



NEWSLETTER

PCaSO PROSTATE CANCER NETWORK
for Sussex, Hampshire and Dorset

Charity No: 1095439

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PCaSO is currently seeking sponsors for our Newsletters and Helpline

THE 'RISKMAN' TRIAL
PCaSO has recently donated £4000 to the Riskman Trial, details of which were in our newsletters earlier this year. Each Branch has contributed £1000, together with a further £1000 from Executive funds. This is the largest donation given by any member organisation. This has significantly helped them to reach their target total to fund stage 2 of the trial.

A KICK IN THE FACE IAN LISTON

I was diagnosed with an advanced form of prostate cancer in 2003. It had metastasised to my bones and the only treatment then open to me was hormone therapy and palliative end of life care, such was the lack of available drugs to treat the disease. To me (and my wife) that was totally unacceptable.

With a hope born of desperation I agreed to participate in a drug trial at The Royal Marsden, working in collaboration with the Institute of Cancer Research. That first trial drug improved my condition and led to a second trial on a different treatment and then a third

before I was enrolled in late 2006 on a post-chemotherapy Phase II trial for Abiraterone. This drug stabilised my condition to such an extent that I took Abiraterone at standard dose, as part of the trial, for three and a half years (44 cycles) with very few minor side effects before I moved on to yet another new drug trial (Olaparib) in late 2010.

Such is the way in which statistics seem to be interpreted that the success of several years on the Abiraterone drug trial – not only for

me but also for many other men – is interpreted by NICE as 'prolonging life for *an average* of four months'. That interpretation is so skewed and many men on the trial, such as myself, have several years to be thankful for – in my case, before I was able to transfer to another trial for a new drug more appropriate to my condition. (The 'Olaparib' trial I

am now on is based on breakthrough technology in genetics and molecular pathology which identified a drug more relevant to my particular prostate cancer).

Throughout my illness (since 2003) I have led a full and active life, working

full time and never claiming any form of benefit. I'm 63 and feeling fit and well thanks to these treatments – and I'm not by any means the only man who can relate a similar story, thanks to Abiraterone.

Abiraterone (Zytiga) was discovered and developed initially in the UK at The Institute for Cancer Research in conjunction with The Royal Marsden as early as 1990. They entered into collaboration with various pharmaceutical companies (ultimately Johnson and Johnson) to



develop the drug. Most countries in the western world now regard it as the drug of first choice to treat advanced prostate cancer. Except, that is until a couple of months ago, here in UK where it could only be prescribed on a trial or by special application by a Regional Health Authority to the government's Cancer Drugs Fund. Even now, it is still refused in Scotland. And it's only available for those men who have undergone both hormone and chemotherapy.

This has been a shameful state of affairs. It was the second refusal from NICE in the last five months (the other being Cabazitaxel) for a drug that can tackle advanced prostate cancer. Although not everyone has positive results from

Abiraterone, or can tolerate it, to many men it can extend life for a considerable period. Cabazitaxel (Jevtana) was developed by Sanofi-aventis and is likewise designed for those with hormone-refractory advanced cancer after standard chemotherapy treatment. Although it was approved in the USA two years ago, NICE simply says that it "does not recommend Cabazitaxel for people with hormone-refractory metastatic prostate cancer who have had Docetaxel", although it was on economic grounds that it was refused. It is not scheduled for review again until 2015.

Such refusals by NICE must seem like hammer blows to patients desperately waiting for a drug that will fight their disease. Consider too

the effect on dispirited researchers and clinicians here in the UK who have spent many years working on the development of these new drugs. Who could blame them if they leave the UK to seek research posts in other countries where their work will be appreciated and put to the beneficial use of patients without quibble over cost?

Also, let's not forget all those who have spent considerable efforts fund-raising so that these new drugs can be researched and developed in the first place. It's a kick in the face to them too.

Ian Liston
(Bolney, West Sussex)

ANOTHER POSTCODE LOTTERY?

MIKE VINCENT

My father and his brother died from prostate cancer. I was fifty four and considered myself fit, having just been accepted for the Seven Sisters marathon in October 1994 when it was found that my PSA was rising rapidly.

