

prostate matters

the voice of prostate cancer patients and their families

Newsletter of the Prostate Cancer Support Federation  Issue 15 Winter 2012

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Worried or concerned about prostate cancer?

National Help Line

0845 601 0766

Prostate Matters Editor: Hugh Gunn
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You can download this newsletter direct from our website. Go to:

www.prostatecancerfederation.org.uk/ProstateMatters_latest.pdf

The Federation email address is:
info@prostatecancerfederation.org.uk

This newsletter is published 4 times per year

If you would like to comment on an article, or publish a report of your event in Prostate Matters, please contact The Editing Team

 Prostate Cancer Support Federation

the voice of prostate cancer patients and their families
Reg. Charity No. 1123373

Abiraterone - A Call to Action!



On February 2nd, NICE announced that in the first consultation paper for Abiraterone, they are not recommending its use. This is the first stage of the process and we all have the opportunity to have a say and try to reverse this decision.

It is very important that we all contribute to this appraisal and register our disapproval. Here's how. Log onto:

<http://guidance.nice.org.uk/TA/Wave26/4/Consultation/DraftGuidance>

There, you will find a form in which you can send your comments to the NICE panel. This needs to be done by February 23rd 2012, please do not miss the deadline! If we can all contribute, it will carry a lot of weight.

Abiraterone is the only EoL treatment currently under consideration by NICE, as they have just refused Cabazitaxel. It is highly successful and long lasting. It is easily administered, just four tablets a day and the side effects are minimal. Nothing worse than current hormone therapy. It should give us all great hope for the future and it must be passed for use by the NHS.

In view of the fact that NICE has already refused Cabazitaxel, it is even more important to try to make sure that Abiraterone is made available for general use in the N.H.S.

At the moment, until 2014, Abiraterone is available under the Cancer Drugs Fund for men who have failed chemotherapy, as is Cabazitaxel.

2012 Annual Conference and AGM of the Prostate Cancer Support Federation, 25th April 2012

SCREENING FOR PROSTATE CANCER - ARE WE MAKING PROGRESS?

The Royal Pump Rooms, Leamington Spa, commencing at 1100. Save the date!



Attendance is free – to book your place go to the Federation Website or call 01614 74 82 22 and leave a message stating name, contact number or email, name of member group and any dietary restrictions

Prostate Matters is kindly sponsored by



Penile Rehabilitation

www.iMEDicare.eu

MY PERSONAL PC JOURNEY

By Nigel Lewis-Baker



I always considered myself very fit being slim and active with military service and a busy life in international airlines behind me. When I began to need to urinate more frequently I just worked round it and adjusted as well as I could, until I realised it was becoming a problem. Having my own business I had to travel to London quite often and it became a matter of programming to ensure I could get from one place to another without being taken short. I could almost draw a map to be called 'Toilets of London'. Eventually I decided I had to seek medical help – but where would my income come from if I had a more long term problem to sort out, and who thinks they have 'Cancer'? My first task was to get a paid job and serve my six months' probation to qualify for sick pay, but eventually the opportunity came and I dashed off to the surgery. Like most chaps, I went with some other ailment and only mentioned the real reason for my visit on the way out. He, also typically, dismissed the problem as age related – and I was only 58! As the discomfort was increasing I went back to see another doctor and he immediately took a blood sample and it was only a day later that he called to say he had made an appointment with a Urologist.

After the usual tests the urologist called me in to tell me I had inoperable, incurable, local advanced prostate cancer. It meant nothing to me as I had no knowledge of the 'prostate' and my brain and ears closed down after the word CANCER! I drove home wondering if I would see Christmas and trying to list things I had to do, see, buy or experience in the time I might have left and, having had a very full life, the only item I really wanted and had never had was a two-seater sports car – so I stopped on the way home and bought a Mazda MX5, which I still have and cherish. The news that I had probably had prostate cancer for five years did nothing to soften the blow but my only anger was that I had not known about this gland and that there had been no

tests, essential in my case with no symptoms, until too late. That was the start of my campaigning although I had no idea where and how at that time.

