

UPDATES

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

The Force Within
Fighting Cancer with Fitness
PcaSO talks to GP nurses
10K sponsored run
Patient Story
Trustees Report
PSA testing in Dorset



Issue No. 63
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The Pinnacles, Dorset

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www.pcaso.org

Charity No: 1170536



**The PCaSO
"Knowledge
Empowers"
information
booklet is now
available through
the PCaSO
branches**

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Hampshire Branch Secretary

At the AGM in May 2018 the Hampshire Committee were re-elected, however there was no one present willing to act as the Secretary. Hampshire are still looking for someone to take on that role. It is not an arduous function, but it is an important one. We hold a Committee Meeting about every 3 months in Waterlooville that lasts no more than 2 hours. The Minutes are currently being taken and distributed by someone else.

There are fairly minor duties outside the Committee Meetings, but they are not time consuming. Please get in contact with anyone on the Hampshire committee if you are interested in filling this necessary position. **We really need some help, please!**

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.

The Force Within – boosting the immune system to fight cancer

Following the AGM at Fareham on 31st May 2018, PCaSO were delighted to welcome Dr. Edd Jones of the Centre for Cancer Immunology at the University Hospital Southampton. Dr Jones spoke about immunology as the new way to fight back against cancer. The Centre for Cancer Immunology is supported by Cancer Research UK and is currently the first dedicated research centre of its kind in the UK.

Cells and normal cell division

Edd explained there are over 200 different types of cancer and that cancer is a disease of the cells.

New cells are continually being created inside one's body by the process of cell division, so as to:

- enable growth from birth to adult
- heal wounds, etc
- replace old cells.

One's body is so replaced over a period of about 8 years. There are over 200 types of cells, e.g. nerve cells, skin cells, gut cells, red blood cells, brain cells. They each replicate at different speeds. For example in one minute we each create:

- 40,000 skin cells
- 300 million red blood cells
- 12,000 million gut cells

Gut cells are replaced very quickly, but some other cells, like nerve and brain cells, take much longer.

Normally everything about cells is completely controlled with each cell having its own DNA instructions for doing its specific 'job', also instructions for when to divide and when to stop dividing.

Causes of transformation into cancer cells

Most cancers start when a normal cell in the body goes wrong.

There are several reasons why

normal cells might transform into cancer cells:

- natural cell processes – (errors from the copying of billions of DNA instructions. It is these errors that contribute to ageing)
- environmental influences (e.g. smoking, alcohol, UV rays from sunshine)
- inheritance (genetic)
- viruses (for some cancers, e.g. the HPV virus can cause cervical cancer)

One's risk of cancer increases with age and around 75% of all cancers occur in people aged over 60.

What defines a cancer cell?

A cell that becomes cancerous does not care about its 'job' and :

- ignores signals to stop dividing and thus avoids normal cell death
- replicates indefinitely and uncontrollably and can form clumps of cells that become a 'lump' or tumour
- avoids destruction by the immune system and can also 'hijack' the immune system to increase growth of the cancer
- needs more energy so will seek out blood vessels to supply more oxygen and nutrients to feed itself (angiogenesis)
- can spread to other parts of the body, via blood or the lymphatic system

One's immune system monitors the body and is able to seek out and identify 'rogue' cells that are pre-cancerous or have developed fully into cancer. It is doing this continually and is daily killing cancer cells without us realising it, by means of the killer T-cells of the immune system. The immune

system has memory and (like with vaccines) the next time it recognises a similar threat it already knows what to do.

How cancer hides from T-cells

Cells display 'flags' of fragments of protein from within the cell on the outside of the cell.

Roaming T-cells scan them and if recognised as normal the T-cells move on, but if not will kill them

However, cancer cells evolve so they can hide from the immune system to prevent it attacking them. Cancer cells can evade the killer T-cells

by modifying the information they display on their 'flags', such as:

- reducing the number of flags on the cell surface
- changing the protein fragment on the flags
- changing the flag information to something the T-cells cannot read

Cancer cells can also switch off the immune response. When the immune system has dealt with an anomaly in the body (say when one has had flu) then there is a negative PD-L1 signal to the T-cells to stop attacking the cells. Cancer cells can hijack this and send a negative signal. T-cells are thus neutralised as they can recognise the cancer, but cannot deal with it because of the negative signal.

