

UPDATES

The Quarterly Newsletter of PCaSO Prostate Cancer Support Organisation

Dorset • Hampshire • Sussex
& surrounding areas



**Developments in Diagnosis
and Treatment**

Tomatoes and Cancer

Macmillan Health Professionals

New Website

Branch News

Meetings

PSA Testing Events



**Issue No. 60
August
2017**

Fishing Boat, Worthing

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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

Hampshire Branch representative:
Peter Weir 01489 892168

Dorset representatives:
James Davis 01202 580436 (jamdavis@talktalk.net)
Allan Higgin
Derek Pilling

Federation representative:
Allan Higgin 01202 691710

Pastoral Counsellor:
Nicholas Frayling

Newsletter Editor:
Tony Ball 01903 783540 (editor@pcaso.org)

Design:
Colin Woodman

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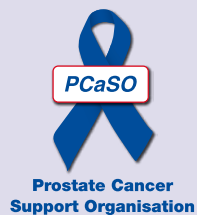
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Catherine Woolford (*speakers*)
Allan Higgin (*PSA testing*) 01202 691710

PO Box 66, Emsworth,
Hants PO10 7ZP

National Help Line:
0800 035 5302

www.pcaso.org

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Founder: David Rowlands

Medical advisers:

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Dr Chris Parker, MRCP, MD, FRCR
Dr Angus Robinson, MBBS, MRCP, FRCR

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PCaSO does not receive any government grants to fund the work we undertake and is largely dependent on membership subscriptions, donations and sponsorship.

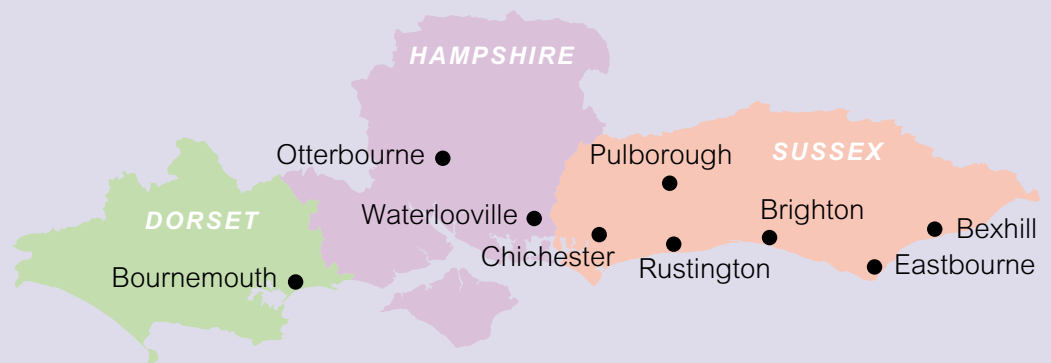
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Alternatively, go to the website www.pcaso.org and click on the red Virgin Giving button on the front page..

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.



Exciting developments with prostate cancer diagnosis and treatment

Progress is being made with diagnosis and treatment for prostate cancer, from changes to practice following results of trials and more use of technological advances. Current practice 5 years ago may no longer be current best practice. This may be by doing different things, but sometimes just changing the order or timing. Available options are increasing and this can provide more personalised care for the individual's circumstances, but can be dependent upon funding limitations and on where the centres of excellence are located.

We had an insight into such changes when Mr Simon Woodhams, consultant urological surgeon at Royal Surrey County Hospital, Guildford and Andrew Hart, uro-oncology clinical nurse specialist at Worthing Hospital, kindly gave their time to talk to the PCaSO Rustington Group on 6th June 2017.

DIAGNOSIS

Imaging

Traditionally if an MRI was done, it was done after the biopsy. Now it is usually done before a biopsy and as an mpMRI (multi-parametric MRI). If cancer has developed the MRI can provide a good picture of it. It can also be used to provide reassurance in low-risk patients that they do not harbour more aggressive disease. In some cases the patient may not need to proceed to biopsy at that time, but instead be returned to their GP for further PSA monitoring.

Fusion Guided Biopsy uses software which 'fuses' the MRI with the real-time ultra-sound probe, overlaying the images, so allowing the urologist to pin-point the suspicious areas with much greater accuracy.

