Prostate Cancer Support Federation

Prostate Matters

Newsletter

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Contents

PM Editor: Roger Bacon
email: editor@prostatematters-uk.org

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

Worried or concerned about prostate cancer?

National Help Line
0845 601 0766

Charity No. 1123373

The Great PSA Debate – a breakthrough for early detection?

On November 10th in Leamington Spa, the Prostate Cancer Support Federation, in collaboration with Prostate UK and the Graham Fulford Charitable Trust, held "The Great PSA Debate", to discuss the motion: "Every man at risk of prostate disease (i.e. all men over 50, and those 40 with other risk factors) should be encouraged to check his PSA every year."

Nearly 100 representatives of patient groups joined in the debate with a panel of 6 experts representing clinicians, charities and patients. With such an audience, it was not surprising that, at both the start and the end of the day, the votes on the actual motion were overwhelmingly passed with only those formally opposing the motion voting against it. However, the number who would call for formal screening reduced over the day from 78% to 59%.

After an afternoon session that concentrated on looking for points of consensus, a vote on an alternative motion: "Every man at risk of prostate disease [etc.] should be made aware of the PSA test, its benefits and limitations and should be able to freely exercise his right to have it" was carried unanimously, with one abstention. This is a significant breakthrough, as it means that patients and two of the UK's largest charities working in this field are at last able to sing the same tune. We intend to build on this unprecedented consensus and exert pressure on the Dept of Health to move things forward.

A further significant outcome from the debate was the emergence of a potential approach to risk assessment which, in combination with PSA testing of appropriate men, might have a significant impact on the early diagnosis of dangerous cancers, whilst not diagnosing irrelevant ones.

A full report of the debate will be published in the next edition of Prostate Matters.

Sandy Tyndale-Biscoe
Chairman PCSF

National Prostate Cancer Awareness Day (The Great Drag Race)

As announced on page 3 of the last edition of Prostate Matters (August 09), the Prostate Cancer Support Federation has been invited by The X Foundation, a non-profit agency specialising in philanthropic projects, and the Prostate Cancer Research Foundation, to join them in promoting and benefitting from National Prostate Cancer Awareness Day, a new annual event which will take place on June 10th (the day before Father's Day) next year.

A key part of this event will be a march or run in which all the participants are dressed as women. The Federation has received distinctly varied feedback about the desirability of being associated with this event. Below are set out summaries of the arguments for and against. The Trustees of the Federation will not involve it in any activity that is against the wishes of its members. We invite comments from our readers on whether they consider this event should be promoted under the banner of the Federation. Please send your comments to:
gdr@prostatecancerfederation.org.uk or by post to: PCSF, Cedarcroft, Sunnyway, Bosham, Chichester, West Sussex, PO18 8HQ.

The 'Against' argument

A history of men in drag reveals that this artistic device relies strongly on entertainment value — specifically, humour and ridicule often highlighting the physical and emotional vagaries of women. Take the standard pantomime dame, the music hall, vaudeville and revue artiste, the Hinge and Bracket/Danny laRue/Lily Savage/Old Mother Riley and RuPaul entertainers; no-one takes them seriously because they don't have a serious message to make. The point is that men in drag run the risk of not being taken seriously and though raising a laugh, may not raise awareness.

The second point is that it is false. Men who parade in drag are recognised by the general public as being false. They are not what they seem. They are projecting an image which is neither true to themselves (though they may well delude themselves into thinking otherwise) or to others. None of the above entertainers wore drag in their day-to-day living. It was reserved for that part of their world of make-believe, a pretence, a facade. Their costumes, wigs, make up, prosthetic additions, gait and effeminate gestures cannot disguise the fact that it is all fake (though the last two may not be!).

So what kind of genuine message can the film *Bedraggled* or the 26 mile *Drag Race* get across? I suspect a large number of the population will feel at best, uncomfortable - even bewildered and at worst, dismissive or indifferent.

