

UPDATES

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



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Spring
2019

Prostate Cancer Screening
House of Commons Report
PSA Testing in 2018
NPCA report 2018
My Patient Story
PCaSO Clothing

King Alfred Statue, Winchester

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**Prostate Cancer
Support Organisation**

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

PCaSO have partnered with Penny Brohn and Genesis Care to provide courses for PCaSO members and their wives/partners on 'Living Well with Prostate Cancer' (see page 6). These courses are free to PCaSO members and are highly recommended. So book your place!

Hampshire Branch have a new Secretary. Thanks to Roger Smith for stepping forward.

The European Association of Urologists (EAU) are pushing the European Parliament for population based screening for prostate cancer (see page 3). The cost of early curative treatment is €15,000, but long-term treatment for advanced prostate cancer is €300,000. It is clearly cheaper to 'catch it early' and far better for the patient.

Nationwide screening for prostate cancer was discussed at a reception at the House of Commons (see page 4). Things move slowly however, especially where extra funding and resources are required. Meanwhile PCaSO carries on at record levels of PSA testing! (See page 5).

The National Prostate Cancer Audit is reviewed on page 7 with some statistics of interest. What is new in the audit is that patients score their sexual function after surgery or radiotherapy far lower than clinicians have stated it could be.

Prostate Cancer Screening

European Prostate Awareness Day (EPAD) on PCa Screening.

Brussels, 22/1/19

This is a synopsis of the latest expert information on screening and early diagnosis of PCa given to the European Parliament. To see the full EPAD programme and report, go to: <http://epad.uroweb.org/programme/epad-2019-presentations/>

Background

The UK lags well behind its European neighbours for early diagnosis and cure of Prostate Cancer (PCa). It is our commonest male cancer with deaths now exceeding those for breast cancer.

As there is no way of preventing PCa, our efforts should be to detect it early when it is confined within the prostate and thus curable. The only practical way to do this is with the blood test PSA (Prostate Specific Antigen); there is no other simple, cheap marker on the horizon.

Since its widespread introduction as a PCa screening tool in the early 1990s, the death rate from PCa has fallen consistently in all countries making significant use of the test. Unfortunately this came at the cost of substantial over-diagnosis and over-treatment of non-aggressive, insignificant PCa that has possibly outweighed the benefits of early diagnosis and cure for many other men. As a consequence there has been a downturn in screening both in the USA and the UK, where the death rate has stopped falling and the presentation of cases of metastatic PCa has risen, raising the spectre of the pre-PSA era when most men presented with advanced, incurable disease. This is unacceptable.

EAU Policy Paper on PSA Screening for PCa

The longest, clinically valid trial evidence on the benefits and harms of PCa screening comes from Europe. The speakers at this

event presented clear, objective evidence showing that the benefits now easily outweigh the harms. They then lucidly outlined strategies to implement life-saving, cost-effective screening programmes.

http://epad.uroweb.org/wp-content/uploads/EAU_policy-briefing_PSA.pdf

What follows is therefore not mere opinion, but hard, objective, scientific evidence from screening studies running for up to 20 years.

The Facts

- PSA-based screening trials have reduced PCa mortality by up to 64%.
- After 20 years' follow-up the number of patients needed to screen and to diagnose PCa have fallen to 101 and 10 respectively to prevent 1 PCa death – figures substantially lower than for diagnosing colorectal and breast cancers.
- Quality of life studies show that early treatment of PCa lowers the risk of complications such as incontinence and impotence whereas treatment of metastatic disease has a disproportionately negative effect on quality of life for both the sufferer and his partner.
- Early measurement of PSA in a man's 40s can largely define his lifetime risk of dying from PCa. Low risk men with consistently low PSAs (<1ng/ml) can stop screening in their 60s as subsequent risk of death from PCa is only 0.2%.
- Early PSA measurement should be linked to family history, ethnicity and freely available risk calculators to further define lifetime risk.

- Second line biomarkers provide further information that assists identification of aggressive PCa.
- mpMRI scans should now be used before biopsy to better target significant disease and avoid the need for biopsy where significant disease is unlikely to exist.
- Active surveillance is a proven, safe, management option for “insignificant”, low-grade, low-volume PCa.
- In the UK treatment options are determined jointly by multi-disciplinary teams and informed patients to avoid over-treatment, the rate of which has fallen to 4%.
- The cost of early curative treatment is approximately €15,000 compared with approximately €300,000 for long-term treatment of advanced PCa.