Choline PET-CT scans are now in use (eg at the Clinical Imaging

Science Centre at the University of Sussex, Brighton) and are likely to be more used in future as they can show whether cancer has spread to areas other than the prostate. The patient is injected with a tracer, a radioactive isotope, that seeks out prostate cancer cells.

Biopsies

Traditionally the TRUS biopsy has been and still is used, it is done under local anaesthetic and can be somewhat uncomfortable and undignified for the patient. Only about 10 or 12 core samples are taken from the prostate, so it can miss some cancer. Now there is the option of using Template Biopsies, done under general anaesthetic and so more comfortable for the patient. These take 30, 40 or even 50+ cores, so are far more likely to pick up cancerous tissue. [*PCaSO part-funded Template Biopsy equipment for St Richard's Hospital, Chichester. See Updates, November 2016*]

TREATMENTS

Radiotherapy

LDR (Low-dose rate) brachytherapy is available at Guildford and HDR (high-dose rate) brachytherapy is available at Brighton. [*See articles on Radiotherapy in Brighton in Updates November 2016 and February 2017*] HDR brachytherapy is best for high-risk cancers.

EBRT (external beam radiotherapy) is available using linear accelerator radiotherapy machines at Brighton and there are two newer Tomotherapy machines at Preston Park. 3D-Conformal radiotherapy is becoming available at some locations, this can shape the beam area to an irregular shape (not just a square target) to spare the bladder and rectum. IMRT (Intensity Modulated Radiotherapy)

goes one step further and allows for varying the radiation levels on a gradient across the target area.

Surgery

Traditional 'open' surgery is not often used. Surgery to remove the prostate gland is now laparoscopic, with robotic laparoscopy becoming mainstream current practice and is available at Guildford where they have two machines (total cost £2.8million). Mr Woodhams used to do prostate surgery, but now does robotic bladder surgery. His colleague Mr James Hicks currently performs the robotic prostate surgery at Guildford. There are four 'arms' to the robot (see photo below), one arm with the camera and three operational arms. The surgeon commands the robot from a nearby console, using his/her hands and feet.

Although not cancer, BPE (Benign Prostatic Enlargement) can also be treated surgically, Traditionally TURP was used, but now TURi is available as a day case at Southlands Hospital, Shoreham, with an improved technique for 'reaming out' the inside of an enlarged prostate.



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Homone therapy

The hormone Testosterone present in all men can feed prostate cancer cells so drugs are used to reduce it from a usual level of about 20ng/ml to less than 1ng/ml. Traditionally Zoladex and Prostop have been used. The newer drug is Degarelix (Firmagon), which does not require pre-treatment with anti-androgen as there is no risk of tumour 'flare'.

2nd-line treatments (for hormone resistance) are Abiraterone (Zytiga) and Enzalutamide (Xtandi) [see article on Enzalutimide in Updates, November 2016].

Abiraterone is taken as 1000mg (4 tablets) once a day. Taken with steroids (usually prednisolone twice a day). It stops testosterone production in the gonadal pathway.

Enzalutamide is taken as 160mg (4 tablets) once a day. It blocks the action of testosterone at the cell level (it binds to androgen receptors).

Abiraterone is also being trialled early in the treatment process for curable prostate cancer, alongside hormone therapy. (cost however is around £2000/month). Recent reports (June 2017) have shown in STAMPEDE and LATITUDE trials improvements in progression-free survival in locally advanced prostate cancer and overall survival in metastatic prostate cancer if Abiraterone is given at the beginning of treatment.

The STAMPEDE trial continues and as it was set up as a MAMS (i.e. multi-arm) it keeps going, trying new aspects. Apart from the new use of Abiraterone, the drug Metformin (which is used for Type 2 diabetes patients) is being trialled for prostate cancer.

Chemotherapy

If they are fit enough, patients can have chemotherapy with hormone therapy as well. As an outcome of the STAMPEDE trial Docataxel is now being used upfront as a 1st-line treatment (administered intravenously- 6 cycles, 3 weekly). Cabazitaxel is used as a 2nd-line treatment.

Bone Therapy

Radium 223 (Alpharadin, Xofigo) can be used where prostate cancer has spread to the bones. [see Updates, February 2017]. Radium 223 is available at Brighton and consists of 6 injections, once every 4 weeks, for 6 months.

Immunotherapy

Future treatment options may include drugs such as Ipilimumab to help the body's own immune system to find and destroy prostate cancer.