Many men are on hormone treatments, one described how he had been robbed of his manhood by growing breasts, by losing his libido, by being (effectively) castrated and now, as an added insult, would be further humiliated by this project.

For further up-to-date information on how far this event has gone, please click on the website for **thexfoundation.org** and then access the link on the right hand side of the page entitled "bedraggled" – it's actually arrived! View for yourself just where the emphasis lies! Do we really want to be connected with this?

It's a false supposition that dressing as women is necessary to draw attention to a man's point of view. Basically, although women have been successful, men should aim to do things in a man's way.

Prostate Cancer is a man's complaint and we must deal with it as men. The "Great Drag Race" is a scurrilous, demeaning and cheap way of raising awareness.

Jim Davis, PCaSO Dorset Branch

The 'For' argument

Why do it in drag?

Why is it that breast cancer gets ten times the attention that prostate cancer gets, when the latter kills almost as many men? Maybe it's because prostate cancer is seen to be a disease that affects a little known part of the body, of little known function, from which 'only' old men suffer; whereas, we all know about women's breasts, and it's so sad to see so many young women cut down in their prime from this awful disease. Maybe it's because the authorities don't dare tangle with the ladies, always so much more effective than us men when it comes to their own health. Whatever the reason, it's a gross inequality.

The light-hearted message of The Great Drag Race is that perhaps if men pretended they were women, they might get the attention they deserve. It is not supposed to be a serious argument, just a stunt. Like all stunts it trivialises the issue, but that's no bad thing. See for example, the Prostate Research Foundation's totally tasteless "Give Bob a Bob" campaign, which brings Bob Monkhouse, with the full approval of his family, back from the grave to warn all men about prostate cancer. There are plenty of messages out there that are deadly serious. They've been there for years, but nothing much has changed. This new event has already started to attract media attention, entirely because of the dressing-up element, and it could possibly become the biggest awareness-raising event ever staged on behalf of the disease.

To correct a few misapprehensions: there is no suggestion that prostate cancer patients like dressing in drag – on the contrary, the emphasis is on the bravery of men, patients or not, prepared to risk the ridicule of their mates for a cause they believe in. Nor is it intended to belittle those many men who suffer emasculating effects of treatment – we hope that most of them will see the irony and the humour of the situation. The event is not aimed specifically at those affected by prostate cancer. Only a few of them are up to doing 26 miles anyway. No, it is aimed at men and women who want to strike a blow against this dreadful disease – sons, daughters, brothers, sisters, and friends of prostate cancer sufferers.

If you cannot support it, please don't try to stop it.

Paul Thomas – The X Foundation
Emma Halls – Prostate Cancer Research Foundation

The Prospect Web-Site and a Federation grant

www.prostatecancerbristol.org.uk

Why did we want to redesign it?

Prospect is the Bristol and District Prostate Cancer support group run by Prostate Cancer survivors for the benefit of the local community. Our aim is to reach out with support and information to prostate cancer patients, their wives, partners and carers.

As the World-Wide-Web becomes ever more important as a primary source of information, and as older people are amongst its prime users, we considered it essential to use the web to best advantage: to raise awareness of prostate cancer; to keep patients in touch with up-to-date knowledge of medical developments and changes in the local arrangements for treatment; and to champion the cause of prostate cancer patients. We believe passionately that knowledge benefits the patient, enabling him to play an active part in, for example, selecting the best treatment for his case.

We have had a web-site for some years, but the Committee felt that it was not appropriate as a shop-window for our group. It duplicated matters available on other sites, it had too much focus on American sites and treatments, it was not up-to-date, and did not have a sympathetic, simple design that was easy to use. Its content was not well edited. We felt we could do better. Previously we had contracted out the design. This time we did it ourselves with the help of a web specialist, Ian Cutts. This also saved us a lot of money.

The concept was to build a site that gave men access to the information they might need in a clear, simple, attractive way. Thus it has three principal roles – to give information about our group and what we are up to, to give basic information about the prostate and the diseases that can affect it, and to act as a 'gateway' to the excellent sources of information available both locally and nationally from other web-sites. We wanted to enable somebody starting from scratch to brief themselves in a straightforward way to a high level.

