	New Milton (Dorset)	9.30am – 12.30pm	
May	Sat 16th	Petersfield (Hampshire)	10am - 2.30pm	
June	Sat 6th	Horsham (Sussex)	10am –1pm	
June	Sat 6th	Gosport (Hampshire)	10am – 2.30pm	

PCaSO Members

At most events we need help to make them run smoothly. Checking men in at the door, calling them forward and pre-briefing.

Most events are on a Saturday and usually finished by mid-afternoon. If you are available on any of the dates stated you will be most welcome! Please call:

 Roger Bacon (Sussex)
 01903 775783

 Peter Weir (Hampshire)
 01489 892168

 Allan Higgin (Dorset)
 01202 691710

Submission to UK National Screening Committee

On 31st January 2020 Tackle reported the following:

"In partnership with **CHAPS** and **ORCHID**, Tackle has submitted our views on prostate cancer screening to the UK National Screening Committee (NSC).

In their last review in 2015/16, the NSC did not recommend screening for the following reasons:

Evidence suggests prostate specific antigen (PSA) testing could reduce prostate-cancer related mortality by 21%. Despite this, the major harms of treating men who incorrectly test positive still outweigh the benefits.

The PSA test is a poor test for prostate cancer and a more specific and sensitive test is needed. The PSA test is unable to distinguish between slow-growing and fast-growing cancers.

Current evidence does not support a population screening programme using any other test. Valuation is currently taking place which could have the potential to improve the accuracy of PSA testing to identify men at greater risk of fast-growing prostate cancers.

The NSC is due to review prostate cancer screening again this year. As part of our campaign for earlier diagnosis, Tackle has long supported national screening for prostate cancer, particularly for men at higher risk and the evidence supports its introduction. So, we wanted to make our views known to the NSC.

We are extremely grateful to Chris Booth, a member of our Clinical Advisory Board, who has put together the submission on our behalf, the conclusion of which is:

The UK's current annual death rate of 12,000 men – that's one death every 45 minutes – is unacceptable and the argument that the harms of screening outweigh the benefits is no longer valid.

Despite awareness campaigns raising the profile of prostate

cancer, the low rate of PSA testing in the UK has resulted in little opportunity to use the tools we already have for early detection, discrimination between aggressive and non-aggressive cancer and the cheaper option of early, curative treatment compared with late, expensive, palliation of advanced prostate cancer. Adoption now of proven, best practice use of PSA on a national scale could halve the UK death rate. However, Primary Care does not have the capability to manage such a programme.

In the light of this evidence, the status quo discriminates against men, is financially unsound and medically unsustainable. We therefore recommend a fundamental change in the utilisation and delivery of PSA screening commencing with men at high risk as the first steps in establishing an adequate, national approach to reducing the UK's unacceptable death rate from this most pernicious cancer."

Prostate Cancer now the most commonly diagnosed cancer in England!

That's the awful news men are now hearing. On Monday 27th January it was announced in the press and by Prostate Cancer UK that Public Health England data revealed 49,029 men had been diagnosed with prostate cancer in England in 2018, the highest number ever recorded, with 7,828 more men diagnosed than in 2017 (a 19% increase). These figures only refer to men in England, but they're indicative of UK-wide trends. full UK-wide data will be released in the spring and it is likely to be well over 50,000, the last UK figures recorded were averaged over 2014-2016 and stand at 47,740.

The dramatic increase in diagnoses shown in the Public

Health England data is likely due to more men having a PSA test. In early 2018 firstly Stephen Fry and then Bill Turnbull spoke out about their prostate cancer journeys, which dramatically increased awareness and created what we call now the Turnbull-Fry effect. We don't know whether diagnosis rates will remain at this record high, and we also don't know how many of these cancers may never have been detected and never caused men any harm. We do know that for some men, the earlier diagnosis made possible by this increased awareness may well have saved their lives.