Development of Immunotherapy

Cancer treatments have been developed over a long period of time and usually include one or more of the following:

- Surgery (used mostly when the cancer is believed not to have spread from the organ it arose in) *(continued overleaf)*

cancer cells evolve so they can hide from the immune system to prevent it attacking them

The Force Within *(continued from previous page)*

- Radiotherapy (which can damage DNA or kill healthy cells as well as cancer cells)
- Chemotherapy (which can harm cells trying to divide)
- Hormone therapy

Immunotherapy is starting to be added to this list and is an exciting treatment for the future as it can replace or supplement some or all of these traditional treatments.

Immunotherapy utilises and reinforces the body's own mechanisms to fight cancer rather than the radical external treatments such as surgery or radiotherapy. Immunotherapy will have fewer and milder side-effects (usually like cold or flu symptoms) and may help people become 'cancer-free' in the future. Immunotherapy has the added benefit of treating the whole body whereas chemo and RT only target specific parts of the body. Significantly, cancer cells that

survive chemo become resistant to that chemo.

Work at Southampton

The Centre for Immunology, which is primarily funded by Cancer Research UK, is aiming to combat cancer using immunotherapy in three main ways:

Antibody therapy – to target cancer and highlight it to the immune system

DNA vaccination – to help enhance the immune response to cancer

Checkpoint inhibition – to release the brakes on the immune system to attack the cancer. This is the principal focus of the work at Southampton.

Personalised cancer therapies

Increasingly cancer is being personalised to the needs of the individual in dealing with the particular cancer they are experiencing. Currently it takes 6-hours to determine the whole (genetic) genome of a specific cancer.

Immunotherapy can provide biomarkers (molecular signatures) on cancer at the genetic level.

Improvements to existing "one size fits all" treatments have increased overall cancer 10-year survival rates from 24% in 1970, to 50% in 2010. Immunotherapy offers the possibility of a personalised approach to treatment which might enable survival rates to reach 75% in another 20 years.

The University of Southampton believe that immunotherapy has the potential to cure all cancers and they have already had considerable success in trials, e.g. lung and skin cancer. Ongoing research includes breast, prostate and colorectal cancers.

We can all help ourselves, as the healthier one is the healthier our immune system will be (and vice versa). Exercise, diet and reduction of stress all play their part in improving the health of the immune system.

Cancer United - fighting cancer with fitness

In March, Dwayne Clevett of Cancer United's CU Fitter gym in Angmering, spoke to the Rustington Group and gave a demonstration of exercises with fitness bands and suspension trainers (see photo). Dwayne explained that its founder Jan Sheward is herself a breast cancer survivor. Dwayne had been a personal trainer at a large local gym and he met Jan in 2012 and qualified as a cancer rehabilitation instructor. Several PCaSO members have used the gym, and participate in other activities, and from our experience it is excellent and very professional in what it does. Cancer United is a registered West Sussex charity for cancer patients and survivors, and the trainers are not only trained as one would expect in the physical stuff, but have also undergone advanced training in

cancer rehabilitation so are considerate for people with cancer. Through fitness they aim to relieve anxiety and depression and 'help people out of dark places'. There is an initial consultation and specialist trainers will use a series of tailored cancer exercise options to assist in your personal cancer recovery. At its friendly small gym (for about 10 to 12 persons) there are exercise groups for men with prostate cancer as well as other groups, some mostly with ladies, who have or have had breast or other cancers. Partners can also join and exercise to provide encouragement.

CU Fitter is open to those at any of the stages from cancer diagnosis, treatment or recovery and looks to help people back to leading



Dwayne Clevett demonstrating fitness exercises at the Rustington Group meeting.

a more active life. As well as the gym, there are other activities, such as walking football, yoga and Nordic walking. Cancer United also run local cancer support groups in Worthing and Wick, social outings and also a seriously good choir!

See their website at <https://www.cancerunited.org.uk/cancer-exercise/> or telephone 01903 779880

Team run 10k to raise money and awareness for PCaSO Dorset

Chris Falla was diagnosed with prostate cancer earlier in the year. This came as a complete shock to him as initially, he found it difficult to accept that a fit, active man could contract such a disease. However, his experience also affected him in a very positive way and brought about a significant change in his life. Having known very little about prostate cancer, after all it was only something that happened to other men, he engrossed himself in reading and studying as much as he could about the subject. His own experience had taught him an important lesson, that there should be more emphasis on raising awareness of the disease so that men with prostate cancer could be diagnosed and action taken at the earliest opportunity.

This led him to organise a team with family and friends who would enter



Chris Falla, in the centre, holding the PCaSO logo, and his team who entered the London 10k run on the May bank holiday).

the London 10k running alongside Mo Farah – well, a little way behind him! Chris's ambitious aim was to raise £3,000 which would help him to achieve his objective for Dorset men. Would he and his team be able to do it? It took a great deal of determination (and of course, time) to get in touch with possible contributors and to advertise the event, but after a few months and intensive training the target was in sight.

