

Issue 55 May 2016

Corfe Castle at night

(Photo Allan Higgin)



# Updates

The Newsletter of  
PCaSO Prostate Cancer Support Organisation



## SALVAGE SURGERY FOR PROSTATE CANCER

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Those present at our AGM on 22nd April were privileged to hear a talk by Professor Christopher Eden on this subject.

Although surgery is possible after failed radiotherapy – or, indeed other treatments such as cryotherapy, HIFU or Photodynamic therapy, it is a difficult operation for the surgeon, and an even more difficult decision for the patient to make.

Radiotherapy (including brachy-

therapy) is still the most common radical treatment for prostate cancer, and recurrence after treatment is quite common. In England alone, over 25,000 were treated for urological cancers in 2011/12 (the latest statistics). With the advent of newer techniques in radiotherapy, there is a 10-20% chance of the cancer recurring. The higher the stage and grade of the cancer, the more likely will be any recurrence.

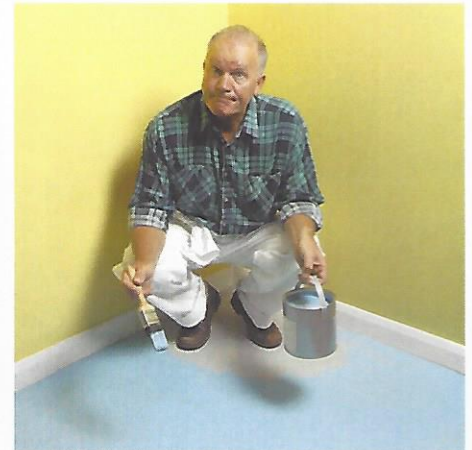
Any form of radiotherapy treatment will inevitably leave some scarring, some fusion where the tissues are stuck together, and poorer blood supply. This makes the surgery much more difficult, and therefore can lead to high complication rates, poor cancer control and poor functional outcomes.

Professor Eden then showed us examples (on screen!) of the prostate bed from a man before any treatment and the same after radiotherapy treatment, which clearly showed the damage that had been done by the radiotherapy. Surgery after radiotherapy therefore can lead to (in order of likelihood) incontinence, narrowing or fusion of organs, and rectal injury.

Therefore salvage treatment with HIFU or cryotherapy should generally be considered a better choice than surgery.

The other problem is that secondary malignancies can occur some years after external beam radiotherapy treatment – notably bladder, colorectal and rectal cancers. With brachytherapy, however, the risk was confined to bladder cancer, with no evidence of increased risk of rectal cancer.

The message therefore is that surgery should be treated as a best first option for men with higher risk prostate cancer who are suited to this treatment. So.....



don't paint yourself into a corner!

## PCASO ANNUAL GENERAL MEETING

Our AGM was again held at the Langstone Hotel, Hayling Island on 22<sup>nd</sup> April, with 29 members present. On this occasion the car park was unusually full, and our members found themselves having to battle their way through wedding guests and a murder mystery activity! Our comfortable room was however, remarkably quiet.

### Chairman's Report

Roger Bacon reported that PSA testing had played a significant part of PCaSO's activities in 2015, which was undertaken by both East and Dorset branches. We believe we have tested



around 5000 men since we started this. Over the year we have become concerned at the accuracy of the small testing machines we use and are working with the manufacturer to improve our confidence in them. As a fall-back we have introduced venous blood tests for those with raised

readings to double-check the result.

Test events are an excellent way of raising awareness of prostate problems. It enables us to talk directly to men and to give them our literature. In many events we work directly with the Lions and other similar charitable organisations. PCaSO has invested in polo shirts and fleeces to show we exist, and these are worn at our events.

Last April the Executive were joined at one of our meetings by Roger Wotton, the (then) new chairman of the National Federation of Prostate Cancer Support Groups – which is

also known as Tackle Prostate, often shortened to 'Tackle'. They sit on national committees and contribute to large studies putting forward the patient's point of view. We have agreed to work with them to put on a regional conference for support group leaders across the Southern region, which is to be held at the Langstone Hotel in September.

