



NEWSLETTER

PCaSO PROSTATE CANCER NETWORK
for Sussex, Hampshire and Dorset

Charity No: 1095439

PSA TESTING DAY

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East Branch held a successful PSA Testing afternoon in central Brighton on the afternoon of Saturday 8th October. This was run in conjunction with the Graham Fulford Trust.

Graham Fulford, based in Warwick, set up the Graham Fulford charitable trust six years ago after two close friends, both under the age of 60, died of the disease. Since then, he has organised talks and events to encourage men to have themselves screened throughout the country. These events are done in conjunction with David Baxter-Smith, MA, M.Sc, MB, B.Ch, BAO, FRCS, a consultant urological surgeon,

In some cases, a Free-to-Total PSA is done at the same time, which, together with the standard PSA, can give a more accurate result.

After about three weeks each man will receive one of three letters, each giving the actual result: a green letter saying that the result was normal, but with a caveat that it is not conclusive, an amber letter saying that the result was just above normal and advising a visit to the GP, and a red letter advising an early visit to the GP.

As an indication, 89% of men receive a green letter, 5% an amber one and 6% a red one. (See also page 8).



David Baxter-Smith gives his talk at Brighton



The nurses administering the PSA tests

who gives a preliminary talk on the prostate and the test, at each event. The Trust has raised over £250,000 to pay for these free blood tests through various fund-raising activities.

At the event each man fills in a simple questionnaire and consent form, and a team of nurses, organised by PCaSO, administer the test. The samples are then sent away to a laboratory.

The Brighton meeting, organised by the PCaSO East Branch was extremely well organised, with a team of helpers welcoming the visitors and directing them to the test room, where ten nurses were doing the tests. Over 100 men had the test done. Our thanks go to Roger Bacon and Barry Cocum and all their helpers who made the afternoon such a success.

Ian Graham-Jones
More photos overleaf

This newsletter is sponsored by



Our Help Line

0845 650 2555

is kindly sponsored by



CANCERPARTNERSUK

PCaSO Prostate Cancer Network, PO Box 66, Emsworth, Hants PO10 7ZP

Help Line: 0845 650 2555

Website: www.pcaso.org

PSA TESTING DAY AT BRIGHTON



Above:
Graham Fulford introduces
the event



Above (from left):
David Baxter-Smith, Graham
Fulford (GFT) Roger Bacon,
Barry Cocum (PCaSO), Margaret
Ticehurst (chair of Sussex Cancer
Network Partnership group)



Right:
Registration
(Graham Hatfield, Mike
Croghan, Christina Cutting)

**To date the trust has tested
over 17,600 men and some
435 cancers have been
found.**

THE MEDIWATCH PSA BIOSCAN SYSTEM

The Graham Fulford Trust are the first to purchase the latest portable PSA Bioscan machines, which will give an accurate reading within 10 - 15 minutes. The system consists of a small machine with a tray for a blood sample. Alternatively, it can take a fingerprick blood sample for those with a fear of needles, although the accuracy by this method is said to be not quite as good.

The PSA Bioscan covers a range of between 0.5 and 25µg/l, so it will not cope with the required high sensitivity PSA results (as, for example, for post-prostatectomy patients), nor will it be suitable for extreme high readings. The whole kit comes with a 'Bluetooth' wireless printer for the results, and all the required accessories. The Trust have trialled these extensively on behalf of Mediwatch with several groups of men, and it has proved to be extremely accurate.

The new system will not only obviate the need for waiting time before results come back, but will enable prostate cancer charities such as PCaSO to run smaller events.



The PCaSO committee has agreed to purchase four Mediwatch PSA Bioscan machines, with all the necessary equipment. These will be shared over the three Branches of PCaSO.

We have been offered a special price of £3,200 complete at a special charity rate, as opposed to £7,000, through the auspices of the Graham Fulford Trust.

Staff from Mediwatch will offer a special training session, and we are aiming to have at least two trained people in each Branch to be in charge of the events where

these are used. (Anyone interested in becoming a leader for this please contact David Smith – details on page 8). In addition, we are hoping to recruit a Urology CNS from each region who would be able to oversee their use.

The same system of green, amber and red letters, as used by the GF Trust, will be used, and details of a contact number of a urologist will be given, with whom a patient can discuss any suspicious result.

