# Updates

The Newsletter of
PCaSO Prostate Cancer
Support Organsiation

Issue 52 August 2015


High tide at Bosham harbour

# Tackle's AGM

## A Report by David Hurst

PCaSO is a member of the National Federation of Prostate Cancer Support Groups which draws together groups from all over the country and aiming to provide a single voice for all of the patient support groups. Recently they introduced a brand name 'Tackle' and use it as 'Tackle Prostate Cancer'. However it is also known as 'The Fed'.

Nearly 90 delegates attended their AGM in Birmingham representing over 30 groups. The morning was taken up by the administrative matters required by all organisations. Roger Wotton from Aylesbury was confirmed as Chairman and Ken Mastris from Essex was confirmed as Secretary. Sandy Tyndale-Biscoe, the previous chairman and once chairman of PCaSO, was voted to the position of Honorary President.

There were changes to the Constitution and the management in order to streamline the processes that govern the working relationships. These are detailed in Tackle's magazine 'Prostate Matters' that will be published at the same time as this magazine.

## In This Issue



### STAMPEDE Trial Report

Lunch was followed by two presentations that were both equally the highlights of the event. Both were filmed and can be found on You Tube or via a link from the Fed's website. Nick James' slides are freely available on the **www.stampedetrial.org** website.

Professor Nick James of Warwick University described the STAMPEDE trial and the results. This was the first presentation of the results to a non-clinician audience. The trial had lasted 10 years and involved around 7000 patients drawn from almost every oncological department in the country. Certainly there are PCaSO members involved.

The main requirements for recruits to the trial were to have newly diagnosed patients with any of metastatic, node-positive, any two of stage T3/4, PSA greater than 40 and Gleason 8-10. There were other more detailed requirements (see website).

There is a control arm of the trial that has at least twice as many patients as each of the treatment arms, almost 1200 as opposed to nearly 600 in each treatment arm. The standard arm has the current normal treatment but even that arm has closer monitoring than a man not on the trial.

The trial then added arms of particular treatments; zoledronic acid, docetaxel, celecoxib and then zoledronic acid plus docetaxel and zoledronic acid plus celecoxib. In 2011 celecoxib was stopped and in 2013 the docetaxel and zoledronic acid arm was stopped. Abiraterone was started in 2011 and another arm trialling abiraterone and enzlutamide started in 2013.

Professor James reported that the trial had shown that zoledronic acid added little to the survival rates. However, for the specific patients being tested (metastatic, in the lymph-node, PSA above 40, stage T3 or 4, Gleason 8 to 10) then docetaxel, a chemotherapy drug, improved survival especially if started early. It also showed that multi-arm, multi-stage trials were practical and efficient. He said it was important that patients asked their oncologists about docetaxel to ensure the treatment was considered early after diagnosis. He said that every oncology department had been sent the results of the trial but that patients asking questions encouraged oncologists to reconsider their standard practices.

The STAMPEDE Trial is continuing to recruit and will be adding further drugs to compare. Robin Millman of the Teesside Support Group is a patient representative on the trial management committee. If anyone who was part of the trial would like to comment then write to **robin.millman@ntlworld.com.**

### The GP's View of Prostate Cancer

Dr Jon Rees outlined the GP's view of prostate cancer. He had trained as a urologist and then moved into general practice in Bristol. However he missed urology and now does three days as a GP and two days as a urologist taking patients from surrounding practices and advising GPs on current urology practices and treatments.

He said that general practice was going to change as it could not keep going the way it currently seems to be. He said that GP consultations had increased by 24% since 1998 and the average person saw their GP six times a year, twice the rate of a decade ago. In addition there had been a huge increase in bureaucracy and box-ticking. In a recent survey 6 out of 10 GPs were considering retiring early and 3 out of 10 were actively planning it. There is also a huge drop in the number of trainees – not surprising given the media coverage of GP problems.