Because we believe in the beneficial role of our group, we are keen to recruit new members and the site provides a very convenient, cost-effective way of telling people what we do. For example we have printed visiting-card sized cards to be handed out by GPs and Specialists and by ourselves at clinics and events, containing details of the site.

I am pleased to say that we have had good feedback on the new site www.prostatecancerbristol.org.uk and even a donation to our funds! But it should not stand still. Please take a look and if you think there are things to do to improve it please let us know.

All this would not have been possible without the grant monies given by the Federation to help us to redesign our site and also to maintain it. We are now able to change or add to the site with almost immediate effect to ensure it remains current and relevant. The grant application process is not onerous and we would urge any support group which requires funding for a specific project to investigate what grants are available via the Federation.

Mike Andrews

If your group have a project that needs funding, then why not apply for a 'Federation grant' you can download an application form from our website or contact Sandy Tyndale-Biscoe on 01243 572990

Federation 'Real PCRMP' leaflets

As the Department of Health has now issued revised guidelines to GPs on PSA testing, we have updated and re-printed our own guideline sheet to distribute to GPs. If your group would like a further supply of these leaflets, contact 0161 474 8222

Federation AGM

24th April 2010
at
Penny Brohn, Bristol

full details in our next issue

Newsletter Distribution

Member groups of the Federation, can order as many newsletters as you want. Every individual member of your group should be receiving their own copy.

Further copies of Prostate Matters Issues 3 and 4

are available, should your group require them.

Contact by email: editor@prostatematters-uk.org or phone 01903 775602 to enquire/order

Group Membership fees to the Federation are now due

At our AGM in April this year a vote was carried which levied a membership fee for each 'group' to join the Federation based on £1 for each of 'their' members up to a maximum payment of £100.

Research may point to some enhanced prostate treatments

"If someone told you that an over-the-counter cheap pill could improve your prostate journey, you'd be interested, right? What if you also heard that there's a significant chance several hundred of you will get osteoporosis and bone fractures? Relevant to both questions is Vitamin D3".

For a number of years, researchers have been looking at whether Vitamin D3 can prevent or affect prostate cancer treatments. Here are some examples:

In October 2002, Drs. Rao, Woodruff, Wade, et al, Dept. of Cancer Biology, Winston-Salem, found synergism between genistein (a soy isoflavenoid) and vitamin D compounds on prostate cells. Both genistein and vitamin D inhibit prostate cancer growth but together even more so.

In late 2004, Woo, Vieth, et al from the University of Toronto presented a paper at the November NIH conference on vitamin D and cancer. They showed that 2,000 units of simple vitamin D3 either reduced or prevented further increases in PSA in the majority of men with advancing prostate cancer. For the first time, a human interventional trial indicted that simple vitamin D was effective in fighting cancer.

In Sept 2005, researchers at the Stanford University School of Medicine discovered that there is a synergistic effect using calcitriol (metabolised by the body from Vitamin D3) in combination with anti-inflammatories such as ibuprofen. They saw a 25 percent reduction in prostate cell growth using only calcitriol, and approximately the same reduction using only ibuprofen. But in combination, they saw up to a 70 percent reduction. This result was obtained using from one-half to one-tenth the concentration required for either of the drugs used alone. This study was done using cell cultures in a lab.

A 2007 US study estimated that men with higher levels of vitamin D have a 52% reduced incidence of prostate cancer. But not everyone agrees. A case-control study nested within the European Prospective Investigation into Cancer and Nutrition EPIC (1994-2000), published in May 2009, concluded that there was no evidence in support of a protective effect of circulating concentrations of vitamin D on the risk of prostate cancer. So more research is needed on prevention.