Additional examinations including biopsies confirmed that I had cancer. The Royal Marsden consultants were fantastic, discussing everything I raised, and I opted for surgery, which in 1994 meant an open radical prostatectomy. But there was a problem! The date chosen for the operation clashed with the marathon, and I wasn't about to waste all that training! The operation was put back a week, which enabled me to have a cathartic burst of tears at the 14 mile feeding station, which came as a complete surprise to me as well as the volunteers manning the post!

The tumour was completely

contained, so I resumed my life, training as a counsellor. On a hot sunny day half way through my second year I nipped out to telephone the Marsden (no mobiles in 1997) for the results of my last PSA blood test. It was like a hammer blow to be told that it was 2.4 when I was expecting 0.02! Further investigation hypothesised that my rectal tissue had been seeded when the biopsy was taken. Initially surgery was used followed by androgen deprivation using Zoladex and five weeks of radical external beam radiotherapy to my pelvis and peri-rectal areas, which was completed in July 1998.

My PSA continued to rise, albeit slowly. By December 2009 my PSA was 20.4 and a Bone and CT scan indicated lesions in my right sacroiliac joint. Use of Zoladex and Casodex androgen blockade hormones quickly became ineffective and my tumour was

defined as castrate resistant in September 2011.

But science had not been sleeping, and it was now possible to have a PET scan to find prostate tumours! My result indicated that the only one was in my right sacroiliac joint. But it had a diameter of about 6cms and it was agreed with my consultant that radiotherapy was the best means of removing this tumour, and strongly advised the use of stereotactic radiotherapy, using *CyberKnife*, which the hospital had recently acquired.

Stereotactic radiotherapy is not funded by the NHS. Having read the review, a case such as mine was not considered, only its use to radiate the prostate; neither was the benefit to patients of having only three or five treatment sessions over ten days compared with up to seven weeks of external beam visits.

My consultant applied to West Sussex PCT for funding even though they had rejected all other applications made. As far as I know they did not ask to see the scans, which showed that the tumour was already beginning to grow towards the nerves fanning out from my spine, and was probably as large as could be treated by *CyberKnife*. It would appear not to have been a medical decision, and it came as no surprise when they refused to fund the treatment.

I was advised that it was unlikely that I could receive an ablative dose of radiotherapy without using stereotactic technology, and so my wife and I decided to use some of our savings to have the treatment privately.

There was an advertisement on the



television that showed cars being painted by automated arms. The *CyberKnife* uses the same principles, but instead of paint it uses radiation that is very accurately focussed to attack the tumour with high dose X-rays. I found the whole experience relaxed and calming. The staff were very knowledgeable and answered all the questions that I had. Apart

from tiredness for a couple of weeks I had no side effects. The result is that, nine weeks after the treatment, my PSA has dropped from 35 to 7.1 with further reductions predicted!

A closing comment: whilst at the treatment centre I spoke with other patients and was very annoyed to find that, had I lived one mile from where I did, Surrey PCT would probably have funded my request as they had done every request put to them so far for stereotactic radiotherapy!

Another postcode lottery on the NHS.

Mike Vincent is now pleased to report that 'Cyberknife' has been completely successful in eradicating the tumour.

EN2 PROGRESS

This time last year (August 2011 issue) we reported on the work of a promising new marker EN2 for identifying the presence of prostate cancer, which was proving considerably more accurate than PSA. This is being developed by the Guildford University and the Royal Surrey Hospital research teams. We have received an update on this from The Prostate Project, the charity who have helped fund the research. Professor Pandha, who leads the research team, writes:

At the moment we are at a stage where the first studies have been completed and we are designing further studies to try and get this into the clinics. We have established that EN2 is a credible marker for prostate cancer using a simple urine test and our second study was published recently showing the levels of EN2 may tell us how much disease is present thereby potentially aiding the urologist in making a decision about treating or surveillance.

We have three other studies in the US and Hungary looking at the same thing and these will be completed, we anticipate, this summer.