Despite the radiotherapy and hormone treatments I managed to keep working for a further three years until fatigue and lack of concentration made me decide to take early retirement from a responsible job although only 61 and four years from state pension. Until I was 65 we had to live off savings as we did not qualify for any benefits or grants, which made me think of all those people without the backup we had managed to squirrel away.

Not being brain dead I looked for something I could do to help cancer charities and tripped over the CRUK website in which there was an appeal for committee members for a new Relay for Life at Ascot and, although I had no idea what Relay was, it was only 20 miles away. That led on to becoming a Cancer Voice for them, Macmillan Cancer Support and the Prostate Cancer Charity giving talks and media interviews and campaigning for better treatment and welfare for cancer patients and their families. I also review publications for these charities prior to their release, which is a job anyone with a cancer experience can do from their own home in their own time. Nowadays I can add lobbying MPs in Parliament, attending All Party Parliamentary Groups on cancer and men's health, interviews on TV, radio and local and national press and a trip to New York to talk with the United Nations about a then forthcoming summit meeting on non-communicable diseases. Locally I found no support group to talk with and learn from so I started Topic of Cancer that now has 46 listed members and we meet on the second Thursday of every month with guest speakers, demonstrators, trips to the theatre and other ideas brought in by the members. The Great Drag Race was another opportunity to raise awareness and embarrass my wife and family. Invitations to speak have come from charities for patients, families, supporters and staff, from hospitals, conferences, Festivals of Carols and business and charitable organisations. Before my diagnosis I was terrified by the thought of standing on a stage talking but I now have something to say and relish the chance. I consider I have a new career rather than an illness.

Along the way the treatments began to fail and I volunteered to move to the care

and clinical trials of a research team that had been created and is co-funded by a group of 12 volunteer trustees, patients and consultants, called the Prostate Project. This was a decision that changed my life and gave me back some control of my situation with a small group of scientists and nurses to whom I was once again a real person. In 2010 I became hormone resistant and was put on the 'Enthuse' trial, which had very uncomfortable side-effects, and whilst I was at a very low ebb I received a couple of e-mails. Macmillan Cancer Support made me a Cancer Champion and the American Cancer Society named me an International Hero of Hope. Later I became an Ambassador for Cancer Research UK and in 2011 they presented me with their 'Flame of Hope' award as joint Ambassador of the Year whilst the ACS promoted me to Global Cancer Ambassador and flew me to New York.

Now, having organised some fundraising events for the Prostate Project, I have been made a Trustee myself and am buried in organising the greatest appeal we have ever launched to raise £3m for continued research into the EN2 urine test for prostate cancer, the HXR9 trials and other work being done by our research team We also plan to bring medical and clinical research together under one roof with a state of the art



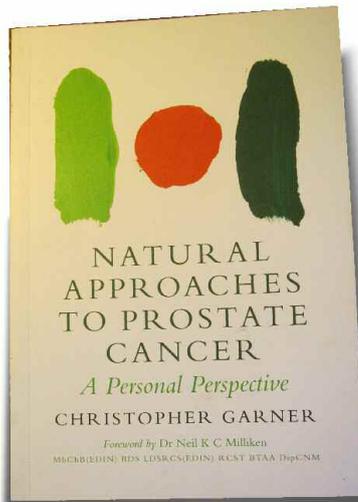
urology centre – so watch out for The Love Train, it could be coming your way very soon. Please jump on board to support us and all men with this dreadful disease.

I have agreed to write this article about myself over almost eight years in the hope it will show other chaps with a similar diagnosis that it is not necessarily the end – it might be just the beginning. Give it a try, you will probably enjoy it and you will certainly be helping others as well as Natural Approaches to Prostate

Natural Approaches to Prostate Cancer: A personal perspective

by Christopher Garner

Reviewed by Sandy Tyndale-Biscoe



This well written, and entertaining book is aimed at men who are diagnosed with low or intermediate risk prostate cancer (PSA < 10, no symptoms). It is, in essence, a very personal account of a man in his early 60s (“he’s a young man, about my age”) who, after a PSA test initiated diagnosis of a small prostate cancer tumour of Gleason score 6, chose to ignore his clinician’s advice, reject conventional treatment and go for Active Surveillance, at the

same time adopting a set of lifestyle and dietary changes that would enhance his body’s natural armoury to protect itself against the disease.

