

UPDATES

The Quarterly Newsletter of PCaSO Prostate Cancer Support Organisation

Dorset • Hampshire • Sussex
& surrounding areas



Trial results

Collections

Patient's Story

Urology open afternoon

Ironman

Branch News

Meetings



Issue No. 61
November
2017

2017 **IRONMAN**
LIKESUNGLAND

708

Chris

M25-29 Male Pro

Chris Cocum,
Ironman Event

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Prostate Cancer
Support Organisation

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www.pcaso.org

Charity No: 1170536

The opinions expressed in this newsletter are not necessarily those of PCaSO Prostate Cancer Support Organisation.

All men and all cases are different and you should always discuss any changes to your treatments with your doctor and in the light of your own personal circumstances.

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Dr Chris Parker, MRCP, MD, FRCR
Dr Angus Robinson, MBBS, MRCP, FRCR

Are you on Active Surveillance for Prostate Cancer?

SO ACTIVE: Exploring significant other experiences of undergoing ACTIVE surveillance for prostate cancer: an exploratory study

The University of Southampton is undertaking a research study to explore the experiences of men undergoing Active Surveillance for Prostate Cancer, and the experiences of their significant others (wife, partner, other relative or close friend).

Please note, to take part in this study your significant other must also be willing to take part.

The study involves completing a questionnaire, and possibly taking part in a telephone interview.

OR, if you would rather complete the questionnaire on paper, we'd be happy to post you one out. Let us know using our contact details.

If you are a man on active surveillance go to the following link online to read more and complete the questionnaire:

www.isurvey.soton.ac.uk/25011

If you are the significant other of a man on active surveillance and you are interested in taking part, please get in touch using the contact details below



Email: sh3r11@soton.ac.uk Tel: 023 8059 1787 (leave voicemail)

Address: SO ACTIVE Study, C/O Stephanie Hughes, University of Southampton, 1st Floor Aldermoor Health Centre, Aldermoor Close, Southampton, SO16 5ST

Trial results: IMRT to pelvic lymph nodes *Vivian Miles*

Use of IMRT (intensity modulated radiotherapy) for treatment of the prostate is now widely available in the NHS. For patients with locally advanced prostate cancer, seminal vesicles are often treated with IMRT (my oncologist advised me that it was standard practice for patients with my Gleason score of 4+4 = 8). Pelvic lymph nodes are another area of early spread outside the prostate gland. However, radiotherapy to pelvic lymph nodes has long been controversial because of the perceived risk of damage to bladder and bowel. This means that IMRT to the pelvic lymph nodes is far less widely available despite NICE's statement that "clinical oncologists should consider pelvic radiotherapy in men with locally advanced prostate cancer who have a higher than 15% risk of pelvic lymph node involvement and who are to receive neoadjuvant hormonal therapy and radical radiotherapy."

Research carried out by the Royal Marsden and the Institute of Cancer Research over a 10-year period and published recently demonstrates, according to study leader Professor David Dearnaley, that using IMRT to target the pelvic lymph nodes is safe and effective for men with prostate cancer. This is an early stage trial and, according to the NHS, further trials looking more precisely at the effectiveness of this treatment (PLN-IMRT) are already in progress. More details and comments on the trial results may be found in NHS Choices "Behind the headlines": <https://www.nhs.uk/news/cancer/high-precision-radiotherapy-for-prostate-cancer-shows-promise/>

While I did not participate in this trial, I was treated in a similar way during early 2014 at Queen Alexandra Hospital, Cosham, Portsmouth: IMRT to the prostate and PLN-IMRT combined with long-term ADT (Prostap hormone

therapy). Results so far have been excellent and to my mind worth the risks to bladder and bowel which turn out to have been quite low. Of course, personal experience is anecdotal and not a substitute for clinical trials.

PROMIS Trial – the MRC Clinical Trials Unit at UCL, working with Prostate Cancer UK, have just produced a film series about one of the trials, PROMIS. The trial was looking at better ways to diagnose prostate cancer. PROMIS found that using an MRI scan can improve prostate cancer diagnosis, because it allows doctors to identify men who don't need to have a biopsy. This means that 25% of men could avoid the painful procedure. Two of the films are aimed at clinicians, but there's also a short film aimed at patients. You can find the videos on the website here: http://www.ctu.mrc.ac.uk/news/2017/using_mri_scans_to_diagnose_prostate_cancer_new_films_for_clinicians_241017

Collections – our life blood!