PCaSO, Dorset have benefitted enormously from his passion and commitment to ensure that other Dorset men are aware of the advantages of early diagnosis. We applaud the success of Chris and his team. Not only did they achieve their goal but, with gift aid, they added a significant sum to their total. (In early July it had exceeded the £4,000 mark with a bit more to come). Congratulations and sincere thanks to you all!

PCaSO speaks to GP nursing staff

Sussex branch members were out in force on 12 June to attend an education event near Uckfield in East Sussex for approximately 40 GP Nursing staff. Protected Learning Time is used for staff updating. All the GP surgeries in the CCG close for the afternoon and the different professional groups have learning events. About 80 GPs had a separate session on cancer screening, early diagnosis, cancer survivorship and end of life care. The theme for the afternoon was Cancer and PCaSO were asked to provide further insight into living with and beyond prostate cancer. Jill Gower, the Lead Practice Nurse for High Weald Lewes and Havens Clinical Commissioning Group (CCG), approached Debbie Hatfield from the Eastbourne Support Group having seen the group's website. Jill had asked for more information on prostate cancer and the specific

treatments as the nursing staff see many men with prostate cancer attending their GP practices.

The afternoon was divided into three sections beginning with Debbie and Chris Cutting providing an overview on prostate cancer, its diagnosis and various treatments and outlined what the group does to support men and their families. Brian, Jim and Barry gave their personal stories talking about how they were diagnosed, what treatments they opted for and what the choices have meant for them in terms of recovery. Wives Karen and Linda were on hand to add their perspectives. Collectively, they covered high dose brachytherapy, low dose brachytherapy, radiotherapy and laparoscopic surgery together with topics such as dietary changes, bone health and erectile dysfunction.

PCaSO chairman Roger Bacon concluded the session by talking more generally about PCaSO and what the charity does including PSA testing. PCaSO answered a number of questions from the audience.

The PCaSO session was well received with opportunities for some productive conversations. Jill commented that it had reinforced that GP practices can promote the message to asymptomatic men over 50, that they can have a free PSA test if they request it.



Roger Bacon talking to GP Nursing Staff

My Patient Story by Mark Giddings, Rustington Group

Firstly, I must thank Roger and his wife Lauren for their dedication and work in running PCaSO with such commitment - without Lauren's persistence to take their routine PSA test some 4 yrs ago, my life would be on a vastly different course!

I have since been on, frankly, a remarkable journey of 'self realisation' culminating in the Royal Marsden offering a 'first' and unorthodox suggestion for particular treatment last November. I did evaluate the potential consequences of side-effects for a few weeks, but, on balance accepted this trial treatment. My tests since have indicated a successful result and this "trial treatment" is now being given, albeit on a limited basis, to others with similar diagnosis.

The following is a brief account of my journey to date, with a bias towards the more 'holistic' remedies I deployed in the period leading up to the offer of this particular treatment (as I felt this had been crucial) and is written as a 'positive' story to others who may find themselves in a similar position.

In March 2014, I was at a local Tai Chi class with Lauren, when, fortunately, she convinced me to attend a forthcoming 'free' PCaSO PSA test. – I had no idea what PSA was, nor where my Prostate was or even what its function was either! Suffice to say the test results indicated a higher than average level with a recommendation that a further test by my GP should



be carried out ASAP. For a 58 year old, my PSA should have been circa 3.0. A week later I was told mine was 126, yet I had absolutely zero symptoms!

Subsequent biopsy, MRI and PET scans later, it emerged that my cancer was Gleason 7 and that it had spread outside to nearby lymph nodes and the seminal vesicles. Thus surgery was not an option as I was classified "terminal" and the prescribed treatment was 3 monthly Zoladex stomach injections on a "watch and wait" basis ... with daily Bicaltumide tablets prescribed soon after to enhance the treatment. When pushed, they did say that my expectancy could well be only between 18 months and 3 yrs! I set out with a vengeance to give my body the best

"I don't know what it is you're doing, but whatever it is, don't give it up!"

fighting chance it could possibly have.

From the very start I shared a belief that "Nature had brought this"... and thus that "Nature could cure". I was a typical candidate for cancer; unfit, overweight, stressed to the max with running a business and finding refuge in "all the wrong things" including a bad diet, alcohol and late night sugary meals!!