His rationale for this approach follows this line of argument: first of all it is a holistic view; the human body, as a total organism, is very well adapted to fight intrusive diseases such as cancer, and has a wide variety of weapons with which to do this. It is an unarguable fact that all conventional treatments of prostate cancer effectively undermine these defence mechanisms. For sure, none of the conventional treatments for prostate cancer do anything to assist the body’s own defence mechanisms against cancer. Some of them (chemotherapy and hormone therapy, for example) clearly act against these natural mechanisms. Garner does not say it, but I guess he would regard conventional prostate cancer treatment as a treatment of last resource.

The book does not discuss conventional treatments, as the author recognises that they are well covered elsewhere. Instead it acts as a guide to the bewildering array of complementary (possibly alternative, but it is unwise to use the “A” word in medical company) treatments under four broad headings:

- we are what we eat and drink,
- we are what we do or don’t do,
- we are where we live, and finally, and least well addressed elsewhere
- we are what we think and feel.

And a remarkably comprehensive guide it is. I cannot go along with all the ideas put forward (indeed, I’m not sure the author does), but as a wide ranging review of all the options available to a man to help himself fight prostate cancer it is unmatched. What is for sure is that none of approaches described will harm a man in his fight, and quite a few of them will do positive good. It has the further advantage of being an entertaining read, containing, in particular, one of the best risqué jokes I have read in a long time (it’s on p39 for those who are interested).

Above all, this is a holistic view of how to fight prostate cancer. Of course, the problem of the holistic, “mind based” approach is it only takes a few to fail (out of thousands) for the whole idea to be rejected. Someone ought to point out that “no-one said it was easy!”

The book reviewed is a version published 2 years ago, and we here at “Head Office” still have a few copies left. These are available free (plus postage and packing), and the reader is invited to make a donation to the Maggie’s Centre. This version of the book can be downloaded from the Edinburgh and East Lothian Prostate Cancer Support Group website: <http://tinyurl.com/89q3nqd>

A revised version will shortly be published, which contains latest information on the complementary scene. Furthermore, the text is de-Scottified. The original was written with Scottish audience in mind (and was funded by Edinburgh & Lothian Group & offered free). The revised version has a UK/International perspective. This version will be available on Kindle and is expected in March. For details see: <http://tinyurl.com/7sw6nvd>.

Prostate Cancer Support Federation Appoints Rowena Bartlett as Development Director

The Prostate Cancer Support Federation is pleased to announce that, thanks to the continuing long-term support of Prostate Action, we have been able to appoint Rowena Bartlett as Development Director, with effect from 1st February 2012. The purpose of this appointment is to develop and implement the strategic goals of the Federation, to lead in developing and implementing a fundraising strategy, to provide sound financial management and to manage day to day operation of the Federation.

Rowena initially worked in the arts, first as an antiquarian bookseller and then at Sotheby’s in London. She then moved into the not-for-profit sector and ran the Friends of the Royal Scottish Academy of Art in Edinburgh, raising funds for the Academy. Later followed a position as a fund-raiser for Kidscape, a children’s charity in London.



She was then asked to set up The Haven, a breast cancer support charity which now has centres in London, Hereford and Leeds. She was their Chief Executive from 1997 to 2002, then became a Trustee for seven years, before returning as interim CEO between 2009 and 2010. She also took on the role of governor at her local primary school in Hampshire.

Rowena’s initial priorities will be to develop the Federation’s funding position into one in which it will be self-sustaining over the long term and in a position to achieve its strategic goal of being recognised as THE prostate cancer patients’ voice across the UK.