Retail 'bucket' collections may not be the most glamorous method of raising cash but are the most effective without any costs. The Hampshire branch, formerly 'Central', has been very successful at these because of the dedicated efforts of the very small cohort of helpers. These number only about 25 individuals out of a membership of 300 plus! This small cohort has raised some £38,493 over the period from 2010 to the last event at Asda, Fareham in July this year. This has enabled us to support the new template biopsy equipment for St. Richards (£20k) and similar kit for Southampton (£15k), fund research at Portsmouth and Southampton universities. In addition to all this we run meetings and PSA test days (not a cheap activity) publish the KE booklets and awareness leaflets. All this costs money.

The volunteers who hand out the awareness leaflets frequently hear tales of doctors who tell their patients to wait for symptoms and ones (Doctors) who tell the 'collectors' that the test has so many errors that it is unreliable. What tests are 100% and as there is no other, what else can be used?

As many of you know I took this duty over from the late Dave Smith in 2009 but I now have other commitments that require my attention so I am relinquishing these duties. Although I have organised and cajoled you into helping, without your help we could not have achieved very much, so my heartfelt thanks to the small cohort for your support. You all know whom I am thanking.

We need someone or a small team to take over.

The work can easily be split up amongst two or three people; the stores have to be contacted to

arrange dates, the team has to be maintained and the manning schedule planned. The cash has to be sorted, paid in and 'thank you' letters to the stores written. As can be seen the function can be divided up amongst several people as long as they have good contact with one another.

This is your charity so please step forward and help.

John Harmer



My patient story

by Tony Ball (Rustington Group)

France – Beginning the journey.

In 2008 my wife and I left Angmering, West Sussex and moved to reside in Brittany. We registered with the French health service and the local GP, who gave us each a good check-up, which in my case included a PSA test with a satisfactory result of 2.5. A year later at the annual check-up my PSA had risen to my age threshold of 4.0, which concerned the French GP. A further PSA test 3 months later resulted in a rise to 9.5 and the GP referred me to a consultant urologist.

The consultant took a TRUS biopsy and at the follow-up appointment explained, in French, how he was going to perform the surgery to remove my prostate. My wife was present and asked him if I had cancer, as he had not even mentioned it! *Mais oui!*, he replied.

Rather dazed we went back to our GP and had a long chat. He said that as my DRE was normal and only 1 in 3 referrals were cancerous, he had not expected the referral to result in a cancer diagnosis. He then, very knowledgably, explained at length in his excellent English the options of surgery or radiotherapy. If I were to have surgery then I could have radiotherapy later if needed, but if I chose radiotherapy then any subsequent surgery became very difficult because of the hardening of the prostate. In May 2010 after a bone scan and an MRI, I had open surgery to remove my prostate. [Pathology on the removed prostate gave a result of pT3a N0 MX, 3+4, with a small focus (0.4%) of Gleason 8. This was higher than the T2a from the biopsy].

England – Return

For family reasons we returned to live in Angmering in 2011. When we left France I wrote to the GP

thanking him for the care and for finding the cancer.

Back with the NHS my post-operative monitoring continued. I also joined PCaSO and began to learn about all the information and support that would have been helpful to me had I known about it earlier! I phoned Prostate Cancer UK specialist nurses and found them very helpful.

Several years of PSA results in France/UK at 0 or 0.01 demonstrated the success of the surgery. However by year 4 (in 2014) a slight rise was detected and each successive PSA test showed either a rise or a pause, but the upward trend was clearly discernible. In 2016 when the PSA was at 0.14 the MDT (multi-disciplinary team) at Worthing referred my case to the consultant oncologist and he arranged for me to have a whole body PET-CT scan. This scan was at the Clinical Imaging Science Centre, University of Sussex, Brighton. I was injected with a Choline F-18 tracer, specific for locating prostate cancer cells. The radioactive tracer was delivered from London by courier in a hazard marked box! I had to wait in a room on my own, monitored by video for an hour, for the tracer to circulate around the body before I had the scan. The whole body scan took about 30 minutes and then there was a further scan just of the pelvic area that took 10 minutes. I had to lie very still on the bed as it moved into the scanner as PET and CT scans are both taken and have to correlate. Once complete I was required to leave the building immediately as one is radioactive for a while! One can eat and drive straight away after the scan.

My PET-CT scan did not reveal any cancer in the 'prostate bed' (where the prostate had been) nor any spread of prostate

cancer elsewhere in the body (metastases) that would otherwise render radiotherapy to the 'prostate bed' unviable.

