

UPDATES

The Quarterly Newsletter of PCaSO Prostate Cancer Support Organisation

Dorset • Hampshire • Sussex
& surrounding areas

Radium 223

The PROACTIVE project

PACE B trial

Patient story

Brachytherapy

Healthy on hormones

Branch News



Issue No. 58
February
2017

Winchester Cathedral
by Peter Weir

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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



Penny Brohn have for some time now been running courses for anyone affected by cancer. The Living Well with the Impact of Cancer course is FREE and available for anyone living with cancer and their close supporter.

Non-residential courses in the South Coast area:

1st & 8th March 2017 at Brookfield Hotel, Emsworth

23rd & 30th March 2017 at Field Place, Worthing

To book Email: bookings@pennybrohn.org.uk or
Phone: 0303 3000 118

www. pennybrohn.org.uk

PO Box 66, Emsworth, Hants PO10 7ZP



Prostate Cancer
Support Organisation

National Help Line:
0800 035 5302
www.pcaso.org

Charity No: 1095439

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.

Radium-223 (Xofigo) therapy

Bone metastases can be treated in a variety of different ways including painkillers, chemotherapy, external beam radiotherapy or Radium-223. Sometimes several of these approaches are needed.

What is radium 223

Radium-223 is a type of internal radiotherapy treatment, a mildly radioactive form of the metal radium. It used to be called **Alpharadin**. Radium-223 is suitable for men with prostate cancer that has spread to the bones (advanced prostate cancer) and has stopped responding to hormone therapy. If there are cancer cells in more than one area of bone, radium-223 can work well to treat those areas leading to better pain control, an improvement in the quality of your life and longer survival.

How radium-223 works

A small amount of radioactive substance is injected into a

vein, only taking a few minutes to administer and behaves in a similar way to calcium and collects in the bone metastases. If there are cancer cells in more than one area of bone, the radium can work well to treat all those areas at the same time.

Cancer cells are more active than normal bone cells and so are more likely to pick up the high energy radioactive particles which kills the cancer in the bones, but doesn't damage surrounding healthy cells, therefore reducing the cancer cells and the pain that these can cause. The therapy is given as a course of 6 treatments, at monthly intervals.

How safe is the treatment

Some radioactivity will be present in the body for a while after treatment. The total amount is very small and gets lower each day until the next treatment. The effects of the Radium therapy are

limited to the areas in the body in which it concentrates, so it will not cause any harm to other people through contact.

When radium 223 is used

Radium-223 is available in England, Wales, Northern Ireland and Scotland for men who have stopped responding to hormone therapy but haven't yet had chemotherapy. Or for men who have already had hormone therapy and the chemotherapy drug docetaxel.

Possible side effects

The side effects of radium 223 can include diarrhoea and sickness but these are generally mild. Sometimes the treatment can cause low levels of blood cells after a few weeks. This can lead to an increased risk of infection, anaemia, and bruising more than usual. So regular blood tests after the treatment are advisable.

The PROACTIVE Project at Southampton University

When a prostate cancer patient is being monitored before possible treatment, or has been discharged after treatment, the NHS often has little to offer. Individual counselling or various forms of personal training might offer significant benefits but they are typically too expensive for wide scale use.

Is there another way? One recent idea, developed at Southampton University and other centres, is to offer a tailored programme of mentoring via the Internet.

This was the basis of the ongoing PROACTIVE study of **"PROstate ACTIVE surveillance support"**, its development started with a £10K initial funding from PCaSO and run by Southampton University Psychology Department under the leadership of Prof George Lewith.

With further funding from PCUK, a group of up to 60 patients who have entered active surveillance within the last year will be recruited to a pragmatic trial via their routine clinical care. The programme involves six weekly interactive web-based sessions developed at Southampton using the platform 'LifeGuide'.

They will also participate, with their partners, in up to three 90 minute group sessions, facilitated by a clinical nurse specialist and focusing on specific themes including lack of information, uncertainty, and anxiety/distress.

The Southampton team have created a series of dialogues which will lead them through the basic steps of evaluating their own lifestyle, setting targets for

improvement, and monitoring progress towards their goals. The aim is to explore the feasibility of delivering a psycho-educational support intervention via the Internet, and the project will be deemed successful if it can be shown that this intervention reduces anxiety, improves well-being and educates the man in all matters concerning the prostate. It is hoped that it will reduce the number of patients opting for radical treatment based simply on anxiety, rather than a clinical indication that treatment is needed.