The problem is that we are all getting old and living longer and most older

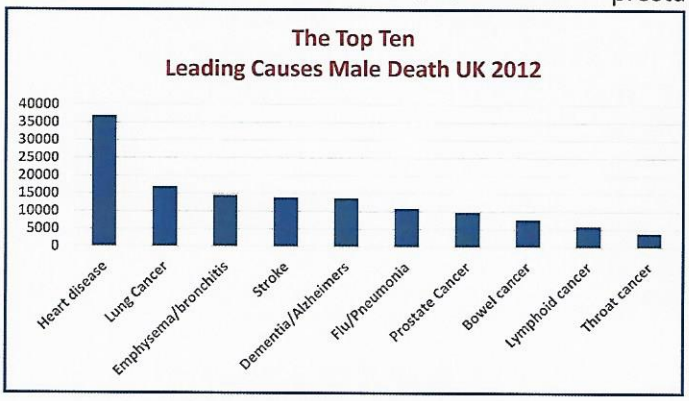
people have more than one thing wrong with them. We are also less prepared to accept illness so we want new hips and knees, cataracts removed and other miracles of surgery so we can continue to travel the world and enjoy life.

Rees believes that there will be more horizontal and vertical integration of medical services. GP surgeries will federate so that they become Multispeciality Community Providers. GPs cannot know everything about every illness so there will be local experts in particular aspects. Rees is performing that function for urology in his area of Bristol. Not just prostate cancer but many other areas of urology.

Where does prostate cancer stand in the GP's view? How many new cases of prostate cancer does a GP see every year? In 2010 there were 40,975 new cases of prostate cancer and in the same year there were 41,349 GPs practicing. So, on average, each GP sees one new case every year. (My local surgery in Sussex has 12,500 patients on their list and has about 100 men, less than 1% of patients, diagnosed with prostate cancer – author.)

GPs in general know very little about urology. Only 42% of medical students have any compulsory attachment to a urology department and that is usually just a week in five years. GP training has about 2 hours of training on the whole of urology. Add to this that two-thirds of GPs are female. How many women are going to take a particular interest in the male urological system? And every GP gets an average of four new clinical guidelines every week.

The top ten causes of male death in the UK are shown in the graph below:




*Heart disease in all its forms is way out ahead in the concerns of GPs. Prostate Cancer is 7th in the causes of male deaths.*

At the moment all the average GP does is a DRE (maybe) and a PSA test and then refers the patient to the hospital. There is usually no further interest unless hormone injections are required.

There is no reason why the GP should not take on the treatment survivors. The hormone injections are taken as read but they could take on the long term follow-up of low-risk patients with a stable PSA and they can manage the side-effects of other treatments. Prostate cancer is becoming a chronic disease and by 2040 it is expected that 2.3% of the total male population will be a prostate cancer survivor. Currently the figure is about 0.8%.

So, if you are living with prostate cancer as a chronic disease there are various side effects that may be present. Sexual function, continence, bowel function, cardio-vascular health, metabolic syndrome, bone health and psychological well-being. Who is going to look after those? The primary care GP currently is unlikely to have the skills or the capacity. The secondary care urologist will also have capacity and skills issues. The CNS might be better placed but there aren't enough of them so currently it is left to the charity sector.

# Help for GPs

As Dr Jon Rees said (see above) most GPs have little knowledge or experience of prostate cancer. We who have prostate cancer know how important it is to treat it early but the average GP can only start to do anything when a man comes forward with symptoms – and that's often too late.

Tackle, together with the University of Warwick and others, and with some money from PCaSO and other support groups started the Riskman Trial to develop a targeted way that GPs could identify men who are more likely to get prostate cancer and screen them. This has been developed and has passed initial trials and now awaits a sponsor who can put up the £1 million or more that the next stage requires.

The Prostate Cancer UK Risk Assessment project started last year and is still continuing. It is similar to Riskman but more short-term. Tackle is following both systems with interest.

The Prostate Cancer Advisory Group (jointly chaired by PCUK and Tackle) is also starting another project this year called the PSA Consensus Project which is chaired by Peter Kirkbride, an oncologist, and with a broad membership including clinical and patient representatives from Tackle. This is considering guidance regarding PSA testing for men, a baseline testing protocol and taking into account those with higher than average risk.

NICE has recently published a set of Quality Standard statements of what men should expect in prostate cancer treatment and care. Tackle chaired a working group that provided input to these guidelines and will be taking their contribution forward, beyond the subset adopted by NICE.

PCaSO was in the early stages of a campaign to persuade the Chief Medical Officer to reissue the PCa Risk Management Programme to ensure that GPs knew that men over 50 were entitled to have a PSA test free on the NHS. In the light of the projects above, to say nothing of Jon Rees' statement that doctors receive three or four guidelines a week, this has been put on hold for the moment.