PCaSO have had a helpline from the early days but, as the number of calls have steadily reduced, we have decided to transfer those calls to the Tackle helpline. That will happen increasingly as our leaflets are reprinted.

In Brighton we are working closer with Macmillan, and once the new Sussex Macmillan Cancer Centre opens in Brighton, very soon, we hope to re-launch the PCaSO Brighton group, and use the venue for meetings, hopefully starting this summer. We also have another new group launched in Sussex in Bexhill, which is starting to establish itself.

PCaSO donates money to various causes. We have promised St Richards Hospital in Chichester £25,000 towards buying a template biopsy kit, but have still not passed the money over as they are not in a position to use it until the commissioning group agree on funding the procedure. Queen Alexandra Hospital, Portsmouth were promised £10,000 and Eastbourne District General Hospital has also been promised £10,000, this time for waiting area furniture for the new radiotherapy centre. Two years ago we gave Southampton University £2,500 towards the development of a programme to educate GPs about PSA testing and dealing with patients on Active Surveillance. Following initial interviews with GPs to find out what knowledge they had in these areas, a web programme is being developed that will help GPs advise men on the PSA test and to reassure men who are on Active Surveillance. We have seen the drafts and will be feeding back our comments before it goes out to test.

In the coming year we are looking at changing the charity's legal status. We hope to update and have a new

website design. We are updating our booklet *Knowledge Empowers*, which will have a new section on the psychological pressures some men feel after a diagnosis. We will be asking our members what treatments they have had and whether they are willing to talk to other men about those treatments so those men are better prepared for what is coming. Our membership has slowly increased since last year. Geoff Bailey, who does an excellent job as our Membership Secretary and also distributes the newsletter to everyone, informs me that we now have 1104 members across our region.

Roger Bacon then thanked the outgoing Executive committee members for their commitment over the last year, and also thanked all of our volunteers who help run our groups and those who stand outside supermarkets collecting money and promoting PCaSO. Without that army of 50+ people PCaSO would not be able to continue. We constantly need new volunteers to help spread the load, so all are encouraged to contact a member of the committee.

#### Treasurer's Report

Viv Miles, Treasurer showed the accounts for 2015 formatted in the way the Charity Commission now requires. These had been scrutinised by an independent person and they are now signed off. The accounts showed that we had receipts of £43,670 and payments of £22,700 over the year. This gave a surplus of some £20,000 and we had cash in hand of £127,000. About £35,000 was earmarked for donations already promised and another £65,000 was on deposit earning very little. Roger thanked Viv for his work in making the accounts accurate and understandable.

#### Charity Governance

David Hurst, Secretary, said that the charity had been set up in the late 1990s as an unincorporated association which was the correct thing in those days. This meant that the charity had no legal entity and that the trustees were personally

liable for debts. Insurance was taken out to allow for this.

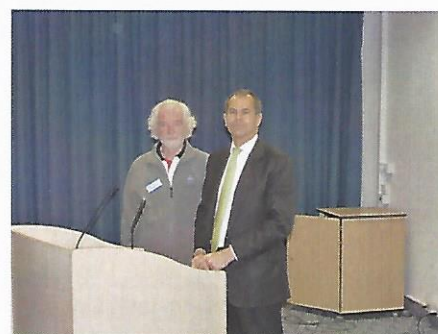
In 2011 the new Charities Act introduced alternatives and the trustees had decided to proceed towards becoming an Incorporated Charitable Organisation. This meant closing down the current charity and opening another with the same name but different charity number and transferring the assets – just cash, literature and PSA testing equipment – to the new charity.

He apologised but he had been unable to get the paperwork prepared for this AGM but hoped to get to this stage during the coming year, as there were various Charity Commission documents to be complied with.

#### Elections

As there were no new nominations and the officers and outgoing committee were willing to stand again, all were re-elected. The new committee is therefore: Roger Bacon (Chairman), Viv Miles (Treasurer) and David Hurst (Secretary), with Stuart Thompson (Central Branch rep.), Geoff Bailey (Membership Secretary), Jim Davis, Derek Pilling and Allan Higgin (Dorset Branch), Ian Graham-Jones (Publications).