Conclusion

The UK cannot continue to overlook PCa, our commonest male cancer, now that the twin threats of over-diagnosis and over-treatment are clearly outweighed by PSA-based screening programmes coupled to recent advances in clinical practice.

The UK does not require further screening trials but should implement proven screening strategies based on multi-disciplinary international guidelines.

More support and funding should be directed to PCa screening programmes and research.

The evidence is clear. The only thing lacking is the political will.

C M Booth, MBBS, FRCS
Clinical Advisory Board, TACKLE Prostate Cancer
Clinical Director, CHAPS Men's Health Charity

“Should the NHS now be screening for Prostate Cancer?”

Report on House of Commons Reception - 27 Feb 2019

PCaSO attended this event organised by like-minded prostate cancer charities including CHAPS, Tackle and Orchid. Despite over 11,000 deaths each year, prostate cancer still has no NHS screening programme, unlike breast, bowel and other cancers. Hence PCaSO turned out in force, with Roger Bacon (Chair), Viv Miles (Hon Treasurer), James Davis (Dorset), Peter Weir (Hampshire) and Lance Allen (Sussex).

James Cleverly MP spoke briefly of the need to ‘thrash out policy decisions such as funding’. He recognised the importance of prostate cancer charities in informing the process.

Roger Wootton, as chair of Tackle, said there were now over 90 prostate cancer support organisations across the UK. He saw Tackle as the ‘Patients’ Voice’ and was keen to grow awareness.

Professor Monique Roobal from Erasmus University Medical Center in Rotterdam, gave a fascinating talk, focused on the ‘risk stratification’ of how diagnosed patients are treated. PSA testing was initially trialed 35 years ago, and quickly led to a decline in metastatic spread (e.g. to bones) and in mortality. Some resistance to PSA testing was seen amongst medical professionals due to over-diagnosis leading to unnecessary intrusive biopsies. There is still some resistance in 2019!

Professor Roobal then spoke of Risk Stratification trials, aimed at targeting PSA monitoring on those with higher risk, such as known PSA levels (from initial blood test), family history, and higher-risk ethnicity background.

A key step forward has been the use of MRI scanning as the first stage of investigation, rather than biopsies. Hence reduced over-diagnosis, and only those patients with identified prostate irregularity would proceed to biopsy, which itself would be a more focussed procedure. “Hitting the target has never been so easy”, said Professor Roobal, who finished by saying “Keep Calm and Keep Screening!”..

Professor Sir Mike Richards then spoke. Professor Richards is a distinguished cancer specialist - he was the ‘Cancer Czar’ for 14 years from 1999, and more recently the Care Quality Commission’s Chief Inspector of Hospitals. He stated that before the millennium there was little knowledge of, or research into prostate cancer, perhaps GPs could perform PSA tests, but there had been little talk of screening.

He believed that the UK could in future use Risk Stratification, particularly to achieve targeted, rather than ‘random’, biopsies. There were still too many late diagnoses, i.e. at Stage 4. We were getting closer to the right answer, but it is not in place yet.

Q & A Session. There was a notable sense of frustration amongst the Reception’s attendees, that action, rather than words, was now needed. PCaSO’s Jim Davis made an impassioned plea for the introduction of screening, saying that promises had been heard for 30 years; that the situation [compared to other countries] was a national disgrace, that men were disadvantaged

compared to other cancer screening programmes. The old arguments against PSA testing had now been firmly swept aside.

Other comments included whether GPs were aware of the increased risk for Afro-Caribbean men; that the Gleason Score system was 30 years old - was it still fit for purpose; and that instances of over treatment had dropped from 12% to 4% in the last 3 years.

A key step forward has been the use of MRI scanning as the first stage of investigation, rather than biopsies. Hence reduced over-diagnosis.... “Hitting the target has never been so easy”, said Professor Roobal

Sir Bernard Jenkin (the ‘host’ MP) noted the sense of anger and frustration and would ‘take this forward’

It was noted that Orchid, a charity for male cancers, is involved with an all-parliamentary cancer group chaired by Maria Caulfield MP (for Lewes - on PCaSO’s patch!).

