Prostate Cancer Support Federation

Prostate Matters

Newsletter

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Contents -

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Inaugural Conference

The Prostate Cancer Support Federation arose from the perceived need to provide a focus for, and a single voice to express, the views and concerns of the patient-led prostate cancer community in the UK. It was recognised that this could be best achieved by a federation of independent patient-led prostate cancer charities and support groups.
Currently, there are many such support groups throughout the Country which are very active in providing help support and information to patients and their carers. Many are also active in raising awareness and acting as advocates for our common aims. The establishment of the Federation will in no way interfere with any of these activities. However, we can make more impact together than we can individually. A single voice, where this can be agreed across the Country, will be more effective than comments from any single group.
In this first newsletter we mention some of the issues which the Federation can consider to express the patient view.

Organisation

Frequently, we ask “why do women with breast cancer seem to get a better deal than men with prostate cancer”. They are, of course, different diseases and the answer is not straightforward. Nevertheless, one reason for the disparity is that women have grouped to form a very strong central association from which country-wide views can be developed, focused and expressed. Organisations of this kind are also evident in the case of several other types of cancer.
The Federation can provide us with this facility, and will also, via our membership of Europa Uomo, keep us in touch with developments in Europe. Our constitution provides for ‘Organisation Membership’ to organisations which, although not patient-led, share our interest in prostate cancer and support our ‘objects’. Links with major charities will be strengthened.

Research Directions and Funding

One area of continuing interest and concern is the direction and extent of the research effort. Differences in research funding for breast and prostate cancer have not, over the years, favoured prostate cancer. Nevertheless, there is, currently, considerable research into the understanding and treatment of prostate cancer. The underlying causes of prostate cancer are not yet understood, and fundamental research into genetic and biochemical features, and to a lesser extent into environmental and life-style effects, is aimed at clarifying the position.
This is a very worthy, long term aim, which we all support. However, the concerns of patients tend to be shorter term…. *continued on back page>>>*

NICE Prostate Cancer Guideline comment by Sandy Tyndale-Biscoe

Many of you will be aware that, towards the end of February this year, the long awaited NICE Guideline on the diagnosis and treatment of prostate cancer was finally published. It was met with deafening silence from the media. The lack of media interest was deliberate and planned by NICE themselves. At the time of publication, lawyers for certain medical equipment manufacturers were threatening to sue, and NICE were keen to get the Guidelines out with minimal impact.

Thus did NICE notch up a further betrayal of men who suffer from prostate cancer. Those of us who had played a part in the public consultation about these Guidelines had hoped that, however much we expected to dislike what we suspected was coming, at least publication would attract publicity and the chance to raise awareness of prostate cancer, the lack of which is the chief cause of the fact that the death rate from prostate cancer has remained unchanged for the last 15 years.

Much of the content of the Guideline was as expected, particularly for those who had participated in the consultation process and submitted comments. The impact on prostate cancer sufferers varies from good, through not so good, to bad. On the good side is the decoupling of a single elevated PSA Test result from automatic biopsy and the slippery path to treatment. The Guideline says "The serum PSA level alone should not automatically lead to a prostate biopsy", which is a step in the right direction (although an over-simplification), as the belief that it does do exactly that is often used as an argument against the PSA Test.

The not so good news is the approach recommended for men diagnosed with "low risk" disease (PSA ≤ 10ng/ml AND Gleason ≤ 6 AND T1-T2a) appears to be Active Surveillance, with the recommendation that "Men with low-risk localised prostate cancer who are considered suitable for radical treatment should first be offered active surveillance". It is intriguing that this wording was altered, by NICE, not by the Guideline Development Group, from something that was altogether less dogmatic, and merely offered Active Surveillance as an option. Again, in countering the anti-PSA argument, Active Surveillance should be encouraged *where there is strong confidence that the disease is not currently life threatening,* but, the insertion of the word "first" in the recommendation very much changes the emphasis, and in a way that was not intended by the clinicians who worked on the Guideline. There is concern, not only amongst patients, that this will be used to save money by suggesting to men in this category that they forego immediate treatment, when their instincts may be otherwise.