The meeting was followed by a no-holds-barred talk by Professor Christopher Eden MS FRCS (Urol), Medical Adviser to PCaSO, on Salvage Surgery for Prostate Cancer, which is summarised on page 2. He also answered various questions on aspects of prostate cancer and drew attention to his interactive website [www.theprostateclinic.org/community/](http://www.theprostateclinic.org/community/)



Roger Bacon with Prof. Christopher Eden

## RADICAL PROSTATECTOMY - ONE MAN'S EXPERIENCE

JONATHAN ALDRED

I was first made aware that I had a prostate (never mind any problem) following a BUPA health check in 2006, when I was advised that I needed to see my doctor urgently as my PSA was 3.9, when the norm for men of my age (52) was in the range 0 – 3.0. Further testing found no evidence of cancer, but I did subsequently start six-monthly monitoring of my PSA level via my GP.

The magic number rose and fell over the years, with a low of 3.1 and a high of 5.3, until January 2014 when a spike to 7.4 caused my GP to refer me to the Portsmouth Queen Alexandra Hospital (QA) Urology team. I recall he was hesitant to do so as the vagaries of the PSA are well known, but I am truly glad that he did.

In July 2014, following an inconclusive MRI scan, I had a biopsy which identified the presence of cancer cells, and I was assessed as having a Gleason score of 6. We continued 'active surveillance' with the plan to repeat the biopsy after 18 months to two years.

My PSA jogged along at around 6, and this seemed to be acceptable. However, prior to each six-month review with the Urology team, my brain would go into a spin as I re-read all the articles and on-line forums to understand what was happening to me. When would 'active surveillance' stop? What if it spreads out from the prostate between PSA tests? If we knew from the biopsy that I had cancer, why not remove the prostate now? Would I be able to cope with the possible outcomes, especially urinary control?

I was re-assured during my appointments that we could safely continue with active surveillance, and have a biopsy probably in December 2015 or early 2016. In January 2016, however, my PSA result rose abruptly to 10.6, up from 6 in June 2015. My

consultant was the most reassuring person you could wish to have sat in front of you to help you assimilate the significance of such a result. He spoke out loud the thoughts which had been swirling round my confused brain: Ok, we know PSA is unreliable, this spike could be caused by many things, but you have the biopsy result, and, like many men, you have this six-monthly emotional roller-coaster as each test result is considered. You've seemed minded in the past to have the prostate removed, so why don't we do that?

Jonathan Aldred



It was such a relief to hear these words. We did agree to have a further MRI scan (techniques had improved dramatically since the previous scan in 2014), which identified a new growth within the prostate, and confirmed the decision to have a prostatectomy.

At this time, I contacted PCasO and took great reassurance from the gentleman I spoke to on the helpline. He was especially helpful in putting some balance on the stories of urinary incontinence you can read about on various websites (even my GP had told me I would be wearing colostomy bag forever if I had my prostate removed!). He confirmed that very, very few men suffer with any long-term problems, and that even if you do, there are more elegant solutions than walking round with a bag strapped to your leg.

I had my prostate removed by robotic radical prostatectomy just two

weeks ago, as I write these words. To say I feel euphoric would be an understatement. Due to the great care and skill of my surgeon and his team, the operation was relatively pain free. I left hospital two days later, on Thursday, and my catheter was removed on the following Thursday. I had a sleepless night before this removal, but when the catheter came out – nothing happened! No uncontrollable fountain, no sense of lack of control. A couple of occasional dribbles, but only when I laugh, which I am starting to do more of! On that day, I walked a few miles along the local foreshore with my wife, had a celebratory ice-cream, and felt almost as if nothing had happened.

I am due to have my first post-operative PSA test result in early May, and I hope that will demonstrate that I am free of cancer.

So, I am 62 years old, I never thought this would be happening to me, and I have come through this process (so far) relatively unscathed, with fantastic support from my wonderful wife, family and friends. I have written this article just to share the experience of an ordinary man, with a lot to live for, going through a worrying process, and hopefully having come out the other side. The most difficult challenge I face currently is remembering to do the pelvic floor exercises, and if you'd told me that two weeks ago, I would not have believed you!