You can meet Rowena and discuss with her how the Federation can better support the needs of member groups by coming to the AGM on 25th April (see front page)

The Confessions of a Kamikaze Cowboy by Dirk Benedict

Reviewed by Trevor Carter

The Confessions of a Kamikaze Cowboy is the autobiography of a lesser known Hollywood actor who, using a typically poetic turn of phrase, describes himself as “just a little nipper faintly twinkling on the edge of prime time”. The subject matter that Dirk Benedict pronounces upon is huge; he provides not only thoughts on food but food for thought on a variety of issues. He is very much concerned with principles rather than specifics, as the underlying message is to find your own path and take responsibility for it while accepting “Mother Nature as the real healer”. The book abounds with homespun philosophy on the psychology of romantic love, how modern womanhood has lost its way and the origin of art. But most pertinently it’s about how his take on the world has enabled him to overcome, amongst other ailments, prostate cancer.



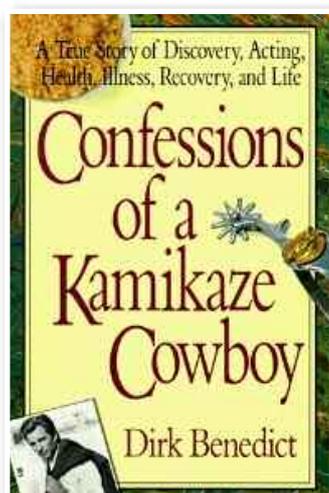
Trevor Carter

Benedict is a natural polemicist. Although he sees life as a quest for natural balance, there is little that is balanced or moderated about his message. For example he describes most art as “the emotional, intellectual discharges of sick people inflicting their diseases on their fellow man,” while psychoanalysis is total “futility”. Benedict clearly feels strongly about what he identifies as the dysfunctions of contemporary American society. And high on his hit list is the American medical establishment, which, in his view, merely manipulates the post-war cancer epidemic for its own ends. Never one to pull his punches, at one point he boldly asserts “As long as you believe that doctors know anything about health, you are lost”. He does not say what his response is to those who appear to have overcome cancer by medical means. We can only conjecture that his position may be that they could have done so without the horrible side effects if they had put their faith in a natural remedy. He readily concedes that doctors may be brilliant at dealing with injuries and physical traumas, but maintains that when it comes to degenerative diseases they have nothing effective to offer. However, he reserves his most venomous comments for the fast food industry, commenting that “to poison generations of children all in the name of money is a crime for which there is no punishment and possibly no redemption.”

Many may find his drama queen style over the top, and

dismiss his ideas on health as either fantasy or delusion. And it may be that he undermines his message by making brash sweeping generalisations. Nevertheless, he offers no off-the-peg prescriptions, and also warns that alternative treatments are “as haphazard as traditional medicine.” He emphasizes that this is not a “how to” book but a “way of life book”. He does not regard himself as infallible and freely admits “my path has always been one of extremes, never knowing what was enough”. For example, he reflects that he made himself seriously ill by changing too rapidly from a dependency on meat and dairy products to a vegan diet. If your reaction is to dismiss this quixotic offering as absurd, then I suggest you consider the following quote from Hippocrates (author of the Hippocratic Oath) which Benedict draws our attention to: “Let food be thy medicine and thy medicine be food”. As my sister is a doctor, I took the opportunity to ask her how much of her medical training covered nutrition. “We didn’t cover nutrition at all”, she said, “but I’d like to find out about it”.

So I wonder has something gone wrong here? Is Benedict on to something? He has, as he points out, survived many of his detractors. He talks a lot about letting go, pointing out cancer is “a disease of the spirit as well as the body”. And even if you disagree with the underlying message, you may nevertheless find this rather abrasive philosophical ramble hugely entertaining, possibly uplifting or even inspiring.



Emma's marathon for Prostate Action



So, can you believe it on 22 April I will be running the London Marathon for my wonderful charity Prostate Action. I realise this is quite surprising, the idea of me running for a bus is amusing, but here I am 5 weeks into my training, doing well with

the running but needed to do better with the fundraising, and that’s where you all come in. For some reason as the boss I thought I ought to set myself a significant target – so have gone for £4,000 – a huge amount. I’m over ¾ of the way there, but need help to hit my target. Prostate Action is a fantastic charity (I know I would say that I’m the boss) so please, even if you can only sponsor me £1 every little helps, and everything I raise will go towards our vital research and education.