THE MARY HOW TRUST



The Mary How Trust, based in Pulborough, offers a comprehensive health based screening for both men and women. Included in that screening is a PSA testing service for men between the ages of 50 and 75. This year the Trust came to PCaSO requesting a donation to support this service.

The committee agreed to approve this grant by offering £2,000 as an initial sum, followed by a further payment at the end of their financial year to fund the service fully. At the same time (but not conditional on our support) was a request to lower the age limit to 45 years to catch the high risk category of men early. The Trustees of the Mary How Trust accepted this and now test men between 45 and 75 years.

Further to our support for this service, Prostate Action, through their grants to the Prostate Cancer Support Federation, has donated £500 towards our costs. They are excited by the initiative of private testing against the backdrop of a government that refuses to accept the results of a number of trials that show a significant percentage of men's lives can be saved by screening and early detection (see our last Newsletter No. 36).



PCaSO members can benefit from the health screening that the Trust offers. It is comprehensive and provides full testing of the conditions that afflict men of that age group, especially those that are taking the drugs and therapies with side effects to combat Prostate Cancer. A full explanation of the screening service can found on their website – www.maryhowtrust.org. They offer a complete health screening which will give a detailed picture of your current state of health. They look for early signs of a number of serious illnesses, including heart disease, diabetes, bowel cancer, prostate cancer, and abdominal aortic aneurysm. There is no charge, but they do ask for donations towards the expenses of the charity.

Mary How was diagnosed with bowel cancer in 1984 and, despite a brave battle against the disease, she died in 1987 at the early age of 46. Her husband and GP founded the Trust in her name to provide a service for the early detection of malignant and other life threatening diseases. Mary's son sits on the board of Trustees, maintaining the link with the family.

David Smith

EXERCISE AND CANCER

Research has shown that exercise or physical activity can play a role in disease outcome and survival after cancer (see our article in Newsletter 34). Recent studies in men with prostate cancer show that it can actually help to maintain and regain their physical functioning after treatment, but also help to improve their quality of life by controlling symptoms such as fatigue.

SHORE-C (University of Sussex; also see <http://shore-c.sussex.ac.uk/>) is planning a short survey (internet-based or postal) to investigate if people living with cancer are interested in taking part in an exercise program. A few questions will be asked to find out what works best for them: for example, would they prefer a home-based program or a group activity? Would they travel to take part? Would they prefer a program during treatment or after?

This survey shouldn't take long to complete (5 mins) and the information will help us to develop a future exercise or rehabilitation program tailored at the preferences of cancer patients, including prostate cancer survivors.

This questionnaire should be enclosed with this newsletter. Please help by completing and returning it in the FREEPOST envelope provided.

If you have not received a copy and would like to take part in this questionnaire-survey, contact Dr Helena Harder telephone **01273 873029** or email h.harder@sussex.ac.uk.

COLLECTORS NEEDED!

PCaSO Central Branch urgently needs collectors to help with collections at

TESCO HAVANT on SUNDAY 4th December and MONDAY 5th December

MORRISONS HORNDEAN on THURSDAY 8th December

If you can spare just one hour of your time – two at most, to help raise funds for PCaSO, we would be most grateful.

Without such collections we would not be able to find the money to support our activities and to raise funds for such items as the PSA scanners (see page 2).



If you can spare an hour or two, please get in touch with John Harmer on

02392 631599 or john.harmer@waitrose.com

EAST BRANCH ACTIVITIES

As reported in the last newsletter's 'East Branch report', the main focus for the Branch has been the free PSA Test event which took place on 8th October at the Brighthelm Church and Community Centre in North Street, Brighton. The event was held in partnership with the Graham Fulford Charitable Trust, whose vast experience of holding similar events in venues throughout the country proved invaluable. We did not know how many men were likely to turn up at the event, so we planned for a large number. The whole event ran very smoothly, with just under 100 men being tested. This was less than we had hoped for but, if we save just one man's life, it will have been worthwhile. On the day it was a team effort which helped things run so well. Members of the branch committee and others who must be thanked are – Barry Cocum, Jo Ambrosio, Debbie and Graham Hatfield, Christina Cutting, Lauren Bacon, Mike Croghan and Margaret Ticehurst, the latter offering to help, even though she is not a PCASO member. We are also indebted to the ten local nurses who came and took the blood samples.



