UPDATES

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

PCaSO

PCaSO visit to Centre for Cancer Immunology Southampton Issue No. 64 Winter 2018 Modern radiotherapy techniques Centre of Cancer immunology "STAMPEDE" trials -Hormone Therapies My Patient Story PSA testing

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Content for Updates

PCaSO are grateful to have medical professionals and other speakers at our group meetings. One of our members may take notes and write an article for the newsletter, so that the essence of the topic and the talk are shared across our membership. Such articles are not prepared or reviewed by the speakers themselves.

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From the Editor

The Cover photo was taken on a visit to Cancer Research UK at the new Centre for Cancer Immunology, adjacent to Southampton General Hospital. It shows three PCaSO Trustees with Dr Edd James. See article on page 5.

We like to include a Patient Story within each issue, this time Brian Holden's 'lucky journey' on page 6. Brian took a PSA test with PCaSO two years ago at Burgess Hill, his result was 'red' and prostate cancer was subsequently diagnosed. The article describes how he, with his family, dealt with his diagnosis, treatment, fitness and motivation.

In the Dorset Branch News on page 10 there is content about the Dorset Helpline. This allows men diagnosed with prostate cancer to be put in touch with others who have already been through similar experiences.

If you have any suggestions as to the type of articles you would like to read in Updates, or any other helpful comments, please send an email to editor@pcaso.org

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.

Localised Prostate Cancer: Modern radiotherapy techniques

PCaSO were delighted to welcome Dr George Plataniotis, Consultant Clinical Oncologist, Brighton and Sussex University Hospitals, to the Rustington Group on 18th September 2018. He talked about radiotherapy and answered many questions from the engaged audience, some of whom were his patients (he has around 300 patients each year).

PSA is a useful tumour marker for prostate cancer. Whereas its use for screening can result in some false negatives and false positives, once a prostate cancer diagnosis has been established it is a reliable marker for disease progression.

T1, T2 and T3 stage prostate cancer is now 85-90% curable. Previously treatments were standardised, but nowadays treatments are tailored to the needs of the individual. The cancer treatment chosen for an individual patient is not decided by a single consultant, but by an extensive multi-disciplinary team (MDT) of oncologists, urologists, radiologists and pathologists who meet regularly. This MDT approach safeguards the patient and brings a greater depth of expertise into decisions for the patient. Consultants maintain and update their expertise through international contacts, greatly helped by the internet. There are no international boundaries to knowledge in the fight against cancer. Patients are also safeguarded as consultants are only authorised to give a treatment approved by NICE.

The development of radiotherapy started in 1895 when Roentgen discovered X-rays and used them to produce an image of the bones in his wife's hand. This was a breakthrough, enabling doctors to see inside patients. The fact that X-rays could "burn" skin also suggested their use as an anti-cancer agent. In 1898 Marie Curie and husband Pierre Curie discovered radium. (Marie Curie died from her exposure). The radiation of particles from radium developed as an alternative treatment to electromagnetic X-rays. Henri Becquerel discovered the biological effects of radium and was awarded a Nobel Prize in 1903 for his work.

PSA is a useful tumour marker for prostate cancer. Once a prostate cancer diagnosis has been established it is a reliable marker for disease progression.

Initially more non-cancerous diseases were treated than cancerous ones. Radiotherapy was in use in Hammersmith Hospital in 1905 and progress was rapid, it soon became a standard treatment for non-cancerous diseases. It was found that splitting the total radiation dose into smaller ('fractionated') doses was better than a single treatment. It was some time before the longer term side-effects of radiotherapy were fully appreciated. In 1946 Muller received a Nobel Prize for the discovery of mutations due to X-ray irradiation, which identified carcinogenic properties.

In the 1980's and 1990's prostate radiotherapy was taking place. Radiotherapy has undergone a technological revolution in the last decade, whereby (3D) anatomical models of the patient through use of CT imaging, often complemented by MRI scans, are used for treatment planning, to enable conformal radiotherapy to be given to the shape of the target area/tumour. Greater accuracy meant that higher doses could be given, making treatment more effective and reducing side effects. Further developments of equipment and techniques followed:

IMRT - Intensity-modulated radiotherapy improves the conformity of the total dose delivered to the planning target volume (prostate and seminal vesicles) while reducing the dose to the risk organ (e.g. rectum) compared to conformal radiotherapy.