A very useful event in which a range of prostate cancer charities had a common voice, strongly in favour of NHS screening for prostate cancer as soon as possible. Our discussions with the other charities on common issues were also very useful.

It was disappointing that due in part to a number of Brexit votes in the House of Commons (and the frequent loud ringing of the Division Bell), only two MPs attended the reception. Nor could NHS England attend. Professor Roobal, however, was outstanding.

Lance Allen



PSA Testing in 2018

The 2018 National Prostate Cancer Audit of prostate cancer diagnosis and treatment has shown that 42,975 men were diagnosed with prostate cancer in England and Wales during the period 1st April 2016 to 31st March 2017. Of these 55% of men were 70 years or older.

UK practice now increasingly mirrors the PROMIS and ProtecT study results with only 4% of men still being “over-treated” for low risk disease (down from 8% in the previous year). Unfortunately however, far too many UK men are still being diagnosed with “advanced” and probably incurable prostate cancer which reflects the low use of PSA for screening in the UK.

What is PCaSO doing? PCaSO will continue to offer “free” PSA screening at organised events throughout Sussex, Hampshire and Dorset. The table shows our PSA testing Statistics for 2018. We tested 4813 men across our region, an 80% increase on the previous year. Of those men tested 359 had a raised reading and were recommended to inform their GP by appointment. 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 men. PCaSO have tested in total 13,510 men since starting a testing programme in 2011.

Thanks go to our PCaSO members, all volunteers, who turned our repeatedly to provide an experienced and knowledgeable team that organised and processed all these men through the PSA testing events across our region. Our thanks also go to the volunteer phlebotomists who took the blood samples and to our partners such as Lions, Rotary and the Masons who participated in organising venues and catering, taking bookings and often paying the costs of the events and testing.

PCaSO have also scheduled an extensive programme of PSA testing events for 2019 (see back page).

PSA TESTING STATISTICS 2018

	Date	Place	GREEN	AMBER	RED	Totals	% A & R	% RED
Hampshire	21/04/18	Hayling Island	275	7	6	288	4.51%	2.1%
	12/05/18	Basingstoke	68	0	2	70	2.9%	2.9%
	22/09/18	Eastleigh	144	6	6	156	7.7%	3.8%
	27/10/18	Gosport	152	4	8	164	7.3%	4.9%
	03/11/18	Alton	134	3	10	147	8.8%	6.8%
			773	113	32	825	5.5%	3.9%
Sussex	10/02/18	David Lloyd	113	5	4	122	7.4%	3.3%
	07/04/18	Uckfield	216	8	3	227	4.8%	1.3%
	23/06/18	Horsham	146	3	5	154	5.2%	3.2%
	25/08/18	Pyecombe	65	2	3	70	7.1%	4.3%
	08/09/18	Worthing	371	12	11	394	5.8%	2.8%
	19/09/18	Hove	265	7	8	280	5.4%	2.9%
	13/10/18	Burgess Hill	420	11	13	444	5.4%	2.9%
	10/11/18	Peacehaven	295	9	14	318	7.23%	4.40%
	24/11/18	East Grinstead	300	13	13	326	8.0%	4.0%
			2191	70	74	2335	6.2%	3.2%
Dorset	27/01/18	Dudsbury	241	20	18	279	13.6%	6.4%
	24/02/18	Blandford	123	5	12	140	12.1%	8.6%
	17/03/18	Weymouth	249	8	8	265	6.0%	3.0%
	07/04/18	Bournemouth	98	4	6	108	9.3%	5.6%
	19/05/18	Verwood	87	3	5	95	8.4%	5.3%
	28/07/18	Wareham	128	4	15	147	12.9%	10.2%
	22/09/18	Dorchester	125	0	18	143	12.6%	12.6%
	10/11/18	Sturminster New	228	2	19	249	8.4%	7.6%
	24/11/18	Isle of Wight	204	8	15	227	10.1%	6.6%
			1483	54	116	1653	10.3%	7.0%
ANNUAL TOTALS			4447	137	222	4813		

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	740	547	986	832	1653	5480	
		Grand total							13510	

Note: a ‘Green’ result indicates the PSA value is within the ‘normal’ range for the age band of the man tested. 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 or a Red result the man is advised to consult his Doctor.

David Rowlands, PCaSO Founder and Member No. 1

We announce the death of David Rowlands, PCaSO's founder and member no.1. He was diagnosed with prostate cancer in 1998 and started campaigning to raise awareness of prostate cancer under the auspices of another charity. However, in 2002 he and others went their own way and set up PCaSO.

