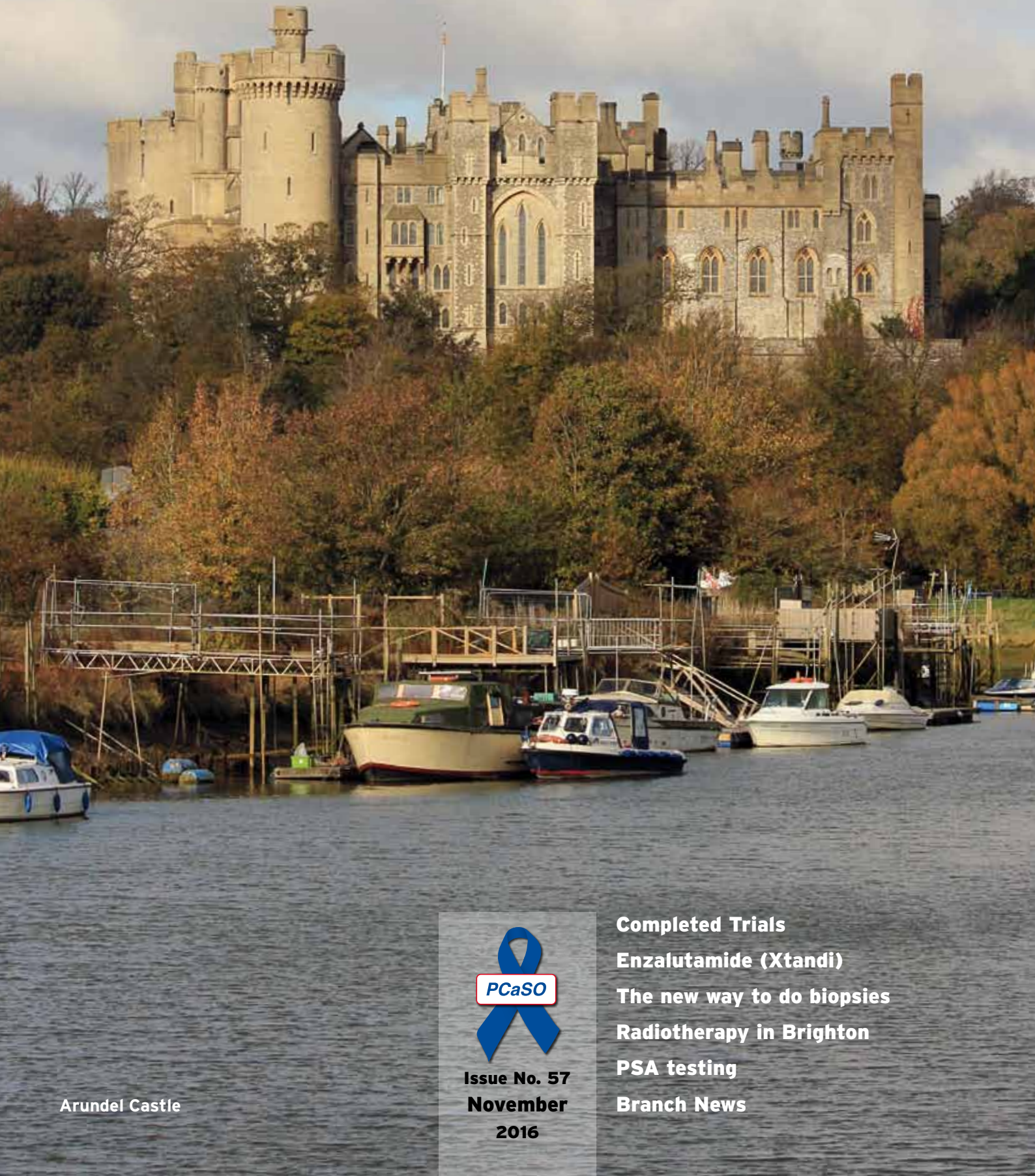


# UPDATES

The Newsletter of PCaSO Prostate Cancer Support Organisation

Dorset • Hampshire • Sussex



Arundel Castle



Issue No. 57  
November  
2016

**Completed Trials**  
**Enzalutamide (Xtandi)**  
**The new way to do biopsies**  
**Radiotherapy in Brighton**  
**PSA testing**  
**Branch News**