On the Saturday before the PSA event, we had an awareness stand and collection in Churchill Square shopping centre in Brighton. Thanks again to the 15 members who helped collect on the day. It was incredibly busy there at times on the last hot day of the year, and just over £224 was collected.

Barry Cocum (standing) gives a Radio Sussex interview with presenter Mark Canter about the Branch activities



Left: Collectors at Churchill Square: (Wally Betts, Melanie Rose Fyne, Barry Cocum, Dawn Betts)

The next meeting dates for groups in the East branch are:

Eastbourne Group on Thursday 10th November – speaker to be confirmed, and Thursday 8th December when Jill Corbyn, Macmillan Involvement Co-ordinator, will speak.

Brighton Group on Wednesday 7th December – speaker to be confirmed.

Rustington Group will not meet again until next year.

Roger Bacon
(Chairman, East Branch)

WEST BRANCH – DORSET ACTIVITIES

The September meeting covered many areas of Dorset activities and interests. There was a further discussion on 'The Way Forward' and as a result, two new members of the group volunteered for the areas of publicity/advertising and the responsibility of investigating the reasons for delayed treatments and unacceptable waiting times locally. Jim Davis gave a brief account of his informal meeting with Oliver Letwin MP and Andrew Cornaby, Head of Urology at the County Hospital, concerning the restriction of treatment options to Dorset men and the unacceptable waiting times for keyhole surgery.

The most controversial issue here is that, despite the lengthy waiting times, the local PCTs are unwilling to send men to other hospitals outside the area where treatments would be available almost immediately. This causes a great deal of distress to patients, many of whom, after five months, have not been offered a firm date for their operation and resulting in one case to one man funding his own treatment. Yet the same PCTs are unwilling to support PSA screening on the grounds that waiting for

the results causes distress to patients!

The group were given a short address from Lionel Fynn who had recently returned from a trip to California where he attended the Annual Cancer Conference of the Prostate Cancer Research Institute. He summarised a number of presentations made by high-ranking experts and presented the organisation's library with a book and notes made at the conference.

At the end of the meeting members were informed of the very successful collection at Sainsburys, Ferndown coordinated by Brian Deacon and strongly supported by members which yielded £915. We also applaud the personal efforts of Colin Seale, the president of the New Forest Bowling Association who, together with its members, raised the sum of £265. The money will be used directly with the 'Raising Awareness' project in 2012. Our grateful thanks go to organisers of both events.

Jim Davis (Chairman Dorset Branch)

THE PROSTATE CANCER CHARITY CONFERENCE 2011

'FROM LABORATORY TO LIFE' : PROGRESS IN PROSTATE CANCER

The greatest WOW factor of the Prostate Cancer Charity's conference was undoubtedly the initial reception that greeted each member of the conference as they arrived and later, during lunch, the staff that were on hand to discuss experiences and answer questions on the work of the Prostate Cancer Charity. The team consisted of young (mostly under the age of 30) men and women who were not only keen, helpful, enthusiastic and willing to engage in discussion of their work but also knowledgeable and eager to listen to the wide-ranging views of the public. If this change is to promote a new and more realistic image for prostate cancer in order to connect with the public, then it is a resounding success and the Prostate Cancer Charity is to be congratulated.



The Friday programme took the form of a series of seminars covering areas such as 'Risk Factors for Prostate Cancer'; 'Future Prospects for Diagnosis and Screening - Moving beyond PSA'; 'Overview of current Clinical Trials'; 'Abiraterone' and 'Why are Clinical Trials important?'

In the opening seminar Professor Ken Muir criticised the lack of research into prostate cancer in the past but was more optimistic about the present situation in which he said that we were catching up but still lagging behind. He attributed this to the false views (still largely held by some who should know better) that a) prostate cancer was an old man's disease and b) men died **with** it and not **of** it.

Unfortunately these attitudes have clouded the real issues. Professor Muir went on to discuss the differences and effects of factors that we can change, such as environmental (including diet and lifestyle) to biological risk factors that we cannot alter (including age and heredity). Both factors form the basis for his research work.