In 2009, researchers in University of California, San Diego, using observational studies combined with a randomized trial, concluded that raising the minimum year-around blood serum level of vitamin D3 to 40 to 60 ng/ml (100-150 nmol/l) would prevent about 58,000 new cases of breast cancer and 49,000 new cases of colorectal cancer each year, and ¾ of deaths from these diseases in USA and Canada. Such intakes also are expected to reduce by half the death rates of patients who have breast, colorectal, or prostate cancer.

Inecalcitol, a synthetic derivative of calcitriol, is 11 times more powerful, and at least 480 times less toxic, when tested on mice with human prostate cancer cells. It reduced tumour growth by 50% in 6 weeks.

Bone health is very relevant to men with prostate cancer. Even if you ignore prostate cancer, 1 in 5 men over 50 are affected by osteoporosis (we're crumblies!) with high risk of hip and spine fractures. For prostate cancer patients, those who have low levels of testosterone (most of us who are on Zoladex, etc.) will have a progressive weakening of bones of a few percent per year, in addition to the general weakening which occurs as we get older.

Prostate patients should have regular Bone Mineral Density (BMD) checks. It is a simple 15-minute, non-invasive scan while fully clothed, lying on a couch. It is called a "DEXA" scan (Dual Energy X-ray Absorptiometry), and can be arranged by your GP. Output from the DEXA scan will include a "T score":

⇒ Above minus 1.0 is normal

⇒ Between minus 1.0 and minus 2.5 is "osteopenic" (low bone mass)

⇒ Below minus 2.5 is osteoporosis

My wife has recently been diagnosed with osteoporosis, with a T score of minus 4.0. (That's 4 standard deviations below the average level for adult women). The GP has prescribed "Calcichews" twice a day – a combination of calcium and Vitamin D3, and Alendronic acid (a bisphosphonate drug which slows the "resorption" of minerals out of the bone and into the bloodstream).

1 in 2 women over the age of 50 are likely to have osteoporosis.

Diet and calcium. In the western world, dairy products are an important source of calcium, but there are many other sources, including for example sardines, fruit and vegetables, bread, nuts and seeds. Many prostate patients have adopted a "dairy-free" diet as recommended by Professor Jane Plant, so the other sources are important, though some of the soya alternatives to dairy can now be obtained with added calcium. Regular exercise such as walking will help stimulate bone cell growth.

NB. Smoking, too much alcohol, caffeine and salt cause the body to lose calcium. There are also hereditary factors; you may have inherited a weak bone density.

Vitamin D3. Technically not a "vitamin," vitamin D is in a class by itself. Its metabolic product, calcitriol, is actually a secosteroid hormone that targets over 2000 genes (about 10% of the human genome) in the human body. Research has implicated it as a major factor in the pathology of at least 17 varieties of cancer* as well as heart disease, stroke, hypertension, autoimmune diseases, diabetes, depression, chronic pain, osteoarthritis, osteoporosis, muscle weakness, muscle wasting, birth defects, periodontal disease, and more.

* It regulates cell growth, differentiation, apoptosis (programmed cell death), and a wide range of cellular mechanisms central to the development of cancer.

Vitamin D3 has also been known for a long time as a vital "ingredient" to help fix calcium in our bodies.

Different measurements are used:

- In the body, vitamin D3 is usually measured in UK as nmol/l, in US as ng/ml (0.4 of nmol).
- In food and supplements, it is measured as micrograms (µg) or IU (international units). 1 IU = 0.025 µg.

Our bodies use between 3,000 and 5,000 IU per day. In a US trial they aimed at a body level of 200 nmol to reduce the incidence of fractures among a group of elderly patients in a nursing home, who had low exercise, and not much sun. They were given supplements of 5,000 IU per day. An intake of 400 IU typically raises levels by about 10nmol, (but this declines as we get older).

When more Vitamin D enters the body than is needed, the surplus is stored in fat, and can be drawn down when needed – a useful mechanism.

