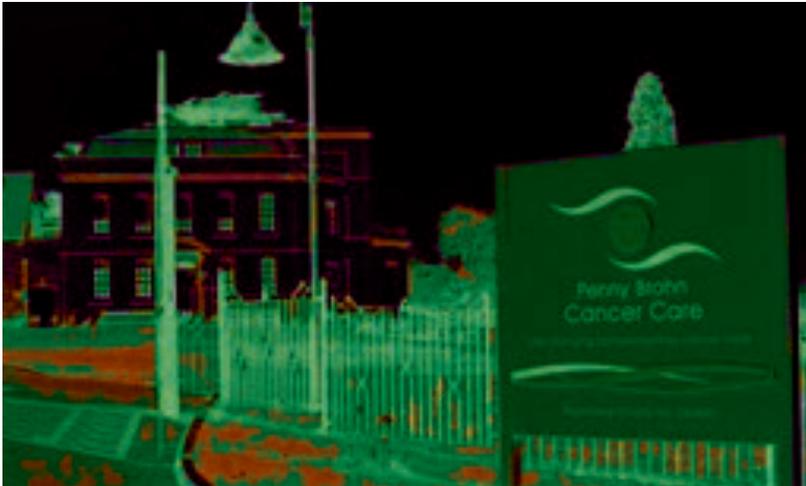


prostate matters

Newsletter of the Prostate Cancer Support Federation

Issue 8 Spring 2010



The Great PSA Debate shows results! The Prostate Cancer Risk Based Screening Trial

By Sandy Tyndale-Biscoe

As all our readers are well aware, the issue of prostate cancer screening, and its potential for saving many of the 10,000 men who die of the disease in the UK each year, has been stalled because of the very well documented shortcomings of the only currently practical test that could be used, the PSA Test. Prostate cancer, in its early, curable, stage, normally has no symptoms. It is also, in a harmless form, extremely common and many men are never aware that they have it.

Patients, almost to a man, have for years been calling, if not for full PSA-based screening, for at least an awareness programme that encourages men at risk to take the test. However, clinicians, concerned about the harm that would be done by the diagnosis and treatment of irrelevant cancers that will never trouble a man, are largely sceptical about benefits about any such course.

So, official policy about PSA testing has been, at the very least, equivocal, with a strong bias towards not encouraging men in any way to have the test. (I recently encountered the 2001 edition of the BMA's Family Health Guide. In a long article about prostate cancer, it doesn't mention PSA at all.) It is the belief of the vast majority of patients that this is leading to late diagnosis and unnecessary deaths.

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In March last year, results of a large European trial were published that, for the first time, showed clear a reduction in mortality from PSA-based screening. Unfortunately, results also show that this was accompanied by a large measure of over-treatment, and did nothing to resolve the controversy – if anything it fuelled it.

Last November, the Prostate Cancer Support Federation, responding to patients' continued frustration at the lack of movement on the issue, held "The Great PSA Debate". Led by acknowledged experts from both sides of the argument, we achieved a remarkable 100% consensus that what is needed is a more sophisticated, risk-based, approach to early diagnosis, in which a number of factors, including PSA, are taken into account before a man is recommended for invasive biopsy. Although there seems to be general agreement amongst clinicians that this is the way forward (and not only for prostate cancer), the real problem is how to get it adopted, soon, into clinical practice, and start saving lives.

Directly as a result of The Great PSA Debate, a trial is now being proposed that is the result of that consensus, and it is already gaining widespread support from some of the top clinician-researchers in the country. That's Patient Power!