IMRT involves the head of the linear accelerator moving around the patient, delivering therapy from fixed positions that are determined during the planning process.

Volumetric arcing treatment (VMAT) involves treatment of the whole target volume using one or two arcs of beams from a machine that rotates around the patient continuously while delivering therapy. This form of EBRT (External Beam Radiotherapy) simultaneously adjusts for both the shape of the beam as it rotates around and the dose intensity.

IGRT - Image-guided radiotherapy is a technique whereby regular imaging is used to confirm that the target and surrounding organs are truly in a position appropriate for the radiotherapy, thus ensuring that what is planned is delivered.

In prostate cancer, IGRT can be achieved by implanting small inert seeds or a CT scan can be taken once the patient is in the treatment position.

Tomotherapy - a specialised Tomotherapy machine employs a 360-degree revolutionary treatment system to deliver tens of thousands of radiation beamlets, focused precisely to the target area, while minimizing radiation exposure to healthy tissue. It is also a form of intensity modulated radiation therapy (IMRT), as well as image guided

(continued overleaf)

Localised Prostate Cancer: Modern radiotherapy techniques (continued from previous page)

radiation therapy (IGRT), but more current as to imaging. Each day prior to treatment, the Tomotherapy unit develops its own CT scan and the radiologist can guide treatment based on what the prostate looks like at that time. This makes it easier to target only the prostate and minimise radiation to surrounding critical structures, such as the bladder and rectum. (Tomotherapy is available at the NHS clinic at Preston Park, outside Brighton, where they have two machines).

Preparation for Radiotherapy – micro-enemas and full bladder

Patients receiving radiotherapy need to have an empty rectum ('back passage') and for this they are provided with tubes of microenemas (i.e. not a full enema) for them to use at the radiotherapy centre. These can work quite quickly and the patient then proceeds to the next requirement of a reasonably full bladder, by rapidly drinking several cups of water (patients' bladder sizes vary) then waiting for a period before the radiotherapy treatment starts.

Costs, efficiency and patient time

The NHS is trying to reduce the number of treatments to reduce the number of days each patient has to attend. Specialised modern radiotherapy machines of different types can all treat localised prostate cancer well, however the faster machines enable more patients to be treated in a day, thus reducing waiting lists. One type of machine may be faster but more expensive than another, however if patient throughput is increased it may also be better value for the NHS.

The techniques listed above are for External Beam Radiotherapy (EBRT), but there are also internal techniques:

Brachytherapy treats the prostate directly. To receive brachytherapy potential patients

Fractionation options

Progression of radiation therapy trials within the United Kingdom during the past 15 years



Abbreviations:

RT01 Medical Research Council RT01.

- **CHHiP** Conventional or hypofractionated high dose intensity modulated radiotherapy for prostate cancer.
- **PACE** Prostate advances in comparative evidence.

should have no urinary symptoms such as frequency or urgency, be fit for general anaesthesia and have a prostate volume less than 55 ml. Patients go home the next day.

Brachytherapy is given as either Low Dose Rate (LDR) for low risk patients, or High Dose Rate (HDR) for high risk patients.

LDR brachytherapy – uses lodine-125 permanent implants, the sources decay with a half-life of 2 months, they remain in the prostate. A single treatment, only for patients with low risk prostate cancer, T1-2 N0 M0, Gleason 6.

HDR brachytherapy – uses Iridium-191. Needles are inserted, dosage is delivered and needles retracted. No implants are left in the prostate. Used for higher-risk patients, locally advanced, T3-T4 N0 M0, Gleason 8-10. Usually as a "boost" to EBRT, but occasionally as a sole treatment if EBRT is not recommended because of comorbidities.