## Executive Committee

**Chair:** (chair@pcaso.org)  
Roger Bacon 01903 775783

**Hon. Secretary:** (secretary@pcaso.org)  
David Hurst 01798 875758

**Hon. Treasurer:** (treasurer@pcaso.org)  
Vivian Miles 01243 814129

**Membership Secretary:** (memsec@pcaso.org)  
Geoff Bailey 01962 713579

**Hampshire Branch representative:**  
Peter Weir 01489 892168

**Dorset representatives:**  
James Davis 01202 580436 (jamdavis@talktalk.net)  
Allan Higgin  
Derek Pilling

**Federation representative:**  
Allan Higgin 01202 691710

**Pastoral Counsellor:**  
Nicholas Frayling

**Newsletter Editor:**  
Tony Ball 01903 783540 (publications@pcaso.org)

**Design:**  
Colin Woodman

**Founder: David Rowlands**

**Medical advisers:**  
Prof. Christopher G Eden, MS, FRCS (Urol)  
Dr Chris Parker, MRCP, MD, FRCR  
Dr Angus Robinson, MBBS, MRCP, FRCR

**Patrons:**  
The Duke of Richmond and Gordon  
The Very Rev. Nicholas Frayling  
Baron Palumbo of Walbrook  
Bill Beaumont, OBE

## Donations

PCaSO does not receive any government grants to fund the work we undertake and is largely dependent on membership subscriptions, donations and sponsorship.

To make a donation please send a cheque to:

The Treasurer  
PCaSO Prostate Cancer Support Organisation,  
PO Box 66,  
Emsworth, PO10 7ZP.

Alternatively, go to the website [www.pcaso.org](http://www.pcaso.org) and click on the red Virgin Giving button on the front page..

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.

## Dorset Branch Committee

**Chair:** Jim Davis 01202 580436

**Treasurer:**  
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Brian Deacon (*fundraising*) 01202 487708  
Derek Pilling (*website*)  
Ray Bona (*publicity*)  
Clive Duddridge (*membership*) 01202 693976  
Catherine Woolford (*speakers*)  
Allan Higgin (*PSA testing*) 01202 691710

## Hampshire Branch Committee

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Chris White (*publicity*) 02392 264042  
Geoff Bailey (*membership*) 01962 713579  
Nicky Annells (*Fareham*) 01329 843828  
Peter Weir (*Southampton*) 01489 892168

## Sussex Branch Committee

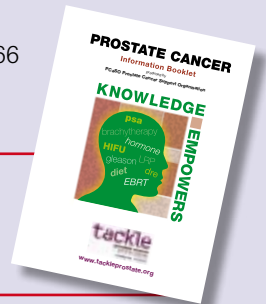
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**Treasurer:**  
Vivian Miles 01243 814129

**Secretary:**  
David Hurst 01798 875758

**Marketing/Promotions:**  
Christina Cutting (*East*) 01323 641513  
Barry Cocum (*West*) 01273 387371  
Debbie Hatfield 01323 638021  
John Proctor (*Bexhill group*) 01424 532866

The latest edition of the "Knowledge Empowers" booklet is now available through the PCaSO branches



Prostate Cancer  
Support Organisation

PO Box 66, Emsworth  
Hants PO10 7ZP

**National Help Line:**  
**0800 035 5302**  
**[www.pcaso.org](http://www.pcaso.org)**

Charity No: 1095439

# Outcome Report on Trials

## CHHiP - Radiotherapy:

### 4 weeks as good as 7 weeks

The results of the CHHiP trial, led by Professor Dearnaley from the Royal Marsden, were published in August and will change practice. Until recently, the standard course of prostate radiotherapy was 37 treatments over 7.5 weeks.

The trial, which included over 3000 men with localised prostate cancer, compared this with a shorter course of 19 or 20 treatments over 4 weeks. The results showed that a 4 week course was as effective and as safe as the standard 7.5 week course.

Since the results came out, hospitals across the world have been shifting to the 4 week course. This is obviously more convenient for patients and will also save precious NHS resources.