DH

# A Sorry Saga

We don't want to point fingers; we don't want to have a fight with doctors, the NHS or a hospital.... we only want the truth.

This sorry saga started eight years ago, in August 2007. My husband was getting up several times each night to use the toilet, so off he went to the GP. She agreed there was a problem and referred him on to the prostate care nurse.

December came and still no appointment, so we called the GP who made contact with the nurse and my husband was given a date in January. That was then cancelled and re-booked for February. The nurse expressed concern and said he needed to see the urologist and would probably have to have a biopsy. There was one problem: we had a holiday booked since July, before this all started, and it was now imminent. The biopsy was deferred for 10 days, and but then it was decided not to do it but to go straight for a TURP procedure, which was done early in 2008.

It's now April of 2008 and the results of the operation and bloods are now in. Not good. Although my husband's PSA was only 5.8, the Gleason score was high (9) and there appeared to be a wide spread of cancer in the prostate, so immediate hormone implant treatment was recommended.

Over the following two months two MRI scans were done. The second in July 2008 appeared to show metastatic cancer in all bones. The prognosis was bad and my husband was told he probably had just two years to live. I started to fight: I asked for a second opinion and was advised that, as my husband's case had gone to the multi-disciplinary team, several 'second opinions' had already been given. This proved to be a bad mistake! We should have pushed and possibly gone elsewhere. But we trust our doctors, don't we?

Over the next couple of months it became clear to me that we couldn't get on with the urologist we were seeing and it was as important to both my husband and me that we had someone we could talk to. The consultant, clearly a chauvinist, could not believe that a mere woman could understand about cancer and its treatments. So we called on our GP's help and got changed to a really nice urologist, who listened and talked.... Great.

It was at this time that I came across PCaSO when I saw details of it on a poster in a hospital. We subsequently joined and received their booklets, which also included a leaflet from America about bone health. Zometa was discussed in the leaflet and we in turn took it to the urologist. A fantastic response: "We'll try and get it for you". We had a chat with an oncologist who claimed that at that time it was only available for breast cancer patients. Why? Anyway we were told to have another think about it and went back to the urologist who decided an immediate start on the drug could be made.

For thirteen months my husband had the hormone infusions, blood tests and the discomfort that goes with such treatment. At that point the oncologist stopped the treatment. The PSA was steady (at lower than 1) and his general health was good... except, of course, time was ticking away.

2009 came and went, as did 2010. In 2011 we decided we would have 'the holiday of a lifetime': we would do the first sector of a world cruise and travel by train across America.

INSURANCE loomed its ugly head. I am not exaggerating when I say I approached 30 companies. I started phoning in April. Most of them declined, one made an offer of £3,000 on condition we went in the next two weeks (even though the boat didn't sail until January!). Our bank insurance initially said yes then, after we had booked, called with a change of mind. (That's another saga that I won't go into now.) So finally we had to give up and cancel the booking. The whole process of trying to get insurance was very distressing and left us both totally drained and not a little fed up. Since then we have found a company MIA that seems to be willing to give cover for Europe.

2012 came and went, as did 2013. Finally in July 2014 the oncologist called for an MRI scan as my husband had not had one for six years. We were told to call in to get the result and possibly get an earlier appointment. Imagine our surprise when we were told it was clear – there was no evidence of metastatic bone cancer. We queried it, and then we queried it again. There was clearly something seriously wrong here. Was it a miracle? (If so how lucky my husband is!). Can hormone therapy really have this effect? Or is it a misreading of the scan – i.e. human error? I asked repeatedly to see the current radiologist for him to talk us through the findings but I was told that he did not see patients. We finally got to see him in July 2015, a full year to the day after the scan. He explained the scans and his reasons disagreeing with the previous radiologist, from which it became clear the first scans had been "over-stated".

So it seems that our stress, upset and belief that time was running out, let alone the traumas with insurance over the past seven years, were all unnecessary and could have possibly been avoided if I had just had the courage to stand up to the clinicians and to insist on a second opinion back July 2008. Furthermore my husband probably didn't need to have Zometa (what a waste of NHS

funds!) with all the discomfort he suffered at that time.

