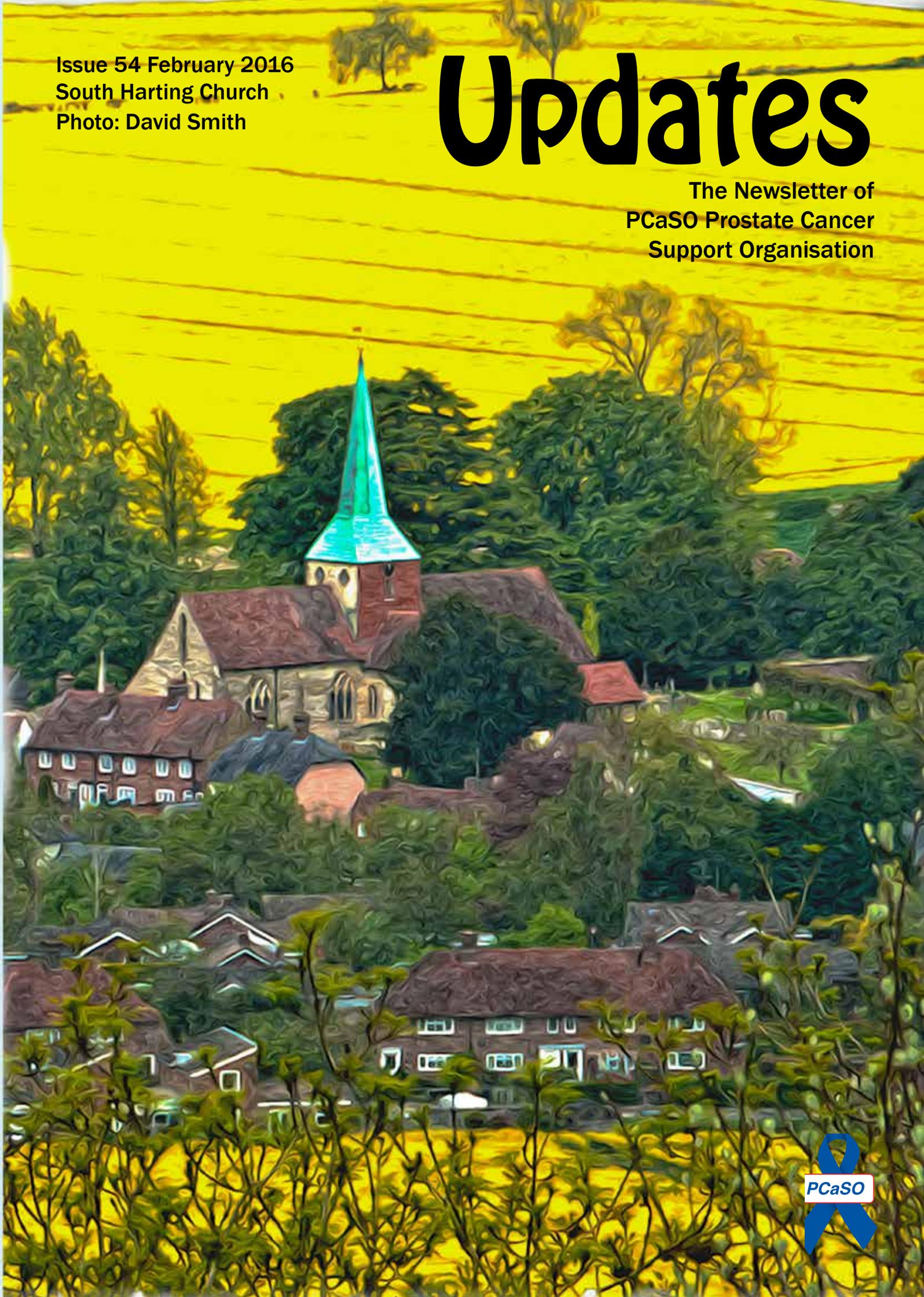


Issue 54 February 2016
South Harting Church
Photo: David Smith

Updates

The Newsletter of
PCaSO Prostate Cancer
Support Organisation



STAMPEDE TRIAL – FIRST RESULTS

The first results of the STAMPEDE trial published on 21st December show that having early chemotherapy improves survival for men with prostate cancer.