EN2 is being evaluated in a UK national study called PROMIS along with other markers where we will see

a head to head comparison with other markers such as PCA3. PROMIS is due to start this year. The lead is Prof. Mark Emberton.

There are no current studies men can participate in but this situation will change – we do need other centres to use the EN2 biomarker and design their own studies so as to validate our work. I have had discussions with groups in the UK/USA and Canada about this.

We are finding the assay itself difficult to move from the research lab to the commercial setting for technical reasons – the test itself continues to perform well.

Government regulations regarding diagnostic tests demand that we have to produce and validate a test in a prescribed way then men can access it by purchasing it initially. This “kite marking” is mandatory and we would be breaking the law if we had not completed this process. More importantly this “kite marking” process ensures quality control so important clinical decisions are not based on something that is not robust.

We will keep everyone posted with progress.

Professor Hardev Pandha

THE BIG WALK

A 3,200 km walking odyssey of trials and discoveries

DAVID WILSON

(Dave) Wilson, is 76 years of age and a recent sufferer of prostate cancer. In 2009, at the age of 73, he walked around England for Cancer Research UK, the ACRF (Australian Cancer Research Foundation and the Malagahn Institute of New Zealand.) His book, 'The Big Walk' about this five-month odyssey was released on the 31st March this year. Copies of this 366-page book can be ordered direct from: www.davesbigwalk.com at £14.95 (incl. p. and p.); a 'Kindle' edition is also available from Amazon.

This book I hope will appeal to a wide variety of readers. To begin with, it might bring encouragement to those individuals that have been affected in some way with prostate cancer or other forms of the disease, that there can be a good life after treatment.

For those wishing to start walking seriously, a section at the back of the book is aimed at achieving fitness through a walking activity programme entitled 'Step-by-Step'; a formula based on my own walking experiences. It might also provide inspiration to the many senior citizens among us who would like to improve their fitness levels, and in consequence, their lifestyles.

When walking long distance, thoughts slide uninvited into the conscious mind, some to be mulled over, while others come and go in rapid succession. Memories of the distant past emerge; a recollection of events and times long forgotten; the war years, a father killed, a mother's grief, evacuation, the post-war period, impoverished childhood and teen age years; a parallel journey that becomes interwoven within the pages of the book. Some aspects of the publication will enlighten many on the geographical details of England; for instance, I didn't know that there was a town in England



called Boston; I was unsure where places like Lowestoft, Maryport or Chelmsford were located on the map; I'd never heard of places with intriguing names like Sandwich or Seahouses, and I once thought that Skegness was in Scotland! Those of you interested in history will gather significant information in the 'Notes of interest' section about the town or area where I stop after each day's walk, for much of this information will be of an historical nature.

Most important of all, the book gives you the opportunity to accompany me through some of the most beautiful parts of England. You'll become aware of the remoteness of the northern Pennines, and reflect upon the dramatic and rugged coastlines of Northumberland and those breath-taking coastal stretches seen from the south/west coast path, or you might ponder

over the geological wonders of the Jurassic coast. Follow me along sealed pathways that were once the route of steam trains from days gone by; paths that will take you through the lovely Wirral Way or parts of the Tarka Trail or through some of Yorkshire's scenic countryside and coastal region. We'll follow dykes made by a self-imposed king of the 6th century and discover places like the charismatic Welsh border village of Tintern and the evocative but beautiful ruins of Tintern Abbey in the River

Wye valley.

While turning the pages you might visualise the grandeur of the Lake District or imagine the tranquillity of walking along a canal tow-path in Lancashire or maybe glimpse a scene or two from yesteryear. So wander with me around this land and I'll lead you along delightful coastal paths and through charming villages, but also through unsightly industrial regions and uninspiring city urban areas. We'll walk through verdant, canopied byways and leafy, overgrown bridle tracks; places unfrequented that busy lives have long forgotten.

Discover an England that many have never seen!

We hope that David Wilson may be able to come to give a talk to PCaSO about his journey at some future point.



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A unique course that can optimise your healing potential, for everyone affected by cancer.

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Need a Holiday?