Sources of Vitamin D3. There are 3 possible sources: diet, sunlight, and supplements,

- **Diet.** Oily fish is the best source, but even an optimum diet would not exceed a few hundred IU per day.
- **Sunlight.** 20 minutes a day sunbathing (with no sun cream) could provide up to 4,000 IU. BUT, it needs to be hot sun, sufficiently high in the sky. Above 37 deg latitude (UK lies roughly between 50 and 60) the sun is not adequate to give any IU in the months from October to end of March, so the chances are you're deficient. Government warnings about the risk of melanoma are deterring many from getting enough sun. 20 minutes a day is safe, provided that it is taken in short sessions of a few minutes, with time in the shade in-between
- **Supplements.** Some UK vitamin pills and cod liver oil capsules are available, but the amounts of Vitamin D3 provided are very low. Some pills may say "Vitamin D", but these are often D2 not D3, so much less effective. "Calcichews" typically contain 400 IU's of Vitamin D3. A US supplier (www.iherb.com) offers pills which contain 5,000 IU each. A tub containing 360 cost me £13.18 delivered in about 2 weeks (less than 4p each). NB. I have no commercial interest except as a customer.

Safety.
Until recently, D3 safety levels were thought in the UK to be at max 2,000 IU daily. The UK Recommended Daily Allowance on one pack is shown as 5µg (200 IU). Overdosing can cause hypercalcaemia, but this occurs at about 375 nmol. In a US study this took 40,000 IU daily for 6 months to achieve. So 5,000 or 10,000 IU per day should not cause problems, provided that your level is checked regularly.

Testing your Vitamin D level
This is done by a simple blood test, called a "25-Hydroxy VitD" test. The blood needs to be analysed fairly soon, so it is unlikely that a GP surgery will be able to do it. My oncologist in Southampton General Hospital (where there is an onsite lab) has agreed to include the test every 3 weeks along with my chemo blood tests.

Vitamin D3 deficiency is bad for you

A Norwegian study published Feb 2009 looked at whether Vitamin D3 affected death rates from prostate cancer. Vitamin D3 levels were measured, and patients divided into 3 groups; low (<50nmol), medium (50-80nmol) or high (>80nmol). Mortality was *significantly less* for those in the medium and high groups.

This is also the conclusion of a study in the British Journal of Cancer (Feb 10, 2009) by Tretli et al: men with biopsy proven prostate cancer who had the highest vitamin D levels, were ***up to 6 times less likely to die*** than men with the lowest levels over the 4 years of the study.

In the Roswell Clinic in Buffalo NY, Dr Donald Trump, a medical oncologist, has found most of his cancer patients to be "Vitamin D deficient", i.e. below what he believes is an ideal level of 150-187nmol. This is not specific to cancer, just that Buffalo doesn't get enough sun in winter. He believes that cancer patients need a higher level, because the body might need more vitamin D3 to fight the cancer problems. He has started trials giving prostate cancer patients varying amounts up to 10,000 IU. See him on video (Dec 2008):
http://www.youtube.com/watch?v=KOUR9JSmY3w

Dr Cannell, of the Vitamin D Council, believes prostate cancer patients should have a level of 200-225nmol. www.vitamindcouncil.org
This website is a mine of information about Vitamin D3. The Vitamin D Council, 585 Leff Street, San Luis Obispo, California, United States 93401 are a non-profit, educational corporation whose aim is to inform on the risks of vitamin D deficiency.

In the Journal of the American Geriatrics Society, September 2009, Dr. Ginde et al from the University of Coloroado, report on a study of older adults. 3,408 men and women who had an average age of 73 were followed up over a '7-year' period, during which time 1,493 died. After taking into account a variety of factors that could influence the results, low vitamin D was independently associated with an increased risk of death. They found that the risk of death from any cause was 47% higher among those with vitamin D levels between 25 and 49.9 nmol/L, relative to those with vitamin D levels of 100 or higher. The difference was even more striking comparing those with less than 25 nmol/L: 83% higher than people with vitamin D levels of 100 nmol/L or higher.
Low vitamin D levels, had a risk of death due to heart disease more than twice as high in people with vitamin D levels less than 25 nmol/L.