Sandy Tyndale-Biscoe, later chairman of PCaSO and then of Tackle, knew him then and writes "I first came to know David Rowlands in 2002 shortly after I was treated for early stage prostate cancer. I had joined PCaSO because I was extremely angry that I had reached the age

of nearly 60 without knowing of the danger of this awful disease, and it seemed to me that David, and his team at PCaSO were doing great things to spread awareness. He introduced me to colleagues in other support organisations and lobbying groups who were working to improve services for men with prostate cancer and their families. Out of these activities arose the Prostate Cancer Support Federation now known as Tackle. David was an inveterate campaigner, and all men and their partners affected by prostate cancer owe him a huge vote of thanks for the enormous efforts he put into the cause."



David and his wife, Shirley, retired to Norfolk in 2004 where he died at home in the early hours of Monday 11th March 2019, aged 86. He is survived by his wife and a son and daughter.

Living Well with Prostate Cancer

Course over 2 days offered FREE to PCaSO members

PCaSO have partnered with Penny Brohn and Genesis Care to offer a course over 2 days that is designed to help you manage all the different ways that cancer has affected your life.

This course explores the various aspects of the Penny Brohn whole life approach (see *Updates 64*) and how it can help you live as well as possible for as long as possible with the impacts of cancer.

You'll discover simple ways to eat well, manage stress and stay active to support your ongoing health. You will find out how to relax, make time for the things in life you love and have a greater sense of control over your health and wellbeing.

Learn more about your immune system and how it works to detect and destroy cancer cells in your body, you'll discover some of the things that you can do to strengthen your health and build your resilience.

This is a fully-catered, two-day non-residential course. It will give you the time and space to focus on what matters to you, to meet and spend time with people in a similar situation. You will leave with a detailed plan for any changes that you want to make and usually having forged some friendships to support you along the way and it's offered for free. You can book a place on the course with your wife/partner or on your own. Numbers are limited to 12 per course, so early booking is recommended.



Arundel

Venue

The White Swan, 16 Chichester Rd, Arundel, BN18 0AD

Dates

Wednesday 19th June
Wednesday 26th June

Time

Start at 9.45am and finish around 4.45pm each day.

To Book a place email: bookings@pennybrohn.org.uk

or phone: **0303 3000 118**

Havant

Venue

Langstone Hotel, Hayling Island

Dates

Thursday 9th May
Tuesday 14th May.
Contact David Harris
(02392 795909) for
info@pennybrohn.org.uk.



National Prostate Cancer Audit annual report 2018

The fifth National Prostate Cancer Audit annual report for England and Wales was published in February 2019 and its statistics cover the period 1st April 2016 to 31st March 2017.

The audit and report were commissioned by the Healthcare Quality Improvement Partnership (HQIP), funded by NHS England and the Welsh Government to support improvement in the quality and outcomes of care for men with prostate cancer in England and Wales. Performance indicators now apply to all Trusts in England.

The full report is 62 pages and is mainly for health professionals, but contains some interesting statistics for patients, we show a few statistics and findings here. Where statistics for England and Wales in the report are listed separately we show only England for this newsletter. To see the full report go to <https://www.npca.org.uk/reports/npca-annual-report-2018/> then click to open the report itself (or, as they plan a patient friendly version shortly, you could wait for that!).

Diagnosis and Staging

In England 40,948 men were newly diagnosed with prostate cancer

Ages

12% - less than 60 years
33% - age 60-70
37% - age 70-80
17% - age 80 or older

PSA values

46% - less than 10
22% - 10-20
32% - greater than 20

Multiparametric MRI (mpMRI)

no mpMRI - 42%
before biopsy - 46%
after biopsy - 12%

Gleason Scores

22% - 6 or less
48% - 7
30% - 8 or more

T-stage (form of primary Tumour in the prostate)

T1- 17% (doctor unable to feel tumour or see it with imaging)
T2 - 43% (can feel tumour seems confined to the prostate)
T3 - 35% (cancer has begun to spread outside the prostate)
T4 - 5% (cancer has spread to other tissues outside the prostate)

N-stage (the spread to pelvic lymph Nodes)

88% - No (no apparent spread)
12% - N1 (tumours up to 2cm)