Salvage Radiotherapy – treating recurrence after surgery

For those who have had a radical prostatectomy to remove the prostate, there is a chance of recurrence of the cancer several years later. This would be detected by PSA levels rising again over time from the almost undetectable level post-surgery. The patient can be treated with EBRT radiotherapy

once the PSA level has risen above 0.2 and it is given to the area of the 'prostate bed', i.e. the area where the prostate was before it was removed. Because the prostate has been removed the bladder will have moved down within the pelvis and the salvage radiotherapy will be actually given to an area that includes the descended bladder. Consequently the dosage cannot be more than 2 Grays per fraction as otherwise damage to the bladder can occur. (Typically one is looking at 33 fractions of 2 Grays, a total of 66 Grays). Therefore the recent developments of hypo-fractionation for higher dosages to the prostate cannot be used for recurrent prostate cancer where the prostate has been removed.

The Future:

The technological revolution in radiotherapy now allows questions to be asked which a decade ago would have been impossible to answer. The increased precision in every step of radiotherapy might allow us to further hypo-fractionate prostate cancer radiotherapy, perhaps even down to a single fraction, such as has been demonstrated with brachytherapy. Radiotherapy could be delivered using CT or MRI guidance, intrafraction MRI, automatic contouring, and fast online and real-time adaptive re-planning. These developments lie ahead and high quality clinical research is necessary.

Tour of the Centre for Cancer Immunology, Southampton

In August 2018 a small group of PCaSO members/trustees visited Cancer Research UK's facility at Southampton and were greeted by Liz Allaway, Research Engagement Manager for Cancer Research UK. We were also joined by Dr Edd James from University Hospital Southampton, who had previously given talks to PCaSO at Bournemouth and Fareham (see article in UPDATES Summer 2018), and his colleague Dr Emma Reeves.

Liz gave an overview presentation of the work of the Cancer Research UK charity. They are the world's leading charity for cancer research, with around 4,000 scientists, doctors and nurses and several such cancer science centres across the UK. Only Southampton has the new Centre for Cancer Immunology.

Edd and Emma guided us around the new Centre for Immunology. There is one large open-plan laboratory, which at the time of the visit was only partially occupied, waiting for visiting scientists from the USA to work in some of the newlybuilt space. Other laboratories are:

- Histology: with tissue samples frozen at -20C or preserved in paraffin
- Blood cancer samples
- Cancer tissue samples
- Bacteria: to grow any required bacteria
- Biochemistry: providing things requested by researchers, e.g. make a specified protein
- A laboratory which processes cells at a rate of 40,000 per second!
- A 'black room' which is completely dark so researchers can use lasers to view even a single molecule within a single cell.

It was a very interesting tour and we are grateful to Edd, Emma, Liz and Cancer Research UK for the visit.

University of Southampton Clinical Trials Unit are trialling new immunotherapy drugs with men whose prostate cancer has become



PCaSO members outside the new Centre for Cancer Immunology.

hormone resistant. Two such trials are -

ProCAID a phase I and phase II trial of an immunotherapy drug AZD5363 used in combination with chemotherapy drugs docetaxel and prednisolone. This study is looking at different dose rates of the trial drug.

POLERISE a study looking at an immunotherapy drug called pexidartinib used in combination with enzalutamide. This trial is for men whose cancer has become hormone resistant.

'STAMPEDE' Trials – Hormone therapies

(Synopsis of talk to Talbot Woods group, Bournemouth, given by Dr. Susannah Brock on Sep 26th 2018).

STAMPEDE is the largest prostate cancer treatment trial ever, with more than 9,000 men taking part in more than 100 hospitals in the UK. The trial, which continues to recruit new men, has an innovative multistage, multi-arm design, which was developed and run by the MRC Clinical Trials Unit at UCL. All the men taking part in the abiraterone comparison of STAMPEDE had high-risk prostate cancer, or prostate cancer that had already spread to the nodes or other parts of the body. They were also starting long-term hormone therapy for the first time and were fit enough to have chemotherapy.

The trials were "multi-arm" and have been running for over 10 years (they commenced in 2005). The arms started at different dates and if some showed no benefits over the standard treatment to the men in that cohort, they were reported and then closed. However, there were others that showed significant benefits and some of these are still running.

The aim was to find the best combination of hormones to give patients who were on standard hormone treatment. Life expectancy in some arms showed an increase in survival rates of more than a year/18 months. It was worth noting that abiraterone not only prolonged life, but also lowered the relative chance of relapse and reduced the relative chance of serious bone complications. Enzalutamide is also effective, but cannot be used in conjunction with abiraterone as they have a different approach to the same problem. Enzalutamide can have some nasty side-effects in some patients.