## ProtecT

### Active monitoring versus radiotherapy versus surgery

The long-awaited results of the ProtecT trial were released in September. This British trial, led by Professors Hamdy, Neal and Donovan, from Oxford and Bristol, will be of great interest to men diagnosed with screen-detected localised prostate cancer. Over 1600 such men agreed to undergo randomisation to active monitoring, surgery, or radiotherapy.

After 10 years of follow-up, the risk of death from prostate cancer was very low (around 1%) with no significant difference between treatments. Of the three treatments, surgery had the greatest negative effect on sexual function and urinary continence. Bowel function was worse in the radiotherapy group at 6 months but then recovered.

ProtecT provides some of the best information available anywhere to help men choose how to manage their prostate cancer. The first decision that many men face is whether to have any treatment or not: The fact that survival after surgery or radiotherapy was no better than after monitoring will come as a surprise to many people. However, it is quite possible that a survival benefit will emerge with longer follow-up. For those men who do have treatment, the information from ProtecT will be invaluable in helping them to choose between surgery and radiotherapy. The results indicate that surgery and radiotherapy are equally effective, but with a different pattern of side effects.

## Current Trial

### REASURE

#### Currently recruiting men with bone secondaries

Radium-223 is now a standard treatment for men with prostate cancer that has spread to the bones and is no longer responding to hormones. Although radium improves survival and has very few side effects, the ideal dose is not yet known. REASURE is comparing two different doses of radium.

Men in the study have no fewer than 12 MRI and PET scans during the six month course of treatment, so REASURE is most suitable for men who live reasonably close to one of the participating hospitals. The study is currently open at Brighton (Dr Angus Robinson) and Royal Marsden (Dr Chris Parker).

**NB.** Both Dr Parker and Dr Robinson are Medical Advisors to PCaSO

## Enzalutamide (Xtandi) formerly MDV3100

Enzalutamide, marketed by Astellas Oncology, has been around for a while now, initially being prescribed to patients through the Cancer Drugs Fund, before being approved by NICE. It is a drug called an anti-androgen, which is a type of hormone therapy. Taken in pill form, it is usually used to treat men when other drug treatment no longer works.

It works by blocking the activity of hormones (such as testosterone) called androgens, by so doing it stops prostate cancer cells from reproducing and growing. Prostate cancer cells have androgen receptors on their surface and when androgens come into contact with these receptors, it sends a signal to help them grow. Anti-androgens help block the signal, stopping the cancer cell growth.



The usual dosage is 4 capsules taken at the same time once a day. Like all medication, side effects

from this treatment will vary from man to man, the most common being feeling tired(33%), hot flushes(20%), headaches(10%), there are others likely to affect 1 in 10 men. Success of the treatment is monitored by PSA tests and trials have shown a high percentage of men respond well to the drug with PSA levels dropping after a month of treatment.

Enzalutamide is now usually given after chemotherapy, but following several trials some men are now given the drug as a second line treatment before chemotherapy, after first line drugs such as Zoladex or Prostatep fail to work and the PSA starts to rise.

Roger Bacon

# The new way to do biopsies

Almost every prostate cancer patient has had to have a trans-rectal ultrasound (TRUS) biopsy – some have more than one. We all know it is uncomfortable and undignified and, because of where it is taken it is open to infection. Unfortunately it has been the easiest way for the doctors to get 8-12 samples of the prostate so they can judge under the microscope how aggressive any cancer is and give it a Gleason score. At least, nowadays, a multi-parametric MRI scan is done before the biopsy, which can indicate exactly where any tumour lies.

Now things are changing. PCaSO has donated £25,000 to the Western Sussex Hospital Trust (WSHT) that runs St. Richards, Worthing and Southlands hospitals to help buy an £85,000 Hitachi Hi Vision Preirus Ultrasound Scanner that will enable Template Biopsies to be done. Essentially the main box is a highly specialised computer and display screen connected to a beautifully engineered mobile arm.