Thus started a journey to transform my body and mindset. Early on, I met an energy healer who advised me to "look after and nurture my body as if a new born child" - both in quantitative terms and in "love" too... what a wonderfully simple edict !! This was soon followed (on a personal

recommendation) with a long Skype call to Chris Woolhams, the author of "The Rainbow diet" and "Everything you need to know to overcome Cancer" (Two highly recommended books to this day). He outlined that in his experience, one needs to understand the need to create a new holistic and balanced "Me".

Long story short - my PSA fell consistently; 3 monthly test results being; 126, 11, 3.0, 0.42, 0.20, 0.14, 0.07, 0.04, 0.04... and then "undetectable" (ie approx. 0.03 or less). My fitness levels increased substantially and I felt more alive than had been for many years previous... with a consequential new goal to learn Kitesurfing !!

As some of you may know, this Androgen Deprivation Therapy normally lasts a max of 2 – 3 yrs before the PSA starts to rise,

necessitating a different course of treatment. So, the Royal Marsden found it unusual that my PSA was still undetectable after 4 years, so much so, the Consultant said "I don't know what it is you're doing, but whatever it is, don't give it up!"

At the next meeting, the Consultant Dr Chris Parker said he'd been thinking about my results and suggested an "untried" option – namely, to give a 37 day course of intensive radiotherapy to not only the original prostate zone, but also to two upper areas (mid and high abdomen) to where such cancer cells would normally have spread by now. He thought I was strong and fit enough to handle this "triple dose" albeit with an

“Consultant suggested an ‘untried’ option – namely, to give a 37 day course of Intensive radiotherapy to not only the original Prostate zone, but also to two upper areas (mid & high Abdomen) to where such Cancer cells would normally have spread by now”

option to reduce to single-dose have a further 25 days of RT to the 2 upper zones after Xmas, if I did experience likely side-effects. He was honest and said he couldn't

give me statistics of potential short or long term damage to my bowels, bones or "nether" regions, but suggested on the upside that there could be a "50/50" chance of eradicating all cancer cells completely

After lengthy consideration, I commenced this treatment last October. There certainly were some initial side effects (my 0-60 mph dash's to the loo after the RT were notorious!!), but this soon calmed down. The potential nausea was never there, but I strove to maintain my diet and 1 to 2 hrs of strenuous cycling/walking/running throughout the entire treatment. I also (on a friend's recommendation) took Sambucol throughout to reinforce my immune system and had weekly acupuncture sessions throughout, together with work-outs in the UK's 1st "anti-Cancer" Gym, here in our own village of Angmering - oh how lucky are we !!

At my latest review after treatment, I was told my PSA was still, remarkably, "undetectable" and that all drugs could cease immediately! In light of this success, the Consultant said that they were now extending such trials to 2 other men, with others in the pipeline.

The challenge now is to maintain my health and nutrition doctrines... and to increase the height jumped from 5.6 m to 7.5m on my Kitesurf Board!

MARK'S REGIME

Spirit Mind and Body

I started on this regime immediately and threw myself with gusto into this transformation of Diet, Exercise, Lifestyle and Attitude, soon realising that there is a very powerful and profound connection between "Spirit, Mind and Body", which I have since classified into these main groups;

Nutrition

Including knowledge of Acid/Alkalinity of foods, Provenance of foods and a bias towards an organic non-dairy, non sugar, non processed / high vegetable diet.

Clean Water

Including installation of water purifier at home to remove any chemicals and Oestrogen from our drinking supply

Blood Oxygenation

Including importance of Hyperbaric Oxygen

Body/Cellular Processes

Including knowledge of the Lymph system and removal of cellular toxicity

Mindfulness

Including elements of Yoga, Tai Chi and Qi-Gong, so as to understand the body "from within"

Exercise

The reasons for doing so, including mapping Body weight and the dangers of "fat" around Organs etc

Conventional Medicine

How this guidance must be followed, albeit with certain caveats.

Support And Communication

Including attendance at Penny Brohn Courses in Bristol and Cancerwise at Chichester.



Penny Brohn UK
Living Well with Cancer

Their courses which are free of charge (Thanks to charitable and voluntary contributions) are on their website. They are usually two days duration. The next 'Living Well with Cancer' course within PCaSO area is 21st and 28th September 2018 in Bournemouth

Phone: **0303 3000 118**

Email: **bookings@pennybrohn.org.uk**

Website: **https://pennybrohn.org.uk**

Trustees Report – from the AGM on 31st May 2018

PCaSO have no offices, no paid staff, we are all volunteers working from our homes to make this charity happen.