The oncologist explained the threshold for further treatment, by radiotherapy to the 'prostate bed' was a PSA of 0.2, and he was happy to proceed with this as soon as I was ready, as he expected the PSA to continue rising, but I opted to wait for a further result. [I discovered a research paper that suggested there was no extra benefit in 'ultra-early' treatment, that the threshold should be two successive PSA results of 0.20 or greater and leaving it beyond 0.5 was detrimental].

My next PSA turned out not to have risen, but stayed at 0.14, but 6 months later it had risen to 0.24. I then agreed to have the radiotherapy, but requested it be at Preston Park as it was accessible for me, had fairly new equipment and a good reputation.

Seven years later:

My recent 'salvage' radiotherapy treatment

Planning - my planning scan, at the Cancer Centre at the Royal Sussex County Hospital in Brighton, was to allow the team to study my pelvic area and specify the radiotherapy treatment I was to receive, as to the area to be treated and intensity (not just the prostate bed, but also I believe some of the bladder area at a lower intensity).

The work of the team after the scan is quite involved (up to 9 persons in the process, including a physicist and quality assurance), so it is usually about 3 weeks before treatment can commence following the planning scan.

Treatment - The Park Centre at 177, Preston Road, Brighton is



The Park Radiotherapy Centre, Brighton

opposite Preston Park, a nice green space with a couple of cafés. As well as the Radiotherapy Centre there is also breast cancer care (but not radiotherapy) elsewhere within the building. There is permit parking for those attending the Radiotherapy Centre for treatment. (I mostly took the train to Brighton, then walked). The reception is on the first floor and the treatment suite is on the ground floor, with two Tomotherapy machines designated Tomo 1 and Tomo 2. These differ from the linear accelerator machines used elsewhere. The Tomo machines are used mainly for delivering radiotherapy to the pelvis, such as for prostate, bowel and anal cancers, but I did meet a couple of men who were having treatment for brain tumours on the Tomo machines. Although mostly men were having treatment, there were some ladies having pelvic radiotherapy. There was a good camaraderie in the waiting room and sometimes a sharing of intimate personal details as to treatment and side effects not usual in other social settings! All of the staff were very friendly, considerate and helpful.

Some prostate cancer patients were receiving radiotherapy as primary treatment, usually after a course of hormone therapy, others

were having 'salvage' radiotherapy like myself, without hormone therapy. What struck me was how different each radiotherapy patient's treatment regime was, very personalised for their particular case and cancer, yet we were all processed through the Tomo machines with about an 18 minute interval between patients for each machine, with no delay due to set-up for each individual's treatment plan.

I had to arrive one hour before the treatment time allocated on my schedule (which was usually 13.42pm, Monday to Friday), use a micro-enema (to clear the back passage), drink four cups of water (500 ml) within 5 minutes, then wait 40 minutes to the treatment time. I had to be aware of any delays occurring to 'Tomo 2' I was on and adjust the start of my drinking accordingly. One needs a comfortably full bladder for the treatment, so the 40-minutes was optimum for this, I found it ok.

Downstairs as I was called into the treatment room they checked my identity and I could see my photo and details on the monitor screen.



I had to lie on the treatment couch and two radiologists aligned my position so that red lasers lined up with the three tiny tattoos on pelvis and hips that I had been given at the time of the planning scan. They left the room, the large door closed and the couch moved into the 'donut' of the machine. The machine took a scan and then the couch moved out again, there was a wait whilst outside they checked the scan, slice by slice, to ensure that everything complied with the plan. Once satisfied the radiologists sent the couch back into the Tomo machine and the radiotherapy took place (about 2 to 3 minutes of treatment in my case, 2 Grays per day).

I was scheduled to have 33 'fractions' of radiotherapy, but after about a week the consultant reduced this to 30 fractions (60 Gy) to reduce the risk of bowel damage, as often a loop of my bowel could be seen on the daily scan as being in the higher-intensity area being radiated.

I did not experience any significant problems during the treatment period of about 6 weeks, but some minor problems followed, peaking about two weeks after treatment. A PSA test at 3-weeks after treatment showed a reduction to 0.06 (down from the previous 0.24). The consultant was very pleased and I will have another PSA test and appointment in December 2017.

In conclusion - before we moved to France in 2008 there were no PSA checks through the NHS, I did not know PCaSO existed or even where my prostate was or what it did!

I have been very satisfied with my prostate cancer treatment on the NHS and in France. I remain grateful to my GP in Brittany. If we had not moved to France then prostate cancer may not have been discovered until I had symptoms, too late for curative treatments.