M-stage (Metastasis-any spread to other parts of body)

83% - Mo (no apparent spread)
17% - M1 (spread to bones or other distant sites)

The proportion of men presenting with metastatic disease remained at 16%

MRI

80% of men had a pre-biopsy MRI.
58% of men had a multiparametric MRI (mpMRI)

Biopsy

88% of men had a TRUS biopsy.
12% of men had a transperineal biopsy

Treatment

In England 6,462 men underwent radical prostatectomy surgery

81% - robotic
10% - open
9% - laparoscopic

In England 13,341 men underwent radical radiotherapy

89% - Image Modulated (IMRT)
11% - 3D conformal

Potential 'over-treatment' of men with low-risk disease declined to 4% (down from 8%)

Slightly more men with locally-advanced prostate cancer were potentially 'under-treated'. The report recommends that specialist multi-disciplinary teams (MDT's) ensure that all men with locally

advanced prostate cancer are considered for radical treatment. The report stressed the importance of appropriate treatment, especially with an ageing population.

Complications

13% of men were readmitted within 3 months following surgery.

Within 2 years after treatment:

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

1 in 10 men experienced gastrointestinal complications after external beam radiation (EBRT).

Patient Reported scores

The report found patients and clinicians view and report sexual function and incontinence very differently and recommends patients are counselled appropriately and honestly as to the likelihood of experiencing continence and/or sexual problems after treatment, whether following surgery or radiotherapy.

It found that patient reported sexual function scores (higher score means better function) at:

23 out of 100 after surgery
17 out of 100 after radiotherapy
were much lower than those in published urological literature.

After surgery the patient reported urinary incontinence score was 71 out of 100.

After radiotherapy the patient reported bowel function score was 85 out of 100.

Date for the Diary

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 3rd July 2019
at
7.00 pm

My Patient Story

by Colin Woodman, Rustington Group



In 1997 my father was diagnosed with Prostate Cancer with a high PSA reading well into double figures, I

have a vague recollection it was over 50. I do not know the full details because, like many of his generation, he would not talk about it. At this time I had no knowledge of what and where the prostate gland was.

Over the next 3 years I watched him go through Radiotherapy and how it affected him. He did not respond to the treatment and the Cancer spread up his spine and into his neck. He died in October 2000 aged 70.

In 2001, through my wife's employment at a bank in London, I was able to have what was called a "Lifestyle Medical". At my first appointment I was asked about any family illnesses. I mentioned my father's Prostate Cancer and also that my mother had been treated for Breast Cancer. When my blood was sent for the standard tests, my consultant also asked for my PSA to be checked. Which came back as normal. I was 42 at the time. I had my PSA checked regularly for the next 3 years while my wife was working at the bank.

In April 2006, while seeing my local GP for another reason, my PSA was checked and came back as abnormal at 2.9 (age 46). My GP asked me to come back for further test in 3 months. Before my next PSA test was due I moved to West Sussex, in all the chaos that is part of moving I forgot to get tested.

On 17th June 2011, after a routine PSA test where my results were minimally raised at 3.55 (Age 51). I was referred to the Urology

Department at Worthing Hospital and saw the Consultant Urologist Mr Liston on the 27th. After a rectal examination which showed a small to moderate size benign feeling to my gland and with my family history it was decided that I should have a transrectal ultrasound (TRUS) examination of the prostate with the view of taking a series of biopsies. I had this procedure on 8th July. After my results came back, my case was discussed by the Local Multidisciplinary Team and also the Specialist Multidisciplinary Team on July 27th and it was decided that I should be offered potentially curative treatment for my carcinoma and advised that I should have a radical prostatectomy. I then had a discussion with Mr Liston and we agreed that I would have a laparoscopic nerve sparing radical prostatectomy. I had already made up my mind that if I had cancer I would have the operation if possible, rather than radiotherapy or chemotherapy. This was because I had seen what my

father had been through and also my sisters father-in-law who had open surgery with no noticeable side effects.