**The computer brings together the pictures from the ultrasound probe and the previously-taken MRI scan to show the surgeon exactly where the tumour is. The picture is changed using the foot pedals.**



**l-r: John Harmer, Upper Marden, PCaSO fundraiser. Mr Paul Carter, Head of Surgery, WSHT, Mr Barnaby Chappell, Consultant Urological Surgeon, WSHT, David Hurst, Pulborough, PCaSO Secretary, Ian Graham-Jones, Westbourne, PCaSO trustee at the time.**

The procedure is carried out in an operating theatre and the patient is asleep and his legs are raised. The surgeon sits facing the patient's bottom and aims to take the samples through the perineum, the skin between the testicles and the anus. The arm is fixed to the side of the operating table and the white ultrasound probe is inserted into the rectum so it can give the surgeon a view of the prostate. The stainless steel grid, or template, is placed against the perineum.

The computer software enables both the ultrasound probe image and the MRI images to be displayed together on the screen, at system called Fusion Guided Biopsy. The surgeon can see where the tumour is and the computer tells him to use template hole, say, D9. He inserts the needle through hole D9 – just like the 'Battleships' game – and he can see on the screen how deep the needle is and when it reaches the tumour. He takes the sample and withdraws the needle. Depending on the size of the tumour he can do this a number of times, maybe up to 40 if necessary, and be sure of getting a tumour sample every time.

The patient wakes up in a ward and usually stays a night for observation and then goes home with a bit of a sore bottom. The huge advantage is that the surgeon can be very sure he's got the samples required so biopsies don't have to be repeated (I had three for my diagnosis back in 2011) and chances of infection are greatly reduced.

The downside is that it is expensive. Buying the kit is one thing but the procedure needs an operating theatre and team plus a ward for recovery for each patient. Paul Carter, Chief of Surgery, said that there would be no chance of having the procedure available if PCaSO, along with other local charities, hadn't raised the money for the capital cost. He said he was very pleased and very impressed with PCaSO's work. And that from a man who ran a marathon and raised £12,000 on his own!

Although the equipment was bought for biopsies the surgeons believe it can be used for brachytherapy which requires small seeds to be placed accurately in the prostate and they are already developing the technique.

# Radiotherapy for Prostate Cancer in Brighton

Radiographers from Brighton and Sussex University Hospitals kindly gave a talk to the Rustington Group on 20th September 2016.

## External Beam Radiotherapy:

Preston Park Radiotherapy Centre (in north Brighton) has two new Accuray Tomotherapy machines for the treatment of cancer by (EBRT) external beam radiotherapy. These are smaller and faster machines than those in use at Brighton Hospital, each with the capacity to treat 40 patients per day. A beam of radiation is delivered from a moving and rotating gantry, taking about 2 to 5 minutes per daily session. Although newer, smaller and faster they are similar in treatment for the patient to the linear accelerators in use in Brighton Hospital. Radiotherapy has long been used for treatment of various forms of cancer, but over the years changes have been mainly with the improvements in beam focus, using advancing technology for better imaging of the target area (in our case the prostate).

Whichever machine is used (Tomotherapy or linear accelerator), the patient has daily imaging of the pelvis before treatment, with tiny tattoos used to aid guidance of the beam. The beam works like a high-intensity X-ray, and treatment is given daily from Monday to Friday for several weeks.

## Brachytherapy - general:

Rather than an external beam, brachytherapy involves radiation therapy inside the prostate itself and can be used in addition to external beam, or just on

its own. It can be either low dosage, where the seeds are permanently implanted in the prostate and remain there, with radiation gradually reducing over time, or in high dosage with a temporary implant which is removed at the end of treatment. This is a non-repeatable, one-off lifetime event.

## HDR Brachytherapy process:

The machine for giving high dose rates of radiation, by means of temporary implants, to localised prostate cancer was installed in Brighton in March 2014 with the 100th prostate treatment in September 2016. It is used every other Thursday and two people can be treated over a period of 14 hours. The implants, a sample of which was shown to the meeting and are like very narrow plastic straws, are inserted into the prostate using a guide similar to that for a template biopsy, while the patient is under general anaesthetic or spinal block/sedation.

As well as the prostate itself the seminal vessels can also be treated. The patient has a temporary urinary catheter. Under computer control between 15 and 25 implants are inserted, then the radiation source, a bead of Iridium-192, is passed down each insert in turn and then withdrawn. The treatment takes between 10 and 25 minutes. At the end of the treatment no radioactive material remains in the prostate. The stiffeners in the implants are also then removed to improve patient comfort during recovery. The patient recovers overnight in the ward before going home the next day, once the urinary catheter is removed..

