

Updates

The Newsletter of
PCaSO Prostate Cancer
Support Organisation



Issue 53 November 2015

TEN POUNDS FOR TEMPLATES

The Western Sussex Hospitals Trust has for some while urgently needed to update its diagnostic equipment for prostate cancer, and during the year PCaSO has been involved in negotiations to assist financially with this project. This will mean that the Trust will have brand new facilities for TRUS biopsies, the latest fusion biopsies (linked to the MRI scans) and, most importantly, template biopsies, all on the one site.

PCaSO Central and East branches have agreed to contribute £25,000 towards the cost of the facilities. Further donations are promised from Chichester Masonic Lodge and Rotarians, with others to be confirmed.

One major contribution has come from urologist Mr Paul Carter who, on 12th September ran what has been described as the “wackiest” marathon – the Medoc Marathon, which involves running costumed from vineyard to vineyard with, no doubt suitable refreshments on the way. This has to date raised over £12,300 through Virgin Giving, and at the time of writing the fund was still open.

The following is a report of the event:

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Paul Carter, Chief of Surgery for Western Sussex Hospitals Foundation Trust and Consultant Urological Surgeon recently threw caution to the wind to take part in the 26 mile Medoc Marathon on 12th September. The marathon takes place annually running from vineyard to vineyard in the Bordeaux region of France and the spectacle features an outlandishly costumed field.



Mr Carter (above) completed the course in an impressive 4 hours and 50 minutes as part of a fundraising scheme supported by West Sussex Urology LLP to raise money towards funding new equipment for diagnosing prostate cancer.

All the money donated will be used to help buy prostate template biopsy equipment which will improve the speed and accuracy of diagnosing prostate cancer. It will also benefit some men who have prostate cancer but who are being monitored, by giving them the reassurance that monitoring their condition is the correct pathway of care. The equipment costs almost £90,000 and enables urologists to investigate the

whole prostate gland giving a much more accurate diagnosis.

The current total on the Just Giving site stands at over £12,300. The page is still accepting donations and the hope is that this, along with the PCaSO pledge of £25,000, £10,000 from the Chichester Masonic Lodge and other donations that are still being confirmed, will raise the money needed to buy the equipment!

Mr Carter explains: “Prostate cancer diagnosis and monitoring has evolved significantly over the last 5 years, with the advent of MRI scanning with contrast. This can identify lesions in the prostate which can then be targeted using the template biopsy system. The prostate template biopsy equipment will have a huge impact on the lives of the men we see in clinic and the whole process will be much quicker and better for the patient. Everyone donating to ‘Ten Pounds for Templates’ will be making a real difference to men’s health and we’re hoping that we can raise enough money to be able to provide the diagnostic procedure at St Richard’s Hospital in Chichester, rather than patients having to travel outside the area.’

If you would like to donate please visit <https://www.justgiving.com/TenPoundsforTemplates>

Below is a photo of the team of urologists who will be using the new equipment.

LR: Simon Woodhams, James Hicks, Tom Liston, Suzie Venn, Philip Britton, Barnaby Chappell and Paul Carter.



EQUIPMENT FOR QUEEN ALEXANDRA HOSPITAL

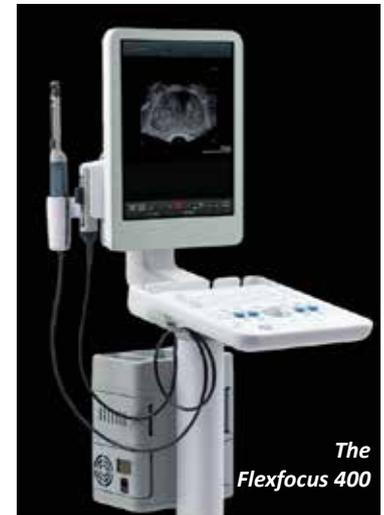
PCaSO Central Branch has approved a donation of £10,000 for the purchase of a Flexfocus 400 Scanner for the urology department of Queen Alexandra Hospital, Portsmouth. Mr Dominic Hodgson, consultant urologist, explained that this equipment, supplied four years ago on loan from Oncura, is used to map and determine the quantity of brachytherapy seeds required and to assist in the implantation of the seeds. As Oncura now no longer hold the contract to provide the seeds, they have requested that the scanner be either returned or bought at a considerably reduced cost. Once bought, the scanner will be housed in the urology outpatients department.