Continued on back page

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Federation Conference & AGM

The third Annual Conference and AGM of the Prostate Cancer Support Federation was held at the Penny Brohn Cancer Centre on 24th April 2010. **Sandy Tyndale-Biscoe** welcomed those present and outlined the programme for the day. He then went on to introduce the first speaker **Michael Connors** from Penny Brohn who explained the *Penny Brohn approach to Living Well with Cancer*, the centre in the past had a reputation for 'alternative' medicine but is very much a support centre for those living with cancer and works in partnership with the NHS and Macmillan on the National Cancer Survivorship Initiative. Penny Brohn provides a 'living well' model which looks at the whole person – psychological, emotional, spiritual, social, physical and financial and has just started to offer a 2 day residential course which is free and open to donation only. Following on from this short 2 day course are 3 and 5 day courses to help further personal development where space and a relaxing atmosphere can develop greater understanding where you can learn and improve skills in relaxation, eating well, living stress free and reflecting on how cancer has impacted on your life. Penny Brohn also hopes to increase its intake of male clients this year by 20% and have four dedicated residential men groups.

The second speaker in the morning was **Liz Butler**, also from Penny Brohn, Liz is a senior Nutritional Therapist and gave an interesting talk about *Eating Well with Prostate Cancer*. She first talked about the research studies that underpin her work and explained how the 2007 report by the World Cancer Research Fund and a European Prospective Investigation into Cancer & Nutrition (EPIC) which is an ongoing research study have found evidence to suggest a diet enriched with fruit and vegetables particularly those rich in lycopene, selenium and vitamin E, decrease the risk of cancer. Saturated fat may increase risk along with red meat and a high calcium intake through dairy can also increase risk of prostate cancer. Liz highlighted the limitations of nutritional studies as it is very complex as diets are difficult to measure with complete accuracy, foods and drinks contain thousands of constituents some unknown and unmeasured. There is also a lack of funding for research. Levels of two essential fats should also be in balance to ensure a good immune system with a healthy inflammatory response, omega 6 and omega 3 should be balanced in the ratio of 4 : 1, however the modern western diet is up to 20 : 1. It would help to avoid processed fats (chips, crisps, biscuits, cakes and processed food), avoid margarine use butter instead and choose extra virgin oil for cooking. The disruption of certain hormones is implicated in many cancers including prostate, you can support hormone health by avoiding or limiting dairy, alcohol and keeping a healthy body weight, also drinking plenty of water is recommended. You can download the new 'healthy eating guide' from Penny Brohn by going to:

www.pennybrohncancercare.org

Worried or concerned
about prostate cancer?

**National Help
Line**
0845 601 0766

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You can download this newsletter
direct from our website. Go to:

[www.prostatecancerfederation.org.uk/
ProstateMatters_latest.pdf](http://www.prostatecancerfederation.org.uk/ProstateMatters_latest.pdf)

The Federation e mail address is:
info@prostatecancerfederation.org.uk

It is intended to publish this
newsletter 4 times a 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

The last speaker before lunch was Julie Flynn from the NCRI Complementary Therapies Clinical Studies Development Group. Julie started by defining what is meant by 'complementary therapy' as she showed us many therapies that were currently being practiced which could be sometimes mistakenly termed 'complementary' rather than 'alternative'. Research in America showed 30% of people there use complementary therapy compared with 21% in the UK. There was a need for more research work to be carried out as there is a need to create a greater evidence base which would inform patients and professionals and support the commissioning process. One study in the development stages is looking at acupuncture for prostate cancer patients.

After lunch the business part of the day took place, with the AGM of the Federation. The chairman reported it had been a good year with the PSA debate taking place, the national helpline establishing itself with twelve helpliners taking on average 6 to 7 calls a week, the quarterly Prostate Matters newsletter is now sponsored by Mediwatch, the Federation launched its own version of the PCRMP aimed at GPs, we have a range of information sheets, knowledge empowers booklet and 'a man's thing', we have also been offering grants, funded by Prostate UK, to member groups and support the commissioning process. One study in the development stages is looking at acupuncture for prostate cancer patients.



Our treasurer, **Hugh Gunn** then gave a summary of the accounts: The Federation Started the year with a **balance** of £4,057.51. It now stands at £8,938.43. This consists of, **Affiliation Fees**, £1810.00, **Restricted Grants** from **Prostate UK** and **Mediwatch** totaling £4,43.61 to be used for Prostate UK Grants and printing Prostate Matters. We Also had a donation of £5000 from **PSA** which is to be used for Printing, Website and The Help Line.