<http://www.justgiving.com/Emma-malcolm2012marathon>

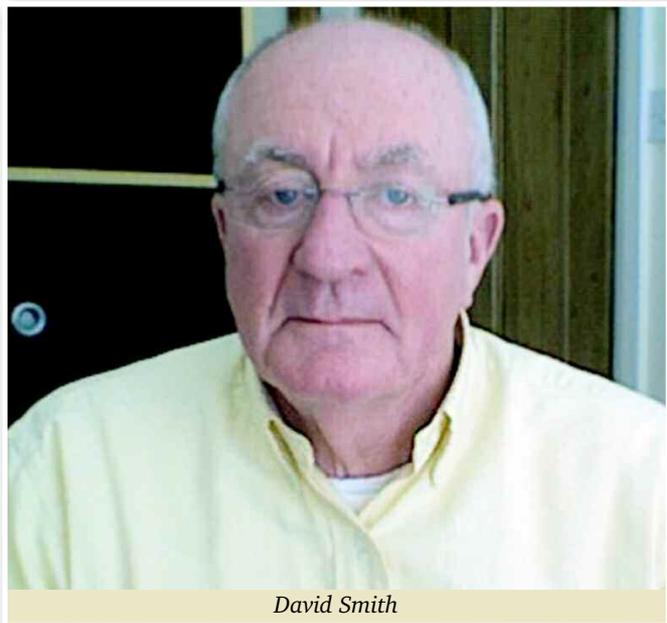
or if you’d rather just send a cheque to our office, whatever is easier, just please do sponsor me, as it will give me even greater incentive to get over that finishing line.

The conference is 3 days after the event, so I’ll even bring pictures to give you all a laugh!!

Emma Malcolm, CEO Prostate Action

“Riskman” Trial Progress

by David Smith



David Smith

A brief recap for those readers who have not heard of the “Riskman” trial funded by the Federation with contributions from Sanofi-Aventis.. The trials aim is to put a prostate cancer biopsy decision tool on the desk of every GP in the country; it is hoped that this will reduce the number of men who have to have this procedure. “Riskman” is a four year trial being carried out for us by Professor Ken Muir and his team, of the Warwick Medical School, Mr. David Baxter-Smith a urologist and Graham Fulford through his charitable Trust. The cost of the trial will be in the order of £2.5M and to contain this the wives of David and Graham give a great deal of their time pro bono for data analysis.

The decision tool, a nomogram created and trialled in Canada has been adopted by the Prostate Cancer Support Federation (PCSF) as the best of a number of risk calculators for the GP market place. The tool incorporates seven factors that are considered key indicators for the potential presence of prostate cancer and factors them according to their degree of importance. For instance PSA is included but actually has a lower numeric value than the digital rectal examination score. Others factors are the ethnicity, familial history, age, urinary symptoms score and finally the factor that carries the heaviest weighting is the Free-to-Total PSA score. The latter is an adjunct to the PSA test and measures the percentage ratio of proteins attached to PS antigen to those that are free. Below 20% free is considered a significant factor in the possible diagnosis of a high- grade cancer.

The initial phase of the trial has been completed and the team is about to go out and gain acceptance to publish the data in two journals that are read widely by the GP population. The raw data for the trial came from the countrywide PSA testing carried by David and Graham under the auspices of the Graham Fulford Charitable Trust. Over 21,000 men have been tested and each has received a letter advising him of the result of the test. Back at the office these were coded green for clear, amber for on the cusp and red for definitely needs further investigation. Subsequently the

team has developed a survey given to 3,000 of these men, randomly selected, that questions them on a number of issues; typically did they follow up and what were the results if they did, how happy were they with the process, did the GP co-operate, what treatment if any did they have, did they experience symptoms of erectile dysfunction. The team worked hard to get the survey questions right and unambiguous. The response rate of 70% shows just how successful they were. Just to pick out two conclusions from the survey: 98% of the men were happy with the process and would recommend it to their friends and family, which makes a nonsense of the government line that men would worry about having a PSA test and need counselling. The second item that had the team chuckling was that there were more greens experiencing ED than reds!

