

Updates

The Newsletter of PCaSO Prostate Cancer
Support Organisation

Issue 56 August 2016



Jack and Jill windmills
Clayton, East Sussex



PCASO NEEDS SOME FRESH MINDS WILL YOU HELP?

Many of you reading this probably help one organisation or another, a sports team, nature reserve, something in your town or village, church or social club.

You've been hit by prostate cancer. You know what it felt like. We want your help to help the men who don't yet know they've got it. We want a bit of your time to help men get diagnosed earlier. PCaSO is run by patients for patients. It is registered with the Charity Commission and has an income of around £50,000 a year.

Familiar?

Yes, you're right. You have seen this before. It came round in an email and one person, just one person, put their hand up and offered help. Think about it. Please.

Here's some background and ideas where you might help.

PCaSO has nine trustees who sit as an Executive Committee. They



can co-opt others who need not be trustees but sit for specific reasons. Because PCaSO is spread across Sussex, Hampshire and Dorset we have three Branches who look after local fund-raising, donations, PSA testing, etc. in their county.

Three Executive members sit on each Branch committee and there are others, such as Group Leaders, who sit on their respective Branch committee. Those branches look after their local groups, nine of them at the moment. Each group has one or two people who lead them.

Prostate cancer is, largely, an older man's disease and most people who get involved in helping PCaSO are around retirement age. Often we have partners getting involved in the groups or branch committees. Some people who get involved at retirement then stay with it through until their late 70s. Not everyone, but some. In the last couple of years two of the Executive Committee have died from prostate cancer.

Where we need help

Geoff Bailey, who looks after the membership list, is in his late 70s and wants to stop doing that job sometime soon.

Ian Graham-Jones, who looks after leaflets and the newsletter and is also in his late 70s, has decided, for various reasons, to move away to be

nearer to his family.

Roger Bacon, the Chairman, who hasn't reached 70 yet, will have been doing that job for five years and wants to step back and let someone else take the organisation forward.

John Harmer has run a group that shakes buckets outside supermarkets. He always needs more people to spend a couple of hours chatting to those coming and going. Raising awareness, we call it. He's in Hampshire branch and both Sussex and Dorset branches would like to have someone doing a similar job of organising the collections because they don't happen much there.

Debbie Hatfield and Chris Cutting, who have run the very effective Eastbourne group for many years and are definitely not at retirement age yet, want to hand that group on to other people.

As the older generation we are not good at Facebook, Twitter and other social media and our website is too complicated. We need a social media enthusiast who can help get us up to speed and keep us there.

In short, we need some fresh minds to tackle the problems and work as part of the local and nationwide movement to focus the minds of men, researchers and clinicians on stopping prostate cancer killing 10,000 men a year.

What's involved?

Of course every job is different and, to a large extent, what you do is up to you but these are what's involved now. You may have better ideas.

Chairman

No-one is going to be asked to be chairman who hasn't been on the Executive Committee for at least a year. Roger is very knowledgeable

IN THIS ISSUE

Will you help?	2
Prostate Cancer Specimen	4
The Mary How Trust	4
Eastbourne activities	5
Fareham community showcase	5
2016 Pro-Ro cycle ride	6
New Brighton centre	6
FORECAST Trial	6
PCaSO Branch structure	7
Newsletter editor	7
PCaSO Support Meetings	7
Meeting venue details and PCaSO Contacts	8

about prostate cancer and acts as a focal point for the charity. His main task is to chair the quarterly Executive Committee meeting but he chooses to get directly involved in many different aspects of the charity's work.

Membership Secretary

Currently Geoff receives the membership forms and enters the details on an Excel spreadsheet which is circulated to the Executive. We have over 1000 members on the books but we don't always hear when some die, or move, or change their email address so that number is, shall we say, optimistic. He ensures the Data Protection licence is up to date. Is Excel the best way to do this job? Someone with more computer experience might have other ideas.

Every three months Geoff also mails out the copies of the newsletter to those who don't have email, thankfully a reducing number. That means printing labels, sticking on stamps and stuffing envelopes. It would be easy to separate the mailing job from the membership job. Would you take this on? Perhaps two or three people sitting round a table stuffing envelopes could make this an occasion?