Expenses are made up of :

Sponsored News Letter , £1,105.61, Prostate Grants, £3,328, this make the total grant payment £4,999 for the current tranche. Conference expenses, £900.00, website, £140.77, meeting venue hire, £284.72, travel expenses, £494.26, postage £123.19, accountancy, £585.31 and insurance, £327.40.

Graham Fulford reported on membership, saying we have 44 member groups of which 7 are new this year. He called for ideas on increasing the number of groups and hoped everyone would support him in spreading the word. The election of officers and trustees then took place, with the following results

Chairman: Sandy Tyndale-Biscoe, Secretary: Mike Lockett, Treasurer: Hugh Gunn, Trustees: John Dwyer, David Smith, Roger Bacon, Rob Banner, Graham Fulford. It was proposed from the floor that the Federation should try and recruit a vice chairman, as the present chair has indicated he will be stepping down next year. Activities and Funding were then discussed – it was thought we would continue to hold an autumn seminar, the 'Man Van' project was outlined by **Rob Banner**, a promotional video of the Great Drag Race was shown which potentially could bring in a lot of money for the Federation and raise awareness

of prostate cancer, Rob Banner also explained a 'direct marketing' scheme which the Federation had been approached to take part in.

The remaining sessions of the day were taken up first by the chairman outlining what happened at the Great PSA Debate last November at Leamington Spa, then **David Baxter-Smith**, the Federation's medical advisor, talked about moving forward from this and educating the man in the street about his prostate, educating surgeons about prostate cancer and educating GPs. **Professor Ken Muir** then spoke about the pilot trial of 'risk-based screening' which has come out of the PSA debate and would take four years to complete at an estimated cost of £2.2m. He explained the importance of trials and reported the outcomes of some previous PSA studies in America and Europe. Graham Fulford then gave some thoughts to raising £200k in order to start this trial and called for all the groups present to help with this.

The chair then summed up the day and closed the conference.

Using Nitroglycerin to Treat Prostate Cancer Shows Potential

Posted on: Tuesday, 9 February 2010

Treatment of prostate cancer using a very low dose of nitroglycerin may slow and even halt the progression of the disease without the severe side effects of current treatments, Queen's University researchers have discovered. The findings are the result of the first-ever clinical trial using nitroglycerin to treat prostate cancer.

The 24-month, Phase II study targeted 29 men with increasing levels of prostate-specific antigen (PSA) following prostate surgery or radiation. PSA levels are a key predictor of cancer progression.

"We were very excited to see a significant slowing in the progression of the disease as evidenced by the men's PSA levels, and to see this result in many of the men who completed the study," says Robert Siemens, the leader of the study and a Professor of Urology at Queen's University and urologist at Kingston General Hospital.

The researchers are encouraged by the results, particularly because safe and effective treatments for men with rising PSA levels following surgery or radiation are limited. They note that further testing needs to be done to confirm the results of this very small study.

Awareness Event at Leicester City Football Club on 14th April 2010

PCSF member, PROSTaid operates in Leicestershire, Rutland and Northamptonshire, Our aim is to help local Urologists & Oncologists improve the treatment and care of local men with prostate cancer. We raise money for medical equipment and less invasive treatments. We also fund a Prostate Cancer Nurse Specialist at the Leicester General Hospital and later this year, a community based palliative care nurse specifically to care for men with prostate cancer who are at the end of their treatment journey. This is a unique concept in the UK.

Awareness for African-Caribbean men and all men with the disease in their Family



Expert urges men to take prostate cancer check-up

The focus of the event, was to raise awareness, with the emphasis on men with a family history of the disease and African-Caribbean men who have a three times higher risk.