The trial is still going on because other questions have been added since the original groups started.

The talk was very informative and was supported by clear diagrams and uncomplicated graphs. It was also refreshing to have Dr. Brock presenting the topic in which she had actively participated and the audience clearly appreciated the presentation.

My Patient Story by Brian Holden, Brighton Group



BRIAN'S LUCKY Journey

Why 'Lucky'? Well, if I had not been out shopping in Burgess Hill for my wife, Karen's, ruby wedding anniversary present, one Saturday afternoon in October 2016, I would probably have advanced prostate cancer by now, with bone secondaries, and still no outward signs or symptoms of cancer.

The Lions, with PCaSO, were holding a PSA testing day in the Martlets Hall in the centre of town. Over the last ten years my GP had repeatedly advised me against having a PSA test as I apparently had no "symptoms", and so I decided on the spur of the moment to take the test. It was a simple blood sample taken by phlebotomists from a local hospital. Unfortunately, the test result sent back to me by post was RED, indicating a slightly high PSA of 5.48. I was somewhat surprised and rather than trouble the GP with what I imagined could have been a distorted test, I had another test done by PCaSO a few weeks later, yielding a further RED score. At this point I was more concerned, and went to see a GP, not my usual one, who immediately put me on the fast track appointment

system at the Royal Sussex County Hospital, Brighton.

At all times I kept my immediate family informed of progress, following the initial GP referral. I am fortunate in having a daughter who is an oncologist registrar, in another region, with some knowledge and contacts in the field. She helped my understanding of procedures and has given me extra support.

Maintaining fitness levels and a positive attitude to the outcome is essential, I feel. As is gaining as much knowledge as possible of prostate cancer, the main websites I've used being PCaSO, Macmillan and Prostate Cancer UK. Karen's research showed I would have more chance of a successful longterm outlook if a healthy diet were followed, so I made extensive changes.

Karen and I straight away volunteered to help at PCaSO PSA testing events and, coincidentally, back at the Martlets Hall for our first event as volunteers, a year after my first test, we met another chap called Brian, who had also been tested on the same day as me by PCaSO the previous year. This meeting was fortuitous, as Brian was following the same treatment path as me but was a few weeks ahead, and thus we were able to compare notes and commiserate on side effects and treatment. I have since volunteered to take on the role of Gift Aid Coordinator for PCaSO, allowing me to give more back in the pursuit of helping more men like me, who may have PC without having any symptoms.

Once the preliminary, preradiotherapy, hormone treatment was started, the main side effect was hot sweats, resulting in poor sleep, and increased frequency to wake at night for a pee - sometimes hourly. At this point Karen had seen the Horizon

Centre at the Royal Sussex County Hospital in Brighton, and the complementary treatments being offered there, so I called in on the off chance. Michaela suggested that I tried acupuncture for the hot sweats, and duly booked me in for a session with Jane. Within days the treatment had had an effect. reducing the sweats, and resulting in much better sleep. Treatment continued throughout the following months at regular intervals, and was a great success. I also had a couple of massage sessions for muscular pains and strains caused during the course of my efforts to maintain fitness, and again these were successful, and enabled me to continue my active lifestyle.

Albion in the Community use and support the Horizon Centre in offering health and fitness training for those in Brighton. As I live in Mid Sussex, I was offered 'Move More', another programme to encourage health and fitness activities. I found this too easy – I am used to lots of off-road cycling on the South Downs, and it was this level that I wanted to achieve



Cycling up Ditchling Beacon

once again. However, it was good to meet regularly with one of their experienced trainers for motivation.

The morning after my HDR brachytherapy treatment, I headed from my hospital bed to the Horizon Centre to meet Karen, and found an almond croissant and coffee waiting for me - the perfect treatment, brilliant!

During one visit to the Horizon, I saw a poster for a Nordic walking course, and being a keen walker, I thought I could further improve my overall fitness and arm strength. This has proven to be the case, and will now be another great means of exercising outside in the fresh air.