Anxiety is measured using the Hospital Anxiety and Depression Scale (HADS) and an improvement of 10% will be considered significant. We hope to report on the outcome in a future article.

Geoffrey Sharman & Roger Bacon

The PACE B trial

Currently recruiting men with low and intermediate risk localised prostate cancer.

Radiotherapy is a very effective treatment for localised prostate cancer. We now know that most radiotherapy courses can be completed in 4 weeks, rather than the historic 7.5 weeks, without any increase in side effects or reduction in cure rates.

The PACE trial seeks to go one step further, testing the now standard 4 weeks of radiotherapy versus just 5 treatments of radiotherapy, delivered with very precise image-guidance radiotherapy machines.

The 5 treatment radiotherapy, called Stereotactic body radiotherapy (SBRT for short) can be delivered on any IG radiotherapy machine, although there are some dedicated machines such as the Cyberknife that can deliver this.

The 5 treatment doses are very precise and deliver a higher intensity, giving 7.25 Gy per dose compared to the standard 20 fraction treatment giving 3 Gy per dose.

There are 20 UK centres open for recruitment. In the south the trial is open in the Royal Marsden hospital in Sutton (Dr Tree) and Chelsea (Dr van As). Patients who have intermediate risk localised disease who are interested should ask their local oncologist in the first instance for details, although enquiries can be made direct to the PACE trial team by email to: pace-icrctsu@icr.ac.uk

Dr Alison Tree

My 'Patient Story'

I made a rare visit to my GP during 2009 for a check-up. I knew nothing of prostate cancer, so didn't mention it. Neither did the GP. This was an opportunity missed.

Your prostate is the size of a lemon; it should be the size of a walnut said my new GP during February 2013. I had mentioned "waterworks" problems. He suggested a PSA blood test. Result: a slightly elevated 5.2. I was referred to urology. (It's worth mentioning that my GP did post-qualifying training in urology.)

A TRUS biopsy soon followed. Trouble-free. No-one seemed to expect a positive result (positive being generally bad in the medical world.)

Bad news: prostate cancer found in 5 out of 12 samples, Gleason 4+4 = 8. Full staging of the disease required said the consultant. He gave me a PCUK booklet. Bone scan and MRI followed. You're extremely complicated said another consultant. Suspected spread to lymph nodes. Possible bone mets in one arm. Next day an MRI to a humerus and chest x-ray, both negative. Biopsy of three lymph nodes was recommended. My impression was they would prove negative enabling early curative intent radiotherapy.

Not so, all samples were positive. You will die of prostate cancer unless you're run over by a bus first. The sky turned black. Why, said the consultant, is it that when I give this news to people I seem to be looking at two blank faces. Treatment would be hormone therapy and localised control radiotherapy. Oncology next stop.

Before meeting the oncologist, I obtained a second opinion from another surgeon. The prostate MRI was unclear because it had been taken after the biopsy, not before.

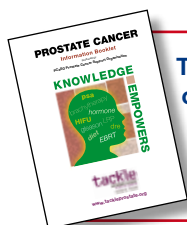
This meant that the diagnosis was wrong as to the disease's extent. The recent lymph node dissection ruled out a radical prostatectomy and lymph node removal which would otherwise have been possible: too many holes in the abdomen. Treatment path was the province of an oncologist, but could be IMRT radiotherapy with curative intent to the prostate and lesser treatment to the pelvic lymph glands.

The consultant oncologist outlined the limitations of MRI scans, indicating that radiotherapy would not kill all the cancer cells in my prostate. This meant that I'd have to stay on hormone therapy for the rest of my life. More scans and meetings with other oncologists followed. Eventually curative intent IMRT was agreed with lesser treatment to the lymph node area. I also joined the STAMPEDE trial which included a clear programme for IMRT and a follow-up schedule of consultations over a 5-year period. No more queues in urology!

There was good news in the early stages: PSA dropped from 5.2 to 0.3 after the first hormone injection. A CT scan during August 2013 showed no disease progression since the April MRI. A later scan showed tumour shrinkage. IMRT went well and PSA has remained undetectable since completion in May 2014.