Eastbourne Group News

Urology Open Afternoon – Eastbourne

Chris Cutting teamed up with two members of the Eastbourne support group on Wednesday 27 September 2017 to attend an open afternoon in the Urology Department at Eastbourne District General Hospital. It was for members of the public wishing to learn more about clinical investigations and treatment procedures carried out in the department. Chris set up a display table with PCaSO information and was on hand together with Jon and Jane Chapman to talk to visitors. They were warmly welcomed by the staff that popped in to say hello between taking visitors around their workplace. Ten to 15 people were keen to learn about the work of the support group which has just clocked up 15 years

since its first meeting in 2002. It has strong links with the department and over the years has raised funds for equipment and facilities that benefit prostate cancer patients. In addition, the group has also held a number of awareness events in the local area about this male cancer .

Right: **Urine Analyser**
Below: **Eastbourne Urology open day 27th september 2017**



Chris Cocum – Ironman Event

2230 competitors started – 1719 finished.

Each competitor has to complete all three events with no rests between sections.

Swim: 1hr 18min - 2.4 miles

The swim went very well with the 'rolling start' looking more like a load of penguins dropping off a cliff than the beginning of an endurance race! It was a two lap course of a lake but if you were to see a sample of the water we were swimming in you might be more correct if you called it a swamp!

Cycle: 7hrs 15mins - 112 miles

Coming out of the swim I was ahead of my projected time and made the decision to change out of my tri-suit which I had just been swimming in. This turned out to be a decision which paid dividends as the weather was pretty awful for the first 4 hours

and I would have frozen to the bike if I hadn't been in my dry clothes. Being one of the hilliest Ironman cycles I was prepared for a tough time and the course didn't disappoint. However I stuck to my plan and cycled in a very low gear to keep my cadence high and this helped save my legs for the running section

Run time: 3hrs 55mins - 26 miles (full marathon)

By the time I started the run the sun was out and this posed the dangerous prospect of overheating. To stave this off at every water stop I would take 4 cups of water; one poured down my front, one on my head, one down the back and one for drinking. This helped a great deal but didn't make me too popular with the water station volunteers who had to pour many more cups! The run was also very hilly and thankfully there was a long downhill to the finish. It was a great feeling crossing the line and the donations of each and every

person was part of the drive which helped me to get there.

Total time including transitions: 13:13

"A remarkable effort by a young man who put in months of training and dedication and raised a massive £2366 in sponsorship for PCaSO. A big thank you to him!"

'Chris is the son of Barry Cocum, leader of our Brighton group'



Dr Sally Appleyard – interim research findings

At the September meeting in Eastbourne, Oncology Specialist Registrar Dr Sally Appleyard presented interim findings from her study on quality of life during prostate cancer treatment. As part of her MD research she recruited patients to take part in a feasibility study to use direct electronic data capture of quality of life questionnaires. It became known as the 'iPad' study as the questionnaires are completed using iPads and tablet computers.

Dr Appleyard's work is looking more broadly at how capturing this information could affect decision making with clinicians about treatment choices. She collected data from both bladder cancer and prostate cancer patients as well as from carers, oncologists and clinical nurse specialists. Data collection and analysis

is ongoing but for the prostate cancer patients she asked men undergoing new non-curative treatments to take part in the study. The questionnaires were repeated at three months after commencement of the treatment. Recruitment was open until March 2017 in Eastbourne, Brighton and Worthing. More than half of the 40 participants were recruited from Eastbourne patient lists. Dr Appleyard reported some of her findings so far about the use of the tablets and iPads with respect to ease of use, font size, where patients prefer to complete the questionnaires and what the next steps might be for this way of completing the questionnaires. After her presentation, several members of the group tried out the iPad questionnaires which provoked further useful discussion for Dr Appleyard's work. She hopes to give the group an update when the study is completed.

Dorset Branch News

At our July meeting member Barrie Hampson, a volunteer educator with the British Red Cross, gave an excellent "hands-on" presentation on CPR and how to use a defibrillation machine.

Our Public Meeting on Sep 27 was attended by 39 people Mr Tim Dudderidge, Consultant Urological Surgeon at Southampton University Hospital, gave a very interesting talk on PSA testing and HIFU and Cryotherapy. He was greatly in favour of PSA screening as long as it was allied to multi-parametric MRI scans that were carried out to exacting standards, and maybe followed by targeted transperineal (NOT trans-rectal) biopsies when necessary. He saw this as the way forward for the detection of PC.