Genetic Testing/PARP inhibitors

In future drug therapies may increasingly target specific genetic abnormalities such as the p53 mutation. This will require the patient to be tested for the specific abnormality prior to treatment.

The TOPARP trial uses genetic testing of DNA to help tailor treatments to a patient's personal genetic profile, with targeted therapies using drugs such as Olaparib, a PARP inhibitor. One patient at the Rustington meeting mentioned he was in this trial.

The things you get involved in....

As secretary of PCaSO I get various surveys and questionnaires from companies and academics wanting to find out about aspects of prostate cancer.

One from Aberdeen University asked what effects of my prostate cancer treatment I thought were important. I answered without thinking too deeply. Later this came round again but included the consolidated opinions of some clinicians and I was offered the opportunity to change my opinions. This sparked my interest and I looked more closely and made some additional comment.

Suddenly I was invited to a one-day expenses-paid conference in Aberdeen to look at the relative

importance of the effects of various treatments.

Medical professionals may find it difficult to use the results of current prostate cancer medical trials to decide on best treatments for patients because each trial focuses on a different specific outcome and measures it in a different way. There are a large number of different treatments for prostate cancer, complicating things further.

Aberdeen University decided to carry out the three-year programme, led by Mr Thomas Lam and Dr Steven MacLennan, to develop a core set of outcomes for localised prostate cancer effectiveness trials.

The team started by looking at over 17,300 academic abstracts

and from these and structured patient interviews distilled 84 outcomes to rate in importance. In the survey that I completed – along with other patients and clinicians – we were asked to rate each of these in importance on a nine-point scale.

The conference was fascinating. There were eight patients plus clinicians and academics from UK, Europe and the US. It went through the 84 outcomes mainly arguing about the outcomes that were in the middle range of importance and distilled the list down to a final 19.

The full report was published in BJU International, 3rd May 2017, ref: 10.1111/bju.13854

David Hurst

Tomatoes and Cancer

PCaSO Hampshire Branch were delighted to welcome Dr. Mridula Chopra, Research Scientist, Dept of Pharmacy and Biomedical Sciences, University of Portsmouth (UofP), to talk to us on their research work on the role of tomatoes and cancer. A summary of her talk follows:

Dietary factors have been suggested to account for 30% of cancer in the Western population. Diets high in animal products, fats and sugars are linked to increased risk. Fruits and vegetable diet, fish, probiotics and olive oil are linked to a reduced risk.

The role of tomatoes in cancer was initially highlighted by Harvard scientists, several population based studies have shown that people who consume processed tomato products and have higher blood levels of lycopene (a nutrient that gives red colour to tomatoes) show lower incidence of prostate cancer and reduces the aggressive nature of cancer. Lycopene has been shown to accumulate in the prostate gland.

Angiogenesis (blood vessel formation) is a tipping point between a harmless isolated tumour, and developing into a harmful tumour from receiving nutrients through a developing blood supply (see figure below).



Laboratory experiments at UofP showed lycopene inhibits the blood vessel formation and a clinical study published in 2014 by Harvard scientists reported that there is a lesser degree of blood vessel formation in the tumour of patients who regularly consumed tomato products.

Lycopene inhibits the migratory properties of cancer cells and inhibits the cancer growth signals at concentrations in the blood of $> 1.1\mu\text{M}$.

How do these blood levels equate to the dietary intake? On average, 25-30mg lycopene per day can produce the desirable lycopene levels in many individuals. Most people consume 3-8mg lycopene from tomato products per day, this produces blood levels of lycopene of $<0.40\mu\text{mol/L}$, a concentration at which very little effect is seen.

Lycopene content of selected food!

Cooked tomatoes	4mg/100g
Tinned tomatoes	5.6 mg/100g
Tomato puree	14mg/100g
Tomato soup	13 mg/100g
Ketchup	9.9mg/100g
Watermelon	3.5mg/100g
Papaya	2mg/100g

How frequently should the tomato products be used?

Current research from UofP and others have shown that if one consumes 30-40 mg lycopene per day from processed tomatoes i.e. tomato puree/soup/sauce/chopped tomatoes and fruits such as watermelon then the maximum increase is seen within the first week

and there is only small increase in the following week i.e. blood saturation reaches within

couple of weeks. Consuming a can of tomato soup (~400g) per day can raise levels of lycopene in semen samples from healthy individuals within two weeks.