The diagnosis made me re-evaluate my life. I decided to "put something back" and became PCaSO treasurer and became more active in my village. I also joined the Cancer United gym to improve fitness and ward off the possible side effects of long term hormone therapy. All in all, I've met many interesting people and feel better than I have done for years.

by Vivian Miles



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

Brachytherapy at Brighton

The High Dose Rate prostate brachytherapy service commenced at the Sussex Cancer Centre in March 2014. To date more than 100 men with prostate cancer have been treated. The service was set up with the assistance of the Urologists, Mr Tim Lerner and Mr Charles Coker, but is now run by Oncologists Drs Ashok Nikapota and Angus Robinson, along with the brachytherapy radiographers and the Physics team.

What it involves

High dose rate brachytherapy involves temporary insertion of radioactive wires into the prostate to deliver a localised high dose of radiation treatment. The brachytherapy enables a higher dose of radiotherapy to be delivered to the prostate, whilst minimising the dose to the surrounding normal structures (rectum and bladder) and has been shown to improve outcomes for patients with intermediate to high risk prostate cancer. The majority of our patients receive brachytherapy in conjunction with

a shorter course of external beam radiotherapy. Our patient group is typically men with higher risk localised disease – the extent of cancer and aggressiveness based on grade, PSA level and MRI scan results. Some patients have been treated solely with brachytherapy (monotherapy), usually in the situation where external beam radiotherapy was otherwise contraindicated. Radioactive seed implantation brachytherapy is an alternative treatment usually used for patients with earlier stage disease as a monotherapy and for our Sussex patients is delivered by colleagues in Guildford.

Evaluation

We have evaluated our treatment and patient reported outcomes for the first 53 patients treated. One patient has developed recurrence disease which has spread beyond the prostate (He initially presented with a high grade and extensive prostate cancer). The other patients (98%) have no evidence of recurrent cancer at this stage. The majority of treatment related



Some members of the Brighton Hospital Brachytherapy team

side effects were urinary, with discomfort and difficulty passing urine the most common, but are within the expected levels for this group of patients. All patients evaluated were either extremely satisfied or satisfied with the treatment received. We are continually evaluating treatment outcomes with a prospective data collection and have enabled telephone clinics to facilitate this.

Our plans for future are to extend the brachytherapy service and move towards a day-case procedure for most patients.

Dr Nikapota & Dr Robinson

Are you healthy on hormones?

I was diagnosed with locally advanced prostate cancer and had 37 fractions of radiotherapy. I was also prescribed hormone therapy (Prostap) for life. So far I've had 16 injections. Men with advanced prostate cancer are also likely to be on hormones for life.

Some effects can appear soon after starting treatment; including reduced libido, erectile dysfunction (ED), hot flushes, dry skin (itchiness), growth of man boobs, fatigue, cognitive impairment, mood swings and depression. I have ED; minor hot flushes that have reduced over the years; dry skin for many years, but that is now worse. Also mood swings in the run-up to PSA tests.

The more worrying side effects are those that develop gradually,

creeping up on one by stealth. Increase in belly fat, loss of muscle mass and osteoporosis. I've come to accept ED (as my GP says, think of the alternative), but not the stealth effects. Self-management tasks to negate stealth factors are very similar to those that health experts encourage everyone to adopt. This ought to make it easier for those of us with PCa.

1. Vitamin D: I've cut out dairy, so take soya milk with vitamin D.
2. Diet: More oily fish, chicken, fibre, vegetables and less red meat.
3. Exercise: I hadn't exercised for years, but Jan Sheward opened her CUFitter gym and I do resistance exercise there twice a

week. Belly fat has shrunk and muscle strength improved. Apart from physical benefits, the classes are fun. I also go to an aerobics class, but I seem to have no sense of rhythm!

4. Alcohol: A glass or two of red wine in moderation.
5. Fitness monitors: My other half swears by her FitBit. She really does walk more and climb more stairs. It keeps her motivated. So far, I've used the apps on my phone. Maybe I'll get weighing scales that measures body fat.