In parallel with the testing data analysis was the very important development of the trial protocol, which details the procedure for the trial and must conform to MRC guidelines and be acceptable to the GP community who in the next phase are going to be heavily involved. There have been some issues that have frustrated the team in getting this document signed off by the NCRI as their chairperson was off on long term sick leave and there was no one else to sign. It has now been signed off and the team can proceed with the GP element of the trial. A survey of a 100 GPs around the country gave resounding acceptance of the trial and its objectives.

Two GP Midland networks with research experience and links to Birmingham Medical School have been selected – Litchfield and Redditch. They will be the pilot phase for the large GP rollout.

It is at this stage that the trial has to go slow or even on hold for lack of funds; commercial organisations are reluctant in this climate to provide grants from their reduced budgets, charities grants in part because of this have become so competitive that only trial topics that hit the headlines are considered. The Prostate Cancer Charity is reorganising the way it allocates its grants under the new CEO and a new Movenber policy. We will get funds because we are constantly going out to foundation trusts and charities but it will take time. The steering committee of the trial meet every month and this is a regular agenda item but we are not the sole source of expertise in fund raising and if any person reading Prostate Matters can give us a funding lead we would appreciate it.

Please Check Your Details

Please would all affiliated members check on the PCSF website, that their details are correct on both the map:

<http://tinyurl.com/429ee7f>

and the contact web page:

www.prostatecancerfederation.org.uk/membershipList.htm

If there are any alterations, please contact:

Sandy Tyndale-Biscoe

Email webmaster@prostatecancerfederation.org.uk

Oxfordshire Prostate Cancer Support Group

Report on Prostate Action's awareness event on ITV's This Morning

Successful, Organised, Chaos

At 6am on Tuesday 15th November, a party of 14 men and two wives set out from Oxford to join up with the rest of their group of 34 at the London South Bank, to take part in the ITV programme 'This Morning' hosted by Phillip Schofield and Holly Willoughby.



Dan Doolan PR for Prostate Action, Paul Ross, George Goldsmith OPCSG, Dr Jon Rees, Simon Lord OPCSG

In the first ever live prostate exam to be shown on national television, Prostate Action teamed up with ITV to raise awareness of prostate cancer and to encourage more men to visit their GP. Volunteers from around the country queued up on the Southbank in London to be given a Digital Rectal Examination (DRE), to prove that the test is quick and painless.

The men were to have no previous experience of a DRE and be willing to undergo the check by a doctor, on the day. They would be questioned, prior to the test, about what they imagined it would be like and later about the actual experience. Three of the volunteers had also said they were prepared to be tested 'live' on TV. They also asked for four men who had, or were having, treatment to be available for interview.

Everyone arrived by the appointed time, 8.30, and were taken up to a 'holding area' for a briefing. There would be a practice run-through for everyone. The event would be in two 'hits' – one prior to the examinations and one later. The filming would all take place outside on The South Bank in a specially adapted trailer/studio. ITV Doctor Chris would be present and in addition, Doctor Jonathon Rees would carry out the tests. Doctor Chris would be carrying out a DRE, live on air, on Paul Ross and Jason Gardner would also be included to discuss the illness.

Then reality began to set in. There was a delay with the practice run-through – it never materialised. The four to be interviewed was suddenly reduced to three without warning or apology. The volunteers were directed to the outside studio where they stood by The Thames for well over an hour with nothing to do, but watch Dr Chris performing on Bertie Bottom. Suddenly we were told that we were on next, live, and would be asked by Philip questions focusing on the after effects of our treatment. We were, not quite but almost, told what we should say and suddenly we were on.

In the meantime, Dr Chris gave Paul Ross a DRE, live on air, which was a very good PR job. The volunteers still waited.

The interviews, in fact, were quite a success – we worked around the questions to get over the message we wanted to. Paul Ross was also interviewed at the same time. The cameras then cut to the volunteers to be interviewed by Holly. She spoke to three of the volunteers who put there points over very well.