What is PCaSO doing? PCaSO will continue to offer "free" PSA screening at organised events throughout Sussex, Hampshire and Dorset. The table on Page 7 shows our PSA testing Statistics for 2019. We tested 5776 men across our region, almost a 20%



PSA TESTING STATISTICS 2019

Date	Place	GREEN	AMBER	AMBER	RED	Totals	% A&R	% RED
HAMPSHIR			ALERT					
02/03/19	Petersfield	164 189		5	12	181	9.39%	6.6%
	Portsmouth FC			8	13	210	10.0%	6.2%
06/04/19	Botley	152		0	6	158	3.8%	3.8%
18/05/19	Hayling Island	297	4	6	6	313	3.8%	1.9%
15/06/19	Basingstoke	64	1	4	2	71	8.5%	2.8%
07/09/19	Emsworth	127		4	4	135	5.9%	3.0%
21/09/19	Southampton	88		1	2	91	3.3%	2.2%
05/10/19	Alton	192		9	8	209	8.1%	3.8%
19/10/19	Gosport	236		4	13	253	6.7%	5.1%
09/11/19	Bordon	60		0	4	64	6.3%	6.3%
		1569	5	36	70	1685		
SUSSEX	6		_	,	,		0.50/	0.70/
06/04/19	Uckfield	131 81	5	4	1	141	3.5%	0.7%
09/04/19	3(,			2	5	88	8.0%	5.7%
11/05/19	Chichester	176 227		6	9	191	7.9%	4.7%
	29/06/19 Horsham			5	8	240	5.4%	3.3%
24/08/19	Pyecombe	76		1	1	78	2.6%	1.3%
07/09/19	Worthing	434		13	22	469	7.5%	4.7%
28/09/19	Hove	291 598	7	6	7	311	4.2%	2.3%
	2/10/19 Burgess Hill			16	23	637	6.12%	3.61%
23/11/19	East Grinstead	394	7	16	23	440	8.9%	5.2%
07/12/19 Peacehaven		307	8	12	19	346	9.0%	5.5%
		2715	27	81	118	2941		
DORSET		335					0.00/	4.407
23/02/19				9	16	360	6.9%	4.4%
23/03/19				12	22	300	11.3%	7.3%
24/04/19				5	2	81	8.6%	2.5%
01/06/19	Weymouth	194		7	9	210	7.6%	4.3%
02/11/19	Bridport	181	4	9	5	199	7.0%	2.5%
		1050	4	42	54	1150		
ANNUAL TO	TALS	5334	67	159	242	5776		
RUNNING TO	OTALS 2011	2013	2014	2015	2016	2017	2018	2019 TOTALS
Hampshire		285	264		50	556	825	1685 3665
Sussex	96	218	678	636	810	1277	2335	2941 8991
Dorset		709	753	547	986	832	1653	1150 6630
-								ID TOTAL 19286

increase on the previous year, which reflects the increase seen in Public Health England data. Of those men tested 401 had a raised reading and were recommended to consult their GP. One of the great benefits of these events is being able to educate men about the prostate and raise awareness of all the problems it can cause them. In order to achieve this, thanks go to all the volunteers, who form an experienced and knowledgeable team that organise and process the men through each test event. PCaSO have scheduled an extensive programme of PSA testing events

for 2020. In 2019 we developed and used a computerised booking system, thanks to Cliff Carter for his expertise, and this year that is being taken a stage further, with men being able to access their result via the bookings website.

All this valuable work in spreading awareness and ultimately saving lives can only be done if we have enough volunteers to help. If you would like to get involved and help PCaSO save lives then do make contact with someone on your Branch committee, contact details are on page 2 of this newsletter.

Roger Bacon - Chairman

Note: A 'Green' result indicates the PSA value is within the 'normal' range for the age band of the man tested. An 'Amber Alert' means that although the PSA result is still within the normal Green scale, it has increased significantly from a previous PSA result. An 'Amber' result that the PSA value is a little above the normal range. A 'Red' result that the PSA value is even higher. This is explained in the applicable letter sent to the man by the Graham Fulford Charitable Trust on behalf of PCaSO. In the letters for an Amber Alert, Amber or a Red result the man is advised to consult his Doctor.

'STAND BY YOUR MAN'

A WIFE'S PERSPECTIVE OF THE JOURNEY OF PROSTATE CANCER

by Nicky Annells - Hampshire Branch

New Year 2012 arrived without ceremony. Neither of us made any earth-shattering resolutions but we were both very happy in the knowledge that both now being retired with more globetrotting holidays planned and more time to enjoy our French home, life was good. Neither of us could have imagined how quickly our lives would be changed. All our plans for a stress-free retirement would evaporate and our lives would take a turn that neither of us could have foreseen.