This arm of the trial looked at the use of a chemotherapy drug called docetaxel. Docetaxel is already used for men with prostate cancer once hormone therapy has stopped working, and has therefore been a 'last resort' treatment. In STAMPEDE the researchers looked at using it earlier, when men are starting long-term hormone therapy. It found that adding docetaxel improved survival for these men.

It also looked at whether the drug zoledronic acid improves survival. Zoledronic acid is used to reduce the risk of bone problems in men whose cancer has spread to their bones, and whose hormone therapy has stopped working. It looked at using it earlier, when men are starting long-term hormone therapy, and found that adding zoledronic acid did not improve survival for these men.

A 15-minute film has been produced aimed at patients and the public that explores these results. You can see this on:

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**The PCaSO ANNUAL GENERAL MEETING will be held on
FRIDAY 22nd APRIL, 7.00pm
at the Langstone Hotel, Hayling Island, Havant PO11 0NQ**

**Our speaker is Professor Christopher Eden on
'Salvage Surgery for Prostate Cancer'**

Full details are on page 5

[https://vimeo.com/mrcctu/
stampederesultsforpatients](https://vimeo.com/mrcctu/stampederesultsforpatients)

but you need to have Vimeo installed on your computer to access it properly.

Men in the group given the standard treatment plus docetaxel lived on average for 10 months longer than men who had the standard treatment alone. Men in the group given the standard treatment plus zoledronic acid did not live any longer, on average, than men who had the standard treatment alone.

Men in the group given the standard treatment plus docetaxel plus zoledronic acid lived longer, on average, than those who had just the standard treatment. However, adding zoledronic acid to docetaxel did not seem to add any benefits beyond just docetaxel and the standard treatment.

Many men already report side-effects from the standard treatment, but men who had docetaxel were more likely to experience unwanted side effects compared to men on the standard treatment alone. The most common extra side-effects men on docetaxel reported were a low number of white blood cells, which increases the risk of infection. However, these side-effects were manageable and were generally short-term. After one year, there was no difference in the numbers of severe side-effects reported by men in any of the trial arms. Very few patients had to stop docetaxel due to side-effects.

The STAMPEDE researchers say that docetaxel should be routine practice in men with newly-diagnosed prostate cancer that has spread to other parts of the body if they are well enough to take it. Doctors should also consider it for men with high-risk prostate cancer that has not spread to other parts of the body, as it delays the disease getting worse.

Meta-analysis results

A further paper issued at the same time brought together the results from STAMPEDE and all similar trials that were available.

It found that, in men whose disease had spread to distant parts of their body, docetaxel increased the proportion of men alive at four years after joining the trial from 40% to 49%. It also increased the proportion of men whose cancer had not come back or got worse, from 20% to 36% after four years.

For men whose disease had not yet spread to distant parts of their body, docetaxel increased the proportion whose cancer had not come back or got worse after four years. However, there was no clear evidence yet that it helped men to live for longer. Further evidence will emerge as more trial results are published and trials like STAMPEDE follow-up patients for longer.

The meta-analysis also found no evidence that zoledronic acid helped men to live for longer.

THE STAMPEDE TRIAL - WHAT IS IT?

Many will have heard the first results of the STAMPEDE trial announced at the end of last year, details of which are on the opposite page. Dr Chris Parker, at our AGM last year, mentioned STAMPEDE as part of his talk but many, particularly those that have been more recently diagnosed, may not know the details of this long-standing trial.