## PSA testing

PCaSO has been offering free PSA tests for around five years. Currently we believe we have tested some 5,000 men with nearly 2,000 in this year alone. Counting the events run across the country by other support groups the figure is around 60,000 men tested.

This is a free service because we want men to take advantage of it though donations are requested. The earlier prostate cancer is diagnosed the more likely it is to be cured. Every event we hold will find a few men, usually around ten per cent, with a higher than normal figure and we advise them to go straight to their GP.

The other reason is that the more men who talk about being tested the more aware the population becomes of prostate cancer. A man who is booked for a test may tell his colleagues at work or his friends in the golf club. Often we get bookings from men who say that their friend came to an event.

PCaSO works with other charities like the Lions, Rotary and the Masons and these volunteers do the hard graft of organising the event, advertising and often taking the bookings. PCaSO volunteers turn up on the day with the kit to take the blood and the paperwork to back it up. We arrange qualified phlebotomists to take the blood and the analysis is usually by a local hospital laboratory.

We always need more volunteers on the day – usually a Saturday – to check men in, make sure they fill in the form and make sure the right name is on each vial of blood. Call Roger Bacon 01903 775783 or Jim Davis 01202 580436 if you can spare a Saturday.



## Dorset Branch Report

We tested about 140 men at Dorchester on Sep 17 and about 100 at Kinson on Oct 1.

In the past, we tested by means of BioScan machines but have now gone over to venous blood tests, using professional phlebotomists volunteering to take the blood. Using this method we can test a lot more men in a given time. We will be testing at Ringwood on Oct 29, and at Colehill on Nov 26. So far our group has tested well over 2500 men in Dorset.

Our speaker at the September meeting was Dr Iain Frame, Director of Research at Prostate Cancer UK, who talked about PC UK's Research Strategy. There will be no speaker at our November meeting, which is a Christmas Social.

Looking way ahead to 2017, there is a speaker booked for the September meeting to talk about the STAMPEDE trials.

One of our female members has kindly offered to provide a helpline service to give words of encouragement or advice to the wives or partners of prostate cancer sufferers. This service was advertised in our Link Newsletter for September. First contact should be via Jim Davis, our Chairman.

### The Ro-Pro sponsored

**bike ride** was reported in our last newsletter, I am pleased to report now that all the sponsor money has been collected and totals £2,146.50 an increase of 30% compared to last year. The Rotary Clubs of Littlehampton, Bognor Regis and Bognor Hotham together with the Angmering Cycle Club provided most of the riders and PCaSO is grateful for their support.



## Hampshire Branch Report

Stuart Thompson - it was with sadness that we learnt of Stuart's declining health and his consequent immediate resignation from both the Executive and Branch Committees. Stuart has been a very active Branch Chairman, a true stalwart of PCaSO and his dedication, enthusiasm and leadership will be greatly missed. Our thoughts and best wishes go to Stuart, Linda and family at this time.

We will be holding an Awareness and Collection Event at Winchester Christmas Market on Sunday 18th December 2016. As this is the last Sunday before Christmas, it is expected that the Market will be busy and an ideal event to publicise PCaSO and raise awareness. If you would like to volunteer to help and handout leaflets, please contact Peter Weir at [weircroft@aol.com](mailto:weircroft@aol.com).

With the resignation of Stuart, a replacement Chairperson is vital for the continuance of the Committee. It is of paramount importance that a replacement is appointed without delay, as the Hampshire Branch is extremely vulnerable and could easily close due to the lack of support. The post is not too arduous, we have four Committee/Support meetings a year and you would have the full support of other Committee members.

### A request from the Hampshire Branch

**Please will SOMEONE step forward and support your Committee. PCaSO is our Charity, but it can only exist with the help of all the members. For further information, please contact either Nicky on 01329 843828 email:naganne@naganne.plus.com or any Hampshire Branch Committee member.**

## Sussex Branch Report

The restarted Brighton group first met on 6th October at the new Macmillan Horizon Centre next to the Royal Sussex Hospital. Despite advertising in local papers, emails and tweets to everyone we knew in the Brighton area the attendance for the consultant's talk was disappointing. We will try another meeting on 6th December.