As the diagnosis and treatment of the disease is moving at an increasingly fast pace, the move towards the use of Fusion biopsies is being increasingly used. (This is where the MRI scan is linked directly to the biopsy, enabling more accurate positioning of the needles directly into the cancerous area itself.)

As a consequence, one of the QAH medical physicists has adapted the technique used on the currently on loan ultrasound scanning equipment to enable it to be used for fusion biopsies as well as for brachytherapy.

As a secondary benefit the equipment can also be used for brachytherapy seed volume measurements. This would mean that the patient would be given instant access to the procedure and importantly reduce the need

for a general anaesthetic and the need for further referral and waiting time.



EUROPEAN CANCER DECLARATION

When I first joined the PCaSO committee back in 2006, I was somewhat befuddled by the language they were using and the many acronyms used. One member started talking about "Easy-peasy" and I was not sure exactly what was supposed to be that simple. Several meetings later I realised it was some amorphous organisation 'ECPC', or the European Cancer Patient Coalition. We have received this letter from them. If you feel able to respond to your Member of the European Parliament, here is what it's all about. Ed.

The most important mission of ECPC is to fight inequalities in cancer care. In 2013, the current Board stressed the role that ECPC can have in providing guidance to policy makers. For this reason, we are doing everything in our power to help the European Parliament to take a strong position against two crucial causes of cancer care inequalities:

1. the unacceptable delays in reimbursement of new, life-saving medicines, which harm the right of patients to receive timely and effective cancer care;

2. shortages of essential cancer drugs happen when cheap, lifesaving cancer drugs are not available, therefore threatening the life of many cancer patients. These shortages are happening in all EU Member States, rich and less rich, and create unbearable differences in survival across Europe.

The **Written Declaration 30/2015** has been supported by 19 MEPs in partnership with ECPC to ask the European Union to:

- Create one single European system to evaluate the benefits of new drugs, therefore cutting the delays in access to new, life-saving medicines.
- Act now to understand why many essential cancer drugs are missing from the market and giving suggestions on how to overcome this problem;

It's fundamental for us to have the document approved, since once approved it becomes an official

decision of the European Parliament. Therefore, the Written Declaration has to be signed by 376 Members of the European Parliament before the end of November to become an official document of the European Parliament. With this powerful decision in our hands, ECPC and all its Members can then ask the Commission and the EU Governments to ACT NOW to end inequalities in cancer care.

Urgent: We need your help to collect those signatures now.

Contact your MEP and ask them to sign the **Written Declaration 30/2015**. If you do not know who are the MEPs elected in your area, just google: writetothem.com and simply enter your postcode.

So far, the ECPC Office have already managed to get only 100 signatures. Please help us to help you: the Written Declaration 30/2015 is a win for all cancer patients in Europe to ensure safer, faster and more equitable access to medicines.

PSA TESTING IN DORSET

Dorset PCaSO's next PSA testing session in November is already fully booked and the calls are still coming in! We intend to use 8 machines, have 3 counsellors and also offer full venous blood tests for those men with an Amber or Red result.

Part of this success is due to the fact that the two lead urologists at the County Hospital have written in the local newspaper urging that all men aged 50 and over should ask their GP for a PSA test. The response has been very positive and happily coincides with our testing session!

We have now received from David Baxter-Smith well over 30 letters from asymptomatic men who have either been successfully treated or have been put on an Active Surveillance programme.

The following four examples provide a good summary of the progress we are making:

'Following an examination by my GP on the Monday following your test, I was referred to my consultant in Dorchester. A further examination confirmed the cancer with a Gleason score of 7. I elected to have keyhole surgery and am pleased to inform you that I have since had two PSA tests indicating no reading. You might be interested to know that the consultant said to me that the test

at Lyme Regis Golf Club probably saved my life.'

'My last reading was 10.2 (as compared to 9.9 at Shaftesbury). I attended Odstock Hospital and received a biopsy which showed cancer in 4 of the 12 samples. I have received an MRI scan and a CT scan. I will be attending Poole Hospital where I will be receiving 4 weeks of radiotherapy.'

'After the blood test by the charity, I took the letter they provided to my doctor. He had a blood test done which came back as PSA 14.0. The biopsy at Dorset County Hospital proved to be positive in 11 of the 12 samples with a Gleason score of 7. Since then, I have had a 2 weeks course of tablets and 3 implants whilst awaiting my radiotherapy treatment which starts in August. Since I have been diagnosed I have urged a few of my friends to take the PSA test. Many thanks to you and your charity for the help and assistance.'