### GP'S PLEASE NOTE

*This is a story we hear repeated many times over from men undergoing this operation, so please don't peddle the old mantra that men will be incontinent and impotent for life. Yes, there is always a risk, but nowadays this is very small.* Ed.

## TEMPLATE BIOPSIES FOR WEST SUSSEX

Mr Paul Carter, consultant urologist and chief of services for surgery at St Richards Hospital, together with Tony Boness, urology care manager, gave a presentation to the Chichester group in February. The topic was around the proposed template biopsy facilities to be available at the hospital, to which PCaSO has offered to contribute £25,000.



Paul Carter started by thanking PCaSO

for all its support over the last 15 or so years. He then went on to describe how referrals are investigated, and how the pathway has improved and hopes to further improve, particularly for men presenting with no symptoms. Many men, who later may turn out to have very low grade cancer have to be referred under the 2-week rule + 62 days referral to the pathway.

Paul then described the old method of TRUS + biopsy, which can miss some cancers out of reach. Three years ago MRI scanning was introduced and is now more effective at telling whether there is (a) a need for a biopsy at all, (b) whether the cancer can be easily biopsied with a TRUS biopsy or (c) whether a trans-perineal template biopsy is best.

Template biopsies can now be linked to the MRI scan, called Fusion

biopsies. Template biopsies, given under full anaesthetic as day cases, need staff training, extra cost in day care, greater costs in pathology, as many more samples can be taken to give an accurate diagnosis. They are, however, safer, with much less risk of infection. The hospitals therefore need to be assured that the service is sustainable.

The funding – £85,000 – is now in place and it has now been approved by all the hospital boards, but the stumbling block is the costing, as the CCG currently only allow the same cost for a template biopsy as for a standard TRUS one.

Currently anyone needing a template biopsy has to go to Frimley Park Hospital, 100-mile round trip. The trust sent 106 men to Frimley for template biopsies last year.

## DONATION FOR SOUTHAMPTON

Central Branch has approved a request for funding support for the purchase of new equipment for MRI/prostate ultrasound fusion software. The package is called SmartTarget and has been devised by University College London. The total cost is £60,000, of which PCaSO Central Branch is offering £15,000.

This will be used in conjunction with template biopsies in order to reduce infection rates and is designed for use with men who have had MRI scans showing lesions who would undergo a targeted biopsy.

If the funds can be raised, then all the main centres along the South coast from West Sussex to the borders of Dorset will have some form of equipment to diagnose cancers more accurately and avoid the need for a standard 'blind' TRUS biopsy.

## PRESENTATION TO QUEEN ALEXANDRA HOSPITAL

On Thursday 14<sup>th</sup> April 2016 three representatives of the Central branch, Stuart Thompson, Nicky Annells and Peter Weir, presented Mr Dominic Hodgson, Consultant Urologist at Queen Alexandra Hospital, Portsmouth with a cheque for £5058.70. Mr Dominic Hodgson is a specialist in the diagnostics of prostate cancer and brachytherapy at the hospital.

The money will be used to support the latest advance in the diagnostic and treatment of prostate cancer. This will include the purchase of Ultrasound equipment including a Flexfocus 400 scanner that is currently on loan to the hospital and was due to have been returned to the medical equipment supplier. With our donation the hospital is now able to purchase the equipment outright.

Diagnosis and treatment of prostate cancer is moving at an ever faster pace and Fusion Biopsies are evolving at a similar rapid pace. With the purchase of this equipment it increases the frequency that fusion biopsies can be undertaken which will enable QAH urology department to diagnose more men more accurately.



Committee members Peter Weir and Nicky Annells with Stuart Thompson (chairman of Central Branch) and consultant urologist Dominic Hodgson holding the equipment.

## FUND RAISING BY RECYCLED



Picture taken by Christina Cutting at the Underground Theatre, Eastbourne, 2 January 2016

The band are performing at the Underground Theatre in Eastbourne on 4th June – a 50s and 60s evening for a Summer Dance Night. Tickets £5.

Popular local band Recycled raised £1,736.95 for the PCaSO Eastbourne support group in 2015, totalling £4713 over the years. The band also donated £1,964.65 to St Wilfrid's Hospice and £870 to Chestnut Tree House.