The bad news is that some aspects of the Guideline fly in the face of modern best practice, and as a result a number of the top clinicians in the country are very concerned. Specific areas where this is the case are biopsy and pathology procedures, dose rates for radiotherapy, the failure to distinguish low and high dose rate brachytherapy, and the criteria for initiating hormone therapy.

The really bad news for many patients is the stance that has been taken over the use of cryotherapy as a salvage treatment, where NICE is almost silent. Whilst the full (long) version of the Guideline does mention that salvage therapies for relapse after radiotherapy include cryotherapy, reflecting the fact that many clinicians believe that this can provide a genuine, curative, last chance option for some men with relapse after radiotherapy as a primary treatment, it makes no recommendation on the matter. The short version of the Guideline, which is the one consulted by most non prostate cancer experts, is totally silent on the matter. NICE came under strong pressure to modify its stance over this, which it resisted. Unfortunately much of the pressure appeared to be (indeed, some was) commercially based, which has generally fouled the atmosphere around the debate.

What can be done to correct what has turned out to be a very disappointing Guideline? Probably not much in the short term. The Department of Health's Prostate Cancer Advisory Group had a lengthy discussion on it last month, at which the Chair of the Guideline Development Group came under considerable pressure. A total of eleven serious issues were noted by Prof Mike Richards, the Cancer "Tsar", some of which I've outlined above. But revision of the Guideline is not planned for another three years at least, and it seems unlikely that NICE will succumb to any pressure to revise its stance in the mean time. However, PCTs are not obliged to follow NICE Guidelines where there is strong clinical evidence that they're wrong. It is hopeful that the Central South Coast Cancer Network is writing to all PCTs in its area stating the consensus amongst its clinicians that salvage cryotherapy is an effective treatment and asking PCTs to fund it. What effect such a letter may have we don't know, but it's a step in the right direction, and other networks may be persuaded to follow suit.

You can order copies of the NICE Guideline via the internet from: www.nice.org.uk/CG058
or phone NICE publications on 0845 003 7783.

Should UK Prostate Cancer Detection Age Be Lowered In line with the United States

report from the British Medical Journal

In many countries prostate cancer screening happens ahead of evidence from ongoing trials. In several countries, early opportunistic screening starts with people aged 50. The Americans have recently adopted a lower age limit after two studies found that raised PSA (prostate specific antigen) levels in males in their 40s was linked to prostate cancer.

A team of scientists in the UK looked at the feasibility of prostate cancer testing, prevalence and characteristics in a random group of younger men. The study involved 442 men aged 40-45 they all agreed to PSA testing. 54 (12%) of them had a high PSA result. They were invited to additional testing, involving an ultrasound-guided prostate biopsy, another PSA test, and a digital rectal examination.

Ten cases of prostate cancer were detected - a similar rate to that found in older men, 2.3%. Five of them had tumours that were potentially risky to health. They agreed to have one of three treatment options - radiotherapy, surgery, or active monitoring.

The study revealed that men under 50 will accept prostate cancer testing at a much lower rate than men over 50, the researchers explained. Therefore, greater efforts would be required to optimize uptake in younger men if screening for them were introduced.

If the 2,236,000 males aged 45-49 in the UK underwent PSA screening, the researchers estimate that 272,905 of them would have elevated PSA, of whom *51,449 would have prostate cancer.* Treatment would benefit some of those with prostate cancer. However, this has to be weighed against the probable distress caused to the 221,456 men with elevated PSA who do not have cancer. Apart from distress, these men also run the risk of undergoing unnecessary treatment and the side-effects that come with the treatments.

The study will inform the debate about PSA thresholds and age limits, say the researchers, but only if prostate cancer screening is proven as effective in ongoing trials. Until we have the results of the ongoing trials, policy should advise clinicians to inform the patients about the benefits, potential harms, and limitations of prostate cancer screening.