I was then referred to see Mr Woodhams who would oversee my treatment. After an initial meeting with Mr Woodhams at Southlands Hospital in August it was decided that I would have my operation at Eastbourne General Hospital. I was admitted to EGH on 13th Sept 2011 under the care of Mr P Rimington. My original diagnosis was Gleason 6 (3+3) adenocarcinoma of the prostate, after the operation a biopsy on the removed gland showed my final histology was Gleason 7 (3+4) margins negative pT2

I was in hospital for 4 nights before being discharged. I count myself fortunate that after my surgery I did not suffer any of the erectile or continence problems that could happen. My subsequent PSA tests have remained undetectable at 0.01ng/ml

Family history and genetic factors in prostate cancer risk

According to Cancer Research UK it is estimated inherited factors explain around 5–9% of prostate cancers, as below.

Family history of cancer

Prostate cancer risk is:

2.1-2.4 times higher in men whose father has/had the disease

2.9-3.3 times higher in men whose brother has/had the disease

1.9 times higher in men with a second-degree relative (grandfather or uncle, nephew, or half-sibling) who has/had the disease.

Family prostate cancer risk is higher in men aged under 65 compared with older men, and in men with more than one affected first-degree relative or with an affected relative diagnosed aged younger than 60.

Prostate cancer risk is 19-24% higher in men whose mother has/had breast cancer.

BRCA2 Prostate cancer risk is up to 5 times higher in men with the BRCA2 gene mutation and among such men under 65 years old it is more than 7 times higher.

Lynch syndrome Prostate cancer risk is 2.1-4.9 times higher in men with Lynch syndrome.

PCaSO Clothing Range

The T shirts and Polo shirts can be ordered with just our logo embroidered on them or with a choice of printed slogan. All the clothing is available for men and

women and can be ordered 'online' by selecting type and size, go to:

www.pinnacleukdirect.com/portal/pcaso/



T SHIRT

with embroidered PCaSO logo only
£7.18



T SHIRT

with choice of printed slogan + logo
£11.14

Printed slogan choices

PROSTATE CANCER
47,000 DIAGNOSED
EVERY YEAR IN UK
11,700 MEN DIE
EVERY YEAR IN UK
GET CHECKED

PROSTATE CANCER
GET CHECKED

PROSTATE CANCER
CATCH IT EARLY

PROSTATE CANCER
DON'T GET CAUGHT



POLO SHIRT

with embroidered PCaSO logo only
£13.56



POLO SHIRT

with choice of printed slogan + logo
£17.52



FLEECE JACKET

with embroidered PCaSO logo
£20.30



SOFT SHELL JACKET

with embroidered logo
£37.30



WATERPROOF JACKET

Reversible with logo
£42.54



We will eventually have a link to the Pinnacle website from our own website, with pictures of the clothing.

Sussex Branch

In the 2018 calendar year the branch tested 2,335 men in nine PSA testing events. There were 144 men with elevated readings, 6.2% of those tested. Not all will have prostate cancer, but they were advised to contact their GP to discuss options. Further details are on page 5.

The PSA test events not only lead to discovery of men who might have prostate cancer, but are also a very good way of increasing the awareness of prostate cancer as many men do not know that they might be at risk or are inclined to ignore any signs. Many men are booked in by their wives or they have heard about the tests from friends. Already in 2019 we have seven Sussex PSA events in the diary, see the PCaSO website for details. Some events are listed on page 12.

Two Sussex members, Cliff Carter and Andrew Collett, are developing IT solutions to help with the administrative burden of running the PSA events. Since we are working with personal medical details it is necessary to check identities, etc to ensure the right details are on every vial of blood, so the right result goes to the correct individual. This project should be making a difference before the end of this year. We plan to trial it on one or more events and roll it out to others when we are satisfied.

Bexhill and Hastings Group had a enjoyable social meeting at the Wheatsheaf Inn to enjoy a tapas. Their next meeting will be on 13th May.

Sussex Branch is working closely with the Penny Brohn charity to run free courses for our members to learn how changing aspects of their lifestyles can help fight the prostate cancer and build their resilience (see page 6).

Dorset Branch

Our Chairman, Jim Davis, has been very busy meeting most of the MPs in the Dorset area. He has seen six MPs so far, but there are still two more he is keen to meet. He has an appointment to see Mr Conor Burns towards the end of February, but so far has been unsuccessful in getting an appointment with Richard Drax.

He hopes his efforts will eventually result in a national prostate cancer screening programme.

Our Branch has been invited to attend and make collections at the Luscombe Valley Railway "open days" in April, July, September and December - a decent source of revenue for the Branch.