In the situation we were in, you tend to lose all sense of time. Holly finished her interviews and told the viewers that the volunteers would be examined.

Immediately, it was a though a 'three minute warning' had been sounded. The (many) camera crews scurried away, quickly followed by the sound and lighting crews. The producer announced that we could all 'go home now'.

Dr Rees who had come from Bristol to carry out the examinations, but had done nothing all day, and the volunteers, looked on in controlled amazement. Emma from Prostate Action asked 'what about hit 2 and the examinations' and was told that they had run out of time. The troops were not amused.

Emma apologised and Dr Rees offered to see anyone who needed urgent advice and suggested that the remainder should make appointments to see their own GPs.

At last something positive for the men. In fact, the first man examined was advised to get an appointment with his own Doctor the next day. (This he did and is awaiting the results of a PSA test)



Dr. Chris Steele and Dr. Jon Rees

Thoughts of the Group, when the dust had settled.

There was disappointment about the way the event had been changed around. This however was outweighed by the fact that the message had gone out to 2million viewers. It had also been most illuminating to see how a live TV programme gets produced and looks very professional, despite the constant changes brought about minute by minute.

In summary – A positive result and event not to have been missed.

Simon Lord

Congratulations to Simon Lord, Chairman of The Oxfordshire Prostate Cancer Support Group, who won the Movember Mustache competition. Unfortunately, it has already all come off!



Also from Oxford, **Dave Beesly** very bravely had a U-Tube video made of his Radio Therapy treatment. You can view it on: <http://www.youtube.com/user/OPCSG?feature=mhee>

Urinary Incontinence Post-Prostatectomy

afex is the answer
for male incontinence management

On NHS Prescription

Fights Rash, Odour and Embarrassment

Comfortable, Convenient and Cost-effective

Comfortable: Loose fit, adhesive free receptacle with double-wall design reduces exposure to residual urine.

Discreet: Briefs conceal system under clothing. Double-sealed collection bags effectively contain odour.

Convenient: Collection bag connects simply with our twist-n-lock design and easily drains.

- Biofeedback is a training program that can be used to reinforce the proper performance of Kegel exercises.

Until urinary control returns

- To control leakage, you can wear an absorbent pad inside your underwear or an AFEX Urinary Collection System. These aids are available via your GP or local continence department.
- Until urinary control has returned, avoid drinking excessive amounts of fluids.
- Limit alcohol and caffeine intake.
- Empty your bladder before bedtime or before strenuous or vigorous activity.

The prostate gland sits just below the bladder and completely encircles the urethra at the point where it leaves the bladder. When the prostate gland is removed in a *radical prostatectomy* or receives *radiation therapy*, damage can occur to the urinary sphincter. Depending on the extent of the damage, temporary or permanent incontinence can result. Following radical prostatectomy, the prevalence of incontinence at 1 month after surgery is high, ranging from 4% to 87%. However, UI tends to diminish over time, and recovery is observed in most cases in 1 to 6 months following surgery.

Stress incontinence, urine leakage with activity, is the most common type of incontinence after prostate surgery. It is usually caused by a weak or damaged urinary sphincter and results in urine leakage when you do anything that strains or stresses the bladder, such as coughing, sneezing, laughing, or exercising. Leakage may range from mild (a few drops with only the most vigorous activity) to brisk (leakage with almost any movement). Stress incontinence resolves in up to 97 percent of men affected after radical retropubic prostatectomy, but can take up to three years to resolve.

Regaining urinary control

- Kegel exercises are the deliberate tightening or clenching of the pelvic muscles. Performed regularly, they tone and strengthen the external sphincter, the rings of muscles responsible holding in urine.
- Your doctor may prescribe or recommend medications to help with incontinence. Anticholinergic drugs, which block messages to the bladder nerves and prevent bladder spasms, are sometimes recommended for urge incontinence.

- Sometimes fat in the abdomen can put pressure on the bladder; losing weight may help improve bladder control.

AFEX: The AFEX system makes managing chronic male incontinence easier than ever. The 96% cotton boxer-briefs discreetly and securely hold a plastic ergonomic curved receptacle inside a front pocket that channels urine into a 500ml reusable collection bag. No tubes or straps are required - just attach the bag directly to the receptacle through the briefs for hours of use without maintenance or changing.