We have been very lucky this year in persuading a number of people to step forward to help with various aspects of running the charity and we thank them.

Andrew Collett took on the membership list from Geoff Bailey, who had done it for 13 years.

Brian Holden took on the Gift Aid administration from Andrew Bloxham and squeezes money from Her Majesty's Revenue and Customs.

Cliff Carter has accepted responsibility for the website and his expertise in suggesting useful changes will become obvious very soon.

Lance Allen has given us much guidance in recent weeks about data protection and will be our Data Protection Officer.

We already had Colin Woodman designing various publications for us. Tony Ball is editor of Updates and with Colin has made that look very professional. Jenny and Ron Linkins receive the newsletters from the printers and put Updates and the Tackle newsletter into envelopes and post them off.

There are many more who have volunteered to help with the PSA testing events that we hold throughout Dorset, Hampshire and Sussex. In 2017 we held 21 testing events and tested 2,665 men and found 231 with a raised PSA number. Those were referred to their GPs to discuss the results and we know from letters received that many have entered treatment. The news that celebrities Stephen Fry and Bill Turnbull had been 'caught' through not having PSA tests have noticeably upped the numbers of men coming to our events and we know from the clinicians that the numbers being referred to hospital have increased as well.

These are free tests and we either support them from our own resources or through donations from those tested or the organisations we are working with.

We are also working to raise awareness of prostate cancer through our group meetings and through taking stands at health and well-being meetings held by other bodies. We also provide leaflets to such things as the Macmillan bus that tours the area setting up in towns across our region. We were approached by Brighton Hospital to produce leaflets for their brachytherapy and radiotherapy departments.

We have donated to support the Federation of Prostate Cancer Support Groups, known as Tackle, which is our voice at the national level.

The brand new radiotherapy unit at Eastbourne District General which opened this year benefitted from some good furniture in the waiting area provided through the fundraising abilities of the Eastbourne group.

Southampton Hospital had a donation to help buy diagnosis equipment.

St Richards in Chichester got a reliable bladder scanner in the urology department.

We supported Southampton University's SOACTIVE project.

We have offered to support a local doctor and Brighton University wanting to prove whether giving men a fitness tracker will encourage them to keep to exercise programmes.

Finally we would like to thank the 26 people on the committees. These include the nine trustees on whom responsibility rests for everything. Each of the three branches, Dorset, Hampshire and Sussex, have a committee which runs matters within

their county. Without these people we wouldn't be able to do nearly as much as we do.

We would like to pay special thanks to Geoff Bailey and Andrew Bloxham. Andrew has finally given up looking after the gift aid having earlier passed the baton of the treasurer to Viv Miles. Andrew Bloxham has been a member since 2006 and Geoff since 2002 and Geoff has been membership secretary for 13 years. He has stood down as a trustee and a member of the Executive Committee from the AGM

“The news that celebrities Stephen Fry and Bill Turnbull had been ‘caught’ through not having PSA tests have noticeably upped the numbers of men coming to our events”

though he remains as a committee member of the Hampshire branch. PCaSO is extremely grateful to both of them for the work, advice and support they have given over the years.

Last year we changed to be a Charitable Incorporated Organisation which meant that the financial year changed to ending on 31 March.

The Treasurer, Viv Miles, distributed copies of the Consolidated Accounts at the AGM for the year to

the end of March 2018. PCaSO had received £55,000 and spent £66,100 and still had £106,800 as reserves.

Of the money spent, donations by PCaSO were £26,500 of which Eastbourne Hospital had £14,400 and St Richards, Chichester had £6,500. TACKLE, the Federation of Prostate Cancer Support Groups had £3,300 as a first tranche of £10,000 promised over three years. University of Southampton had £2,000 and Brighton Hospital £300.

If any member requires more information about the accounts please contact Viv Miles.

The Treasurer repeated his view that PCaSO was not here to hoard money, but publicised donations to good causes seemed to attract more money.

PSA Testing in Dorset

PCaSO (Dorset Branch) so strongly believes in giving men the right to make decisions about their health choices that they are pressing on with the commitment to a PSA testing programme which was initiated here in 2013.

Regrettably there is not yet a UK national screening programme for this male cancer, even though despite all criticisms of the PSA test, there is no known case of prostate cancer where this test (in conjunction with others) has not been used. This lack of a screening programme allows the possibility of symptom-less men remaining undiagnosed. PCaSO, together with other enlightened charities and agencies believe that the benefits of testing outweigh the 'harms' of over-diagnosis.