Hampshire Branch

Hampshire Branch, in association with Genesis, are arranging with the Bristol-based cancer charity Penny Brohn a 'Living Well with Prostate Cancer' course. The event will be held in May at the Langstone Hotel, Hayling Island on Thursday 9th and Tuesday 14th. (Please contact David Harris for information and booking)The course is better attended by the man and his partner, but that is not obligatory.

Some of our members have already expressed an interest in attending the course, but there may be room for a few others. An email will be sent to our members when the course has been finalised.

At Otterbourne on 5th March a talk was given by Mr. Rowland Rees, a consultant urological surgeon based at University Hospital Southampton and one of the UK's leading surgical andrologists, i.e. problems of the male reproductive and urinary systems.

The presentation concentrated on two specific areas following a prostate surgery operation, those of urinary incontinence and erectile dysfunction (ED).

Southampton University Hospital offer a morning clinic helping those with these two conditions and working with them to improve their lifestyles.

Mr Rees explained the two main types of urinary incontinence - urge incontinence and stress

urinary incontinence (SUI), the latter the most common type following prostate cancer treatment, he explained the causes of each, both types can lead to an impact on sport, sex participation and other areas where social issues may arise. Rowland offered a measure of success as being a single pad used per day.

Measures to achieve this were pelvic floor exercises, an artificial urinary sphincter or a 'male sling' made of synthetic mesh. The latter two requiring operations, but with a high degree of success.

The difficult area of erectile dysfunction was addressed. Treatments being oral medication (e.g. Viagra, Cialis, etc.), vacuum erection devices or pumps (VED), intraurethral suppositories, penile self-injections, penile implants and finally penile implanted pumps. Slides showing these options were shown and the success, popularity and side effects of each was offered. The effectiveness of pelvic floor exercises was discussed with an emphasis that general exercise and fitness was also beneficial in helping maintaining a healthy urinary and reproductive system.

The presentation sponsor, Boston Scientific, design and manufacture a range of equipment that is used in the above procedures.

There were thirty-four people at the meeting who enjoyed a really informative and interesting evening.

Eastbourne Group

Active Recovery - cancer rehabilitation

The Active Recovery team from the University of Brighton attended our November meeting which was very fortuitous with Professor Faithfull speaking about diet and exercise. Several of the group have since attended the exercise sessions in Eastbourne and found them beneficial. It is easy to enrol! They are a friendly and motivated team looking to improve cancer rehabilitation. More details are in the Eastbourne December 2018 newsletter, see www.pcasoeastbourne.org.uk.

Fundraising – latest news

Recent purchases include a urine analyser and a platform lift for the Urology Investigations Suite (UIS) at Eastbourne DGH. The platform lift is to help less mobile patients get on and off the examination couches. Both items of equipment have been purchased with money raised at the STAGs Golf Day in May 2018.

UIS is undergoing a major redevelopment and expansion. We hope to hear more in 2019 as matron Susan Crosby-Jones will be speaking at our April meeting. Chris is also visiting UIS in January with Tom and Elaine Chapman (from STAGS) to see the new equipment.

Thank you to our recent donors and fundraisers including:

£214.75 – AMMA

£20.00 – anonymous

£50.00 – John and Mary Carden – bottle top recycling

£1,500.00 – Steve Snook - sponsored South Downs Way walk

Golf Day

The 3rd Annual Golf Day in support of prostate cancer charities will be held at Willingdon Golf Course near Eastbourne on 24th May 2019. All proceeds will be donated to PCaSO and Prostate Cancer UK. 18 holes of golf, 2 course evening



Steve presenting cheque to Chris and Debbie

meal, charity auction and prize giving. Cost £40 per head. Entry forms and more details from Tom Chapman 01323 842745 tomchapmanipfa@hotmail.com

TrueNTH exercise and diet study

How community pharmacists can support cancer survivors to make positive lifestyle behaviour changes.

At the Eastbourne Group we had an excellent attendance at our

November meeting to hear Professor Sara Faithfull from the University of Surrey talk about the 'exercise and diet' study funded by the Movember Foundation and managed by Prostate Cancer UK.

The TrueNTH programme is a world-wide initiative looking to improve prostate cancer survivorship and support.