In the second seminar Professor Norman Maitland outlined the difficulties associated with PSA testing which can help diagnose aggressive prostate cancer early but can also result in over-diagnosis of tumours that might not cause a problem. His research involves identifying new markers for prostate cancer that might one day form the basis for a screening programme.

This is a complex process and more difficult to achieve than breast cancer. There are more than 40 genetic markers associated with prostate cancer, and if only 6 of them are present in a man's genetic profile, there is a 9+ increase in risk of developing prostate cancer.

Professor Maitland's criticism of the articles on prostate screening in PCaSO's August edition of the Newsletter as being 'one man's opinion' was, I felt, both spurious and petty. (In fact there were actually five opinions ranging from Christopher Eden's address given to PCaSO members at the Otterbourne meeting to the National Screening Committee's position). His criticism - he did not quote any passage - was that 'the last statement was wrong'. I felt a conference platform was not the place to refer to any article, particularly one in a regional support group's newsletter, unless the comment was quoted in full.^[1]

Dr Chris Parker then talked about the most promising new treatments on the horizon for prostate cancer and drew attention to the many clinical trials across the world which could

bring real benefits for UK patients within the next few years. He also emphasised the need for research into prevention of the disease developing, though disappointingly, these were not specified. During the conference I was aware that the whole area of Clinical Trials needs to be addressed by all agencies concerned with research, but they are not. It's too easy to off-load on to the patient the responsibility of researching which trials are available and where, which ones are appropriate, registering and then applying for funding/support from local authorities. Most men, newly diagnosed, have enough on their minds without all the added stress associated with trials, even if they all had computers - which they don't! Most men wouldn't have heard of HIFU, Abiraterone, Alpharadin or a trial called RADICALS, so who is responsible and why are they not doing their job? Would it really be outside the interests of the Prostate Cancer Charity to investigate this?^[2]

Chris spent some time in giving details of the very promising Alpharadin trials which involve the bombardment by alpha particles of prostate cancer cells which have metastasised in the bones. These particles specifically target only the cancer cells without damaging the healthy cells of the bones due to the limited range of the particles themselves.

The final seminar of the morning dealt specifically with the latest hormone therapy drug, Abiraterone (a partial acronym for **Androgen Biosynthesis Inhibitor**), and was led by Professor Johann de Bono. The laboratory study that Professor De Bono has worked on has run alongside the major clinical trials that have been carried out in this country, where the main objective has been to kill the cancer cells without affecting the healthy cells. Encouragingly, the progress made in the last two years

THE PCC CONFERENCE (CONT.)

has been significant, but the major problem facing researchers is being able to discover which 'drivers' of the twenty different types of prostate cancers are present; not every prostate cancer is the same. A further problem is that some cancers which metastasise in the lymph nodes are different from those which metastasise in the bones. In answer to a query from the floor questioning the benefits of extending survival by only a few months, Professor De Bono revealed that some patients have survived more than six years. Hopefully, the continued study will enable researchers to predict who will respond to this treatment best and therefore to offer men treatment that is personalised to their cancer.

The afternoon's seminar on 'Why are clinical trials important?' was led by Matthew Sydes, whose lecture would have benefited from a printed hand out as the on-screen slides were changed with such rapidity that a gold in the next Olympics seemed assured. In answer to a question from the floor, his solutions to 'How can we find out about trials?' and 'Who is responsible for informing patients about trials?' were simple: 'It's up to patients to find out' and 'it's up to patients to question their

GPs about available trials'. Not very helpful but then, Mr Sydes *is* a medical statistician.

The final speaker of the day, Ross Fenton, aged 54, was neither a health professional nor researcher. He was simply a prostate cancer sufferer who had had to face what hundreds of thousands other men have had to face – that awful moment when the news is broken. 'Although we all know we are not immortal, you can never really prepare yourself for the day your doctor says, "This could be life-threatening"'.



Ross Fenton

His talk was simple and straightforward with little reliance on emotional trimmings. I have heard many examples of personal experiences but I found Ross's

account one of the most inspiring and positive. Here was a man who, as a result of the support he received at a time when he most needed it, has now decided to pay back by volunteering for the Prostate Cancer Charity in spreading the word to other men. I was moved to thank him personally after the conference ended.