It was standing room only at their first gig of 2016 at the Underground Theatre, Eastbourne in January when several PCaSO members went along to hear favourite tunes from the 50s, 60s and 70s.

PCaSO Eastbourne is extremely grateful to the support from Recycled over recent years and to the audiences who so generously donate. Bryan Naish, at 77, is the band's vocalist, organiser and manager. After their first drummer died of cancer, the band adopted the charity ethic, and find themselves being booked by pubs, clubs, nursing homes. Weddings and fetes. He is joined by Bob, Colin, Tony and Dave, shown in the photo above.

Bryan was a member of Eastbourne's

Evergreen Singers for eight years. He left to form 'Recycled', which came about by accident and coincidence. He met Colin from previous involvement with small skiffle group working for charity. He met Dave through bowls, bingo, etc. who knew Tony, a neighbour whose father served with him in the retained fire service back in the 70s. Their first drummer Mel died after being diagnosed with cancer and Bob came along.

PCaSO Eastbourne group is most grateful for their generosity in fund raising.

## STATINS AND PROSTATE CANCER

Statins, designed to reduce cholesterol levels and often prescribed, have been given a bit of a hard time in the press recently.

However, a study of prostate cancer patients showed that death rates from this cancer have shown to be 43% lower in men taking statins.

Apparently tumour cells need cholesterol to build the cell membranes, and cutting the production cholesterol causes the cells to disintegrate and die.

The US study thinks that this approach could be more effective than toxic chemotherapy, which effectively does the same thing.

Let's wait and see, but it may well be something for those with the more advanced forms of the disease to discuss with their consultant or GP.

## NEWS FROM 'TACKLE'

Tackle, in conjunction with PCaSO, is hosting a southern regional conference on **Thursday 22 September** at the Langstone Hotel, Hayling Island, Havant (where our own AGM was held). There will be representatives from support groups from the southern counties. The programme will be announced later.

See the Tackle website at [tackleprostate.org](http://tackleprostate.org) for details.

## ROTARY CYCLE RIDE

**R**otary in Arun is holding a sponsored bike ride on **Sunday 19th June** from Littlehampton to Bognor and back with a longer route for the intrepid. **All funds raised will go to PCaSO.** Last year this event raised over £1,600 for PCaSO. This year we hope to raise far more. For more information click on the Virginmoneygiving button on PCASO.ORG then 'event' followed by the Rotary logo. If you just want to donate, support our treasurer Vivian Miles who will ride: <http://uk.virginmoneygiving.com/VivianMiles1>.

# 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](mailto:secretary@pcaso.org) or **01798 875758**.

## BRIGHTON GROUP

The Brighton Group is hoping to start up again, using the new Macmillan Horizon Centre. The building work on this impressive centre has been delayed, so there is a provisional date of Wednesday 29 June for its first meeting. Please check with the website or phone Roger Bacon on 01903 775783 for details nearer the time.

## COLLECTIONS

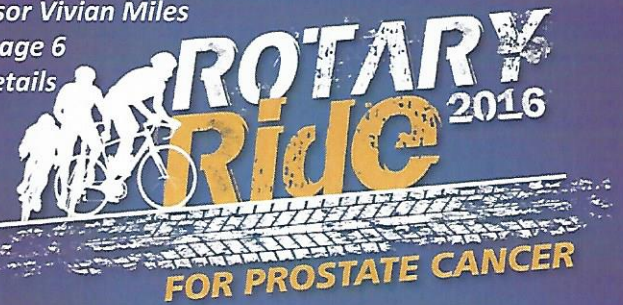
A staunch band of collectors under John Harmer's direction have collected £2,782 at supermarket stores in three collections since the beginning of the year. This is an amazing total, and we would like to thank John for all the hard work he has done in organising these events.

Three more are planned in the Central area: May 7-8 at Tesco Port Solent, June 3-4 at Asda Fareham, and September 22-23 at Asda Havant. John is finding the burden of organising these events too much, as asks if anyone is willing to help in both the organisation and, of course, giving up an hour or two of your time in manning these events.