The trial has some outstanding urologists and oncologists working on its Board, which is led by Professor Nick James of Warwick University, with clinical representatives throughout the UK and Switzerland, including the Royal Marsden Hospital nearest to our area. There are also patient representatives: Jim Stansfeld, one of the founder members of PCaSO, served as a representative almost up to his death in 2009.

STAMPEDE stands for **S**ystemic **T**herapy in **A**dvancing and **M**etastatic **P**rostate **C**ancer: **E**valuation of **D**rug **E**fficacy.

The aim of this trial is to try to prevent the tumour re-growth by adding other treatments to the standard hormone therapy in a range of combinations in order to see which combinations are the most effective. The trial first started in 2006 and is ongoing. Some arms of the trial have now closed; others are current or ongoing. Each arm has a group that receives the trial treatment and a control group who receive the very best standard treatment. These arms are:

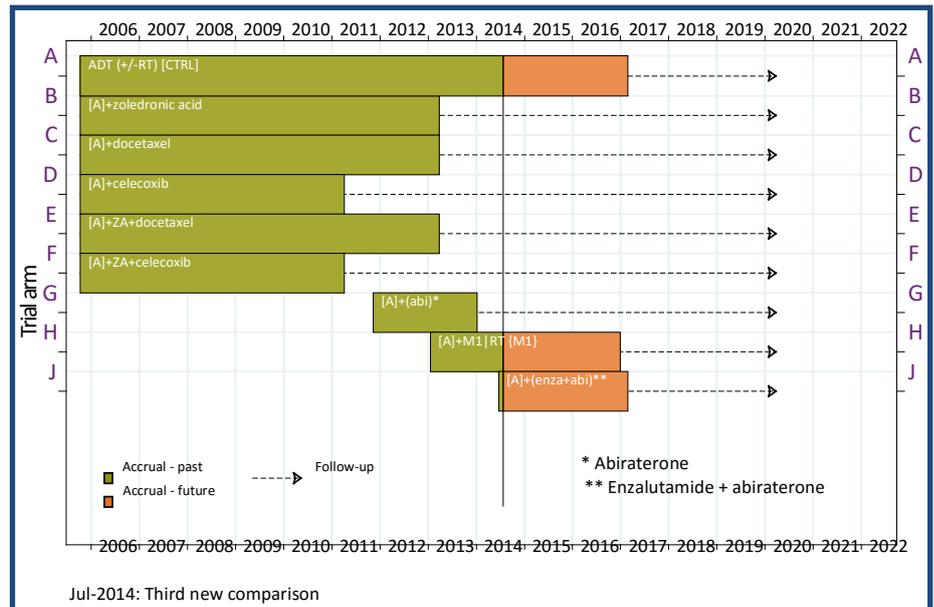
- A. **hormone therapy + radiotherapy:** (ongoing)
- B. **hormone therapy + zoledronic acid:** (closed, and results now out)
- C. **hormone therapy + docetaxel:** (closed, and results now out)
- D. **hormone therapy + celecoxib:** (closed)
- E. **hormone therapy + zoledronic acid + docetaxel** (closed)

F. **hormone therapy + zoledronic acid + celecoxib:** (closed)

All these were started in 2006. With the advent of the newer drugs abiraterone and more recently enzalutamide, these have been added to the mixture, and we now have:

that have proved beneficial in many, but not all patients.

As the results have shown positive benefit to receiving chemotherapy, men who are diagnosed with advanced prostate cancer are now routinely offered six cycles of docetaxel as standard, in addition to hormone therapy.



G. 2011: **hormone therapy + abiraterone + prednisolone** (open)

H. 2012: **hormone therapy + radiotherapy where the cancer has spread** (open)

J. 2014: **hormone therapy + abiraterone + enzalutamide + prednisolone** (open).

A brief word of explanation is needed on these drugs, details of which can be found in our Information Booklet.