Research:

"Detection of prostate cancer in unselected young men: prospective cohort nested within a randomised controlled trial"

J Athene Lane, Joanne Howson, Jenny L Donovan, John R Goepel, Daniel J Dedman, Liz Down, Emma L Turner, David E Neal, Freddie C Hamdy

Advanced Prostate Cancer Can Be Predicted By PSA Testing

A single prostate specific antigen (PSA) test taken before the age of 50 can be used to predict advanced prostate cancer in men up to 25 years in advance of a diagnosis, according to a new study published by researchers at Memorial Sloan-Kettering Cancer Center in New York and Lund University in Sweden. The findings, published in the online open-access journal *BMC Medicine*, should help physicians identify men who would benefit from intensive prostate cancer screenings over their lifetime.

The team's research has shown that a single PSA test at age 50 or younger could predict the presence of prostate cancer in men up to 25 years in advance of diagnosis. "This latest study is a unique, natural experiment to test whether we can predict advanced prostate cancer many years before it is diagnosed," said lead author Hans Lilja, MD, PhD. The findings are based on the research team's analysis of blood samples collected between 1974 and 1986 as part of a large, population-based study of middle aged men called the Malmö Preventative Medicine study. The study cohort, in Malmö, Sweden, included 161 men who had been diagnosed with advanced prostate cancer by 1999 and men of a similar age who had not developed cancer by that time.

The results showed that the *total* PSA level was an accurate predictor of advanced cancer diagnosis in men later in life. The majority, 66 percent, of advanced cancers were seen in men whose PSA levels were in the top 20 percent (total PSA > 0.9 ng/ml). The average length of time from blood test to cancer diagnosis was 17 years.

While this data does not have any immediate implications for general prostate cancer screening guidelines, Dr. Lilja adds, "We have found that a single PSA test taken at or before age 50 is a very strong predictor of advanced prostate cancer diagnosed up to 25 years later. This suggests the possibility of using an early PSA test to determine which men should be the focus of the most intensive screening efforts." Vigilant, targeted screenings in high-risk men could allow physicians to intervene when the cancer is at an early stage.

Prostate Cancer Growth Delayed By Up To 8 Years By Just 4 Months Of Hormone Therapy

Researchers report that just four months of hormonal therapy before and with standard External Beam Radiation Therapy slowed cancer growth by as much as eight years - especially the development of bone metastases - and increased survival in older men with potentially aggressive prostate cancer. This "neoadjuvant" hormonal therapy may allow men most at risk of developing bone metastases avoid long-term hormonal therapy later on. Furthermore, the short-term hormonal therapy did not increase the risk of cardiovascular disease - a potential side effect of long-term hormonal therapy. The study was published online January 2 in the *Journal of Clinical Oncology (JCO).*

Hormonal therapy - called androgen deprivation therapy (ADT) - lowers levels of cancer-fuelling testosterone in the blood. It is an important treatment option for men with prostate cancer that continues to progress despite initial treatment with surgery, radiation therapy, or chemotherapy, but has been associated with side effects such as bone loss, osteoporosis, depression and an increase in cardiovascular risk factors (including blood lipids, abdominal obesity and a syndrome associated with diabetes).

"This study demonstrates that the benefits of short-term hormonal therapy for men receiving radiation therapy for prostate cancer far outweigh the risks," said lead author Mack Roach III, MD, professor and chair of radiation oncology and professor of urology at the University of California, San Francisco. "While four months of hormonal therapy isn't enough to cause significant side effects, we found that it can delay the development of bone metastasis by as many as eight years, which is very significant."

Starting in 1987, Radiation Therapy Oncology Group researchers studied 224 men with high-risk prostate cancer who received ADT (goserelin and flutamide) before and concurrent with external beam radiation therapy, and 232 men with the disease who received radiation therapy alone. After 13 years of follow up, they found better 10-year disease-specific death rates (the rate of death from prostate cancer) for men who received ADT plus radiation (23 percent versus 36 percent of the radiation-only group), disease metastasis rates (35 percent versus 47 percent), disease-free survival (the percentage of men free of cancer at 10 years; 11 percent versus 3 percent) and biochemical failure rates (a rise in PSA levels; 65 percent versus 80 percent).