Mr Frank Chinegwundoh Consultant Urologist from Newham and Barts Hospitals and chair of Cancer Black Care was the speaker. Mr Chinegwundoh said: “There is a general awareness problem across the male community as a whole. Most men don’t know where their prostate is or what it does.

The death rates are comparable with breast cancer, yet women get screened. Men simply don’t approach their GP about the subject. There are tests available and it’s vital men go for them. Every man aged 50 is entitled to one and it is our right to have one. It is more pertinent in the African-Caribbean community, as black men are more likely to be diagnosed. Therefore we want to spread awareness about the signs and symptoms as well as the treatments available”

PROSTaid trustee, Stuart Berry “Prior to being diagnosed I was no different from the average man. I knew little about the prostate. It’s commonly said it’s normal for men to experience urinary symptoms as we get older. It maybe a common condition, but it’s not normal. Something is causing the problem and it needs investigating. It is often said that you die with the disease not from it. Frankly I think this gives men the green light to think it’s okay to

ignore symptoms. Many men who call our helpline wish they had gone to their GP earlier because the disease has already metastasised”

“We realise there are cultural issues, myths and taboo’s in particular regarding the DRE test, We’re trying to work closely with the African-Caribbean community to get them to come forward, particularly if they think they have a problem”

PROSTaid patron, Alan Birchenall MBE, speaking about the importance of getting checked out, urged men not to be embarrassed about the condition. Everyone who attended was given “It’s a Man Thing leaflet” and information about the Charity.

PROSTaid also operates a local telephone helpline. We work closely with The Prostate Cancer Charity and Prostate UK, using their leaflets to promote awareness.

Stuart Berry, an organiser of this recent Awareness Event said: “We work closely with Consultant Urologists and various health care specialists, GP’s etc, to raise awareness of the disease within our local community. We have a variety ways of undertaking this important aspect of our mission. We have a unique range of patient support video’s on our website www.prostaid.co.uk and are arranging for awareness leaflets to be translated into other languages for download. As well as events like this, we hold awareness events at shops and supermarkets, in the workplace, in community centres and other venues”

PROSTaid patron Richard Everard, chair of Everards Brewery has arranged for PEE posters to be displayed in the gents urinals in all of his 168 pubs. It reads - To PEE or not to PEE that is the question If your Flow be Low or somewhat Slow get Yourself checked out - See your GP.

PROSTaid hold fundraising and awareness events throughout the year and have organised large-scale awareness events for the last two years. The charity invite a celebrity to these events and a Urology Specialist to speak about the disease, which is followed by a Q & A session and networking with light refreshments.

PROSTaid promote/advertise these events in the local press and on the radio, on the UHL NHS and PCT Intranet sites, distribute flyers to every GP practice in the city and county of Leicester (shire) and widely throughout the community. Last year Consultant Urologist at LGH Mr Tim Terry who is also a PROSTaid Trustee and Secretary of (BAUS) British Association of Urology Surgeons gave the medical presentation.

Further information is available from –
Stuart Berry PROSTaid co-founder & Director Trustee
stuartberry@hotmail.co.uk Tel No 01455 291752

Should prostate cancer patients start doing Kegels before surgery?

The “New” Prostate Cancer InfoLink has always believed that preoperative training of the pelvic floor muscles (using Kegel exercises) would be likely to improve recovery of continence after radical prostatectomy, but there have never (as far as we know) been any good data to substantiate this belief.

An Italian group has now published data from a small, randomized clinical trial suggesting that, indeed, men who started to train their pelvic floor muscles prior to radical prostatectomy and continued the Kegel exercises after surgery did indeed seem to recover continence sooner than men who only started Kegel exercises after their surgery.

[Centemero et al.](#) enrolled 118 patients who had been diagnosed with localized prostate cancer and who were scheduled for radical retropubic prostatectomy (RP) at their institution. The patients were then randomized to one or other of two groups:

- Group A (the active pretreatment group), in which the patients were asked to start pelvic floor muscle exercise (PFME) 30 days before RP and to continue PFME postoperatively
- Group B (the control group), in which the patients were asked to start PFME only after surgery

The patients were asked to self-report on their continence after surgery. In addition, the patients’ quality of life (HRQOL) was assessed using the male short form of the International Continence Society.