The Grove Hotel, Bournemouth, close to the cliff top, sea front and shops, offers a unique holiday, as it is open only for cancer patients and those with life-threatening diseases and their family or carers. It was opened in July 2011.

There is a qualified nurse on call 24 hours in an advisory capacity. The Grove is owned and operated by 'Macmillan Caring Locally' based in Christchurch, Dorset and is a non-profit making organisation.

*For more details contact the manager,
Brenden Howard, The Grove Hotel, 2 Grove Road,
East Cliff, Bournemouth BH1 3AU (tel: 01202 552233).
www.thegrovebournemouth.co.uk*



STUART'S DALES WAY SPONSORED WALK FOR PCASO - 10-16 MAY

As a casual weekend walker I'm pleased to be able to report that I succeeded in walking the 83 miles that make up the Dales Way. It was never intended to be a sponsored walk until John Harmer put the idea in my head that I should be raising some money for PCaSO; and so the idea was born.

The scenery in the Yorkshire Dales is absolutely stunning and on the days we could see it, made the walk a real pleasure. So to be paid to take part in such a walk was absolutely brilliant. I and four friends travelled up to Ilkley to stay overnight before making an early start the next morning. Our luggage in an act of faith would be left behind at each overnight stop with the expectation it would be waiting for us on arrival at the next day's stop for the night. It worked! Our luggage was always waiting for us.

Early on the morning of the 10th May we left Ilkley in pouring rain which did not cease all day. The Wharfe was in full spate and we had to make a few diversions on the way as we followed the river throughout the day. Thirteen miles later we arrived in Burnsall for the night to dry out and get some rest. This was to be the pattern for the remaining six days and, although we didn't know it at the time, the weather slowly improved through rainy, rain and prolonged showers,

sun and showers and then finally, as we approached Bowness-on-Windermere, a day of sunshine.

On the second day we did the eleven miles to Kettlewell via Grassington, staying at The Bluebell Inn for the night. The Dales Way is very well marked and as it follows river valleys for most of the way it is generally fairly easy walking. We now began to see fellow walkers of different ages and fitness on the route, some we would come across all the way to the end.

The next day, the Saturday, we walked a further eleven miles into some of the most remote countryside on the walk as we left Wharfedale to arrive at Oughtershaw. We stayed the night in B&B in a lonely farmhouse which thankfully was right on the Dales Way. No need to detour and find the overnight stop! Next day was the hardest of the whole walk as we had to climb up and over the Pennines, across moorland and onto the Pennine Way. The views here were stunning but we had little time to stop and enjoy it. Eighteen miles later we reconnected with our luggage in Dent. We were now in Dentedale.

Monday the 14th was a quieter, shorter day as we moved out of Dentedale and walked to Sedburgh. Sedburgh was an interesting town as it considered

itself to be the English equivalent to Hay-on-Wye with a number of bookshops spread throughout the town. The next two days to the finish took us to Windermere via Burneside and into the Lake District.

I found the whole week a unique, almost surreal experience which, besides the physical side, was also an opportunity to get away from the hassle and 'noise' of

modern living. On the days walking you were simply wrapped up in your small part of the world away from the hurly-burly of modern life. I'm very grateful to everyone who sponsored me and pleased to be able to report that it raised £600 for PCaSO.

Stuart Thompson

CENTRAL BRANCH ACTIVITIES

Down House Open Garden

Fortunately the weather was kind to us on Sunday 24th June for the Open Day at Jackie and Mark Porter's wonderful garden at Itchen Abbas. It was warm and sunny but with a blustery wind. A steady stream of cars came throughout the afternoon and as usual the event was very well attended. The garden and vineyard are maturing well and were



thoroughly enjoyed by all. Mark Porter was on hand to answer all manner of questions about flowers and gardening in general. His expertise has been recognised in that he has been elected as one of the 15 Council members of the Royal Horticultural Society. Congratulations, Mark.

An added attraction on the day was generously provided by PCaSO member Paul Blythin and his Alley Catz jazz band. They regularly turn out for this event and are very popular with the visitors who can relax in the garden and on the terrace having tea whilst enjoying listening to the music. Thank you, Paul and the members of your band. Our thanks go also to all those who helped with the teas (including baking cakes), taking the entrance money and controlling the parking. Most of all however our thanks go to Mark and Jackie for hosting this very enjoyable event. The proceeds from the day go to support cancer charities with a

quarter donated to PCaSO. This time the donation to us was £396 which is very gratefully received.