My mini-trial

As I am convinced that Vitamin D3 will give me benefit, I started taking 5,000 IU per day on August 23rd, 10 days ahead of my first chemo (Docetaxel + Prednisolone).
My PSA went down slightly after 6 consecutive rises over the previous year. Encouraged by that, I have subsequently raised my intake to 50,000 IU a week (well it is October already). My first Vitamin D3 test, (and my next PSA) was on 21st October, just prior to my 3rd chemo. (At time of writing I am still waiting for the Vit D result). I already take Soy Isoflavones pills, and occasionally ibuprofen.
For those who wish to follow my results, I will update my profile on the Prostate Cancer Charity message board (http://www.prostate-cancer.org.uk/forums) Click on "members", and select letter P. My profile is PC04MH.
Of course, this is not a double-blind randomised trial, so it won't prove anything, but I have nothing to lose. My PSA test on 21st October was 6.2 (down from 92 on 2nd September). This was too good to be true, so I had another PSA on 28th October via my local surgery. Similar result! It is very encouraging news!
Meanwhile, as it's winter, I'd urge all readers to get some cheap pills. They'll do you good!

Mike Hollingworth

Clinical Trial

PATCH

Prostate **A**denocarcinoma: **T**rans**C**utaneous **H**ormones

A randomised-controlled trial of transcutaneous oestrogen patches verses LHRH analogues in prostate cancer

Principal Aim

To confirm whether oestrogen patches are a safe and effective treatment for prostate cancer.

Rationale

LHRH analogues are increasingly being used to treat prostate cancer and there is concern about long-term toxicity, particularly osteoporosis. Oral oestrogens have previously proven to be effective at controlling prostate cancer, but have been linked to an increased risk of cardiovascular disease, thought to be due to first-pass hepatic metabolism. Transcutaneous patches deliver oestrogen directly into the blood, avoiding exposing the liver to large amounts of the hormone, and theoretically reducing the risk of cardiovascular toxicity.

Eligibility Criteria

Histologically confirmed prostate adenocarcinoma

Newly Diagnosed high risk patients with either:

- Stage T3/4, NO or NX MO, PSA > 20ng/ml, gleason > 6
- Stage T(any) N+ MO, or T(any) N(any) M+
- Multiple sclerotic bone metastases with PSA > 50ng/ml

Relapsing after radical surgery and/or radiotherapy

- PSA > 4ng/ml doubling < 6 months
- PSA > 20ng/ml
- Documented evidence of metastatic disease with PSA >4ng/ml

Exclusion Criteria

Patients with confirmed cardiovascular disease. No deep vein thrombosis or pulmonary embolism, recent history of myocardial infarction, severe angina or severe heart failure.

Locations

42 UK centres throughout the country.
Aiming to recruit 250 patients by early 2010.

Principal Investigator

Professor Paul Abel, Dept. of Surgery, Hammersmith Hospital, London

For more Information

PATCH Trial Manager: Philip Pollock
Tel: 0207 670 4846 email: patch@ctu.mrc.ac.uk
GP/Consultant referral. Full details on website:
www.cancer.gov/clinicaltrials/MRC-PATCH

MRC Clinical Trials Unit

CANCER RESEARCH UK

NCRI National Cancer Research Institute

Exercise for lower prostate cancer risk - less aggressive disease

A moderate amount of exercise most days of the week may contribute to a lower risk of prostate cancer, and lower grade tumours among those men who are diagnosed with the disease following biopsy, say researchers at Duke University Medical Centre and the Durham Veterans Affairs Hospital.

The finding, appearing online in the *Journal of Urology*, adds more fuel to the ongoing debate over whether exercise offers any benefit at all among men seeking to prevent prostate cancer.

Source: Duke University Medical Center: Journal of Urology: Oct. 09

Pomegranate Juice may effectively slow the progression of prostate cancer

Results of a long-term study were presented at the 104th Annual Scientific Meeting of the American Urological Association (AUA) showing that, even when regular treatment had failed, pomegranate juice may effectively slow the progression of prostate cancer.