- **Zoledronic acid** slows the release of calcium to the bones;
- **Docetaxel** is the standard drug used in chemotherapy, and in this trial involves 6 sessions of receiving this.
- **Celcoxib** is an aspirin-like drug that used mainly to treat arthritis, but might also be beneficial in prostate cancer patients.
- **Abiraterone** and **Enzalutamide** are advanced forms of anti-androgens

You should first discuss with your consultant if you think you might be eligible for the trial.

What is the current position?

NHS England have just announced that men with newly diagnosed advanced prostate cancer will now be offered immediate access to chemotherapy that could extend their lives by an average of 15 months.

However, the old NICE recommendation that docetaxel is only available after hormone therapy has failed has not to date been changed. So the position remains fluid. Watch this space.

Remember that your consultant, who will be fully aware of the current situation and your needs, is the best person to ask.

NICKY'S LYCOPENE RECIPES RATATOUILLE

LOVE YOUR LYCOPENE: 3

Ingredients:

- 400g tinned chopped tomatoes
- 1 medium courgette (washed) and cubed
- 1 medium aubergine (washed) and cubed
- 1 medium onion (peeled) and sliced
- Tomato paste (to thicken)
- 1 tablespoon olive oil (or oil of your choice)
- 1 clove of garlic (optional)
- Salt and pepper to season

In a medium sized saucepan, place the oil and heat on a low light. When hot, add the onion and slowly cook until soft and transparent.

Add the aubergine, courgette, garlic and tinned tomatoes.

Cover saucepan with a lid and simmer until all vegetables are soft.



TRACK YOUR PSA

In Issue 46 (February 2014) our Treasurer Vivian Miles did a review of PSA Tracking software for your phone or tablet. A new one has come to our attention, which seems extremely comprehensive, and is more suited to computer or tablet than a simple phone app.



A urologist based at Cambridge has developed a PSA Tracker, called **TrackMyPsa**. This is a simple tool to empower patients who wish to follow their progress, and it supports regular monitoring and tracking. You are able to enter PSA results, treatments and reminders, which will be emailed to you, as well as viewing trends over time. It is also possible for you to allow your GP, consultant or nurse specialist to view your data, should you wish to, but they cannot alter it.

Take a look at the video about the tool at: <http://trackmysa.com/video/standalone/>

Having seen how it works, you can use the tool by going straight to www.trackmysa.com

If you have any problems you can email Jenna at jmk66@medschl.cam.ac.uk or Lorraine at lorraine.starling@addenbrookes.nhs.uk

and they will register your interest and advise how to access the tool.

'FORECAST' TRIAL

Have you had radiotherapy or brachytherapy and are considering further treatment because of a rise in your PSA?

If so, you may be interested in this trial being run by University College London Hospital.

FORECAST, or **F**ocal **R**ecurrent **A**ssessment and **S**alvage **T**reatment, has vacancies.

Each year about 10,000 men undergo radiotherapy, of which one third will present with recurrent disease. Of these, 50% will have metastases and 50% will potentially develop metastases if not given further treatment.

Men entering the trial receive detailed scans, including PET and bone scans, a multi-parametric MRI and a full body MRI scan, followed by a targeted biopsy or template biopsy.

This will be followed by focal salvage treatment. The aim is to target the cancer by treating just the cancerous area (not the whole prostate) with HIFU or cryotherapy.

However, you may not be eligible if you have taken hormones in the last six months, are unable to have MRI scans, or have had any other treatment for prostate cancer other than radiotherapy or brachytherapy.

As at November the trial had recruited 60 of the potential 170 men.

Besides University of London Hospital, treatment is available at Basingstoke and Southampton hospitals, and Brighton will shortly be joining the scheme.