How should the tomato products be used?

Cooked tomatoes with small amount of fat preferably olive oil

is better than raw tomatoes. With regards to the amount of oil, 10-15 ml per 300 g should be sufficient (tomatoes cooked for ~5-10 minutes, ~oil content of 5%).

Negative effects of tomatoes

Tomatoes may not suit all individuals. People with acidity problems, and they can also affect digestion. Tomatoes have also been linked to renal stones, though clear evidence is lacking at the moment, and have also been associated with inflammation and joint pains.

Tomatoes are not the only product with anticancer properties? One should not rely on one food. A single type of food cannot cause or prevent cancer. A healthy diet and lifestyle including regular exercise is important.

Some foods have been shown to be protective against cancer and these include: Cruciferous (broccoli, cabbage, cauliflower, brussel sprouts) and green leafy vegetables, wholegrain foods, probiotics, fish, berries, onions, garlic, turmeric, green tea, etc.

In laboratory studies at UofP there is encouraging evidence that certain types of honey may have a beneficial effect on colon cancer cells.

Dr. Chopra presented a summary of UofP proposed research programs, partly funded by two PCaSO grants:

- To set up a method that can measure biological effects of lycopene.
- Identify a patient group in earlier stages of developing microvessels, that may benefit from a tomato rich diet
- Examine whether tomato product consumption reduces cancer biomarkers in patients with high PSA/Gleason score.

Macmillan health professionals

When our newsletter editor asked me to write a piece about the 'Macmillan nurses' and what they are doing for prostate cancer patients in Eastbourne, I have to confess I was a bit perplexed. How do people see the Macmillan 'brand' I thought? Is it the Clinical Nurse Specialists (CNS) in the hospital supporting newly diagnosed men with prostate cancer through their treatment journey, or the general public view of 'Macmillan nurses' caring for people receiving palliative or end of life care? For the Eastbourne group it has always been about excellence and knowing that Macmillan Cancer Support invests in health care professionals who provide high standards of care for living with and beyond cancer. It is about good practice, investment in posts where funding is sometimes not initially available in the local NHS, and assurance that those who occupy such roles are knowledgeable and accessing high quality support and development.

Over the years we have had good support from the team of urology Clinical Nurse Specialists led by Alison Gidlow at East Sussex Healthcare NHS Trust in Eastbourne. Patients are seen or are in contact with the CNSs at Eastbourne DGH and the Conquest Hospital, Hastings. Alison, Tessa, Jocelyn and Kelly have also been along to the Eastbourne and Bexhill support groups to meet members and give talks about their roles. However, we have also had talks from a Macmillan Dietician (Penny Kaye), a Macmillan Pharmacist (Kingsley Wildman), Macmillan Care Support worker Mark Tolhurst working with Care for the Carers in Sussex, a Macmillan Palliative Care CNS (Anita Ivimy) and the Macmillan Counselling Services Lead Karen Aylward. All

of these individuals have provided informative and engaging talks encouraging group members to ask and seek out further local information. The list is not exhaustive as we have also had Macmillan Cancer Support staff and volunteers talk about the work of the charity in East Sussex. Their own publicity says there are currently 630 Macmillan professionals in the 'Southern area,' (June 2017 'Urgent Appeal').

At our June meeting, Karen Aylward, Macmillan Counselling Services Lead at East Sussex Healthcare NHS Trust, returned to give an update on Mindfulness and counselling services. She has talked to the group several times over the last six years. A few of the men in the group (and their partners) had already attended her Mindfulness courses and personally recommended the benefits. We even had a group 'Breathing Space' session to try out the 'in the moment' technique'. Karen highlighted the benefits of Mindfulness for reducing anxiety and depression as endorsed by NICE – the National Institute for Health and Care Excellence. She cited:

- Increased experience of calm and relaxation
- Higher levels of energy and enthusiasm for living
- Increased self-confidence and self-acceptance
- Less danger of experiencing extreme stress, depression, anxiety, chronic pain, addiction or low immune efficiency
- More self-compassion and compassion for others

So in conclusion, in Eastbourne we see the Macmillan Clinical Nurse Specialists and their fellow health care professionals as

essential to the holistic approach to treatment and living with prostate cancer and beyond. They are helping ensure elements of the Macmillan Recovery package are available to people affected by cancer which is a 2020 target.