"It's very comfortable, and lot drier than pads. It gave me the freedom to do a lot of things that I used to do." Tommy Boyce - age 76

The standard set shown here is designed primarily for active daytime use. For long-term sitting, one can use the afex Sedentary and for wheelchair users, afex Mobility Assisted. Free samples and home assessment available from www.iMEDicare.eu
Or on 02082075627.

Available from your GP on NHS prescription.



Prostate Cancer Support Federation

the voice of prostate cancer patients and their families

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Dr. Thomas Stuttaford OBE

Development Director

Rowena Bartlett

Federation Trustees

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Sandy Tyndale-Biscoe

Vice Chairman:

Ken Mastris

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David Smith

Treasurer:

Hugh Gunn

Trustees:

Emma Malcolm,
John Dwyer,
David Baxter-Smith,
Rob Banner,
Bob Arthy

Medical Advisor:

David Baxter-Smith

To View other roles carried out by volunteers, please visit:

<http://tinyurl.com/3psctpv>

Prostate Matters is published four times a year, providing news, information, personal memoir and opinion about prostate cancer. It also reports, quotes and cites published medical views and research findings about prostate problems.

The Federation does not promote any treatments or dietary, drug, exercise or lifestyle change intended to prevent or treat a specific disease or condition. Anyone who wishes to embark on any such treatments should first consult with and seek clearance from a qualified health care professional on any treatment or lifestyle changes

PROMIS TRIAL and the DIAGNOSTIC ROLE of MRI



Prostate Action trustee Professor Mark Emberton is Chief Investigator of a new trial looking at the use of MRI in diagnosing prostate cancer. The PROMIS study – Prostate MRI Study: evaluation of multi-parametric magnetic imaging on the diagnosis and characterisation of prostate cancer – plans to evaluate whether MRI scans can be used to help men who have been referred for a biopsy in two ways: to determine whether or not men may safely avoid biopsy and to make the biopsies better for the men who definitely need them, by more accurately detecting the size and location of any tumours.



Professor Mark Emberton

Although biopsy is an essential part of the investigating process for determining whether prostate cancer is present, it is an invasive procedure and is not risk free. Urinary infections can occur following a biopsy, as can bleeding, and there is a 1% chance of contracting septicaemia (blood poisoning), which can be life-threatening. Biopsies can also miss small tumours and in some cases may have to be repeated. A top research priority, said Professor Emberton, is 'being able to discriminate between those men that do need treatment from those that do not in early disease.'

We need to be able to discriminate between those men that need treatment from those that do not in early disease.

The road to receiving a referral for biopsy is not fool-proof either. PSA testing can produce 'false-positive' results, meaning PSA scores can be high even when no

cancer is present, causing some men to undergo an uncomfortable and unnecessary biopsy, not to mention the anxiety of waiting for the results. In fact, most men who receive a biopsy will not have prostate cancer. The potential benefits of introducing MRI scans as a diagnostic tool according to Professor Emberton are 'fewer biopsies, better biopsies in those that need them, fewer needle deployments and more appropriate treatment allocation.'

The national study will last for four years and is looking to recruit over 700 men. 'Any man who is told that he needs a biopsy is eligible,' said Professor Emberton, 'provided he is both willing and able to have

an MRI and a general anaesthetic.' The researchers hope that the results will help increase the accuracy of future prostate cancer diagnoses and the subsequent management and treatment of patients. The study is expected to take place between November 2011 and December 2015. For more information or to sign up for the trial, visit the study page on <http://tinyurl.com/7gfs0h9>.

The idea for investigating the use of MRI in the diagnostic pathway of prostate cancer is an example of one of the many research collaborations arising from the Forum. The Forum was the brainchild of PCRF founder Sir Clive Bourne, who decided to bring together the top researchers and clinicians of the day and build a systematic approach to prostate cancer research. The Forum is now an internationally renowned conference and Prostate Action is holding the tenth Forum in Rotterdam in June 2012.

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