A few days into January Graham just casually mentioned that he found going for a pee was painful and occurring more frequently. I soon discovered that this had been the case for about 3 months. Something, a feeling, a premonition, made me decide that he needed to see his GP urgently. This was very much against a backdrop of Graham protesting that he was sure it was nothing to worry about and that I was panicking unnecessarily, and we should wait another few weeks. Graham was 67 and had never really had a day's illness in his life but somehow I knew something was wrong.

In the time-honoured tradition of a happily established marriage I ignored his protest and got him an appointment with the GP, thankfully within a few days. Graham went to the appointment with the mindset that there was nothing wrong but if it stopped me nagging and fretting it was worth it. The GP did a rectal examination and advised that his prostate was about the size of a large plum and arranged for him to have a PSA test. Graham returned home with the news that the GP was not concerned but that he had to go back in a week for the results of the PSA test.

Somehow, I still sensed that something was wrong so we agreed I would accompany Graham for the result of the PSA test. We entered the consulting room at 0820 and it seemed as if we had hardly sat down before, without ceremony, the GP announced "your PSA level is 14 and I think you probably have Prostate Cancer. I will refer you for fast track treatment to Queen Alexandra Hospital (QAH) and you should be seen within 2 weeks." That was it! End of consultation. No advice, no explanation about the disease or of available treatments. We left the room in shock and silence and when we got to the car, I looked at my watch, it was 0824. We had had a 4-minute consultation and in that time the GP had delivered the news that Graham had cancer without any explanation or compassion and our lives had been turned upside down.

I can remember sitting in the car in the carpark, hugging Graham and feeling very scared and frightened of the future as I had no idea whatsoever about the condition/diagnosis we had just been told about. We were both in tears with all sorts of thoughts going through our minds.

Being a person who is normally calm and in control I knew I needed to research and understand the disease so immediately we got home I went straight to the computer determined to research and find out more about this disease that had just entered our lives. Now, the Internet is a marvellous thing, it contains the knowledge of the Universe, but it can give one information overload, and, in my case, it frightened me silly. I started to panic every



time Graham winced or groaned. I imagined the cancer was rampaging through his body.

Graham's hospital appointment eventually came through and he was sent for another PSA test and we were told we would be seen in another month which turned out to be 6 weeks. We were not given a specific Specialist Oncology Nurse, nor any further information and we returned home once again with more questions than answers. All that we knew was that we were on the Watch and Wait care pathway and from our perspective, there was no apparent urgency, which I found very hard to understand.

As a retired Civil Servant, I can do acronyms with the best of them, but I was constantly needing to translate these baffling abbreviations that was the normal language of the PCa Urology world, DRE, Gleeson, TRUS Biopsy, MDT etc.

In the midst of our newly acquired "living with cancer" status, Graham was diagnosed with what was thought to be a hernia and again referred for a Hospital outpatient appointment. The appointment clerk telephoned to say that the waiting list at QAH was very long but we could be seen within a few weeks at Petersfield Hospital. In an effort to try and get something resolved we accepted the appointment and travelled the 22 miles to Petersfield (we later learnt from the Consultant that we could have been seen at Gosport Hospital, 6 miles from home but their appointment systems was not linked to the one at QAH!).

By pure serendipity our trip to Petersfield Hospital was to be the turning point in our quest to learn and understand more about P Ca and shed ourselves of the fear and ignorance surrounding it. After the appointment we stopped at a supermarket and there was our now dear friend John Harmer doing a P Ca Awareness Day. John handed me two PCaSO leaflets, "Don't Get Caught Out" and "Pick Me Up". The words "PCaSO Offers Help, Support and Advice" together with the Helpline number, just leapt out at me. As soon as we returned home, I telephoned the helpline and spoke to now retired Ian Graham-Jones (PCaSO Trustee and Secretary to the then Central Branch), who did an amazing job at answering all my questions and offering to send me the "Knowledge Empowers" booklet. I now look back and realise that this was the point when we realised we were not alone and our fear and ignorance of P Ca started to subside, as PCaSO had provided the lifeline to the information and answers that we both desperately needed.

A further appointment came for Graham to have a TRUS biopsy and we again waited more agonising weeks for the results, but they were at odds with his rapidly rising PSA. At this point we both strenuously requested an MRI scan, which 8 years ago was not the norm. Time was again passing and in desperation to obtain the MRI result we paid to see the Consultant privately. The MRI showed that the cancer was at the back of the gland, hence it had not been detected by the biopsies. Graham and I were adamant that we wanted the gland removed and his Consultant agreed to discuss his case with the MDT.