If you are interested, you must first check with your consultant that it is suitable for your circumstances. Full details can be obtained from:

Mr Hashim U. Ahmed (MRC Clinician Scientist and Honorary Consultant Urological Surgeon UCLH).

email: hashim.ahmed@ucl.ac.uk

PCASO ANNUAL GENERAL MEETING

We are delighted to welcome Professor Christopher Eden of the Royal Surrey County Hospital and the Hampshire Clinic as speaker at our AGM. His talk will be on **Salvage Surgery for Prostate Cancer**



This will be preceded by the formal Annual General Meeting, held at **The Langstone Hotel (Winchester Suite), Northney Road, Hayling Island, PO11 0NQ at 7.00pm.**

We look forward to seeing as many members there as are able to come. Tea, coffee and biscuits will be available before the meeting.



DIRECTIONS TO THE LANGSTONE HOTEL

The turning to Hayling is the A3023 off the A27, just a mile and a half from the A3(M) junction and 10 miles west of Chichester.

Follow the A3023 dual carriageway for one mile, when you will reach the bridge crossing to Hayling Island (single carriageway). Immediately over the bridge take the first left, signposted 'Northney' and you will see the hotel sign along this road.

There is ample parking in the forecourt.



NOTICE is hereby given that the Annual General Meeting of PCaSO Prostate Cancer Support Organisation will be held at the Langstone Hotel, Hayling Island, PO11 0NQ, on Friday, 22nd April 2016 at 7.00pm for the following purpose:

1. Approve minutes of the AGM dated 16th April 2015.
2. Matters Arising
3. Chairman's Report
4. Treasurer's Report for the year ending 31st December 2015
5. Governance of the Charity (see overleaf)
6. Election of the Hon. Officers (i.e. Chairman, Treasurer and Secretary) in accordance with Sections 7 and 16 of the Constitution
7. Election of members of the Executive Committee in accordance with Sections 7 and 16 of the Constitution
8. Any Other Business.

It is requested that nominations for Hon. Officers and Executive Committee are with the Secretary at least 14 days prior to the AGM. Please use the tear-off section below and send to the following address:

4 Skeyne Mews, Pulborough, RH20 2BB.



I wish to submit the under-mentioned nominations for Hon. Officers and members of the Executive Committee:

Chair: Secretary:

Treasurer:

Committee members: 1) 2)

3) 4)

I confirm that I have obtained their agreement. Signed: Date:

Tel: No: Print name:

GOVERNANCE OF THE CHARITY

Further to Item 5 of the Agenda for the AGM, the Trustees will ask the membership to approve in principle the change of the governance of PCaSO from an Unincorporated Charity to an Association Charitable Incorporated Organisation. This latter is a relatively new form of governance suggested by the Charity Commission for those charities who might wish to provide limited liability for the trustees and members.

Currently any commitment or contract made is between individual trustees and the third party as PCaSO has no legal entity. Becoming a CIO makes PCaSO a legal entity able to make contracts.

The trustees believe the opportunity, since it is available, is a sensible way forward. The name and organisation will remain the same and the assets of the Charity will be transferred with no change.

The Trustees plan to table the new constitution at the meeting. If the members present agree the proposal the Trustees can submit a proposal to the Charity Commission for their approval. The Commission warn that the process could take some weeks.

The Charity Commission publishes copious information on this subject on their website. You may care to start at <https://www.gov.uk/guidance/charity-types-how-to-choose-a-structure>.

David Hurst

LOCAL SUPPORT MEETINGS

26 February	Chichester
1 March	Otterbourne
10 March	Eastbourne
22 March	Rustington
30 March	Talbot Woods
14 April	Eastbourne
10 May	Pulborough
13 May	Waterlooville
25 May	Talbot Woods
7 June	Rustington

See back page for venues and times of meetings, contact details etc.

LIQUID BIOPSIES

I was very interested to read in a leaflet from The Royal Marsden Cancer Charity about a clinical trial lead by Dr Nicholas Turner, Consultant Medical Oncologist at the Marsden for tumour biopsies using blood samples as an alternative to the current invasive process of taking needle samples direct from the tumour itself.