Professor Faithfull provided an update on the project which entailed working with community pharmacies in Portsmouth to support 118 men with prostate cancer take up a healthier diet and exercise programme. The full results of the study are to be published in 2020. There will be a second edition of the TrueNTH Exercise and Diet Manual – The Manual – which will also be available in e-format. You can find out more by looking at www.redi.help

[There was an earlier, more extensive report on this study in Updates issue 59, May 2017, accessible on PCaSO's website]



LOCAL SUPPORT MEETINGS *See inside front cover for contacts.*

March

19th (Tue) Rustington	Chris Riley , Penny Brohn. 'Living well with cancer'
27th (Wed) Bournemouth	Mimmi Perrin , Macmillan nurse at Bournemouth Hospital. 'Lifestyle after prostate cancer treatment'

April

3rd (Wed) Chichester	Speaker tbc
11th (Thur) Eastbourne	Susan Crosby-Jones , Matron, Urology Investigation Suite, Eastbourne DGH. 'Update on UIS'

May

13th (Mon) Bexhill	Senior Nurse from new Cancer Clinic DGH Eastbourne
22nd (Wed) Brighton	Speaker tbc
28th (Tue) Waterlooville	1.30pm
29th (Wed) Bournemouth	Speaker tbc

June

11th (Tue) Rustington	Andrew Hart - Uro-Oncology Clinical Nurse Specialist, Western Sussex Hospitals NHS Foundation Trust
13th (Thur) Eastbourne	Speaker tbc
18th (Tue) Pulborough	Discussion of symptoms, treatments, clinicians, hospitals

July

1st (Mon) Bexhill	Speaker tbc
3rd (Wed) Chichester	PCaSO AGM
31st (Wed) Bournemouth	Speaker tbc

September

2nd (Mon) Bexhill	Speaker tbc
3rd (Tue) Otterbourne	Speaker tbc
5th (Thur) Eastbourne	Simon Tyler-Murphy , Urology Nurse Practitioner, East Sussex Healthcare NHS Trust – 'ED treatment following prostate cancer treatment. Are we getting it right?'
10th (Tue) Pulborough	Discussion of symptoms, treatments, clinicians, hospitals
11th (Wed) Brighton	Speaker tbc
17th (Tue) Rustington	Speaker tbc
25th (Wed) Bournemouth	Speaker tbc

VENUES

Dorset

Bournemouth: 7.30pm start
St Marks Church Hall,
Talbot Woods,
BH10 4HY,

Hampshire

Otterbourne: 7.30pm start
Otterbourne Village Hall,
Cranbourne Drive,
SO21 2ET

Waterlooville: 7pm start
Church of the Sacred Heart,
London Road,
PO7 7SR

Sussex

Bexhill: 7pm start
Health Centre, Bexhill Hospital,
Holliers Hill, Bexhill,
TN40 2DZ

Brighton: 7pm start
Macmillan Horizon Centre,
Bristol Gate, Brighton
BN2 5BD

Chichester: 7pm start
Chichester Baptist Church,
Sherbourne Road,
PO19 3AW

Eastbourne: 7pm start
Postgraduate Centre,
Eastbourne District
General Hospital,

Pulborough: 7pm start
Pulborough Village Hall,
Swan View (off Lower Street),
RH20 2BF,

Rustington: 7pm start
John de Bohun Room,
Woodlands Centre,
Woodlands Avenue,
BN16 3HB,

PSA Testing Events:

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

PSA testing is by appointment only. Contact phone numbers for bookings will be displayed on the website 3 to 4 weeks before the scheduled date of the event.

March	23rd	New Milton (Hampshire) <i>run by Dorset Branch</i>
April	6th	Botley (Hampshire)
	6th	Uckfield (Sussex)
	27th	Southbourne, [Beaufort Centre] (Dorset)
May	11th	Bournemouth School for Girls (Dorset)
	11th	Chichester (Sussex)
	18th	Hayling Island (Hampshire)
June	1st	Weymouth (Dorset)
	29th	Horsham (Sussex)
August	24th	Pyecombe (north of Brighton) (Sussex)
Sept	28th	Christchurch (Dorset)
	28th	Hove (Sussex)

At most events we need help to make them run smoothly. Checking men in at the door, calling them forward, writing the details on forms.

Most events are on a Saturday and usually finished by mid-afternoon. If you are available on any of the above dates call:

**Roger Bacon (Sussex) 01903 775783,
Peter Weir (Hampshire) 01489 892168,
Jim Davis (Dorset) 01202 580436.**