I wonder what other members do to mitigate the effect of hormones? Would a special seminar help or more focus on lifestyle issues during group meetings? Do let me know.

Vivian Miles (treasurer@pcaso.org)

Dorset Branch Report

PSA Testing

PSA Testing sessions (full blood samples taken using phlebotomists) were held at Ringwood on Oct 29 (60 men) and at Colehill on Nov 26 (53 men). Colehill was exceptional in that of all the men tested, only 2 had to be referred on to their GP – so a healthy place!

Next session at Bridport on Feb 11

Other venues being considered for 2017 are Maiden Newton, Beaminster, Blandford and Sherborne.

We may participate in an event being organised by the Christchurch Lions in March.

Meetings

The November meeting was the annual "Social" — members enjoyed the Bingo run by Mr Richard Knott of Luscombe Valley Railway.

Hampshire Report

On 7th December 2016, we had a very successful awareness and collection at Tesco in Havant where we handed out loads of 'blue' and 'pink' leaflets and collected over £900 in donations. The 'cohort' certainly did a very good job.

Further collections fixed for 2017 so far are:

According to Richard Knott, there is a possibility that the LVR may re-open in July.

After many years of successfully engaging eminent speakers in the field of prostate cancer for our bi-monthly meetings, we are now having some difficulty finding suitable new speakers. We just managed to get a speaker in time for our January meeting, for an interesting topic, the use of dogs in the detection of prostate cancer.

For a future meeting, we may have a Q&A session between members, but we will also be seeking other speakers. Please keep an eye on the website for more information.

Collections

Tesco at Fleetsbridge on Feb17

Petersfield

February 2nd.

Fratton Park

February 17th & 18th Portsmouth.

Anyone who would be willing to help with the awareness/collection dates please contact John Harmer.

PCaSO Hampshire Branch at Winchester Christmas Market

Founded in 2006, the Winchester Christmas Market celebrated its 10th anniversary in 2016 inspired by traditional German Christmas markets, with over 100 wooden chalets brimming with festive goodies and festive foods, are situated in the Cathedral's historic Close surrounding an open-air real ice rink, the market now attracts more than 350,000 visitors each year, over the four weeks of the event.

Each year the Cathedral allows one chalet to be allocated to a different charity for one day, this year PCaSO Hampshire branch applied and we were allocated the charity chalet for our use on Sunday 18th December, so on a crisp winters day volunteers manned the chalet from 10am to 6pm.

Those who took part found the hour or so spent "on duty" very worthwhile, distributing leaflets and generally discussing prostate matters with the more interested members of the public. Though our main aim was that this would be an awareness event, £223 was donated.

A big thank you to all who helped out and gave their time at what is a busy period of the year.

Hampshire Branch collecting at Winchester Christmas Market

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.





Stuart Thompson remembered

Stuart Thompson joined PCaSO in Aug 2011 having been diagnosed with aggressive

prostate cancer and having received a radical prostatectomy in March 2010 and subsequent radiotherapy.

Almost two years previously the AGM approved the Executive decision to reorganise PCaSO into Branches East, Central and West. The West branch was already up and running very efficiently and the East soon followed but difficulties were experienced in forming a Committee to run the Central Branch which during this time was run from the Executive Committee. Shortly after joining PCaSO Stuart volunteered to take on the role of chairman. The day was saved and a full Committee duly formed. This led to him joining the Executive Committee and becoming a Trustee of the

Charity and Deputy Chairman.

We were all very grateful to Stuart who proved to be an enthusiastic and excellent chairman of the Branch and became involved in all activities of the Branch including fund raising, PSA testing and making donations to various bodies in support of the fight against this disease. Stuart was a regular weekend walker and in May 2012 undertook a sponsored walk of 83 miles along the Dales Way from Ilkley in Yorkshire to Windermere in the Lake District. It took a week to accomplish and he personally raised £600 for PCaSO.

Attending funerals often means we learn what we didn't know about someone we work with. Stuart was a boy racer as a teen riding a Vespa but later became an advanced motorist. In 1972, as well as acquiring a wife, he bought his first TR sports car. With most men the two are mutually exclusive. In 1979 the car was upgraded to a TR4A and he was group leader of the Wessex TR Group with many

examples of the marque at the funeral. And he was with Romsey Lions. And he worked for IBM and he had an MBA. So many conversations we never had.