We look forward to Snowdrop Sunday at the Down House in February at which PCaSO will again be a beneficiary.

Geoff Bailey

Collections

We have held four supermarket collections this year, the two earlier ones raising £919. In the summer the June collection at Tesco Havant raised £928.86 and the July collection at Morrisons, Horndean on 13-14th July raised £964.70.

I would like to thank all the collectors who gave of their time, and especially to Alan and Pat Bristow who, despite severe illness, always turn up and give their support. It is sad to think that we rely on a few dedicated people when there are so many who are better able than some of our team in our PCaSO organisation.

John Harmer

Meetings

We held two meetings this season, both in Chichester. In May we were pleased to welcome Mr James Hicks, consultant urologist at St Richards and Worthing Hospitals, who ably undertook a 'Questions and Answers' evening. This letter from a member says it all; "I thought last night's meeting was absolutely first class. James Hicks was most impressive, combining a dedication to urological oncology and an up-to-the minute knowledge of his specialty area with an obvious and genuine sensitivity to the perspectives of patients." Thank you, James.

On July 25th we were joined by Rowena Bartlett, the new Development Director of the Prostate Cancer Support Federation, who spoke about

her work with the Federation and there was much interest and useful comments from the small audience.

The next meeting at Otterbourne will be on **Monday 3rd September**, with a talk on 'Continuing Care - before and after' by Kim Emery from Macmillan Cancer Support.

Donations

The Branch acknowledges with thanks donations received from the Southampton Valuation Office Sports and Social Committee (£200), Andrew Ferguson (£240) and Basingstoke Tangent Club (£200).

DUMMER 2012

Ironically I'm writing this short article on the day the PCaSO golf day at Dummer was supposed to have taken place and the sun, for a change, is streaming in through the window. We reluctantly had to take the decision to cancel this event about five weeks ago due to the low number of entries we had at that time and the probability we would not have had enough golfers signed up by the 23rd July to have a meaningful day of golf. The event had taken place successfully over the last 10 years, raising a substantial amount of money for PCaSO and the decision to cancel was not taken lightly.

Looking to the future we will still hope to hold a golf day but it may be in a different format and not necessarily every year.

We are very grateful that Andrew Ferguson, one of the few entries, who has donated his entry fee of £240 to PCaSO rather than have it returned.

Stuart Thompson

EAST BRANCH ACTIVITIES

The Brighton Group held its second PSA testing event using the Bioscan machines, at the Robin Hood pub in Brighton on 16th June. The two nurses using the machines were kept busy with a steady flow of men keen to know their PSA. For many this was their first time, having been encouraged by Barry Cocum and Joe Ambrosio, who were outside talking to men about having the test. We tested nineteen men in three hours using two machines; all were normal readings bar one that was borderline; he was recommended to have a further test done by his GP.

Dr Richard Fuller, who works at the Dove Clinic in Twyford, will be speaking at the next Rustington Group meeting on 25th September about the 'Immune System, Nutrition and Prostate Cancer'. Dr Fuller recently carried out a

small stage I trial that some PCaSO members took part in, looking at boosting their immune systems by taking natural remedies, one of which was AHCC, a mushroom compound found in Japan that, when taken on a regular basis, has been shown to enhance the immune system, which helps fight off diseases including cancer. Results shown in this first trial have been encouraging and it is hoped funding from Japan will be available to launch a much larger stage II trial in this country, in which some PCaSO members may be interested in taking part. Dr Fuller will be talking in detail in Rustington on the 25th September about AHCC and how it helps boost the immune system. If you are able to come to the meeting it should prove very interesting. More information about AHCC can be found on the internet; just enter AHCC into 'Google'.

The next meeting dates for East Branch groups are:

Eastbourne on
Thursdays 13 September, 11th October and 6th November, at 7.00pm

Brighton on
Wednesdays 22nd August and 7th November, at 6.30pm

Rustington on
Tuesdays 25th September and 4th December, at 7.00pm.