One theory is that Brighton/Hove is very much a young people's city and prostate cancer affects mainly older men, but that goes against the experience of the hospital Urology Department. Another that parking in Brighton is so awful, though there is parking available at the Centre, that older people don't want to go there in the evening. All ideas welcomed.

As previously reported the Executive re-drew the boundaries between East and Central Branches and called them Sussex and Hampshire. We thus welcome the Chichester group to Sussex Branch. Ian Graham-Jones, who ran that group has moved to Devon so Viv Miles, who is already Treasurer of the Sussex Branch and of PCaSO in its entirety, will take on the organisation for the time being.

Work is progressing at Eastbourne DGH on the linked radiotherapy unit and the first patients are scheduled to be seen next Spring, saving trips to Brighton or Maidstone.

PSA testing continues as this is an excellent way of spreading awareness of prostate cancer as well as finding men who should be receiving treatment. We have tested about 546 men at events in Worthing, Burgess Hill and Hove this autumn and have another two events planned, in Rustington on 12th November and Telscombe on 19th November. We are planning more next Spring, possibly starting with one in Bognor Regis? Watch [www.pcaso.org](http://www.pcaso.org) for details.

## Eastbourne Group

We have had two meetings since our August break and received a generous donation of £650.00 from the *Community Matters* scheme at Waitrose in Old Town, Eastbourne.



**Valerie and John Banks collecting the cheque on behalf of PCaSO Eastbourne from Waitrose.**

Susan Crosby-Jones, Matron of the Urological Investigations Suite (UIS) at Eastbourne District General Hospital (DGH), attended the September meeting to tell us about some important improvement plans. The number of investigation rooms will be increasing to ten, including a quiet recovery area for patients after they have had a TRUS biopsy. Nine urology consultants will be working in the department and seven clinical nurse specialists.

The planned work is due to commence in February 2017. The Quiet Room funded by PCaSO Eastbourne, together with its contents, will be moving to a new location. This will be better positioned for the department and adjacent to the waiting area. It is a similar size to the present room and has natural light from two windows.

At the October meeting, consultant clinical oncologist Dr Caroline Manetta gave an update on clinical trials, in particular recent results from the CHHIP trial. She discussed what this would mean for men having radiotherapy at the new treatment centres. Radiotherapy can now be given over fewer weeks.

## Ian Graham-Jones leaves PCaSO after 12 years

Ian Graham-Jones has left PCaSO after 12 years of continuous work in a variety of posts, most of which he held at the same time.

Ian and Jean moved to West Sussex in around 1973 and he taught music at the Tech – now the University - in Chichester.

In 1993 they moved to Westbourne near Emsworth and in 2004 he was diagnosed with prostate cancer. He happened to call on Sandy Tyndale-Biscoe, one of PCaSO's original organisers, to hand out some music posters and when asked how he was admitted that he had prostate cancer. With that he was ushered in, sat down and immediately recruited into PCaSO.

He had his prostate removed by Christopher Eden in 2004 and by 2005 was Librarian for PCaSO back in the pre-internet days when men had to get books to find information. We had a stock of learned tomes and Ian had to keep track of them. He was soon, reluctantly, persuaded to be Secretary.

In 2006 Ian organised a performance of Handel's

Messiah in Chichester Cathedral, introduced by the Dean, which raised £6,000 for a scanner for St Richards.

In 2007 Roger Bacon arrived and was persuaded to start a support group in Rustington while Ian started one in Chichester and these met alternately.

Ian was then persuaded to take on the newsletter which, with support from Astra-Zeneca, was published in colour for the first time. That's Librarian, Secretary, Chichester group leader, Central Branch secretary, newsletter editor and publications – all at the same time. Things carried on in this way until 2012 when Ian gladly got rid of the PCaSO secretary post to David Hurst.

Since then he has continued with the newsletter and, through his acquired publishing skills, has also produced most of the printed material that we use.