See <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package>

Debbie Hatfield, Eastbourne PCaSO group, Sussex branch.

New website for PCaSO

PCaSO has a brand new website on the same address as the old one, www.pcaso.org.

The old site had been built by a friend of PCaSO, Bob Watson, some years ago.

Initially we tried to find a volunteer to take the task on but after two failed attempts we decided the only way was to pay for it. A company in Bognor Regis, iwebsites.com, was appointed and the result is now online for the world to see.

The idea is to keep it simple and make it available to phones, tablets, laptops and PCs. What you see is only the start as we want to add further elements but those will have to wait until after the summer, giving the site time to bed down and for any bugs to be found.

Mistakes? Of course there are mistakes and if you see anything then do tell by emailing info@pcaso.org saying exactly where it is.

Please use the new site for all information about PCaSO, prostate cancer, our group meetings and PSA testing.

Hampshire Branch News

Hampshire Branch has recently made a donation to Southampton University Hospital to help them with the diagnosis of Prostate Cancer. So in the last couple of years we have made significant donations to hospitals in Chichester, Portsmouth and Southampton.

We have also held PSA Testing Events in Basingstoke (72 men, 2 raised), Hayling Island (159 men, 12 raised) jointly with Sussex Branch and supported by The Lions, Fareham (137 men, 12 raised). Another one is scheduled in Bishop's Waltham on the 12th August - also supported by The Lions.

The financing of these donations has been almost exclusively by the Collection and Awareness Events at supermarkets and those have also been the major funding for the unsupported PSA Testing Events. Unfortunately we are having difficulty manning the Collection Events and consequently we are unlikely to hold another one this year, the last one being in Fareham on the 15th and 16th of July.

The Hampshire Committee has also written to all the Hampshire members requesting someone to step forward to undertake the organisation of the Collection and Awareness Events and someone to take up the position of Secretary, a post that has now been advertised for about 3 years and has been vacant for over 15 months. Unhappily we have had no response for either post. Without our members support we are unable to provide the local facilities we would like which assists with the diagnosis of those men with Prostate Cancer and also assistance to their families.

We have arranged an Open Meeting to be held at Otterbourne on the 5th September where the speaker will be someone from "Medical Detection Dogs", although no dogs are likely to be at hand as they do not like long journeys. However the talk is expected to be very interesting. We have currently not arranged another meeting as that is an activity normally undertaken by the Secretary, but please refer to the website for any future Hampshire meetings.

This is your charity, please help us to help you.

David Harris, Treasurer PCaSO Hampshire Branch.

Dorset Branch News.

At our May meeting, the speaker was Mr Matthew Archer, Urology Nurse Practitioner from University Hospital Southampton. He gave an interesting talk on incontinence problems and erectile dysfunction.

We failed to find a speaker for the July meeting but member Barrie Hampson stepped up with an offer to present a short illustrated talk on First Aid / CPR. We accepted his offer.

The branch has now given free PSA tests to over 3000 Dorset men.

We carried out a PSA testing session at Maiden Newton on June 10. 73 men were tested.

At Christchurch (Mudford) on July 8 we tested 90 men. The event was co-hosted by the Mudford Masons. We were a bit thin on the ground for helpers, but managed to cope with just two phlebotomists and a couple of new people that Jim had roped in.

Firm dates for future PSA testing sessions are:

Sep 23 at Christchurch (co-hosted by Lions)

Oct 14 at Lyme Regis

Also, sometime in **November** an event co-hosted by Wimborne and Ferndown Lions

And next year we hope to test in Blandford and Wareham

Sussex Branch News

Sussex Branch has been considering a problem of lack of people attending group meetings. This doesn't affect all groups, Rustington and Eastbourne have reasonable numbers but Chichester, Pulborough, Brighton and Bexhill have been a bit low. This means that it is embarrassing to invite senior clinicians to talk when only half a dozen people attend. There were discussions about ways to publicise meetings. Most meetings have one or two men attending for the first time who need information and there are usually one or two regulars so that makes the meeting worth the £30-£40 cost of room hire and shows that some publicity works but it is a concern.

Since the last newsletter Sussex have held one PSA testing session in Bognor Regis with Rotary. A total of 97 men were tested with eight having a raised reading. More sessions are planned for the autumn and are listed on the back page of this newsletter.