Publications

Tony Ball has stepped forward to take on the collection of information for the newsletter and other leaflets. Thank you, Tony. He doesn't have the publishing skills that Ian has acquired but Colin Woodman, currently our designer of the leaflets and our Information Book cover, will lay out the newsletter. We'll put his contact details on the back page with the others.

Both the above are currently expected to attend Executive meetings four times a year, currently in Waterlooville, but the rest of the time is home-based, doing as much as you feel comfortable with. They might get involved in branch or

group meetings, but that's up to them. Being at ease with computers and email is essential.

Collections Organiser

Organising collections is a Branch matter. We need someone in the Sussex and someone in the Dorset branches. They need to contact the individual supermarkets and get suitable dates of a collection. They need to hold stocks of buckets, brochures and banners and put them up at the start of the day. They need to pull together a group of people who are happy to turn up for a couple of hours, chat pleasantly to passers-by and give out leaflets. How often the group turns out is up to the organiser – and the group.

Group Organiser

PCaSO will help anyone who wants to start a support group in their local town or village within our area. A group organiser looks after the meetings of a support group local to them and this can be anywhere throughout Sussex, Hampshire or Dorset. It means booking a suitable venue and possibly a speaker (we can help with suggestions). The news of meetings is spread with advertising and by email. On the day the room needs to be set out, refreshments and literature organised and the speaker – if any – welcomed and introduced. Actually all groups need some help. Just turning up early to help put chairs out, or staying after to help wash the teacups is useful.

A group meeting is where men can ask questions and talk about their treatment and symptoms so the organiser needs to be good at talking to people and keeping a conversation going. You don't need to know the answers but you'll acquire a knowledge of who does! The branch treasurer will look after the money so there's no figures skills required.

The group leader would be expected to attend branch committee meetings four times a year so they

know what is going on elsewhere.

Social Media enthusiast

We need someone who knows about this electronic stuff and can tell us what we should be doing and then do it for us! We are on Twitter, @PCaSO1, but a Facebook page would be useful. Or maybe that's all out of date and we need to go in another direction? The website is full of junk and links that don't work and, more worryingly, some information that is now wrong. We'd love to find someone who knows a bit about websites and is open to learn more by sorting ours out. He or she would probably need to attend quarterly Executive Committee meetings but that's open for discussion.

Pay and rations

PCaSO has no offices, no paid executives, no paid staff and everyone who gets involved is a volunteer. Proper expenses are paid if the volunteer requires it. Rations? You might get a biscuit occasionally. But you will have a sense of helping men learn about prostate cancer and encouraging them to get tested early.

Would you help us?

For an off-the-record discussion you can call or email me, David Hurst, secretary@pcaso.org, home phone 01798 875758.

Or one of the branch chairmen:

Sussex – Roger Bacon (01903 775783)

Hampshire – Stuart Thompson (01794 512867)

Dorset – Jim Davis (01202 580436)

On the back page of this current *Updates* newsletter there are phone numbers for the Branch committee members so you can phone your local person. Or go to the website www.pcaso.org and click on the relevant branch page.

David Hurst
Secretary, PCaSO,
Secretary Sussex Branch
Group Leader, Pulborough group.

PROSTATE CANCER SPECIMEN: IT'S JOURNEY TO DIAGNOSIS

Central branch was delighted to have a talk from Dr Neerja Agrawal, consultant pathologist at Queen Alexandra Hospital, Portsmouth on what happens to the specimens taken on biopsy and how the diagnosis and grade of the cancer is arrived at. Dr Agrawal has specialities in both breast and prostate cancer; in regard to the latter, she mentioned that her husband, an oncologist, was a prostate cancer sufferer. A summary of her talk follows.

The latest figures for the numbers diagnosed with prostate cancer in the UK are 47,300. With increasing awareness, prostate cancer is likely to overtake lung cancer as the most common cancer in men.

We were shown a diagram of the three zones of the prostate, mentioning that most prostate cancers (over 70%) are located in the outer peripheral zone nearest the rectum; and while doctors can feel these by DRE, they cannot reach those in the anterior part of the prostate. Those located in the other two zones are more difficult to identify.

Biopsy remains the only way to diagnose prostate cancer. Taking 4 – 6 cores on each side (usually 5 + 5) is most commonly done, but this is not always reliable, as it can miss some cancers. Samples are taken with an 18g needle – the size of a pinprick. Template biopsies, as we know, are a much more reliable way of ensuring a cancer is found and properly graded. The samples are placed in a formalin solution and labelled L and R to identify which side they are taken from.