Soon after completion of my course of treatment, my GP referred me to the Triangle Leisure Centre in Burgess Hill for three months. On meeting my personal trainer I was given a course of light weight and cardio exercises, followed by swimming in the health suite, and sessions in the steam room and sauna. This made a huge difference to my strength and overall fitness. The weather during the winter did not encourage any long-distance off-road cycling, so using the gym regularly was the perfect means of getting exercise.

Just eight months after completing all my treatment, I had regained all my former fitness. I recently cycled the whole length of the South Downs Way, 190 km, in three days, albeit on an electric bike, including an overnight stop in a hike tent in the frost, with no ill effects!

Post-treatment, I have now volunteered to take part in a clinical trial called Add-Aspirin, which will mean regular trips to the hospital and enable me to pop in to the Horizon.

Throughout my treatment the NHS system has been faultless, there were no cancellations, and staff were very professional and caring at every step of the way. I've had a lucky journey!

Here is a summary of Brian's journey so far:-

2016		
8th October	First PSA Test 5.48	
19th November	PSA Test , 5.15	
	GP referral by Dr T Lynch	
20th December	Mr Cheema, Urology - DRE - small, smooth, benign-feeling prostate	
2017		
25th April	Four month review after PSA test - Dr Bratkas. PSA Test , 6.94	
9th May	MRI Pelvis with contrast	
18th May	Ultrasound - guided biopsy - Dr Jonathon Richenberg	
20th June	Mr Andrew Symes confirmed PC, and the team offered me a choice of radical prostatectomy or HDR brachytherapy	
21st June	Consultation - Mr Stephen Garnett, discuss radical prostatectomy	
3rd July	Contacted PCaSO. Inspiring comment from Roger Bacon – " it's treatable and beatable ". Discussed different experiences with other PCaSO members.	
6th July	Consultation - Dr Angus Robinson, discuss HDR brachytherapy, etc	
7th July	I decided to follow the HDR brachytherapy treatment path	
10th July	Pre-treatment baseline PSA test 11.15 Begin hormone tablets .	
14th July	First Zoladex (hormone therapy) injection . Joined PCaSO	
3rd August	Began Horizon Centre complementary therapies	
4th October	Pre-radiotherapy baseline PSA test 0.87	
12th October	Consultation - Dr Robinson	
30th October	CT radiotherapy planning scan	
31st October	Pre-op assessment	
3rd November	Final Zoladex hormone injection	
30th November	HDR Brachytherapy	
18th December	First 'enemy' (enema!) and first of 15 days of daily external beam radiotherapy treatment	
2018		
10th January	Final enemy! And final radiotherapy	
14th February	Post treatment PSA test 1.33 (slightly higher, expected at this stage)	
21st February	Consultation - Dr Robinson. Now in remission	
2019		
14th January	Next appointment due	

Worthing PSA testing event

by PCaSO in conjunction with The Worthing Lions



The event was held at the GuildCare Centre in Worthing on 8th September 2018. Total number of men tested was 394. Results back from Worthing Hospital show there were 23 elevated readings (6%) above the 'normal' level. 371 green - normal; 12 amber borderline above; 11 red - high.

The highest reading was 23.36 from a 68 year old, but more concerning was the number of men in their 40s who will need further checks, 4 ambers and 2 reds.

The photos illustrate the 'process' that takes place during the event to ensure that almost 400 men who wanted to be tested had their blood samples taken. Thanks to those PCaSO members who helped on the day (and at other PSA events) also to the Worthing Lions who took the bookings, helped on the day and provided some help with the funding.

Some of you will know PCaSO use the Graham Fulford Charitable Trust to process and check the results with a consultant urologist before posting/emailing the results to the men we test. Graham has confirmed that with the 394 men we tested in Worthing added to his results database, it exceeds 100,000 men since the whole testing programme began several Left: Reception – with Lauren Bacon and a Worthing Lions helper. They check names of arriving men against the booking times and hand them Consent Forms to complete. *Right*: Men reading leaflets and filling in

Consent Forms.





Left: Roger Bacon giving the talk and answering questions, so that men are suitably informed before they are tested.



Above: Volunteer phlebotomist preparing to take a blood sample.

Above right: Phlebotomists and men, with PCaSO members alongside completing admin.