As Updates goes to press we have just manned a stand on Worthing promenade on Sunday morning and plan a second one on 30th July. All for the Worthing Lions Festival and run by a combined effort of the Rustington and Pulborough groups. A reasonable number of callers including one man who had collected a leaflet on a previous show, went for a test and is now in treatment and very grateful. Makes it all worthwhile when you get thanks like that.

On 30th July the Brighton Group have another stand at the Pride Community event in Preston Park, a slightly more sheltered pitch.

Very well done to Chris Cocum for raising £2366 (including Gift Aid) at the Ironman Fundraising event on 16th July (see Updates May 2017). An article about Chris and the event will appear in the next issue.

LOCAL SUPPORT MEETINGS

See right for venue details and inside front cover for contacts.

Sept 2017

4th (Mon)	Bexhill	Kaen Aylward , (Macmillan) Counselling Services and Mindfulness
5th (Tue)	Otterbourne	Medical Detection Dogs
12th (Tue)	Pulborough	Patient Forum
14th (Thur)	Eastbourne	Dr Sally Appleyard , Quality of life during treatment
19th (Tue)	Rustington	Professor Sara Faithfull University of Surrey, TrueNTH exercise and diet project.
27th (Wed)	Talbot Woods	(Speaker tbc)

Oct 2017

2nd (Mon)	Bexhill	Patient Forum
4th (Wed)	Brighton	(Speaker tbc)
4th (Wed)	Chichester	(Speaker tbc)

Nov 2017

6th (Mon)	Bexhill	Katy Bourne , Sussex Police and Crime Commissioner
9th (Thur)	Eastbourne	Dr F Mckinna , Consultant Clinical Oncologist and Julie Warner , Head of Radiotherapy, Sussex Cancer Centre. Radiotherapy Update.
14th (Tue)	Waterlooville	(Speaker tbc) 1.30pm
28th (Tue)	Rustington	(Speaker tbc)
29th (Wed)	Talbot Woods	(Speaker tbc)

Dec 2017

4th (Mon)	Bexhill	Social
12th (Tue)	Pulborough	(Speaker tbc)

VENUES

Dorset

Bournemouth: 7.30pm start
St Marks Church Hall,
Talbot Woods, BH10 4HY,

Hampshire

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

Waterlooville: 7pm start
Church of the Sacred Heart,
London Road, PO7 7SR

Sussex

Bexhill: 7pm start
Health Centre, Bexhill Hospital,
Holliers Hill, Bexhill, TN40 2DZ

Brighton: 7pm start
Macmillan Horizon Centre,
Bristol Gate, Brighton BN2 5BD

Chichester: 7pm start
Chichester Baptist Church,
Sherbourne Road, PO19 3AW

Eastbourne: 7pm start
Postgraduate Centre, Eastbourne
District General Hospital,

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

Rustington: 7pm start
John de Bohun Room,
Woodlands Centre,
Woodlands Avenue, BN16 3HB,

All groups need help to put the chairs out, make teas, run a raffle, etc. Please arrive early to lend a hand. And remember the room also has to be cleared up afterwards.

PSA Testing Events: Check our website www.pcaso.org for the latest details

PSA testing is by appointment only. Contact phone numbers for bookings will be displayed on the website 3 to 4 weeks before the scheduled date of the event.

Aug	12th	10am-2pm	Bishops Waltham (Hampshire)	Priory Park Hall SO32 1SQ
	26th		Brighton (East Sussex)	Pyecombe Golf Club (near Brighton)
Sept	16th		Worthing (West Sussex)	Guild Care Day Centre
	23rd	9am-12pm	Christchurch (Dorset)	Community Hall, St Catherine's Hill, Christchurch BH23 2RR
	30th		Hove (East Sussex)	Bishops Hannington Church Hall, Nevill Avenue
Oct	14th	9.30am-12.30pm	Lyme Regis (Dorset)	
	21st		Burgess Hill (West Sussex)	Martletts Hall, Town Centre
Nov	4th		Peacehaven (East Sussex)	Masonic Hall, Seaview Road

At most events we need help to make them run smoothly. Checking men in at the door, calling them forward, writing the details on forms. Most events are on a Saturday and usually finished by mid-afternoon.

If you are available on any of the above dates call Roger Bacon (Sussex) 01903 775783, Peter Weir (Hampshire) 01489 892168, Jim Davis (Dorset) 01202 580436.