Other urological work that she

undertakes include samples from men with enlarged prostates, lymph node analysis, and examination of complete prostates after prostatectomy. Here the prostate is painted in colours so that identification of any positive margins can be made, which may increase the risk of some cancer remaining after the prostate has been removed.

She mentioned that identification of the Gleason grade from the cell pattern under the microscope is an art, not a science. As we know, Gleason scores are made up of two grades, the most predominant cancerous cells being the first number. There are in total 25 possible combinations of grades to make the Gleason score, so a new grading system has been introduced:

- Grade 1 = Gleason 6 or <6
- Grade 2 = Gleason 3 + 4
- Grade 3 = Gleason 4 + 3
- Grade 4 = 4 + 4, 3 + 5, 5 + 3
- Grade 5 = 4 + 5, 5 + 4, 5 + 5

After prostatectomy, the prostates, after samples have been taken, are kept in a solution in a plastic box for between 10 and 20 years.

Dr Agrawal then concluded by briefly mentioning some new developments emerging in diagnosing and treating the disease. Although PSA still remains the only marker we currently have, a multi gene-based test, Oncotype-DX, is currently available in the US. This can help identify the cancers which are potentially aggressive. Other treatment options mentioned were Sipulcucel, a drug to stimulate the immune system to fight the cancer, and Ipilmumbab.

A bonus speaker came to talk on the Lycopene trial being undertaken at QAH, to which PCaSO made a grant about 2 years ago. Iolia Akael is a researcher on the trial. The trial group was given a special diet, which included 15mg daily of Lycopene for 18 weeks. This was found to substantially improve BPH and also to decrease cancer cells. Men about to have prostatectomy were also given the diet for 6 weeks prior to the operation and were followed up. The trial is looking for men currently on Active Surveillance.

Both speakers were generous with their time in answering questions.

THE MARY HOW TRUST

PCaSO Sussex Branch donated £1000 to the Mary How Trust, based in Pulborough, West Sussex. The Trust was set up 28 years ago in memory of Mary How who died from cancer. It offers health checks in the pursuit of early diagnosis. Instead of a fixed fee, the Trust invites donations that are dependent on ability to pay. One of the checks is a PSA test and in 2015 they carried out 219 tests finding 15 men with a raised PSA. PCaSO's money supports their work.

PCaSO secretary David Hurst presented the cheque to Gillian Weston, Trust Practice Manager, earlier this summer.



PCASO EASTBOURNE

Monthly meetings continue to be well supported with 28 people attending in July to hear Consultant Clinical Oncologist Dr Fiona Mckinna provide an update on the new Radiotherapy Centre at Eastbourne District General Hospital.

Dr Mckinna is the Lead Clinician for the Cancer Directorate at the Sussex Cancer Centre. Unfortunately, work has yet to recommence since it was 'mothballed' in December 2015 when funding was delayed. A further meeting is due to take place in the near future to confirm the 'Guaranteed Maximum Price' but there is now likely to be a shortfall of several hundred thousand pounds. Consequently, it is unclear when the centre will be ready to commence radiotherapy treatments. Men will continue to be treated in Brighton in the interim.

Simon Whiffin, senior lecturer at the School of Health Sciences, University of Brighton has just built a new website for the group. The site incorporates the PCaSO Twitter feed and also a blog spot for recent news and photographs. The first blog reported the June meeting when members tried out some gentle Tai Chi to improve strength and balance.

Simon was thanked for his hard work at the July meeting when he came

along to demonstrate the site. The new site can be found at www.pcasoeastbourne.org.uk

The remainder of Eastbourne group meetings for 2016 are:

Note: no meeting in August.

8 September – speaker TBC

12 October – Prostate Cancer Clinical Trials: Dr Caroline Manetta, (Consultant Clinical Oncologist).

Please note this is a WEDNESDAY evening.

10 November – Diet and Prostate Cancer: what's the latest evidence? Penny Kaye, Macmillan Dietician .

8 December – Mr Peter Rimington, Consultant Urologist.

Details of venue, time etc. can be found on the back page.