'After my appointment at Bournemouth Hospital I was advised that the results of the biopsy showed signs of cancer and I was informed of 3 courses of action. Within 24 hours I had made my decision and decided the best way forward would be robotic surgery. I came for the PSA test because I saw it advertised in the local freebie magazine. I did not have any symptoms then or now

which would cause me any alarm and make me feel I needed to visit the doctors. I cannot thank you and your team enough for carrying out the test and ringing the alarm that could have saved my life. My little hiccup has caused eight of my golf buddies to go for a PSA test.'

The 5th letter is more worrying:

'After my visit for a PSA test which showed some concern, I booked a visit to see my GP. I immediately sensed some hostility. My doctor did not support the "outside interference" and seemed more concerned with the cost to the NHS of a PSA test which was quoted as £17.50. After further discussion my GP carried out a further PSA test which was in line with the result I received from PCaSO. We agreed a further test in 6 months. I will keep you up to date. Many thanks for your support.'

It is letters such as this which encourages us to keep such GP surgeries (relatively few) abreast of current protocols and management of prostate cancer by sending them the relevant documentation including the official letter from NHS Wessex which emphasises the entitlement of men aged 50+ to a free PSA test.

The battle continues – and we are winning!

James Davis

NEW UROLOGY CENTRE AT GUILDFORD

The Royal Surrey County Hospital at Guildford sees the start of building its new Urology Centre, which will be a centre of excellence in the diagnosis and treatment for urology patients. The Prostate Project, the support organisation based in Surrey, has already raised £1.3 million towards this, which has enabled the building to start work.

It will include 5 consultation rooms, 3 treatment rooms, a lecture theatre and research lab. It will be home to 15 consultants and doctors, 12 specialist nurses and 8 research staff. The new Centre is expected to provide diagnosis and treatment for up to 500 people in its first year and will act as a model of how centralised cancer care should be provided in the NHS. The first turf was cut on 2nd October by Jeremy Hunt MP, Secretary of State for Health, shown in the photo on the right.



COHORT GET-TOGETHER

In the Central branch of PCaSO there are several members that give devotedly of their time, mainly the small group that form the committee without whom there would be no direction or organisation. However there is another group who in the background work and provide the funds to keep the organisation going; this small 'cohort' is the 'Awareness and Collection' team.

This group, though small in number, have raised over £3500 so far this year and have at least three events to do before the year end. The team is made up of members who can regularly be relied on to support events by handing out information, speaking with men and their partners about concerns and hopefully getting some donations. Many members of the cohort say how surprised and rewarded they are by meeting with others and being able to offer support, even if this is just listening to anxieties. Without their efforts and fund raising PCaSO could not meet its objectives. This cohort only totals some twenty people, **so more members are constantly required.** Over the year several members have been lost due to poor health and death.

Even though many of the team had been helping for months, in some cases for years, it was clear that they had never met and did not know one another due to the manning schedules required for the events. The only times that meeting was possible occurred at AGMs or at branch meetings in Chichester and Otterbourne. Therefore the idea of a 'get together' for the cohort was the solution to this problem that John (the co-ordinator) came up with and

this would also show his appreciation for their great and dependable support. After much deliberation the 8th August was settled on as a date that most of the cohort could make; thus a gathering took place at John's house in Up Marden on the South Downs with over half the members and partners attending. This event was different to the normal event in that members meet one another, some finding that they lived a few streets away, being able to chat, enjoy a drink and the sunshine, followed by a light lunch. Regrettably only about half of the full team could



From left to right:

Andrew & Jennifer Bloxham, Paul & Maria Belton, John (stooping), Roger & Lynne Heald, David Nixon, Chris & Elizabeth White, Estella & Godfrey Knight, Dot (striped top) and Barry Phillips (red top) with our treasurer Davis Harris in the background.

attend due to their holidays and other commitments.

The team have only three more events this year, namely: Tesco at Littlehampton on 11th September; Asda at Havant 17th & 18th September (now gone - see p. 7) and in December Tesco Havant on the 10th. There will be two 'Awareness only' events at the B & Q store at Bedhampton on 5th and 16th December.