The results of the study can be summarized as follows:

- 59 patients were randomized to each group.
- At 1 month after surgery
 - o 26/59 men (44.1 percent) in Group A were continent compared to 12/59 men (20.3 percent) in Group B.
 - o The HRQOL of men in Group A was better than that of men in Group B (14.6 vs 18.3).
 - o After age-adjusted logistic regression analysis, men in Group A had an 0.41-fold lower risk of being incontinent than men in Group B.
- At 3 months after surgery
 - o 35/59 men (59.3 percent) in Group A were continent compared to 22/59 men (37.3 percent) in Group B.
 - o The HRQOL of men in Group A was still better than that of men in Group B (8.1 vs 12.2).
 - o After age-adjusted logistic regression analysis, men in Group A had an 0.38-fold lower risk of being incontinent than men in Group B.

The authors conclude that, “Preoperative PFME may improve early continence and [HRQOL] outcomes after RP.”

If you think about it, a man who starts to learn how to train his pelvic floor muscles 30 days before surgery is going to have a 30-day advantage over the man who waits to do this until after surgery. In addition, the surgery itself may delay the training process for the man who isn’t pre-trained. Postoperative pain may make it more difficult to start Kegel exercises for the men who have had no preoperative training.

Although this is only a small study, and we would like to see these data replicated in a larger patient cohort, The “New” Prostate Cancer InfoLink at least feels there is now some justification behind the recommendation to start Kegel exercises well before surgery if that is the form of treatment a patient is to undergo, and this is likely to be true regardless of type of surgery.

[Prostate cancer news reports: Monday, March 29, 2010](#)

Researchers Fishing for Cancer Cure Discover Active DHA Derivatives

ScienceDaily (Mar. 2, 2010) — The next treatment for cancer might come from fish says a new research report published in the March 2010 print edition of the FASEB Journal. In the report, scientists show that the omega-3 fatty acid, "docosahexaenoic acid" or "DHA," and its derivatives in the body kill neuroblastoma cancer cells. This discovery could lead to new treatments for a wide range of cancers, including neuroblastoma, medulloblastoma, colon, breast, and prostate cancers, among others.

"We hope that this study can provide a deeper understanding of the actions of omega-3 fatty acids and their products in cancer cells, and why they can be of such high importance in treatment of the disease," said Helena Gleissman, Ph.D., co-author of the study from the Childhood Cancer Research Unit of the Karolinska Institutet in Stockholm, Sweden. "Ultimately, we hope that we can be able to cure more children with neuroblastoma, and possibly other cancers."

Scientists administered DHA to neuroblastoma cells from the nervous system and analyzed the cells for byproducts as the DHA was metabolized into the cells. Researchers then examined the affect of both DHA and its derivatives on the growth of cancer cells. Results showed that DHA killed the cancer cells, but that the toxic derivatives produced by DHA were even more effective at killing the cancer cells. This suggests that DHA could become a new agent for treating neuroblastoma and possibly many other cancers.

"This is good news for those looking to stop cancer. We now know that DHA plays both offense and defense when it comes to protecting our health," said Gerald Weissmann, M.D., Editor-in-Chief of the FASEB Journal. "It's ability to help prevent numerous diseases is well documented, but now we see that DHA or one of its byproducts might serve as the starting point for a new class of anti-cancer drugs."

Story Source:

Adapted from materials provided by [Federation of American Societies for Experimental Biology](#), via [EurekAlert!](#), a service of AAAS.