We promote, offer and fulfil the already existing choice to men. We fund it ourselves or with partners. We believe that any attempt by anyone to deny or suppress this right to choose is morally wrong. We never recommend a "one off" PSA test, but emphasise that the initial test is simply a yardstick by which subsequent tests can be measured.

"We promote, offer and fulfil the already existing choice to men"

Already during this past year, PCaSO (Dorset Branch) has offered free PSA tests at Bridport, Mudeford, Christchurch, Wimborne, Maiden Newton, West Parley, Blandford, Lymington, Weymouth, Bournemouth and Verwood with future sessions at Wareham (July), Dorchester (September), Sturminster Newton (November), Wimborne (February 2019) and New Milton (March 2019). With each session the number of Dorset men responding to these tests has gathered momentum especially with younger men in the risk group (aged 45-60). We are fortunate to be able to work alongside organisations such as Lions, Rotary, Masons, Sports Centres, Golf Clubs and Bournemouth AFC. We are also very grateful to smaller groups and individuals who, having seen and appreciated the benefits to Dorset men, have given generously to our cause.

"The number of Dorset men responding to these tests has gathered momentum especially with younger men in the risk group (aged 45-60)"

In addition, we have been impressed by the continued support of the public at our various collection events. We appreciate too, the efficient planning and organisation of these events by Brian Deacon and the commitment of the various members and friends of PCaSO who, in providing both time and effort to boost our funds, have made our PSA testing sessions possible.

In Dorset, to date, we have tested almost 5,000 symptom-less men. Approximately 750 men have been referred to their GPs and of these, 250 have either received treatment or are on Active Surveillance. We believe these figures, together with the many supporting letters from men whose cancers have been discovered at an early stage, more than justify our actions. We will not stop until every Dorset man, not only has been made aware of his right to choose, but will be confident enough to exercise his right to be tested.

[You might also wish to read the 'PCaSO view on PSA testing' in UPDATES Spring 2018]

Data Protection

What has PCaSO done to comply with the new GDPR data protection requirements that came into force in May 2018?

One of our members, Lance Allen, as a trustee of the Bluebell Railway went to various courses and became knowledgeable about GDPR. We have benefitted from his expertise and are grateful. He has also agreed to be our Data Protection Officer and will take any calls on the subject.

PCaSO has two sets of data, the membership records, i.e. the information you gave us when you

joined, and the information we gather when we do PSA blood tests following our public PSA events.

The membership records have been considered by a Legitimate Interest Assessment. In other words, we filled in a six-page questionnaire which has to be filed and kept. From those answers we came to the conclusion that we guard that data correctly and do not pass it on to others and, since you gave us the information to join PCaSO, it is reasonable to assume you would expect to be contacted by us with information about the charity and prostate cancer. So we are not writing to everyone pleading to

keep in touch. If someone wants to be removed from the membership records that is tantamount to resigning from the charity.

The PSA test data is covered by a Consent. Any man taking a test is required to tick a box on the PSA Consent Form giving us permission to hold that information securely, pass it to those that process the test results and send them out to the man. We have checked that the processor holds it securely and any data that is retained is only held as an archive and not used actively for marketing.

We have also updated the Privacy Policy which will be on the website.

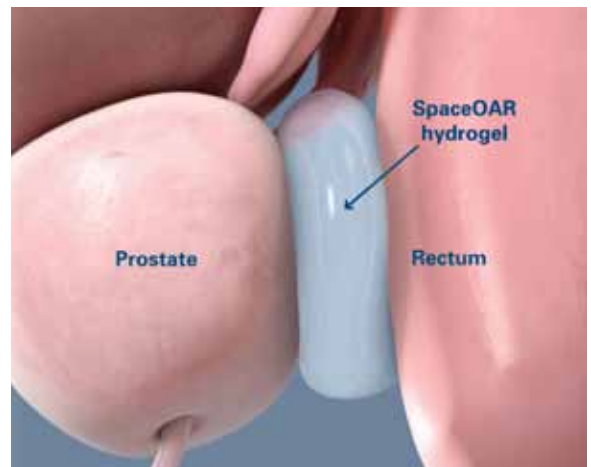
Hydrogel spacer can benefit prostate cancer patients receiving radiotherapy

SpaceOAR® Hydrogel has been designed to reduce radiation exposure to the organs surrounding the prostate. This, in turn, reduces the potential long-term side-effects of radiotherapy such as rectal bleeding, bowel dysfunction, urinary incontinence and potency.