Right: Roger taking all the blood samples to Worthing Hospital Pathology Lab.

years ago across the country with support groups like PCaSO. As a charity group PCaSO have now tested in total over 10,000 men across our region.





Burgess Hill PSA testing event

On Saturday 13th October two charities joined forces to organise a free PSA blood test event at the Cyprus Hall in Burgess Hill. The Prostate Cancer Support Organisation (PCaSO) in partnership with the Burgess Hill & District Lions took blood samples from 444 men, using trained phlebotomists.

The event ran on time throughout the day thanks to the efforts of the volunteers from both charities. Every man was counselled before they had the test, explaining what can cause an elevated reading along with risk factors, such as prostate cancer history in the family and the importance of having a regular check. Roger Bacon, the Chairman of PCaSO said "The PSA test is the only first line simple test we have to determine the health of a man's prostate, a high reading can trigger further tests that indicate cancer



Above: Roger with Bruce Forbes leader of Mid Sussex town Council

within the gland that may need treating, unfortunately there are those that seek to undermine the importance of getting tested".

The event was supported by Sir Nicholas Soames MP, the Burgess Hill mayor and the leader of Mid Sussex Town council, who stayed for over an hour chatting to those attending. The cost of holding the event was funded by the Burgess Hill Lions and donations from men on the day, nearly £2000, were gratefully received and will help pay for the work both charities do. It is hoped to arrange another test day next year.

Below: *L* to *R* Tony Parris (*Lions*), Sir Nicholas Soames MP, Roger and Chris Cherry (*Burgess Hill Town Mayor*)



What is the Bristol Whole Life Approach?

- The Bristol Whole Life Approach recognises that to be healthy we need to pay attention to all parts of ourselves. Specifically, our mind, body, spirit and emotions, which are all closely connected and work together to support our immune system and its ability to keep us well.
- we strengthen our immune system by eating well, physical activity, doing the things we love and managing stress.
- By learning how to self-care and increase our resilience, we are better able to face whatever life throws at us.
- This powerful knowledge offers hope and a sense of control for those with a cancer diagnosis.
- It dosen't mean we are offering the promise or expectation of cure.
- It does mean we can confidently say we each have natural internal resources that, when supported in the right way, can have a powerful effect on our health and well being.



Penny Brohn UK Living Well with Cancer

Sussex Branch news

The effect of the publicity by Stephen Fry and Bill Turnbull has had a marked effect on the PSA test events run by Sussex Branch. At the time of writing Sussex had tested 1247 men so far this year, which is five ahead of the total for the whole of 2017. Already one event had to close the booking list when figures reached 450 and Roger Bacon expects the branch to have tested more than another thousand men by Christmas.



The Burgess Hill testing event was supported by Local MP Sir Nicholas Soames seen here with Roger Bacon Details of forthcoming events are in this newsletter and on the PCaSO website and plans are underway for more events in 2019.

It is obvious from testing events held with Lions and Rotary that having branded clothing makes a big difference to the recognition of PCaSO as the one doing the testing. Roger has made arrangements with a local company to allow all members to be able to buy PCaSO branded clothing from a special website. This will go live in coming weeks so watch out for announcements.

The Brighton group had a good meeting addressed by a representative of the Penny Brohn organisation, a Bristol-based charity that advocates Living Well with Cancer (www.pennybrohn. org.uk) See page 9. Discussions are underway to explore the possibility of free courses for PCaSO members in the future. Watch this space. Rustington Group had a talk in September on radiotherapy from Dr George Plataniotis. See article in this newsletter.

The Bexhill and Hastings group had a talk from Dr. Colin Tourle MBE about the countries he had been to with a team of nurses. to treat patients who would otherwise not have access to medical treatment. These include the orphans in Romania, natives in East Timor and the Syrian refugees in Lebanon. Colin has had prostate cancer and spoke of his experience and treatment. This has still not stopped him from this work and he hopes to go to Lebanon again before Christmas. The next meeting of the group, a discussion of prostate cancer diagnosis, symptoms and treatments, will be on Monday 5th November, 7pm at Bexhill Hospital health centre, Holliers Hill, TN40 2DZ. The January meeting will be social enjoying a meal out. Details to be advised.