As most of you will realise the money raised goes to funding research and specialised equipment. We are the major funding partner for the new template biopsy facilities for the Western Sussex Hospitals

Trust based at St. Richard's Hospital and are helping with items for Queen Alexandra Hospital as well as supporting our own meetings and printing literature. The information booklet 'Knowledge Empowers' is highly regarded amongst the



clinicians and is due for an update in 2016. To enable us to continue, the 'cohort' needs more members to support the scheduled events and so that we can expand the catchment area where we are able to effectively run our awareness events. The geographical expansion of the area covered requires members in Southampton, Basingstoke and Winchester to step forward and pitch in. They will find it rewarding and fun, so call me on 02392 631599 or

better still drop an email to john.harmer@waitrose.com.

We all know that 'Knowledge Empowers', but we need to get this awareness to as many men as possible and to save lives.

If you feel unable to help in this way, perhaps you could take some of our awareness leaflets and distribute these at suitable outlets - perhaps at your surgery or health centre, or take some posters and ask to have one put up at your local club or pub?

It is enjoyable, rewarding and a pleasure to be a member, so join us!

John Harmer

NICKY'S LYCOPENE RECIPES

2: RUSTIC ITALIAN PASTA AND BEAN SOUP

LOVE YOUR LYCOPENE: 2

Preparation and cooking time — 30 minutes

Ingredients (serves 2)

- 1 teaspoon olive oil
- 1 small onion (diced)
- ½ medium carrot (diced)
- ½ small red pepper (deseeded and diced)
- ½ small courgette (diced)
- 1 clove garlic (crushed)
- 8 oz (227g) can chopped tomatoes
- 2 teaspoons tomato puree
- ½ teaspoon sugar
- 1 pint (600ml) low salt vegetable stock
- 1oz (30g) small wholemeal pasta shapes
- 8oz (200g) canned cannellini beans, drained & washed
- 2oz (50g) baby leaf spinach
- Freshly ground black pepper
- Parmesan (if required)
- Bay leaf
- Pinch of mixed/Italian herbs

Method:

1. Place the olive oil in a heavy base saucepan and heat gently. Add the carrot, onion, red pepper, courgette

and crushed garlic. Cook on a low heat for five minutes, stirring from time to time.

2. Add the chopped tomatoes, tomato puree, sugar, mixed herbs, bayleaf and stock to the pan. Bring to the boil, lower the heat and simmer gently for eight minutes or until the vegetables are tender.

3. Add the pasta and drained beans and then bring back to the boil. Reduce heat and simmer for eight minutes, stirring from time to time until the pasta is just cooked. Stir in the spinach and season with black pepper. Cook for two minutes, remove the bay leaf and pour the soup into bowls. Sprinkle with the parmesan (if required) and serve immediately.



NEW PCASO CLOTHING



PCaSO has some new clothing: a grey fleece jacket and a white polo shirt with a navy and red trimmed collar. Each has our logo discreetly on the front and our 'Check it out!' message on the back.

Fleeces are £28 and the polo shirt £17.50 including VAT. They can be purchased by contacting your branch secretary.



The pictures show Christina Cutting from East Branch wearing them at a recent PSA testing session at Rye, and our chairman Roger Bacon speaking at a meeting.

PCASO NEWS

CHRISTMAS TEA SOCIAL

HAVE YOU LOST YOUR PARTNER TO PROSTATE CANCER?

PCaSO Central Branch is holding a social event primarily aimed at members who have been widowed. This will be held on

TUESDAY 8th DECEMBER

**2pm - 4pm at Church of the Sacred Heart,
256 London Road, Waterlooville PO7 7SR**

If you would like to come, please would you RSVP to Stuart Thompson, 4 Ashley Meadows, Romsey, Hants SO51 7LT.

Email: stuart.thompson12@ntlworld.com

If you do not have a car, we will try to arrange a lift for you. Please let Stuart know if you would like transport both ways.

WORKING WITH THE LIONS

In October our East branch organised two PSA testing events in partnership with the Lions charity. The first of these was held in Rye, the furthest east we have ventured with our PSA testing kits. The Rye & District Lions group found a suitable venue, did all the publicity and took the bookings. A small group of experienced PCaSO event organisers, Roger and Lauren Bacon, Barry Cocum, Danny Fyne and Christina Cutting arrived on the day and, with lots of support from Lions volunteers, we tested 135 men. Due to the inexperience of the testers, we did run a little behind schedule with the testing, but comments received from a lot of the men being tested were very complimentary.

The second event in October was in Worthing, where we have been before, again in partnership with the Worthing Lions. We tested 136 men. PCaSO members Roger and Lauren Bacon, Barry Cocum, Viv Miles and Peter Weir attended, with plenty of Lions volunteers helping with refreshments, meeting and greeting and results admin. The Lions again handled publicity and arranged the venue, but we took responsibility for bookings. This time event ran very smoothly and on time.