It is a soft gel that temporarily creates space between the prostate and rectum. It pushes the rectum about 1cm (½ inch) further away from the prostate and hence away from the high dose region. It can also stabilise the rectum

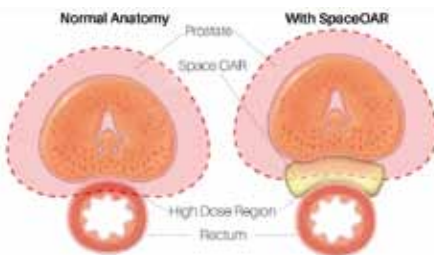
and prostate against movement during treatment. This small space is important – it helps maximise the radiation dose to the prostate gland and avoid unnecessary irradiation of surrounding tissue, minimising harmful side-effects.

It is inserted through a straightforward, minimally invasive procedure, under local or general anaesthetic and guided by ultrasound imaging. It is made of two liquids that when combined is mostly water (hence called a hydrogel). It remains in place for three to six months, after which it is absorbed by the patient's body and cleared in the patient's urine.



For more information go to www.spaceoar.com

Note: Individual hospital NHS Trusts are currently deciding whether to include the procedure on their patient pathway, however the device can be fitted by several private healthcare providers.



Sussex Branch news

There was a good attendance on 4th April at the Chichester Group for the Sussex AGM and the speaker Mr Rob Frymann, Consultant Urological Surgeon at St Richard's Hospital, Chichester. Rob spoke about the HoLEP procedure used to treat bladder outflow obstruction, for either benign or cancerous enlarged prostates, where a laser is used to remove the middle section of the prostate, which is taken in pieces out through the bladder! Rob also gave a most interesting overview of prostate cancer aspects and stated that all men now get an mpMRI at St. Richard's as part of diagnosis for prostate cancer, before a TRUS biopsy, which takes 15 minutes, or a template biopsy, which is a day case theatre procedure with local anaesthetic. They do not yet have Fusion software. Rob talked about the men with increased risks of

prostate cancer, including those with a family history of prostate cancer (on average 2.12 times for a father, 2.87 for a brother and 3.97 for two relatives). The age of the family member at their diagnosis is also significant.

There is now, however, discussion about the future of the Chichester group in that sometimes attendance is so low as to be embarrassing to ask a busy clinician to speak. Approaches have been made to St Richard's hospital to see if the group could meet in the training centre, but the main requirement is someone living in or closer to Chichester to take on the running of the group. If no-one steps forward the group may be closed down.

Rustington Group attendance remains good, and in June Debbie Greenfield and Clare

Manwaring, urology nurse specialists from St Richards Hospital gave talks. Debbie, a Senior Urology Nurse Practitioner, gave a presentation about the two surgical treatments available for urinary incontinence, the Male Sling and the Artificial Urinary Sphincter(AUS). In the following discussion Roger Bacon noted that he had the Male Sling inserted last September and it has proven very successful for him. Another member present stated he had had the Artificial Sphincter fitted. It is also know there are other PCaSO members who have had these surgical interventions. Clare Manwaring spoke about 'prostate cancer pathways' and answered numerous questions.

PCaSO are most grateful to all the speakers for their time and commitment to attend, speak and answer questions at our meetings.

Eastbourne Group News

In April consultant urologist Mr Steve Garnett provided an update on developments for prostate treatments at East Sussex Healthcare NHS Trust and the longer term plans for the Urology Department at Eastbourne DGH. The number of prostate referrals has doubled since Stephen Fry and Bill Turnbull went public with their Prostate Cancer experiences. This is approximately 40 patients a week across Eastbourne and Hastings with an elevated PSA but of course they do not all turn out to have Prostate Cancer.

The Trust received a £200,000 NHS Improvement grant to enable them to purchase the Fusion Biopsy equipment and software. That has been up and running since December 2017. Three types of biopsy are now available: TRUS, fusion and template. The department had already changed practice ahead of the PROMIS findings reported in the media. So first stop for patients is MRI and then biopsy.

Eastbourne District General Hospital is a regional centre for prostate cancer surgery. Peter Rimington and Steve Garnett are both robotics surgeons and now taking patients from the Tunbridge Wells area.

The Urology ward and Investigations Suite is expanding. Work begins later in 2018 with more room for diagnostics and a high dependency area for surgical patients on Hailsham 4 ward. This has probably been hastened by the CQC report which said it was unacceptable to have a Urology Investigations Suite located by a thoroughfare where patients are expected to hold onto full bladders

with lack of toilet facilities!

Other developments include more staff and a replacement like for like for Senior clinical Nurse Specialist Alison Gidlow who retires in July.