Dorset Branch News

As usual, branch focus has been on PSA testing.

Sessions took place at

Wareham on July 28th 117 tested – 19 "Highs"

Dorchester on September 22nd

143 tested - 11 "Highs"

Sessions to come: Sturminster Newton November 10th and Wimborne February 23rd We have now tested over 5000 men in Dorset!

780 were found to have a high PSA reading – of these, 250 went on to be monitored or treated.

Membership stands at close to 300 members

Member Chris Falla recently raised over £4000 by leading a team that took part in a major London 10km run. He has recently been treated with brachytherapy and radiotherapy and, happily, his PSA reading is now close to zero.

Our recent speakers have been:

Ann Duffy, Head of Clinical Service PCUK

Roger Wotton, Chairman of Tackle

Susannah Brock, Clinical Oncologist at Bournemouth & Poole, speaking about the STAMPEDE trial.

See PCaSO website for future meetings

Dorset Helpline

PCaSO (Dorset Branch) runs a local Helpline (Tel. 01202 580436) which not only provides information to men facing some difficult choices of treatment at a time when they are still coping with the news of their diagnosis, but gives them the opportunity to talk to other men who have been through the same process of decision-making. The Helpline is able to link up these men through a system which uses a list of ex-patients willing to talk and exchange information on their own experiences and also to reassure and encourage these men through the various stages of treatment. We also have a lady volunteer who can speak to wives of men accessing the Helpline. The feedback has confirmed that this is an important and positive element in the process of understanding through empathy and much appreciated by the men who use it.

Eastbourne Group news



AMMA event at Herstmonceux - 2 September 2018

Ron and Jenny Linkins (*pictured above*), who dispatch your printed copies of Updates, recently attended a fundraising and awareness day for prostate cancer. Organised by Wulf Yapp from the Artificers Masonic Motorcycle Association (AMMA), it was held at the Woolpack in Herstmonceux in early September. This is what Ron and Jenny had to say about their day:

"We were pleased to represent our local Eastbourne PCaSO group at this function, especially as both a prostate cancer patient and brother Mason, Ron felt he would have something in common with those attending. Our initial trepidation on arrival was quickly dispelled by the friendliness of our welcome and we soon set up the display under our allocated gazebo in an excellent position right next to the entrance to the bar. After enjoying our BBQ pub lunch, Ron was honoured to be chosen by Wulf to help him and the pub landlady judge the bikes in various classes.

"We enjoyed meeting many of the bikers and were able to share with them and their wives our own experiences. Many men need

Hampshire Branch News

At Waterlooville on November 6th Sue Boyes is talking about the work of Prostate Cancer UK and the services and support they can offer our members directly.

On March 5th 2019, at Otterbourne, Mr Rowland Rees, Consultant Urological Surgeon, University Hospital Southampton, one of the UK's leading surgical andrologists and Russell Etherington of Boston Scientific will be talking about functional recovery after prostate cancer treatment.

'Andros' is the greek word for male, and 'andrology' is the study and treatment of disorders of the male genitalia. Incontinence and erectile dysfunction are common problems after prostate cancer treatment affecting a large number of men and their partners.

Mr. Rees will talk primarily about these all too frequent complications of prostate cancer treatment and how they can be treated and the current research into new treatments.

Russell Etherington is a former urology nurse specialist and is now product manager for the urology and pelvic health section of Boston Scientific who partners with urologists to continually advance the quality of patient care with innovative urology solutions. nagging to seek medical advice. We also gave out the blue and pink PCaSO general information leaflets encouraging awareness of men's health and the importance of PSA testing. We had photocopied details of the PCaSO PSA testing dates which many took away to share with their own Masonic lodges. A member of Ron's lodge (Hadrian 2483) visited us at our display. The lodge is currently organising a group outing to the upcoming PCaSO Peacehaven testing event.

"We also met a group of bikers who were not part of AMMA, but just riding past on their Harley-Davidsons, who stopped by for a pub lunch and to look at the bikes. It was interesting sharing information with them and to receive their generous support in our PCaSO collecting tin. However, absolutely priceless is that this chance encounter may have set them thinking about their own health, prompting them to seek further advice which could save their lives."