PCASO AT FAREHAM COMMUNITY SHOWCASE

One Community is an independent charity, established in 1978, to support the voluntary and community sector across the boroughs of Eastleigh and Fareham. It provides a range of information services for both local voluntary and community groups and volunteers themselves.

On Saturday 2nd July, One Community held their first ever Community Showcase at Ferneham Hall in Fareham. The event's aim was to showcase the diversity of voluntary and community activity in the local area. There was extensive advertising around Fareham, across all types of media including Radio Solent, using banners, online, through schools and surgeries.

Attending this free event which was open to any organisation or



Central Branch Committee members Stuart Thompson (chair), Nicky Annells and David Harris at the stand

service wanting to promote and celebrate their services, were over 60 organisations including national support groups such as Citizens Advice Bureau and The Samaritans, local youth and hobby groups, the Lions and Rotary Clubs, as well as health support groups including diabetes, dementia, head injury and

of course PCaSO. Six volunteers from the Hampshire Branch manned our table throughout the day, giving out leaflets and answering queries about prostate cancer. Citizens Advice Bureau were interested in PCaSO as they get men who are recently diagnosed with prostate cancer and are looking for information and support. The Lions and Rotary Clubs also showed an interest in PCaSO with a view to PSA testing. Although not a funding event it brought several groups together to share information and awareness.

Visitors were also treated to performances by local choirs and musical groups. Approximately 500 people attended the event.

Follow up reports appeared later in The Portsmouth News, Southampton Daily Echo, and Solent TV.

THE 2016 RO-PRO CYCLE RIDE

The 2016 Ro-Pro Sponsored Cycle ride from Littlehampton to Bognor and back took place on Father's Day, 19th June, with 23 riders attending. Around half of those riders were from the Angmering Cycle Club who rode the longer return route to Bognor, 40k/25 miles the other more leisurely riders took a more direct route covering 25k/15miles. Starting off at 9am in fine weather all riders were back to Littlehampton around 11.30am.

The Rotary Clubs of Littlehampton and Bognor organised marshals on route so nobody was lost! This is the second year for this event and looks like becoming a regular on our calendar. In 2015 PCaSO received £1600 in sponsorship and this year's event with more riders, it is expected, once all the money has been collected, that the final figure is set to increase.



Viv Miles, our PCaSO treasurer, getting ready to start the ride.

NEW CANCER CENTRE FOR BRIGHTON

The new **Macmillan Horizon Centre** at Brighton is a calm, friendly and welcoming place offering all round support for people affected by cancer. Staff and volunteers there will help anyone affected by cancer to access information, advice and local support services.



The centre will stock a large range of information leaflets to read and take away, offer advice on welfare benefits, emotional counselling support is available from fully qualified volunteer therapists, complementary therapies including aromatherapy, massage, reflexology and relaxation techniques and others will also be available, all on a donation basis only. Fitness session such as yoga, dance, circuit training and health walks will also be offered. The café at the centre will be a place to relax, meet others and eat well. Whether you have been diagnosed with cancer yourself or are a carer, family member or friend, you are welcome to use the café.

There are a number of support groups who will be using the centre for meetings, including PCaSO. **The re-launch meeting of our Brighton group will be at the Horizon Centre on Thursday 6th October 6.30pm for a 7pm start.** All are welcome to attend and look round this magnificent building. The address is Bristol Gate, Brighton BN2 5BD.

TWO TRIALS

The **FORECAST** trial is aimed at men who have had radiotherapy whose PSAs might be starting to increase, and who might consider HIFU or Cryotherapy. It has centres in our area in **BRIGHTON, SOUTHAMPTON** and **BASINGSTOKE**. If you feel that you might be eligible, you could contact your local urology department

Dr Ashok Nikaptota – Brighton

Mr Tim Dudderidge – Southampton

Mr Richard Hindley – Basingstoke

or the trials coordinator at UCLH

uclh.forecast@nhs.net.

More detail see our February 2016 newsletter.

Bournemouth University are conducting a qualitative study which aims to explore the experience of living with cancer and dementia in individuals and their support networks (spouse, family and close friends). We are looking for PCaSO members with a dual diagnosis of cancer and dementia and their support networks to take part in a discussion with a member of our research team about their personal experiences of living with these conditions and the support they receive. The conversation is likely to last no longer than 45 minutes and can either be conducted face-to-face or over the telephone at a date convenient for you. You can be interviewed with your care partner or separately, whichever you prefer. If you are interested in taking part, please contact Emily Arden-Close, tel: 01202 965529 email: eardenclose@bournemouth.ac.uk

BRANCH STRUCTURE

Our three branches, originally designed to be organised by postcode area, have now been restructured and simplified into the three county areas of Sussex, Hampshire and Dorset.