See back page for full details of venues and speakers, correct at the time of going to print. Please check our website www.pcaso.org for any changes and updates.

Roger Bacon

Note: all members of PCaSO are free to attend any meeting of any branch. Non-members and partners are also welcome.

DORSET BRANCH ACTIVITIES

The sum of £625 was raised for Dorset PCaSO through a concert given by the Boscombe Salvation Army Band at Weymouth in June. The concert was organised by Jane and Margaret of Cotton Funeral Directors who shared the proceeds between breast cancer and prostate cancer in Dorset. Jane's husband, Peter, was a victim of prostate cancer and this has inspired her to support existing and future prostate cancer sufferers.

This is the third occasion that the Dorset Branch of PCaSO has benefitted from such a concert, which was very well attended. The widespread reputation of the band is due to the continuing high standard of performance set by Howard Evans, the band's Musical Director. The programme included several arrangements of film music and classic pieces – notably the terrifying performance of the "Dies Irae" from Verdi's *Requiem* which made both church and concert audience reverberate to the sheer power of the band unleashed upon them. The band also has a number of impressively talented soloists who demonstrated their virtuosity in their chosen pieces.



Altogether a very moving and stirring evening and I look forward to similar future occasions. Many thanks Jane, Margaret, Howard and the band!

Jim Davis

Further Dorset fund-raising activities are being held at the Luscombe Valley Railway (17 Brundell Ave, Sandbanks, BH13 7MW) – an Autumn Gala on 8-9 September and Humbug Day on Saturday 22 December, both 11am-4pm.

WHO'S WHO

Patrons:

The Duke of Richmond and Gordon
The Very Rev. Nicholas Frayling
Baron Palumbo of Walbrook
Bill Beaumont, OBE

Founder:

David Rowlands

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WHAT'S HAPPENING

East Branch meetings:

Wednesday 22 August: BRIGHTON (Audrey Emerton Building, opposite the main hospital), 6.30pm

Tuesday 11 September: EASTBOURNE, 10th Anniversary tea, (Post-graduate Centre, Eastbourne Hospital), 2.30pm.

Tuesday 25 September: RUSTINGTON (Woodlands Centre, Woodlands Rd, Rustington, BN16 3HB), 7.00pm. Speaker: Dr Richard Fuller on 'The Immune System, Nutrition and Prostate Cancer'

Thursday 11 October: EASTBOURNE (venue as above), 7.00pm.

Wednesday 7 November: BRIGHTON (venue as above), 6.30pm.

Thursday 8 November: EASTBOURNE (venue as above), 7.00pm. Speaker: Ann McEwan from Prostate Cancer UK.

Tuesday 4 December: RUSTINGTON (venue as above), 7.00pm.

Central Branch meetings and events:

Monday 3 September: OTTERBOURNE Village Hall SO21 2ET, 7.00pm
Speaker: Kim Emery (Macmillan) on Continuing Care – before and after.

Wednesday 7 November: CHICHESTER Baptist Church, (Sherborne Road, Chichester PO19 3AW), **afternoon meeting, 2pm.** A Patients Forum.

West (Dorset) Branch meetings:

26 September, BOURNEMOUTH: (St Mark's Hall, Wallisdown Road, Talbot Woods, BH10 4HY), 7.30pm. Speaker: Mr Robert Crellin on the Role of the Oncologist in the Treatment of Prostate Cancer.

28 November (venue as above): Social Evening.

Responsibilities

Newsletter editor: Ian Graham-Jones
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Secretary:

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John Harmer 02392 631599

Committee members:

Geoffrey Freemantle
Chris White
Geoff Bailey (membership)

DONATIONS

We are grateful for a donation to PCaSO Executive funds of £100 from Mr Lawrence Jones.

The Prostate Cancer Charity is now
renamed **Prostate Cancer UK** –
website: prostatecanceruk.org

Dorset Branch Committee

Chairman: vacant

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Membership Secretary:

Clive Duddridge 01202 893615

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