Forty eight men were followed over six years, each having similar rising PSA readings after surgery or radiotherapy.

They were split into two groups, one group was given eight ounces of pomegranate juice daily, compared to the other group not taking the juice. Despite all having similar PSA scores to begin with, after 56 months there was a significant difference and progression had slowed down dramatically in the men regularly drinking the juice.

These findings suggest pomegranate juice could slow the progression of prostate cancer.

Proactive Prostates Initiative

Call to Action to prevent deaths from prostate cancer in Europe

The following Call to Action has been prepared by a coalition of groups, coordinated by EUROPA UOMO, and is being circulated to the European advocacy community for your support. You can sign up to the Call to Action at: http://www.europa-uomo.org

Prostate cancer is the most frequent diagnosed form of cancer in men, accounting for 24.1% of all cases and the third leading cause of cancer deaths in 10.4% of men in the EU25 in 2006. The figures on incidence and mortality become comparable to breast cancer in 2006. Prostate cancer will become the leading cancer in terms of incidence in the near future.

	Men PCa		Women BrCa	
	Incidence	Mortality	Incidence	Mortality
2004	202,1	68,2	275,1	88,4
2006	301,5	67,8	319,9	85,3

Europa 25* thousands, IARC

Prostate cancers diagnosed by screening do not always need treatment and active surveillance is a reasonable option in selected patients. An individualised approach to treatment is advised, since there is a possibility of over-diagnosis in 30% of patients compared with under-diagnosis in 15% of patients. However PCa can only be cured when it is treated in its early stages, i.e. when the disease is organ-confined. Hormonal therapy, an important treatment, impacts on the quality of life but the side effects can be reduced by physical activity, nutrition and psychological support.

"I urge society to sit up and take notice of prostate cancer so that we can beat this disease - yes we can", said Archbishop Desmond Tutu, the South African Nobel Peace Prize Laureate who has had prostate cancer, and fully supports the call to action.

We have been encouraged by advances in prevention, diagnosis and management of prostate cancer, which have the potential to significantly reduce this burden in Europe.

However, a recent international survey indicated that, although awareness of prostate cancer is Improving:

⇒ Over half of people questioned are not aware that prostate and breast cancer have a similar prevalence

⇒ One in ten people surveyed thought that prostate cancer affects both men and women equally, when in fact only men have prostates.

⇒ Approximately, half of men under-estimate their risk of developing prostate cancer.

We recognise that only a comprehensive strategy will ensure that men at risk are diagnosed earlier and receive optimal treatment with holistic care on an individual basis.

Hence, we are calling for action on:

- **Governments** to make prostate cancer a higher priority in their health agenda to reduce morbidity and mortality.
- **Governments** to ensure sustained support for basic research on new biomarker and clinical research on treatment.
- **Health professionals** to inform and educate patients about the risk factors, such as family history.
- **Physicians** to tailor individual treatment according to the needs of the patient, avoiding over- and under-treatment through appropriate use of PSA testing.
- **Society** to come together through partnerships to reduce the burden of the disease and the existing inequalities on access to treatment.

We commit to achieving these aims by working with all relevant partners to communicate these messages to appropriate policy makers and healthcare professionals.

Sign the Proactive Prostates Initiative Call to Action

We call upon governments, public health institutions, health care workers, and members of civil society to join this Call to Action. Together we must work towards ensuring that all men have access to the best possible information and treatment.

This call has been endorsed by the European Association of Urology, the European School of Oncology, the European Oncology Nursing Society, the European Cancer Patient Coalition and the European Cancer Prevention Organisation, the European Society of Oncology Pharmacy and the European Randomised Study of Screening for Prostate Cancer.

Europa Uomo and the Prostate Cancer Support Federation encourage you to give prostate cancer a voice that will be heard by signing up to Call to Action at **http://www.europa-uomo.org**

The above article is based on the combined efforts of Europa Uomo representatives.