We have had our ups and downs, as you can see, but we are still here to tell the tale. We would urge everyone not necessarily to accept the first diagnosis; to politely question, to challenge, to get a second opinion, and keep on until you are satisfied you have done all you can.

We are of course delighted that the 2014 scan was clear. But things have moved on and this year my husband had to have a further TRUS and biopsy procedure in April and is now due for another scan. But now we will question the results. We have learned a lesson and I hope others will learn from this too. We still hope to sail to America, but now have to await further results.

To the wives and partners of men with this problem I would urge you to be very pro-active in your man's treatment. Take careful notes of all consultations and procedures, ask questions, listen carefully, read up on the latest treatments, and if necessary be a 'pain in the a...'. Both of you must be in charge of the situation – after all, it's your lives that are affected. The doctors are just doing their job – it's you who are living with the disease. We must all bond together to get the sort of recognition for prostate cancer that breast cancer has achieved. (For many years I was very active in that area.)

Finally my husband and I owe a great debt to PCaSO, for the informative booklets and leaflets, for the chats and e-mails exchanged and generally for the support we feel whenever we make contact. Thank you, and keep up the good work.

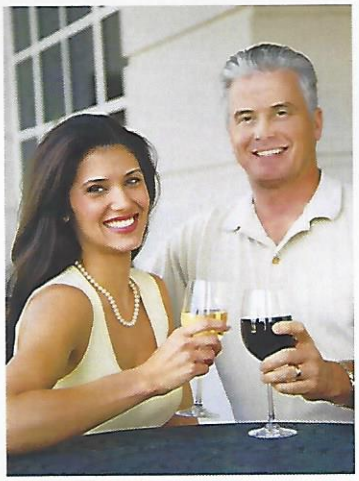
RD

*Ed:*
*As our late Pastoral Counsellor, Norman Last used to say to all who sought his help: "Take charge of your cancer – don't let the cancer take charge of you." PCaSO's Prostate Cancer Information Booklet reinforces this message in the section 'Questions you may wish to ask' on page 11.*

# Moderation Minus One

***The information below summarises a report in the latest on-line issue of 'Lifestyle and Cancer'***

We have always thought that red wine, which contains resveratrol, an anti-oxidant, was no bad thing for us prostate cancer patients. But international health organisations, including the WHO, now agree that any form of alcohol can increase the risk of a number of cancers, such as mouth and oesophagus, bowel, breast, liver and prostate. There is also now some evidence that drinking regularly after cancer treatment can increase the risk of recurrence.



Alcohol causes cancer because the alcohol in our drinks is converted into a chemical called **acetaldehyde**. Acetaldehyde is a carcinogenic, which damages DNA and prevents it being repaired. People who smoke and drink heavily have been found to have very high levels of acetaldehyde in their saliva.

### What about beer?

A study by the University of California-San Francisco has found that heavy drinking, especially beer, gave a greater risk of developing a high-grade than a low-grade prostate cancer. They define heavy drinking as 50 grams or more of alcohol (that's equivalent to four drinks) daily, which was found to double a man's risk of developing a high-grade prostate cancer.

### A recent study

The British Medical Journal showed that "1-in-10 of all cancers in men and 1-in-33 of all cancers in women are caused by past or current alcohol intake". They found that those who had just two standard drinks a day for men and one drink a day for women were particularly at risk of alcohol-related cancers. (A standard drink is defined as one containing approximately 12 grams of alcohol; approximately a 125-ml glass of wine or about half of a pint of beer). These conclusions were made after a large European study of nearly 364,000 men and women over several years.

The report suggests the following tips for cutting down:

- **keep an alcohol diary**
- **set yourself an alcohol limit and stick to it**
- **pace your drinks by sipping slowly**
- **choose non-premium beers**
- **alternate alcoholic drinks with soft drinks**
- **try not to drink at home unless socialising**
- **find something else to do instead – for example, going to the gym, museum, or arts clubs.**
- **have alcohol-free days to remind yourself you don't always have to drink.**

So, as they say, all things in moderation; but perhaps it should now be 'moderation minus 1' in future?