All in all, the day was a great success – and I haven't even mentioned the food (magnificent catering!). I hope the Charity will be encouraged by the response from the public and I look forward to attending the next conference in the not-too-distant future.

Jim Davis

(Chairman, PCaSO Dorset Branch)

[1] At the time of going to press PCaSO is trying to ascertain the full detail of this criticism, and any outcome will be reported to members in the next newsletter. Our current Information Book 'Knowledge Empowers' has a full and balanced view on Screening on page 45.

[2] PCaSO is aware of this problem, and details of how to get on a trial, and mention of some major current trials (as at December 2010) can be found on page 43 of 'Knowledge Empowers'.

Ed.

BRIGHTON RESULTS

At the Brighton PSA Testing Day, we can now report that, of the 96 men tested, all between the ages of 40 and 80, 87 men had 'green' letters, there was one 'amber', and 8 received 'red' letters. Not all of these eight men's high PSA may be caused by prostate cancer – there may well, of course, be other reasons, such as BPH.

Of these eight, one was aged 45, another aged 57.

Men came as far afield as London, Seaford and Bognor Regis, although the majority were from Brighton and Hove.

THE BENEFITS OF OMEGA 3 FISH OIL

Some recent research suggests that a low-fat diet with fish oil supplements eaten for four to six weeks prior to prostate removal slowed down the growth of prostate cancer cells. The low-fat, fish oil diet, in which 5 grams of fish oil in capsules was taken, reduced the number of rapidly dividing cells in the prostate cancer tissue. This is important because the rate at which the cells are dividing can be an indication of how quickly the cancer will progress. This clearly affects not only men who are about to be treated, but all men affected by prostate cancer.

The study, undertaken in the USA, made sure that the meals of the two groups (those taking the supplements and the control group having a standard Western diet) were strictly controlled, so that the study could be scientifically assessed. As a result, a larger study will be undertaken to confirm the initial results.

Omega 3 fish oil capsules can be obtained in various strengths, including the 1,000mg (i.e. maximum 5 tablets daily). This can be varied, depending on whether oily fish is already included in a normal diet.

NEW DRUGS FOR PROSTATE CANCER

For the first time for many years, some new drugs are bringing hope to patients.

Two promising new drugs have been licensed for use in the NHS, Jevtana (Cabazitaxel) and Zytiga (Abiraterone acetate). They are not yet generally available, but if they are appropriate for a patient, your oncologist may make application to the Cancer Drugs Fund (CDF), who will pay for the drug. The CDF is an amount of £200 million per year for three years, which sounds a lot, but it has to cover all cancers, and many of the new cancer drugs cost tens of thousands of pounds per patient per year.

Approval for general use

NICE (National Institute for Health and Clinical Excellence) is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. When a new drug has done well enough in trials (and sadly, many don't) the drug manufacturer applies to NICE initially for a license for use, then, a more detailed case for general use. NICE has to examine the efficacy of the drug (expressed in years of Quality of Life gained), the likely costs to NHS, and the impact of side effects; put simply, would there be a good return on the investment?

The preliminary case for general use of Cabazitaxel was turned down on September 30th but with an opportunity for the manufacturer, clinicians and patients to comment. The deadline for this was October 21st, subsequently extended to October 24th. Patients from PCaSO, The Prostate Cancer Support Federation, and the Prostate Cancer Charity Message Board all made comments. There were detailed technical submissions from the manufacturer (Sanofi-Aventis) and most Clinicians from the NCRI Prostate Clinical Studies Group. The final outcome is expected early in 2012.

The case for general use of Abiraterone (manufacturer Janssen) is still under development.

The drugs may still be available for a patient on a trial, where the manufacturer usually pays for the drug, so cost is not an issue.

So what do these drugs do for us?

Cabazitaxel (Jevtana) is a second-line chemotherapy drug. Patients who have had Docetaxel, but whose cancer is still progressing are eligible for this drug under the CDF. In trials, it has shown the potential to outperform Docetaxel (Taxotere), which has been an approved NHS drug for a few years. Apart from trials, most patients are saying that it seems milder in its side effects than Docetaxel, and good at reducing pain. Patients require careful monitoring for side effects. It will not provide a cure, but should extend life-span, and improve quality of life.