Late July 2012 Graham underwent a Radical Prostatectomy and, although very successful, some nerve endings could not be spared. Of course adjustments have had to be made to the "honeymoon" side of our marriage but that said they are no different to those you would expect or experience by happily growing old together, which thanks to the

surgery we hope to enjoy for many more years. The most important fact I felt, was that all our decisions were discussed and made jointly.

Our P Ca journey started 8 years ago and during that time we have both tried to support PCaSO, men, their families and friends who have been diagnosed or who live with the disease, as it is our way of trying to repay a debt of gratitude to our Charity. We both very much enjoy Awareness Events and PSA Testing Days, as it can be enjoyable and rewarding talking to members of the public and helping to disperse some of the "Myths and Mysteries" that surround the disease.

Thankfully, many things have improved since Graham's diagnosis but as I write this article with the words of the Tammy Wynette song "Stand by your man" running through my head, I can honestly say that our experience was at times hard and frightening but the P Ca journey is a lot easier to travel with a friend or someone you love.

Nicky's Lycopene Recipes:

Tomato, Bean and Carrot Soup. Very Quick and Easy

A few years ago, I submitted an article to Updates with some Lycopene rich recipes using tomatoes. Good sources of Lycopene which is a strong antioxidant are found in cooked/processed tomatoes, as well as other orangey fruits such as watermelon and pink grapefruit.

PCaSO Hampshire Branch has donated to research being undertaken by Dr Chopra, University of Portsmouth, School of Pharmacy and Biomedical Studies, into the study of Lycopene and how it may potentially slow the growth of prostate cancer cells.

A friend recently gave me the recipe below and although I was quite sceptical about such a quick and easy soup, with such unlikely

ingredients I thought I would give it a try. We both really enjoy the soup, which I now make regularly with variations such as adding basil, chilli, paprika, or canned mixed beans.

Ingredients:

- 1 400g tin of chopped tomatoes
- 1 415g tin of baked beans (a brand with reduced sugar and salt)
- 1 300g tin sliced carrots (do not drain)
- 2 small pickled onions, roughly chopped (a good way to use up the ones left over from Christmas!)
- 1 vegetable stock cube, crumbled

Salt and pepper to season

Method:

Place all ingredients, including the water from the carrots into a liquidiser/blender and blitz until smooth. Transfer to a saucepan and add 1 can of water, using the tomato tin as a measure (it's a good way to rinse out the tin). If the soup is still too thick for your liking add some more water.

Alternatively place all ingredients as above, directly into a saucepan and blitz with a stick/hand blender.

Add any flavourings or additions (chilli, paprika etc) that you like, heat and enjoy.

Dorset Branch

Donations

In November, a donation of over £644 was received from the Wessex Hash House Harriers (member Geoff Chidley presented the cheque *-photo right*).

At the January meeting, the branch was presented with a cheque for £9500 from Mr Richard Knott, (photo far right) owner of the Luscombe Valley Railway (LVR) . This 5 1/4 -inch gauge passengercarrying railway is based in the extensive grounds of Richard Knott's home near Sandbanks, and is the result of a lot of work from him and a band of enthusiasts. For the 2019 season, he assigned PCaSO as his chosen charity and allowed PCaSO collections to take place on the days the railway was opened to the public. Mr Brian Deacon, fundraiser for the Dorset branch, organised all the collections.

Speakers

The speaker for January was Dr Richard Tippett, Consultant Interventional Radiologist at Dorchester Hospital. He delivered



a well-illustrated and interesting talk about the modern day benefits of mpMRI in connection with prostate cancer diagnosis and treatment.

PSA Testing

We ran a successful event at Bridport in November in conjunction with the NewMan Group, when 199 men were tested, with 5 being referred to their GPs for further investigation. The booking system kindly developed for PCaSO by Cliff Carter was used and the results were successfully transferred to the Graham Fulford Charitable Trust (GFCT) database, as per PCaSO Sussex practice. Since then, Graham Fulford has implemented a new central system, which has required PCaSO to switch from Cliff's PCaSO system and work with the GFCT to modify their database so that it meets our requirements. This in turn has meant suspension of some further PSA Test events for the time being.



Committee

Clive Duddridge has stepped down after many years as Membership Sec for the Dorset branch. Dorset membership records are now being handled by Andrew Collett.

Although the Dorset Branch Secretary (Ray Bona) will retire (after six years in the post) in May, he has agreed to carry on editing and issuing the bi-monthly branch newsletter (The Link).