When Stuart joined PCaSO his PSA was still rising despite the treatments he had received. Members may remember the article Stuart wrote in the February 2015 issue of the Updates newsletter where he described the journey through a whole range of chemotherapy treatments all of which initially showed promise but subsequently failed. In the end this foul disease won and Stuart died peacefully in The Countess Mountbatten House in West End. As he says in his article, the chemo has changed his life a bit but has not changed his positive outlook. This was clearly the case and he continued to lead an active life and was, according to his brother, a serial holidaymaker with his wife Linda right to the last. He will be truly missed by us all.

Geoff Bailey and David Hurst

Sussex Branch Report

All the six Sussex groups have held meetings since the last newsletter and more are planned for the coming months. We are grateful for senior consultants and other busy clinicians being willing to give their time to come and discuss the current practices in local urology departments.

The lively Eastbourne group has comprehensive details of their meetings on their excellent new website <http://www.pcasoeastbourne.org.uk/blog/autumn-and-winter-meetings>. On 9th February the Sussex Branch Annual General Meeting will be held at Eastbourne where a report of the year's activities will be made. This will be followed by a talk by consultant urological surgeon Mr James Moore on 'Restoring Continence after Prostate Surgery'.

More PSA test events were held at Rustington and Telscombe in November and these took the total of men tested in 2016 in Sussex to 810 with approximately 10 per cent having a higher reading needing further investigation. More events are being planned for the coming Spring and Autumn, (see page 8). In addition to those listed it is hoped to have dates for events in Bognor Regis and Chichester during the year.



PCaSO Sussex Branch secretary David Hurst (centre) received a cheque for £2,000 from Bognor Hotham Rotary Club at the end of last year. The Immediate Past President, Nigel Hasted, (right) had chosen prostate cancer as the subject of his year of office and had chosen PCaSO as it was specifically local to the club. Also present was Dan Hansen (left) who had raised a substantial part of the amount during the year. The club are interested in helping with a PSA testing event that is being considered for this Spring.

LOCAL SUPPORT MEETINGS

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

February 2017

6th (Mon)	Bexhill	Aspasia Soultati (cons.oncologist at Eastbourne DGH)
9th (Thur)	Eastbourne	James Moore (cons. urologist) Restoring continence after surgery Also Sussex Branch AGM
20th (Mon)	Pulborough	Mrs Suzie Venn (cons.urological surgeon at St Richards) Specialist in urinary problems after prostate treatment
22nd (Wed)	Chichester	Ann-Marie Marchant (Penny Brohn) Living Well with prostate cancer (2pm)

March 2017

7th (Tue)	Otterbourne	Hampshire Branch AGM
21st (Tue)	Rustington	Patients Forum with Dr Robinson
29th (Wed)	Talbot Woods	Dorset Branch AGM

April 2017

3rd (Mon)	Bexhill	Mr Roger McPliat (Conquest Hospital, Hastings)
13th (Thur)	Eastbourne	Siobahn Meaker (MacMillan physical activity proj.mgr.) Albion in the community

May 2017

17th (Wed)	Chichester	(Speaker tbc)
19th (Fri)	Waterlooville	(Speaker tbc)
23rd (Tue)	Pulborough	(Speaker tbc)
31st (Wed)	Talbot Woods	(Speaker tbc)

June 2017

6th (Tue)	Rustington	(Speaker tbc)
8th (Thur)	Eastbourne	Karen Aylward (MacMillan counselling services lead) Counselling service and Mindfulness awareness.

PSA Testing Events

February	11th	Bridport (<i>Dorset</i>)
March	4th	Bournemouth, Knole Lodge, (<i>Dorset</i>)
	18th	Rustington (<i>West Sussex</i>)
	25th	Basingstoke Golf Club (<i>Hampshire</i>)
April	1st	Uckfield (<i>East Sussex</i>)
	1st	Lymington (<i>Hampshire</i>)
May	13th	Hayling Island (<i>Hampshire</i>) [tbc]
	20th	Christchurch (<i>Dorset</i>)
June	10th	Maiden Newton (<i>Dorset</i>)
July	1st	Fareham, (<i>Hampshire</i>) [tbc]

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.