AMMA generously raised £214.75 for the PCaSO Eastbourne support group at this event. With thanks to Wulf and his team at AMMA.

Penny Brohn UK Living Well with Cancer

FREE

to attend courses

2 day course on 6th & 13th Dec at **Midhurst Hospital** and 28th Jan & 4th Feb at **Southampton General Hospital**.

Phone: 0303 3000 118 Email: bookings@pennybrohn.org.uk Website: https://pennybrohn.org.uk

LOCAL SUPPORT MEETINGS See inside front cover for contacts.

November

5th	(Mon) Bexhill	Discussion of diagnosis, symptoms and treatments	E
6th	(Tue) Waterlooville	2pm - Sue Boyes , Peer Support Manager, Prostate Cancer UK 'The work of Prostate Cancer UK'	S T
8th	(Tue) Eastbourne	Sara Faithfull , Professor and Lead for Clinical Innovation, University of Surrey – 'TrueNTH exercise and diet study'	E
21st	(Wed) Chichester	Dr Y S Nagar , Consultant Oncologist Queen Alexandra Hospital, Cosham, on radiotherapy.	C
27th	(Tue) Rustington	Patient Forum.	C
28th	(Wed) Talbot Wood	s Speaker tbc	S

December

4th 11	(Tue) Brighton (Tue) Pulborough	Patient Forum Discussion of symptoms, treatments, clinicians, hospitals	- C L P
20 ⁻	19		S
Jan	uary		B
	(Tue) Bexhill ruary	Social Meeting	F F
	(Wed) Chichester (Thur) Eastbourne	Speaker tbc ' One You East Sussex ' The county's new integrated healthy lifestyle service.	B B
Mar	ch		В

Ν

4th 5th	(Mon) Bexhill (Tue) Otterbourne	Speaker tbc Mr Rowland Rees , Consultant Urological Surgeon, University Hospital Southampton, and Russell Etherington , Boston Scientific. 'Functional recovery after prostate cancer treatment'	CI SI PC Ei
	(Wed) Brighton (Tue) Pulborough (Tue) Rustington	Speaker tbc Discussion of symptoms, treatments, clinicians, hospitals Speaker tbc	Po Ea Go Pu Pu
	(Wed) Chichester (Thur) Eastbourne	Speaker tbc Susan Crosby-Jones , Matron, Urology Investigation Suite, Eastbourne DGH. 'Update on UIS'	Sv Rł Ri Jo
	(Mon) Bexhill	Speaker tbc	W

Speaker tbc

VENUES

Dorset

Bournemouth: 7.30pm start St Marks Church Hall, Falbot Woods, 3H10 4HY,

Hampshire

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

Waterlooville: 7pm start hurch of the Sacred Heart, ondon Road, 07 7SR

bussex

exhill: 7pm start lealth Centre, Bexhill Hospital, Iolliers Hill, Bexhill, N40 2DZ

Brighton: 7pm start lacmillan Horizon Centre, sristol Gate, Brighton N2 5BD

hichester: 7pm start Chichester Baptist Church, herbourne Road, 019 3AW

astbourne: 7pm start ostgraduate Centre, astbourne District eneral Hospital,

ulborough: 7pm start ulborough Village Hall, wan View (off Lower Street), H20 2BF,

ustington: 7pm start

ohn de Bohun Room, loodlands Centre, Woodlands Avenue, BN16 3HB,

PSA Testing Events:

22nd (Wed) Brighton

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.

Nov	3rd 10th 10th 24th	Alton (Hampshire) Sturminster Newton (Dorset) Peacehaven (Sussex) East Grinstead (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.
2019			
Feb	23rd	Wimborne (Dorset)	Most events are on a Saturday and usually finished by mid-afternoon. If
March	23rd	Southbourne (Dorset)	you are available on any of the above
	24th	Portsmouth (Hampshire)	dates call:
	30th	Chichester (Sussex)	Roger Bacon (Sussex) 01903 775783,
April	6th	Uckfield (Sussex)	Peter Weir (Hampshire) 01489 892168,
	tbc	New Milton (Dorset)	Jim Davis (Dorset) 01202 580436.
Мау	18th	Hayling Island (Hampshire)	
June	29th	Horsham (Sussex)	