Out of the 271 men tested at these events we had 15 with high 'red' readings, some of which we know will turn out to be cancer. We have one more event planned this year in Rustington on 21st November at the chiropractor clinic, Back2Fitness, where we have tested before. Booking line 01903 775577 for those interested.

PCASO IS ON TWITTER

Twitter is a source of instant information. What you get on your Twitter account depends on who you follow and whatever you see is superseded by whatever is written (posted) next. It lasts, at most, a few days. You don't have to write anything to receive information, just go to www.twitter.com, set up a free account and start following people or organisations. Whether your interest is in ants or zebras, cooking, gardening, bridge or sailing there will be Twitter streams you'll find interesting.



When you see young people flicking through things on their phones they are possibly looking at what Twitter is showing them. They'll ignore some things and look in more detail at others.

PCaSO now has an account called [@PCaSO1](https://twitter.com/PCaSO1) and we will post things that might be of interest about meetings and follow people and organisations that might have useful information on prostate cancer matters. Follow us, or – if you dare – tweet something about us yourself!

PCASO AND PSA TESTING

Your committee has recently undertaken its regular review of its PSA Testing programme and has decided to continue with the PSAWatch machines now supplied by Laborie, as all recent tests have shown to be relatively accurate at 'green' levels, with no false negatives when tested against laboratory samples in this group.

However all men who show a raised level of PSA (i.e. those with 'amber' or 'red' results) will be given the opportunity of having a more accurate venous blood sample which will be sent off to a laboratory. This will be taken by a trained phlebotomist at the event or, if preferred, through the man's own GP at a later date. As a further check, it has been agreed that random samples of 'green' results will be subject to the same venous lab test for a period.

DONATIONS AND FUND RAISING

PCaSO acknowledges with thanks generous donations from MA & MJ Spillett, Mr & Mrs Gaston and from an anonymous donor from Dorset towards the cost of PSA testing.

Central Branch raised £1011 from the collection at Asda in Havant, and the joint collection from East and Central branches at Littlehampton a further £370.

East Branch's Waitrose green tokens at Storrington raised £720 and the summer fete organised by Mr & Mrs Naish at Eastbourne, who are enthusiastic fundraisers for PCaSO, gave £850 towards the furnishings for waiting area of Eastbourne hospital's new RT suite.

WHAT'S ON: SEPTEMBER – DECEMBER 2015

EAST BRANCH SUPPORT MEETINGS

Rustington: held at John de Bohun Room, Woodlands Centre, Woodlands Avenue, BN16 3HB.

Tuesday 24 November - Patients' Forum at 7pm.

Tuesday 22 March - speaker tba.

Pulborough: held at Pulborough Village Hall, Swan View (off Lower Street), RH20 2BF at 7pm.

Quarterly meetings tba.

Eastbourne: held at Postgraduate Centre, Eastbourne District General Hospital, Thursdays at 7pm.

10 December: Dr Karen Leeson: Osteoporosis and PCa (6.30 start)

14 January: Dr Duncan Gilbert

11 February: Alison Gidlow (CNS)

10 March, 14 April (tba)

CENTRAL BRANCH SUPPORT MEETINGS

Chichester: held at Chichester Baptist Church, Sherbourne Road, PO19 3AW (7pm, 2pm in winter)

Friday 26 February, 2pm: Tony Boness (urology care manager, St Richard's Hospital).

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

1 March: speaker tba

Waterlooville: held at Church of the Sacred Heart, London Road, PO7 7SR at 7pm.

May (date tba)

AWARENESS EVENTS

B&Q Bedhampton Awareness days on Sat 5 and Wed 16 December

WEST (DORSET) BRANCH SUPPORT MEETINGS

Bournemouth: held at St Marks Church Hall, Talbot Woods, BH10 4HY, Wednesdays 7 for 7.30pm bi-monthly on the last Wednesday of the month.

Wednesday 25 November: Christmas Social and Bingo

23 March: Members' Forum

SUPERMARKET COLLECTIONS

Thur 10 December, Tesco Havant

PSA TESTING EVENTS

Sat 21 November, Rustington

Sat 30 January, Poole

(See our website for details)

PCASO CONTACTS

EXECUTIVE COMMITTEE

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Peter Weir

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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

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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Help Line: 0845 650 2555

Website: www.pcaso.org

Charity No: 1095439