PSA Testing

90 men were given a PSA test on July 8th at Mudeford, and 10 were referred.

A PSA testing session was held at Lyme Regis on 14th October. We tested 102 men of who 35 were aged 60 or below. This is a very encouraging sign that knowledge of our testing sessions is getting through to younger men. (Incidentally, none of these had a high score). Overall there were 5 reds; 4 ambers; 1 borderline green/amber.

Our next PSA event will be on Saturday 4th November 2017 at the Allendale Centre in Wimborne, in association with the Ferndown and Wimborne Lions Club.'

We hope to have tested over 5000 men in Dorset by next year (we have tested over 4000 now).

Fundraising

Future collections are planned for November 25th at ASDA in Poole, and January 13th at Sainsbury, Alder Hills.'

Sussex Branch News

Since the last newsletter Sussex Branch have held PSA testing events at Pyecombe, north of Brighton; Worthing; Hove and Burgess Hill testing a total of 1093 men and finding 56 with raised numbers. There are two more events to go in 2017 in Peacehaven on 4th November and Rustington on 25th November which should take our total of tested men in Sussex to over 1300 for the year. More events are being planned for 2018 and some are listed on the back of this newsletter.

PCaSO Sussex Branch was approached by Brighton Hospital's brachytherapy department to produce a leaflet explaining the procedure to patients. This request was closely followed by their radiotherapy department asking for help with a similar leaflet for their patients. The concept is that they provide the words and PCaSO then produce and pay for a nicely designed leaflet making the service more attractive to the patient than the photocopied sheets used by some hospitals. The advantage is that we can include information about PCaSO on the back page.

Following a visit to Pulborough branch by consultant surgeon Mrs Suzie Venn and urology nurse Debbie Greenfield back in February, Sussex Branch agreed to help the urology department replace their old flow meter. The administration of the NHS grinds exceedingly slow and only now is it hoped that this machine will be able to be acquired and shown off before our next newsletter!

Sussex Branch have been invited to have a display at a Macmillan Health & Wellbeing event to be held at a new school hall in Worthing over half-term. Such events enable invited cancer patients to have conversations and also they are useful to meet other stall-holders and clinicians.

LOCAL SUPPORT MEETINGS

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

Nov 2017

| | | |
|------------|--------------|---|
| 6th (Mon) | Bexhill | Katy Bourne , Sussex Police and Crime Commissioner |
| 9th (Thur) | Eastbourne | Dr F Mckinna , Consultant Clinical Oncologist and Julie Warner , Head of Radiotherapy, Sussex Cancer Centre. Radiotherapy Update. |
| 28th (Tue) | Rustington | Patient Forum |
| 29th (Wed) | Talbot Woods | Annual Social Event |

Dec 2017

| | | |
|------------|------------|---------------|
| 4th (Mon) | Bexhill | Social |
| 13th (Wed) | Chichester | (Speaker tbc) |
| 12th (Tue) | Pulborough | Patient Forum |

2018

| | |
|------------|--|
| Bexhill | 8th Jan, 5th March, 14th May, 3rd Sept, 5th Nov |
| Brighton | 5th March, 22nd May, 6th Sept, 4th Dec |
| Chichester | 7th Feb, 4th April, 4th July, 3rd Oct, 5th Dec |
| Eastbourne | 15th Feb (Chief Exec, St Wilfrid's Hospice), 12th April (Mr S Garrett , Consultant urologist) |
| Rustington | 20th March, 12th June, 18th Sept, 27th Nov |

All groups need help to put the chairs out, make teas, run a raffle, etc. Please arrive early to lend a hand. And remember the room also has to be cleared up afterwards.

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.

| | | |
|------------|-------------|--|
| Nov | 4th | Peacehaven (East Sussex) Wimbourne (Allendale Centre) |
| | 25th | Rustington Bookings - 01903 775577 |
| Dec | 2nd | Waterlooville |

2018

| | | |
|--------------|-------------|----------------|
| April | 7th | Uckfield |
| | 21st | Hayling Island |

To be arranged – Jan/Mar Blandford, Verwood, Weymouth, Parley, Wareham

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.

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,

Donations

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

To make a donation please send a cheque to:

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

Or pay into our bank account

40-23-20 61303856

Or download and fill in our Standing order form:

<http://pcasoprostatacancersouth.org/forms-leaflets/Standing-order-form-May-2017.pdf>

Or, go to www.pcaso.org and click on the red Virgin Giving button on the front page.