The new technique relies on the detection and extraction of tumour DNA from the blood sample and establishment of its genetic make-

up. Being non-invasive, liquid biopsies can be repeated when required to give the latest information of the tumour make-up in order to select appropriate treatment to target specific mutations.

They give as an example that a liquid biopsy for someone with prostate cancer can predict whether the cancer will respond to the drug Abiraterone or whether it should be avoided.

The expectation for the future is that liquid biopsies will help to match

patients to the optimum treatment pathway and, as has already been demonstrated, identify those at risk of relapse following curative surgery and treatment well before other symptoms appear.

There is already a huge amount of information on the internet on liquid biopsies, mainly from the USA, but a simple summary can be found on the Marsden site at:

<https://www.royalmarsden.org/a-brighter-future-liquid-biopsies>

Geoff Bailey

ANY NOMINATIONS OVERLEAF MUST BE RECEIVED BY 8th APRIL.

REMEMBER THAT PCaSO DOES NOT RUN ITSELF – WE NEED YOUR SUPPORT.

PCASO NEWS

LEGAL HELP

The trustees of PCaSO would like to find a lawyer who would be prepared to offer advice on a pro bono basis. There is no legal dispute around at the moment and there hasn't ever been one but the charity has no-one to whom it can go quickly if some legal question occurs. It seems sensible to have an individual who knows a bit about us before anything proverbial hits the fan.

We are looking for a lawyer, probably a solicitor, who has some charity experience and who would be prepared to answer occasional questions. Ideally but not essentially that person would have experience of prostate cancer, either direct or through a close relative. They might be still working or recently retired.

If anyone is prepared to offer such help, please would they contact the secretary, David Hurst, at secretary@pcaso.org or 01798 875758.

BRANCH AGMS

Each Branch has to hold its own AGM before the full PCaSO AGM on 22 April. These are usually very brief, perfunctory reports on what we have been doing, followed by either a presentation from a professional or a general discussion forum.

These dates are:

Central Branch: 1st March at Otterbourne 7.30pm, with a Patients' Forum

East Branch: 22nd March at Rustington 7pm with Mr James Hicks

Dorset Branch: 30th March at Talbot Woods 7.30pm, a Members' Forum.

Details of venues can be found on the back page.

MALE VOICE CHOIR CONCERT

On 23 January the Bournemouth Male Voice Choir, in which three members of PCaSO sing, gave a concert in aid of the Dorset Branch and raised nearly £800. The programme, in lighter vein, was mainly songs from stage and screen.



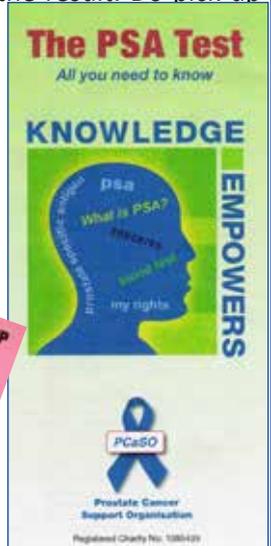
NEW PSA LEAFLET

We now have a new leaflet to add to our stock of information handouts. This is for those attending PSA test events as well as for men who may wish to have a PSA, informing them of what it is, what it does (and what it doesn't do!) and how to interpret the result. Do pick up some copies at the next meeting of your group, or at our AGM. If you would like some sent in the post, we can arrange this. We now have:

Don't Get Caught Out! - Pick Me Up
- Newly Diagnosed - The PSA Test



Leaflets designed by Woodman Design.



AWARENESS AT HAVANT

The Tesco Superstore at Havant was the venue for the Central Branch's first awareness and collection event of 2016 on the 15th and 16th January. As a result of our efforts some £1518 was collected, which will help fund the Chichester St. Richard's Hospital template biopsy equipment and items that we are purchasing for Queen Alexandra Hospital, Portsmouth.