Abiraterone Acetate (Zytiga) is a drug that stops testosterone reaching prostate cancer; (testosterone is the 'feeder' of prostate cancer). Previous hormone treatments (Zoladex, Prostag and the like) suppressed production of testosterone from the testicles; but a small amount can come from the adrenal system, and in advanced cases, prostate cancer seems to survive on very little, and even makes it's own. Zytiga controls prostate cancer by blocking a key pathway between testosterone and the cancer, from all sources. Again, patients require careful monitoring for side effects which can affect kidneys and the liver. It will not provide a cure, but should extend life-span. One patient who started on Zytiga in early trials, is still surviving six years later.

Alpharadin (manufacturer Algeta) is not yet licensed, but was doing so well recently in its final trial that the trial was 'unblinded'. That is, those patients on a placebo were offered the real thing because it would be

unethical not to do so. It is Radium 223 chloride, given by a simple injection. Once in the bloodstream, it mimics calcium, so is taken to bone areas which are most active (i.e. metastases). The powerful radiation then kills the cancer, but has a very short range, so collateral damage is minimised.

There are some other new drugs on trial showing good results. These are:

MDV3100

(manufacturer Medivation), which stops testosterone getting to prostate cancer. Bicalutamide (Casodex) is currently used in a similar way, but MDV3100 works much more effectively and one day may replace Casodex if trials are successful and approval is given.

Custirsen (OGX-011)

(manufacturer OncoGenex) stops cancers resisting chemotherapy, and is given in conjunction with chemotherapy. Trials are taking place in conjunction with Docetaxel.

See also page 44 of our 2010-11 *Knowledge Empowers* for some further information.

Some Internet links

For those who use the internet, there are many good sources for further information:

<http://www.nice.org.uk/>
<http://www.sanofi.co.uk>
<http://www.janssen.co.uk/>
<http://www.zytiga.com/>
<http://www.algeta.com/>
 (for Alpharadin)
<http://www.medivation.com/product-pipeline/mdv3100>
<http://www.oncogenex.ca/>
 (for Custirsen)

... and don't forget the many links from our own website, www.pcaso.org, which you will find under the 'links' tab.

Mike Hollingworth
(Chairman, PCaSO)

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All may be contacted through our website
www.pcaso.org

DIARY DATES

East Branch meetings:

Wednesday 7 December: BRIGHTON (Audrey Emerton Building, 6.30pm)
Speaker t.b.a.

Thursday 8 December: EASTBOURNE Post-graduate Centre Eastbourne Hospital 7pm: Speaker Jill Corbyn (Macmillan Co-ordinator)

Dorset Branch meetings:

Wednesday 30 November: St Marks Hall, Talbot Woods, BOURNEMOUTH, 7.30pm – social evening

Central Branch meetings:

Sunday 19 February: Snowdrop Sunday, 2–4pm – see below

Wednesday 22 February: CHICHESTER Baptist Church, 2pm

Monday 2 April: OTTERBOURNE Village Hall, 7,30pm

**The PCaSO ANNUAL GENERAL MEETING will be held on
FRIDAY 20 APRIL, 7.30pm in CHICHESTER.**
Speaker: The Very Reverend Nicholas Frayling
Full details in the February Newsletter



2 - 4pm
Admission £4

SNOWDROP SUNDAY 2012
THE DOWN HOUSE, ITCHEN ABBAS
nr WINCHESTER SO21 1BT
in aid of PCaSO - teas - riverside walks



Our new T-shirts are now available
for sponsored events, etc.

TEN YEARS ON

Next year, 2012, sees the 10th anniversary of PCaSO, when we broke our ties with the now defunct national organisation 'PSA' (Prostate Support Association) and set up on our own as 'PCaSO Prostate Cancer Network'.

The February issue will feature the history of our organisation, with an article by our founder, David Rowlands.

If any long-standing member has memories of the early days of PCaSO, please get in touch with Ian Graham-Jones — see 'Contacts'.

DONATIONS RECEIVED

PCaSO acknowledges with thanks donations from the following during the last three months:

Waitrose: £330 as a result of the Green Token collection at Waterlooville,

The Deerfold Trust £300,

£100 from the Mayor of Havant and donations of £50 from Anthony Proudman and David Chiswell.

The Prostate Cancer Support Federation towards the Mary How PSA scanning – see page 3.