***Cheers!***

IG-J

# Nicky's Lycopene Recipes

## 1: Roasted Tomatoes and Prawn Linguine

***Rather than have a formal speaker at the Chichester group's summer meeting, committee member Nicola Annells offered to cook three lycopene-based recipes, ably assisted by her husband Graham, which the group was able to try. So delicious were these that we are offering the recipes to our members, in three instalments.***

### Love Your Lycopene: 1

**Ingredients (serves 2):**

250g dried Linguine
10 small cherry tomatoes (washed)
Small bunch of vine tomatoes (washed)
1 clove of garlic (crushed)
Pinch of chilli flakes
400g tin of chopped tomatoes
250g Tomato Passata
1 medium sized leek (trimmed and washed) and sliced
1 tablespoon of olive oil (or oil of your choice)
1 tablespoon of sundried tomato paste
200-250g cooked and prepared prawns (frozen or fresh) washed and dried
50g baby spinach leaves
Black pepper (to season)

**Method:**

**Tomato and Prawn Sauce**

- Place the oil into a medium-sized saucepan on a low heat. When the oil is hot add the leeks and cook until soft (3-4 minutes).
- Add the crushed garlic (being careful not to burn it) and the washed cherry tomatoes and stir, trying to keep the small tomatoes whole.
- Add the tinned chopped tomatoes, passata, sundried tomato paste and chilli flakes. Bring to the boil and simmer gently for five minutes. Season to taste with black pepper.
- Add the prawns together with the baby spinach and simmer gently for a further two minutes.

# The Importance of Awareness

Our charity has 'Support to Members' – all who are fighting this insidious disease, as the reason for its existence. Making men aware and getting them to 'Get Caught Early' is a key element in fighting back against our cancer. As a charity we fight back by having awareness combined with collection events at retail outlets, usually supermarkets. This is rewarding in that those taking part meet men and their partners and can share experiences and give support and encouragement. Raising cash enables us to fund research, specialised equipment and produced our literature; our booklet 'Knowledge Empowers' is a highly regarded publication in the clinical world. Currently we in Central Branch are raising funds for equipment at our local hospitals and with research projects, so the money raised is well spent.

The main task of the store events is awareness. This can be a rewarding experience, even if at times a little harrowing. We need helpers as there are always events in the pipeline and as time goes on the 'team' reduces due to age and infirmity.

John Harmer

*Photos from Tesco Chichester*

*Rt: Elizabeth and Chris White*

*Below: Graham Crane and the late David Smith*



***We in Central Branch need your help!***

**Please contact me at 02392 631599 or email john.harmer@waitrose.com**

# Fund-raising and Awareness Events

## Gift Aid Donors

Can you please advise the Gift Aid Coordinator Andrew Bloxham if (a) you have changed your name and/or address, (b) no longer pay income tax and/or capital gains tax or (c) wish to cancel the declaration. Phone: 01243 378850
Email: abloxham@care4free.net

## Donations

PCaSO acknowledges with thanks the following who have made substantial donations to our funds.

**Central Branch:** Mr & Mrs Chris White, Mr & Mrs Michael Dennison.

Recent fund-raising events: Down House Open Gardens £150 (please note that no further Snowdrop Sunday or Open Gardens events will be happening because of refurbishment).

Supermarket collections raised the following: Asda Fareham £863, Tesco Port Solent £1248, Tesco Chichester £973.

**East Branch:** Barry Cocum, Mr B. Naish.

Recent fund-raising events: a Rustington member's clothing and jewellery event, Westham Village Hall quiz night £222, Sunnyside Caravan Park (Eastbourne) £225, Waitrose Brighton token scheme £527, ASDA Eastbourne £200 (see photo below).


*Debbie and Graham Hatfield (2nd and 4th left), together with members of the PCaSO Eastbourne Group, receive a cheque from ASDA managers Darren Evans and Theresa Parkinson towards East Branch funds.*

## Dorset Branch Sponsored Walk

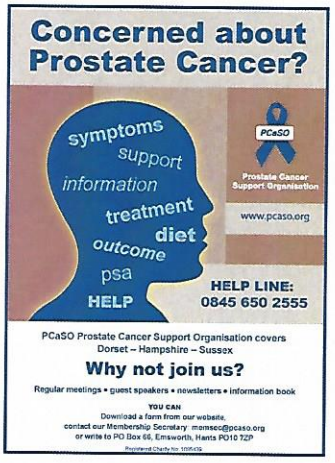
Dorset Branch's sponsored walk in May raised nearly £1000, which will enable their PSA testing programme to continue.