The small cohort of helpers gave out several hundreds of awareness leaflets, had some interesting conversations with men and partners, hopefully providing support and help. We had one new helper, Derek Nugent, who valiantly came by bus from Portsmouth. We need as many helpers as possible, as our small cohort is shrinking due to age, infirmity and regrettably death. We have events later in the year at Fareham, Chichester and Portsmouth, so can all members who are able come and join us, who by their tireless work provide the bulk of the cash needed.

Contact john.harmer@waitrose.com to join this friendly and select band of members.

DONATIONS

PCaSO is grateful to the following recently received donations to our cause: The Emilienne Trust and Barclays Bank (Basingstoke). **Central Branch:** Ken and Kate Mills; Paul Clayson for a very generous monthly standing order.

East Branch: Bryan Naish's band *Recycled* (Eastbourne) raised funds through a 'Dancing through the Decades' event. Mary & John Carden collected 1.25 tonnes of milk bottle tops (i.e. 625,000 tops). Funds go towards the RT waiting room at Eastbourne Hospital.

WHAT'S ON: SEPTEMBER – DECEMBER 2015

EAST BRANCH SUPPORT MEETINGS

Rustington: held at John de Bohun Room, Woodlands Centre, Woodlands Avenue, BN16 3HB at 7pm.

Tuesday 22 March, Mr James Hicks
Tuesdays 7 June, 20 Sept, 22 Nov.

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

Tuesdays 10 May, 9 Aug, 15 Nov.

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

10 March, Courtney Williams
(Macmillan Cancer Support)
14 April.

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) and Paul Carter (head of surgery).

Wednesday 9 July (Hormone therapy - side effects).

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

1 March: Patients' Forum
6 September, Marc Laniado.

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

13 May: Pathology of the Prostate.
15 November.

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.

30 March: Members' Forum
25 May

SUPERMARKET COLLECTIONS

April 8-9, June 3-4 at ASDA Fareham

PSA TESTING EVENTS

Thur 17 March - West Parley

Sat 19 March - Rustington

Sat 9 April - Woodingdean

Sat 9 April - Verwood

(See Branch pages of our website for details of times and venues).

PCASO CONTACTS

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

East Branch representative:

Dr John Storey 01903 783687
(east.rep@pcaso.org)

Central Branch representative:

Stuart Thompson 01794 512867
(central.rep@pcaso.org)

West Branch (Dorset) representatives:

James Davis 01202 580436

(jamdavis@talktalk.net)

Allan Higgin

Derek Pilling

Publications and Newsletter Editor:

Ian Graham-Jones 01243 371128
(publications@pcaso.org)

Federation representative:

Allan Higgin 01202 691710

Pastoral Counsellor: helpline@pcaso.org

Nicholas Frayling info@pcaso.org
0845 650 2555

CENTRAL BRANCH COMMITTEE

Chair:

Stuart Thompson 01794 512867

Treasurer:

David Harris 02392 795909

Secretary:

Ian Graham-Jones 01243 371128

John Harmer (fund-raising) 02392 631599

Chris White (publicity) 02392 264042

Geoff Bailey (membership) 01962 713579

Nicky Annells (Fareham)

Peter Weir (Southampton)

Kathryn Lovering (Chichester)

WEST (DORSET) BRANCH COMMITTEE

Chair: Jim Davis 01202 580436

Treasurer:

Barry Taylor 01202 696107

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

EAST BRANCH COMMITTEE

Chair:

Roger Bacon 01903 775783

Treasurer:

Vivian Miles 01243 814129

Secretary:

David Hurst 01798 875758

Marketing/Promotions:

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Barry Cocum (West) 01273 387371

Debbie Hatfield 01323 638021

Joe Ambrosio

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

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.

PCaSO Prostate Cancer Support Organisation: PO Box 66, Emsworth Hants PO10 7ZP

Help Line: 0845 650 2555

Website: www.pcaso.org

Charity No: 1095439