Mike Lockett - Europa Uomo and PCSF

References

Space necessitated the exclusion of references, but these can be provided on request.

These activities are made possible through an unrestricted educational grant from the European Association of Urology and GlaxoSmithKline.

Prostate Cancer Support Federation

Mansion House Chambers
22 High Street, Stockport
Cheshire SK1 1EG
Tel: 0161 474 8222

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.

www.prostatecancerfederation.org.uk
e mail: info@prostatecancerfederation.org.uk

Decision support for prostate cancer patients

One of the more difficult decisions for a man newly diagnosed with localised prostate cancer is what treatment choice to make when a number of treatment options are available and when each approach has possible pros and cons. For example, surgery can remove the cancer completely but there may be complications during surgery and negative side effects after treatment. But as many men will know, side effects are not limited to surgery alone. Callers to our Helpline frequently state this confusion to be a major concern, especially at this early vulnerable stage.

Until now men have depended on a variety of information from various sources (including the internet and ad hoc leaflets) and on the communication that they have with their medical team. The result is that the quality of information and help varies tremendously for different patients.

Similar difficulties exist in other fields of medicine, but to overcome this problem in the specialist field of Urology the NHS has developed its first decision support materials (in the UK) for patients to help them make difficult choices between treatment options. In this case for patients diagnosed with localised prostate cancer or benign prostatic hyperplasia (BPH).

About the IDM (Informed Decision Making) materials

The IDM consists of a pack of 3 main items (available on-line at a future date):

- **A booklet – "Booklet for Patients: localised Prostate Cancer"**

This has facts for patients newly diagnosed with early stage (localised) prostate cancer. The content of the materials has been agreed with NHS clinicians, outlining information about the condition, treatment options, possible benefits and harms of different treatments and the probabilities of those side effects occurring.

The information is designed to objectively inform the patient (and partner/family) of the facts and to stimulate him to think about his own situation in the light of his diagnosis.

- **A DVD**

The DVD gives more information about having prostate cancer and treatment options available. Also on the DVD a number of patients and their partners talk about their experiences of treatment and impact on their lives.

- **Personal Decision Forms – a questionnaire**

The Personal Decision Form is a questionnaire to be completed by the patient after reviewing the information about his condition. This form provides the basis for discussion with the Nurse: it tests the patients understanding of the facts and helps him to consider the possible outcomes of the different treatment options in his own circumstances, which in turn helps him to identify his preferences and make a good decision.

Roll out The project was trialled at a number of hospitals throughout England and Wales earlier this year, and the decision support materials will be introduced to urology departments nationally with support to help implementation. Plans are underway to develop the materials online, and arrangements will be made for regular updating. The materials were officially launched at the House of Commons on 5th October by Bernard Crump, the Director of the NHS Institute of Innovation and Improvement, who commented that "We know from research in Ottawa that patients who don't have decision support are > 59 times more likely to change their mind > 23 times more likely to delay their decision and > 5 times more likely to regret their decision. Helping patients make the right decision will help avoid these outcomes, ensure that resources are invested in the right place to help patients, and support patients so they don't undergo unsuitable procedures".

The decision support materials have been established by a project led by Dr Mary Archer, Chairman of the Cambridge University Teaching Hospitals NHS Foundation Trust. Dr Archer thanked all of those who had been involved in the project. Many of those involved were at the launch.

Mike Lockett (PCSF), speaking from a patient's viewpoint, stated that "most men make their decision as part of a team consisting of their medical advisors (their consultants, urological nurses), their family and themselves. But one of the facts about communication between patients and physicians is that it varies from excellent to very poor according to the hospital and the medical team. This project was established to change that and he would like to think that all urology staff will be trained and that this pack will become a mandatory item, given to every man when he receives his diagnosis, so he can be armed with the knowledge to ask questions, to expect straight answers and to really contribute to the treatment decision".