Journal Reference:

1. Helena Gleissman, Rong Yang, Kimberly Martinod, Magnus Lindskog, Charles N. Serhan, John Inge Johnsen, and Per Kogner. Docosahexaenoic acid metabolome in neural tumors: identification of cytotoxic intermediates. The FASEB Journal, 2010; 24 (3): 906 DOI: 10.1096/fj.09-137919

Letter from Graham Fulford

Development Officer - Prostate Cancer Support federation

Dear Members,

Prostate Cancer Diagnosis – Risk Trial

As “Development Officer” for the Federation I am writing to make you aware of the Prostate Cancer Risk Based Screening Trial which has effectively developed out of the Federation’s Great PSA Debate, held in Leamington Spa last year. In broad terms it is an attempt to distil and improve the present PSA testing mechanism with the main aims of:

1. Reducing the number of biopsies whilst
2. Finding at least the same number of cancers (and, we hope, finding more aggressive cancers).

I’m sure we would all agree with these sentiments.

Without going into too much detail a pilot trial is being set up in which a combination of factors – **total PSA; free to total PSA; DRE** and risk factors such as ethnicity; family history etc are all reviewed to calculate with as much accuracy as possible the risk any particular man has of developing an aggressive cancer. The Federation’s own medical advisor **David Baxter Smith** – is working very closely on the project with Consultant Oncologist **Chris Parker** and **Professor Ken Muir** of Warwick University. **Prof John Anderson**, president-elect of the British Association of Urological Surgeons, will act the clinical lead in urology. This is a very exciting development which the Trustees of the Federation are very keen to support and which would, in 3 or 4 years time, change the way PSA is used and provide the breakthrough in effective early diagnosis we have all been waiting years to see.

But doing that requires robust evidence, and that doesn’t come cheap. Whilst it’s very early days we believe we should do all we can to help promote the initial pilot. You will see from the attached very outline cost projection that the whole trial will cost upward of £2m, and the first year’s work could cost of the order of £200,000. These sorts of figures are outside the means of patients’ groups, and will take time to raise, primarily from the big funders such as Cancer Research UK and the Prostate Cancer Charity, but we cannot wait that long. The Trustees are determined to get things moving now by raising whatever is needed to get the trial design started and ethical approvals etc in place.

As somebody who has raised some £200,000 over the past 5 years to fund PSA testing – see attached results of our joint efforts with the Kidderminster PCSG – I’m passionate about trying to help find the “holy grail” breakthrough the pilot might just lead to. My small charity is therefore happy to start the ball rolling with a donation of £3000. I’m very hopeful around 6/7 other sizeable groups will contribute at a similar level – and I would beg you all to help in any way you can. For the preliminary work for the trial to start now, we need to get commitment for between £10,000 and

£20,000 in the next few weeks. No donation is too small and once we get the ball rolling I’m sure there will be other doors to knock on such as Partner Members of the Federation, Prostate UK and the Prostate Cancer Research Foundation. Clearly the more we can do the easier it will be to persuade others. Lloyds Bank; Barclays Bank and National Grid have “matched giving” schemes whereby if their employees help good causes they will match up to £500; £750 or £400 respectively I’m sure other major organisations offer similar schemes. If you know any, or benefactors, or others who could help – please let me know.

AGES OF KNOWN CANCERS			
	Kidderminster	GFCT Trust	Totals
40-44	0	0	0
45-49	1	6	7
50-54	3	11	14
55-59	9	24	33
60-64	16	35	51
65-69	21	45	66
70-74	25	21	46
75-79	8	19	27
80-84	5	5	10
85-89	0	2	2
TOTALS	88	168	256

TREATMENTS			
Active Surveillance	15	35	50
Hormones	15	17	32
R.A.G.O.	3	1	4
Rad. Prostatectomy	14	44	58
D.X.R.T.	32	49	81
Brachy	4	9	13
H.I.F.U.	0	3	3
Perineal Prostatectomy	0	1	1
Unknown	5	0	14
TOTALS	86	188	256

SUMMARY OF PSA RESULTS						
	No of Events	No of Tests	Red letter	Amber Letter	Green Letter	Known Cancer
GFCT	77	8216	497	347	7372	166
KIDDERMINSTER	43	3889	272	218	3399	87
TOTALS	120	12105	769	565	10771	256