PCaSO Chairman, Roger Bacon, presented Ian with an engraved salver, as a token of appreciation for the immense contribution he made to the support of prostate cancer patients and to the work that PCaSO does.



**The 2016/17 PCaSO Executive Committee: (left to right) David Hurst, Jim Davis, Stuart Thompson, Geoff Bailey, Roger Bacon, Ian Graham-Jones, Viv Miles, Derek Pilling, Peter Weir and Allan Higgin (front).**

## LOCAL SUPPORT MEETINGS

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

### November 2016

10th (Thur)	Eastbourne	Penny Kaye (Macmillian dietitian): Diet and prostate cancer
15th (Tue)	Pulborough	Andrew Hart, Uro-Oncology CNS, Worthing.
15th (Tue)	Waterlooville	Patients' Forum <b>(2pm)</b>
22nd (Tue)	Rustington	Dr Ashok Nikapota (cons. oncologist)
23rd (Wed)	Chichester	Patients' Forum
30th (Wed)	Talbot Woods	Social evening

### December 2016

5th (Mon)	Bexhill	Social evening
6th (Tue)	Brighton	Patients' Forum
8th (Thur)	Eastbourne	Mr Peter Rimington (cons. urologist)

### February 2017

9th (Mon)	Eastbourne	James Moore (cons. urologist) Restoring continence after surgery
21st (Tue)	Pulborough	(Speaker tbc)
22nd (Wed)	Chichester	(Speaker tbc)

### March 2017

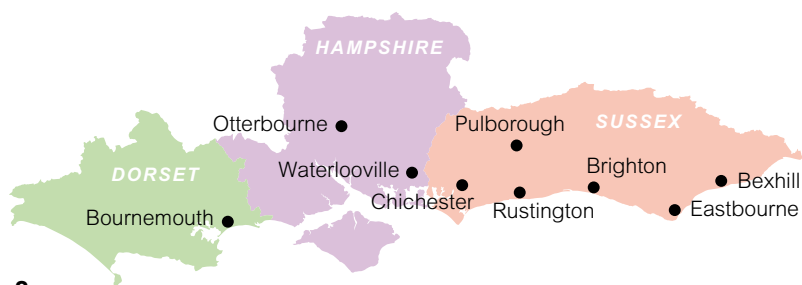
7th (Tue)	Otterbourne	(Speaker tbc)
21st (Tue)	Rustington	(Speaker tbc)

### April 2017

13th (Thur)	Eastbourne	(Speaker tbc)
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## PSA Testing Events

- 12th November – Rustington (*West Sussex*)
- 19th November – Telscombe (*East Sussex*)
- 26th November – Colehill, Wimbourne (*Dorset*)



## VENUES

### Dorset

#### Bournemouth:

St Marks Church Hall,  
Talbot Woods, BH10 4HY,  
*Meetings start at 7.30pm*

### Hampshire

#### Otterbourne:

Otterbourne Village Hall,  
Cranbourne Drive, SO21 2ET  
*Meetings start at 7.30pm*

#### Waterlooville:

Church of the Sacred Heart,  
London Road, PO7 7SR  
*Meetings start at 7pm*

### Sussex

#### Bexhill:

Health Centre, Bexhill Hospital,  
Holliers Hill, Bexhill, TN40 2DZ  
*Meetings start at 7pm.*

#### Brighton:

Macmillan Horizon Centre,  
Bristol Gate, Brighton BN2 5BD  
*Meetings start at 7pm..*

#### Chichester:

Chichester Baptist Church,  
Sherbourne Road, PO19 3AW  
*Meetings start at 7pm*

#### Eastbourne:

Postgraduate Centre, Eastbourne  
District General Hospital,  
*Meetings start at 7pm.*

#### Pulborough:

Pulborough Village Hall, Swan  
View (off Lower Street), RH20 2BF,  
*Meetings start at 7pm.*

#### Rustington:

John de Bohun Room,  
Woodlands Centre, Woodlands Avenue,  
BN16 3HB,  
*Meetings start at 7pm.*

*All groups need help to put the chairs out, make teas, run a raffle, etc. to take the load from the group leader. Please arrive early, maybe 30 minutes, and lend a hand. And remember the room has to be cleared up afterwards. Please.*