To conclude the session, Mr Garnett showed diagrams of the Urolift procedure for benign prostate enlargement. The result looks similar to treasury tags! The tags are made of titanium and pull back the lobes of the prostate so that the urethra is not compressed or restricted by the enlargement of the gland. He said longer term it is not clear how this might impact on subsequent MRI investigations but problems with sexual function and incontinence are limited.

See this patient leaflet for more information. https://www.baus.org.uk/_userfiles/pages/files/Patients/Leaflets/Urolift.pdf

Golf Day Raffle – 25 May 2018

Eastbourne group members Tom and Elaine Chapman organised the second annual Golf Day in aid of Prostate Cancer UK and PCaSO. It was held at Willingdon Golf Club near Eastbourne at the end of May and once again the weather was warm and sunny. £1,000 was raised (see below).



Below: Tom & Elaine Chapman with raffle prizes generously donated for the event.

Hampshire Branch News

Cancer Rehab in Hampshire reported by Geoff Bailey

Our speaker in Otterbourne in March was Jane Bullock, Bachelor of Nursing (Hons), Cancer Exercise and Rehabilitation Specialist.

Jane explained the value of exercise to keep cancer at bay, slow disease progression and ease the side effects of treatment. At least 150 minutes a week of 'moderate' activity and strength exercises that work all major muscles. Alternatively, 75 minutes of 'vigorous' activity, with strength training. If we could talk but not sing during the exercise, that was 'moderate' but if we could do neither, it was 'vigorous'. Some men would not be able to meet these standards, but small amounts of physical activity would still be beneficial.

As men age, they tend to put on weight around the midriff and we should try to keep this below 38 inches.

Exercise should be fun. Activities such as walking, cycling and dancing may be more enjoyable than a workout in a gym. As we grow older, muscularity reduces year on year. Muscle strengthening exercises can mitigate this to some extent. Jane showed us some strength building and flexibility exercise using an elastic exercise loop which can be obtained quite cheaply from most sport shops. Cancer-related fatigue can be overwhelming, but can be helped by improving sleep patterns through exercise. Pelvic floor exercises can help with problems of incontinence.

The main goal of palliative care is to maintain independence and wellbeing towards the end of life. Jane works with patients, on an individual basis if appropriate, to meet their particular needs. Jane is available to be contacted by email jane@cancercover.co.uk or by phone 07796 545546.



LOCAL SUPPORT MEETINGS

See right for venue details and inside front cover for contacts.

September

3rd (Mon)	Bexhill	Dr Colin Tourle , GP
4th (Tue)	Otterbourne	Speaker tbc
6th (Thur)	Brighton	Speaker tbc
11 (Tue)	Pulborough	Discussions of symptoms, treatments, clinicians and hospitals.
13 (Thur)	Eastbourne	Open Forum
18 (Tue)	Rustington	Dr George Plataniotis , Clinical Oncologist, Sussex Cancer Centre, Brighton and Sussex University Hospitals
26 (Wed)	Talbot Woods	Dr Susannah Brock , Consultant Uro-Oncology, Poole and Bournemouth Hospitals. Subject: STAMPEDE trials.

October

3rd (Wed)	Chichester	Speaker tbc
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November

5th (Mon)	Bexhill	Social Meeting
8th (Tue)	Eastbourne	Sara Faithfull , Professor and Lead for Clinical Innovation, School of Health Sciences, University of Surrey – 'TrueNTH exercise and diet study'
27 (Tue)	Rustington	Patient Forum.

December

4th (Tue)	Brighton	Speaker tbc
11 (Tue)	Pulborough	Discussions of symptoms, treatments, clinicians and hospitals.

Hampshire Awareness Events

Aug 25th	Asda Havant
Oct 24th	West End Parish Centre

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.

Aug	25th	Pyecombe Golf Club (Sussex)	Book by phone:	Matt Bolton on 01273 845372
Sept	8th	Worthing (Sussex)	Book by email:	psa@worthinglions.co.uk or phone 0845 650 2555 (premium rate call)
	22nd	Eastleigh (Hampshire)	Bookings will open later	
	22nd	Dorchester (Dorset)	Bookings will open later	
	29th	Hove (Sussex)	Bookings will open later	
Oct	13th	Burgess Hill (Sussex)	Bookings will open later	
	27th	Gosport (Hampshire)	Bookings will open later	
Oct/Nov	tba	Alton (Hampshire)		
Nov	10th	Peacehaven (Sussex)	Bookings will open later	
	24th	East Grinstead	Bookings will open later	

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.