Allan Higgin will step down as Chairman at the May AGM. He had agreed to fill the post for one year only.

We urgently need volunteers for the executive posts of the branch. No candidates have so far come forward, which puts the future of the branch after the May AGM in doubt.

Hampshire Branch

Waterlooville

In early December 2019, the Hampshire Branch of PCaSO held a special end-of-year members' meeting at Waterlooville. The theme of the meeting was to reflect upon and celebrate the many things the Hampshire Branch had achieved during the year. This was the first time that the present Committee had held such an event and thanks to some good publicity, a record breaking thirty-six members

attended.

Peter Weir our
PSA lead, gave
a presentation on
the PSA testing
events that we
had covered,
together with
statistics and

pictures. Our secretary Roger Smith then gave a "run through" of our significant achievements. This covered 'Awareness Days' that had been supported by both Members and the Committee; the Members' meetings that had been held with their key note speakers, and finally the equipment that we have purchased for both Queen Alexandra Hospital (QAH) and University Hospital Southampton (UHS).

When you put all the events and functions together, I think the Committee and the Members should feel very proud of what we have achieved. At the occasion, we were joined by Matt Fox, the chairman of Hampshire Hackers, who presented us with a very generous cheque for over £4,000, and received a loud

round of applause for helping us in our work.

Obviously, given the successes of the year, these needed to be celebrated! So, with Christmas nearly upon us, everyone enjoyed mince pies, mulled wine and a Christmas themed brainteasing quiz. Feedback from all about the meeting was really 100% positive, so we will be planning to repeat it next year.

Nicky Annells - Acting Chairman





Eastbourne Group

November meeting

Preoperative optimisation, enhanced recovery and survivorship was the title of a captivating talk from consultant urologist Ed Calleja. Ed has recently taken up post at East Sussex Healthcare NHS Trust having been the surgical research fellow in robotic surgery under the expert guidance of Mr Peter Rimington.

The main messages from the talk related to the importance of mentally and physically preparing for a robotic prostatectomy. Mr Calleja presented several case scenarios looking at postoperative recovery and how this could be improved if physical fitness, weight loss and mental preparation were enhanced beforehand. He argued this would be similar for other urological cancers requiring the Da Vinci robot. It could also apply to other prostate treatments such as radiotherapy and brachytherapy.



Ed Calleja, Consultant Urologist gave a talk on Preoperative optimisation, enhanced recovery and survivorship

He likened it to an athletic mindset preparing for a major event and elaborated how handgrip strength, fitness trackers and counselling could be employed. He then outlined his plans for introducing such a programme and answered questions from the

audience which included members from the Active Recovery team at the University of Brighton.

PCaSO water bottles

The Eastbourne Radiotherapy Department has recently taken delivery of 500 water

bottles which PCaSO have purchased for men undergoing radiotherapy for prostate cancer.

This idea was first suggested by Hampshire branch member Nicky Annells, (See Updates 66 -

Summer 2019)

Kate Harley, Macmillan Senior Review Radiographer at the Eastbourne radiotherapy centre says the bottles have been a great success.

Sussex Branch

Chichester Group

At the November meeting Andrew Hart, CNS at Worthing Hospital, spoke on developments in treatment. One particularly interesting initiative Andrew discussed was "Supported Self-Management" which would allow patients to co-ordinate their own care and follow-up in collaboration with health care professionals to provide more personalised care. One important change would be scheduling of appointments as needed, not on a regular schedule. Appointments could take innovative forms including phone consultations, video conferencing drop-in sessions and PSA tracking via smartphone apps. Changes of this sort would require some patients to change their attitudes from "my doctor is in charge of my health" to "I am my own advocate." There is surely scope for support groups like

PCaSO to help patients with this transformation.

For the first time in quite some years we held a meeting during the first week of January. Fortunately, it didn't rain too hard and we had a respectable turnout for a Patients' Forum. The talk continued until well after 9pm!

Donations:

Sussex Branch agreed to donations of £1,000 each to Cancerwise (Chichester), Cancer United (CU Fitter gym and other activities at Angmering) and Mary How Trust of Pulborough. We have been supporting these charities for quite some years. Cancerwise and Cancer United are used by PCaSO members and Mary How includes PSA testing as part of its healthcare screening programme. A PCaSO member's dentist's prostate cancer was detected when he was referred after a PSA test at Mary How. PSA testing makes sense!