3 Mill Street Warwick Warwickshire CV34 4HB
07831 156071
gfhcharitabletrust@tiscali.co.uk
www.gfhcharitabletrust.co.uk

This is an almost unique event. A major change in clinical practice (in effect the screening programme we have all been calling for) could be brought about as a result of patient pressure. Come on – be proud and supportive of your Federation and let’s be the generation who made REAL inroads into beating this insidious disease. Please contact me in any of the above ways gfhcharitabletrust@tiscali.co.uk.

Yours sincerely,

Graham Fulford

Graham Fulford

PS I’m so confident the pilot will be a success, I’m sure Ken and Chris will open doors for the bigger picture.

Let’s go to it!

The Great Drag Race

a Daughter's View

On 19 June this year it will be my pleasure to travel to London and proudly support my father and all the other courageous men participating in the Great Drag Race. The aim of this 10K race, in which men will be dressed as women, is to “drag” the issue of prostate cancer into the spotlight.

I can't speak for the other participants but I know that for my Dad (a fairly conventional man of 64), the idea of dressing up in drag and parading around in public is completely alien and excruciatingly embarrassing. He is terrified of looking an idiot. Despite this, my father is involved with the race because he believes that the only way to fight prostate cancer is to raise awareness and encourage more research.

Since my Dad was diagnosed with prostate cancer nearly 5 years ago at the age of 59, we have encountered myths and misconceptions about the disease. The most common of these is that only the elderly get prostate cancer, that it is slow growing and that men tend to die with it, not of it. This line of thought seems to feed into a lack of funding and consequently, limited screening and treatment options. Personally, I have a sneaking suspicion that the government doesn't want to focus its resources on old men. Why bother? – they're probably not economically active and historically, haven't kicked up a fuss.



It is not true that only the elderly get prostate cancer. Nor is it correct that it is always slow growing. 30,000 men a year are diagnosed with prostate cancer. Of these approximately 30% will die as a direct result of the disease. In the UK prostate cancer kills 10,000 each year and the UK has one of the worst survival rate in Europe. This is not acceptable and must change.

The issue of prostate cancer desperately needs attention and the men with it deserve better treatment. Lives will be saved if more screening and treatment options can be developed. I strongly believe the Great Drag Race can help:

Free to Total testing: currently, there is no national screening programme for prostate cancer. One of the justifications for this is that it is impossible to tell from PSA screening whether or not the cancer is aggressive or slow growing. Therefore (so the argument goes), a national



screening programme could do more harm than good by triggering unnecessary and invasive investigations. This argument is blown out of the water by Free to Total testing. The aim of Free to Total testing is to determine, via a simple blood test, not just whether cancer is present but whether or not it is aggressive. The Great Drag Race aims to raise £40,000 for research into Free to Total testing.

Ensure that modern cancer drugs are available: prostate cancer does not have a high profile and attracts relatively little funding and research. Once the cancer has spread, treatment options are limited. Most men whose cancer has metastasised are offered hormone therapy. This is broadly the same treatment that was used in the 1950s. Little progress has been made. Raising awareness of Prostate cancer could lead to better treatment. I hope that the Great Drag Race will help to do this.

Offer support to men with PC: there are many reasons why men are reluctant to talk about having prostate cancer. Some experience impotence and/or incontinence. Hormone treatment can cause extreme exhaustion and some find it hard to express their emotions, especially if they are afraid. It is vital to talk about this illness and the effect it has. It is important to publicly recognise that there is no shame in having prostate cancer and that the men living with it are courageous every day. Their bravery should be celebrated.

So, is it embarrassing to wear a dress in public if you're a man? Quite possibly but surely it's got to be better than suffering in silence? On Saturday 19 June I will be cheering on all the brave men who have the courage to don a dress and drag this issue into the spotlight.