Brian Deacon, the branch's fund-raiser (in the tabard) with some of the walkers.

## Sponsored Cycle Ride

The Arun Rotarians organised a ride – the 'Arun Ro-Pro Cycle Ride', on Father's Day (21st June) from Bognor to Littlehampton and back and at the same time one from Littlehampton to Bognor and return. This was to support PCaSO and all sponsorship money will go to our charity. Although the Rotarians held the event nationally on Father's Day, Arun Rotary Club decided they would like the funds raised by them to go to the local prostate support group. At the Bognor end Eamonn Kelly and John Harmer were at the start helping to erect the tent and give out water, and Roger Bacon and Viv Miles from our East Branch at the Littlehampton end. The Rotarians provided some 10 riders and Dr Malcolm Ridley and his 'team' are shown in the photo. There were 19 riders in all. Unfortunately PCaSO muster two riders, Barry Cocum and his wife Jessica from Brighton. It is hoped that the ride will become annual event, and so and Central and East branches will need to get a team assembled well in advance. The date may well change as Father's Day, whilst being emotive, also means that families are very likely occupied and therefore unable to participate.

Our thanks to the Rotarians for their generous support in fighting this deadly disease. The monies raised will go directly to the appeal for a new Template Biopsy facility to be housed at St Richard's Hospital, Chichester.




## New Poster

PCaSO has a new poster designed to match the theme on the cover of our leaflets and Information Book. We are grateful to PCaSO member Colin Woodman of Woodman Design for undertaking this for us. If you can display these anywhere (pubs, health centres, etc) do ask for some.

# What's On: September – December 2015

## East Branch

### Support Meetings

**Rustington:** *held at John de Bohun Room, Woodlands Centre, Woodlands Avenue, BN16 3HB.*
**Tuesday 15 September:** Catriona Brooks - Diet and Cancer
**Tuesday 24 November**

**Pulborough:** *held at Pulborough Village Hall, Swan View (off Lower Street), RH20 2BF at 7pm.*
**Tuesday 8 September** (speaker tba)

**Eastbourne:** *held at Postgraduate Centre, Eastbourne District General Hospital, Thursdays at 7pm.*
**10 September:** Julie Warner (Radiotherapy Sussex Cancer Centre)
**8 October:** (tba)
**12 November:** Geoff Brown (Macmillan Horizon Centre)
**10 December:** (tba)

## Central Branch

### Support Meetings

**Chichester:** *held at Chichester Baptist Church, Sherbourne Road, PO19 3AW (7pm, 2pm in winter)*
**Friday 6 November, 2pm: Patients' Forum**

**Otterbourne:** *held at Otterbourne Village Hall, Cranbourne Drive, SO21 2ET at 7.30pm*
~~**Tuesday 1 September:**~~
***MEETING CANCELLED***

**Waterlooville:** *held at Church of the Sacred Heart, London Road, PO7 7SR at 7pm.*
***Please see website and email notices to follow for a proposed pre-Christmas event.***

## West (Dorset) Branch

### Support Meetings

**Bournemouth:** *held at St Marks Church Hall, Talbot Woods, BH10 4HY, Wednesdays 7 for 7.30pm.*

**Wednesday 30 September**
**Wednesday 25 November**

## Awareness Events

### Supermarket Collections:

Fri 11 September, Tesco Littlehampton
Thur-Fri 17-18 September, Asda Havant
Sat 3 October, Morrisons Verwood
Thur 10 December, Tesco Havant

### PSA Testing Events

Sat 19 September, Bournemouth
Sat 10 October, Rye
Sat 24 October, Worthing
(See our website for details)

# PCaSO Contacts

## Executive Committee

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

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David Hurst 01798 875758

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(east.rep@pcaso.org)

***Central Branch representative:***
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Allan Higgin
Derek Pilling

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***Federation representative:***
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***Pastoral Counsellor:*** *helpline@pcaso.org*
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**Secretary:**
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Geoff Bailey (membership) 01962 713579
Nicky Annells
Peter Weir

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Brian Deacon (fundraising) 01202 487708
Derek Pilling (website)
Ray Bona (publicity)
Clive Duddridge (membership) 01202 693976
Catherine Woolford (speakers)
Allan Higgin (PSA testing) 01202 69171

## East Branch Committee

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**Treasurer:**
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**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