Another impending departure is your **Newsletter Editor**, who, for family reasons is intending to leave the shores of the Solent for those of the Exe. This, therefore, may be the last newsletter that members will receive in this format.

*Sponsor Vivian Miles*

*See page 6  
for details*



## LOCAL SUPPORT MEETINGS

See back page for venue details

10 May (Tu)	Pulborough	Jane Woodhull: Hormone treatment and its effects
12 May (Th)	Eastbourne	Debbie Davis, community bladder and bowel adviser
13 May (F)	Waterlooville	Dr Neerja Agrawal: Pathology of the Prostate
25 May (W)	Talbot Woods	Prof. Sara Faithfull: Support after Prostate Cancer
7 June (Tu)	Rustington	Andrew Hart: role of the CNS, Jane Woodhull update.
9 June (Th)	Eastbourne	Sally Hemmings: Tai Chi
29 June (W)	Brighton	(provisional date)
6 July (W)	Chichester	Jane Woodhull: Hormone therapy, coping with side effects
14 July (Th)	Eastbourne	Dr Fiona Mckinna: Radiotherapy update
27 July (W)	Talbot Woods	Stampede Trial (speaker tba)
9 August (Tu)	Pulborough	
6 September (Tu)	Otterbourne	Mr Marc Laniado:
8 September (Th)	Eastbourne	
20 September (Tu)	Rustington	Dr Ashok Nikapota (cons. oncologist, Brighton)
12 October (W)	Eastbourne	Dr Caroline Manetta (consultant oncologist)
15 November (Tu)	Pulborough	
15 November (Tu)	Waterlooville	
22 November (Tu)	Rustington	Patients' Forum

# MEETINGS AND VENUES 2016

## EAST BRANCH SUPPORT MEETINGS

**Rustington:** held at  
John de Bohun Room, Woodlands  
Centre, Woodlands Avenue, BN16  
3HB at 7pm.  
Tuesdays 7 June, 20 September,  
22 November.

**Pulborough:** held at  
Pulborough Village Hall, Swan View  
(off Lower Street), RH20 2BF at 7pm.  
Tuesdays 10 May, 9 August,  
15 November

**Eastbourne:** held at  
Postgraduate Centre, Eastbourne  
District General Hospital,  
Thursdays at 7pm.  
12 May, 9 June, 14 July,  
8 September, 12 October (Wed)

## CENTRAL BRANCH SUPPORT MEETINGS

**Chichester:** held at  
Chichester Baptist Church,  
Sherbourne Road, PO19 3AW  
(7pm, 2pm in winter).  
Wednesday 9 July,  
Wednesday 23 November

**Otterbourne:** held at  
Otterbourne Village Hall,  
Cranbourne Drive, SO21 2ET  
at 7.30pm  
Tuesday 6 September  
Tuesday 7 March 2017

**Waterlooville:** held at  
Church of the Sacred Heart, London  
Road, PO7 7SR at 7pm.  
Friday 13 May,  
Tuesday 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.  
25 May, 27 July, 28 September

**A Sponsored Seafront Walk** will  
take place from Mudeford Quay to  
Highcliffe (4Km) starting at 10am  
on Saturday May 14th. Please  
contact Brian Deacon (01202  
487708) for details.

## PCASO CONTACTS

### EXECUTIVE COMMITTEE

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

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

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Vivian Miles 01243 814129

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Geoff Bailey 01962 713579

**Central Branch representative:**  
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**West Branch (Dorset) representatives:**  
James Davis 01202 580436  
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Allan Higgin  
Derek Pilling

**Publications and Newsletter Editor:**  
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Allan Higgin 01202 691710

**Pastoral Counsellor:** helpline@pcaso.org  
Nicholas Frayling info@pcaso.org  
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### CENTRAL BRANCH COMMITTEE

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**Secretary:**  
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Nicky Annells (Fareham)  
Peter Weir (Southampton)

### WEST (DORSET) BRANCH COMMITTEE

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01202 693976

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### EAST BRANCH COMMITTEE

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Debbie Hatfield 01323 638021  
John Proctor

**Founder:** David Rowlands

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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

National Help Line: 0800 035 5302

Website: www.pcaso.org

Charity No: 1095439