It was felt that the terms 'Central' and 'East' were meaningless unless the coverage of PCaSO was clearly defined. We have had many queries from members asking which branch they belonged to. This was particularly confusing in the Chichester and Bognor areas, who were (with PO postcodes) part of Central branch, but will now be in the Sussex branch.

We also have a number of members outside these counties who, perhaps may have moved out of our area but who still wanted to maintain contact with PCaSO, or just wanted to receive our newsletters and booklet. These are designated as UK members. All, regardless of county, are members of PCaSO, and are free to attend any support meetings held throughout our region.



NEWSLETTER EDITOR

You have seen in David Hurst's leading article a request for members to step forward and help. We are grateful to Tony Ball for his offer of collating and editing the content of our newsletters, and for Colin Woodman to do the layout and design work. This will start from the November issue.

Our newsletters are quarterly, in February, May, August and November. These are set to coincide with the issues of Prostate Matters, the Federation's newsletter, so that the two can be mailed together to those who prefer to be sent postal copies.

The deadline for articles for the next issue is 15th October, and the deadline for the completed artwork to be sent to the printers is 31st October, so that members should receive their copies a fortnight later.

We welcome any articles from members, and it is always good to have an account of one man's prostate journey in each issue. If you have a story to tell, do send it to Tony Ball. This can be anonymous if you do not wish your name to be revealed – though if you do, a photo is always good.

Likewise, a short account of activities, events, fundraising, or any interesting talks to your group is welcome.

All future articles, please, should be sent to Tony at: publications@pcaso.org, tel: 01903 783540

LOCAL SUPPORT MEETINGS

All at 7pm, unless marked. See back page for venue details and contacts

9 August (Tu)	Pulborough	Patients' Forum
5 September (M)	Bexhill	Mr Roger Plail, (cons. urologist)
6 September (Tu)	Otterbourne (7.30)	Mr Marc Laniado (cons. urologist)
8 September (Th)	Eastbourne	(speaker TBC)
20 September (Tu)	Rustington	Dr Ashok Nikapota (cons. oncologist, Brighton)
28 September (W)	Talbot Woods	(speaker TBC)
3 October (M)	Bexhill	
6 October (Th)	Brighton	Dr Angus Robinson (cons. oncologist)
12 October (W)	Eastbourne	
12 October (W)	Eastbourne	Dr Caroline Manetta: Clinical trials for prostate cancer
7 November (M)	Bexhill	
10 November (Th)	Eastbourne	Penny Kaye (Macmillian dietitian): Diet and prostate cancer
15 November (Tu)	Pulborough	Andrew Hart, Uro-Oncology CNS, Worthing (tbc).
15 November (Tu)	Waterlooville	Patients' Forum
22 November (Tu)	Rustington	Patients' Forum
23 November (W)	Chichester	(speaker TBC)
30 November (W)	Talbot Woods	Social evening
8 December (Th)	Eastbourne	Mr Peter Rimington (cons. urologist)

SUPPORT MEETINGS AND VENUES 2016

SUSSEX BRANCH

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

20 September, 22 November.

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

9 August, 15 November.

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

8 September, 12 October (Wed),
10 November, 8 December.

Bexhill: held at
Health Centre, Bexhill Hospital,
Holliers Hill, Bexhill, TN40 2DZ at 7pm
Mondays
5 September, 3 October, 7 November.

Brighton: held at
Macmillan Horizon Centre, Bristol
Gate, Brighton BN2 5BD at 7pm.
First meeting 6 October.

Chichester: held at
Chichester Baptist Church,
Sherbourne Road, PO19 3AW at 7pm
Wednesday 23 November.

HAMPSHIRE BRANCH

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

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

Tuesday 15 November.

DORSET BRANCH

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.

28 September, 30 November.

PSA TESTING EVENTS

10 September, Worthing
17 September, Dorchester
8 October, Burgess Hill
19 November, Telescombe

PCASO CONTACTS

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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