By Louise Morris

**Come and
Support Us on
June 19th**

**THE
GREAT
DRAG
RACE**

Prostate Cancer Support Federation

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Charity No. 1123373

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Prostate Matters is published four times a year. It provides news, information, personal memoir and opinion about prostate cancer. It also reports, quotes and cites published medical views and research findings about prostate problems. Anyone who wishes to embark on any dietary, drug, exercise or other lifestyle change intended to prevent or treat a specific disease or condition should first consult with and seek clearance from a qualified health care professional

Why can't we just give all men at risk a PSA Test?

Continued from Front Page

A serum PSA test, on its own, is a poor measure of the likelihood that a man has prostate cancer, unless the reading is very high. Approximately 20% of dangerous prostate cancers show no significant raise in PSA levels, and, in more than 75% of the cases where it is raised, subsequent biopsy does not show the presence of cancer. So, as a screening test it fails on both the key counts: it is not specific (abnormal results indicate cancer in only a third of cases) and it is not sensitive (cancer can exist without raised PSA).

The significant reduction in mortality shown by the European Trial was bought at enormous cost in unnecessary, painful and occasionally dangerous biopsies. It is estimated that, for every 1000 men screened, the number of biopsies would rise from 192 to 368 (i.e. nearly double) and the number cancers discovered rise from 48 to 82, but only a single life would be saved. The problem, of course, lies not in the PSA test per se, but in the way the results are handled. Automatic referral for biopsy, against some notional age-related threshold value, is never going to work. Recent research, however, has shown that when you factor in a number of other indicators, such as ethnicity, family history, presence (absence, actually) of urinary symptoms, and, significantly, the ratio of free-to-total PSA, you can get an accurate assessment of the risk that a man has a dangerous cancer.

The aim of our proposed trial is to show how use of such a technique, could significantly reduce the number of biopsies, without reducing the number of significant cancers discovered. If such were demonstrated, it would be a major step on the road to the change in clinical practice that would save lives.

The Risk Based Screening Trial

To change clinical practice, NICE needs evidence, and that doesn't come cheap. Randomised trials represent the "gold" standard for evidence, otherwise, advocacy or pessimism can have strong effects. A large, "well-powered" study is required to provide robust evidence and change clinical practice.

The risk based screen would be employed in General Practice as this

represents the first point of contact for most patients. GPs' practices would be randomised to deliver an active intervention using a risk based assessment (the Sunnybrook risk calculator) or to use the current threshold based PSA test, with no active encouragement.

There will be 3 main phases of the trial:

- Trial protocol approved and ethics committee and other governance approvals obtained – 4 months starting Summer 2010
- First practices recruited (Oct 2010 – Mar 2011)
- Full recruitment and main body of work and analysis (Mar 2011 – Jun 2014)

The trial will be run by some very eminent researchers and clinicians, including, Prof John Anderson (president-elect of the British Association of Urological Surgeons), Prof Kenneth Muir (Warwick University), Dr Chris Parker (Royal Marsden) and David Baxter-Smith (PCSF Medical Adviser)

Funding

As already noted, good evidence does not come cheap. Total costs for the trial are estimated to run to about £2M, with nearly £200,000 needed in the first twelve months. Because the trial is in tune with general medical trends towards risk-based approaches to screening, the principal researchers are confident that the major funders will be supportive. But getting our hands on their money takes time, and we are at the wrong point in their budgeting cycles.

From patient's perspective, time is of the essence. If we get this trial started now, there is a reasonable hope that clinical practice could be changed significantly for the better by 2014. This is why the Prostate Cancer Support Federation, a charity with very small resources, is committed to raising, over the next two or three months, from its member organisations between £10,000 and £20,000 to provide seed-corn funding to get the work started. We have other potential sources we are approaching to cover the rest of the first year's work.

Elsewhere in this edition you will find a letter from our Development Officer, Graham Fulford, exhorting Federation Member Organisations to support this effort. Please give it your backing, and help make Patient Power a reality.