Rustington Group

Social coffee morning held at Angmering Manor Hotel. Further coffee mornings are planned for 10th March and 12th May 2020

LOCAL SUPPORT MEETINGS Check our website www.pcaso.org for latest details.

Mar	ch					
18	Wed	Chichester	'Diet and Exercise' by Dawn Bradley registered nurse and Holistic Practitioner			
24	Tues	Rustington	Services that Macmillan can offer to men diagnosed with PCa and to their carers, partners/wives. By Mark Whitcomb , Macmillan Engagement Lead.			
25 Apr		Bournemouth	CANCELLED			
9	Thurs	Eastbourne	Sussex Branch AGM			
9	Thurs	Eastbourne	Mindfulness, by Karen Aylward , Mindfulness Teacher & Practitioner (this follows the Sussex AGM)			
May	/					
4	Mon	Bexhill	Tbc.			
6	Wed		Speakers from Chichester Wellbeing			
13	Wed	Brighton	Victoria Sellick, Lead Research Nurse, The Royal Sussex County Hospital, Brighton. 'The PROFILE study and recruitment of men who have a family history of Prostate Cancer'			
27	Wed	Bournemouth	Dorset Branch AGM. Speaker Tbc			
Jun	е					
2	Tues	Waterlooville	Note 11am start . SpaceOAR Hydrogel use in prostate cancer radiotherapy treatment. Talk by Charlotte Hogg , Boston Scientific.			
4		Eastbourne	Speaker to be confirmed.			
9	Tues	Rustington	Rustington Proton Beam Therapy: the Patient Experience. By Timon Colegrove , a patient who will talk about his treatment experience and his understanding of PBT.			
23		Pulborough	Tbc			
July	/					
1	Wed		PCaSO AGM (the speaker to follow AGM tbc)			
6 29	Mon Wed	Bexhill Bournemouth	Tbc Tbc			
Sep		Doumemoun	100			
1	Tues	Otterbourne	Tbc			
2	Wed	Chichester	Tbc			
7	Mon	Bexhill	Tbc			
8	Tues	Pulborough	Tbc			
9	Wed	Brighton	The The			
10 15		Eastbourne Rustington	Tbc Tbc			
30	Wed	Bournemouth	Tbc			

NOTE: PSA Testing Events are on Page 5, for this issue

Donations

PCaSO does not receive any Government funds and is dependent on Membership subscriptions, donations and sponsorship.

To make a donation please send a cheque to:

The Treasurer, PCaSO, PO Box 66, Emsworth, PO10 7ZP.

Or pay into our bank account (40-23-20 61303856)

Or download and fill in our Standing order form at **www.pcaso.org** or, click on the red Virgin Giving button on the front page.

VENUES/CONTACTS

Dorset

Bournemouth: 7.30pm start

St Marks Church Hall, Talbot Woods, BH10 4HY,

Allan Higgin

E: dorset@pcaso.org **T:** 01202 691710

Hampshire

Otterbourne: 7.30pm start

Otterbourne Village Hall, Cranbourne Drive, SO21 2ET

Geoff Bailey T: 01962 713579

Waterlooville: 7pm start

Church of the Sacred Heart, London Road, PO7 7SR

Roger Smith

E: secretary.hampshire@pcaso.org

T: 01243 378856

Sussex

Bexhill: 7pm start

Health Centre, Bexhill Hospital, Holliers Hill, Bexhill, TN40 2DZ

John Procter

E: bexhill@pcaso.org **T:** 01424 532866

Brighton: 7pm start

Macmillan Horizon Centre, Bristol Gate, Brighton BN2 5BD

Chris Hawkes

T: 07716 276911

Chichester: 7pm start

Chichester Baptist Church, Sherbourne Road, PO19 3AW

Viv Miles

E: chichester@pcaso.org

T: 01798 839117

Eastbourne: 7pm start

Postgraduate Centre, Eastbourne District General Hospital,

Chris Cutting/Debbie Hatfield

E: cuttingchris@btinternet.com

T: 01323 641513

Pulborough: 7pm start

Pulborough Village Hall, Swan View (off Lower Street), RH20 2BF.

David Hurst

E: David.hurst@pcaso.org

T: 01798 875758

Rustington: 7pm start

John de Bohun Room, Woodlands Centre, Woodlands Avenue, BN16 3HB,

Roger Bacon

E: rustington@pcaso.org

T: 01903 775783