Among men who received neoadjuvant hormonal therapy, there was up to an eight-year delay in the time it took 40 percent of patients to develop bone metastases compared with men receiving radiation alone. Men who develop bone metastases often require long-term hormonal therapy, which can increase their risk for side effects. "So by taking a little bit of hormonal therapy early, patients may avoid having to take a lot of it later," added Dr. Roach.

Article adapted by Medical News Today from original press release.

New Urine Test More Accurate

ScienceDaily (Feb. 5, 2008) — An experimental *urine biomarker* test developed by researchers at the University of Michigan more accurately detects prostate cancer than any other screening method currently in use, according to a study published in the February 1 issue of Cancer Research, a journal of the American Association for Cancer Research.

The researchers say a simple urine test that screens for the presence of *four* different RNA molecules [GOLPH2, which is generally over-expressed in prostate cancer; SPINK1, over-expressed in a subset of these cancers; the PCA3 transcript expression; and TMPRSS2:ERG fusion status] accurately identified 80 percent of patients in a study who were later found to have prostate cancer, and was 61 percent effective in ruling out disease in other study participants.

This is 5 percent better than PCA3 alone and far more accurate than the PSA blood test currently in use worldwide, which can accurately detect prostate cancer in men with the disease but which also identifies many men with enlarged prostate glands who do not develop cancer, researchers say.

"Relative to what is out there, this is the best test so far," said the study's lead author, Arul Chinnaiyan, M.D., Ph.D., director of the Michigan Centre for Translational Pathology at the University of Michigan.

He also says that this *first generation multiple biomarker test* will likely be improved upon as researchers continue to uncover the molecular underpinnings of prostate cancer. "We want to develop a test to allow physicians to predict whether their patients have prostate cancer that is so accurate a biopsy won't be needed to rule cancer out," Chinnaiyan said. "No test can do that now."

Zeolite and the Pfeifer Protocol a report by Ann Rowland Dip ION

The research into complementary medicine and its role in helping people with cancer still goes on apace and I find it difficult to keep up with it all but last autumn I went to a lecture in London given by Professor Pfeifer of the Aeskulap Klinic in Switzerland on his anti-cancer protocol. I was particularly interested to hear him speak as quite a few people had been asking me what I thought of Zeolite. Having listened to a fascinating talk I was very impressed with the science behind this product and think it well worth trying.

Zeolite is a mineral found in volcanic soil that was deposited in lakes and the sea and has been used for over a thousand years in Asian medicine. Scientists in Croatia have found a method of reducing the Zeolite to nano particles and it is in this form that research is showing benefits in the fight against cancer.

It appears to have the ability to remove heavy metals, pesticides, herbicides, dioxins and radio-active materials from the body but, unlike other chelating agents, it leaves the healthy minerals behind. It also appears to prevent the absorption of nitrates into the digestive tract. It helps to keep the body alkaline, acts as a powerful antioxidant alongside the other antioxidants and helps to reduce the symptoms of allergy. Once the heavy metals have been removed it also appears to reduce the viral load on the body.

Zeolite is a mineral found in volcanic soil that was deposited in lakes and the sea and has been used for over a thousand years in Asian medicine.

Professor Pfeifer uses Zeolite alongside a whole regime of nutritional supplements and herbs as well as diet and gets some very good results. I was particularly interested to hear that he advises the use of Curcumin, which is a herb that I have been recommending for a while now because there is so much research into its ability to reduce inflammation.

It was fascinating to hear that initially he was not a believer in the benefits of a dietary regime but a colleague developed one that Pfeifer has now introduced as the final point in his regime. Interestingly it is very similar to the dietary advice I give, in that dairy is out, fruit and vegetables are in and the grain carbohydrates are bad and everything as organic as you can manage!

I queried with the Professor the use of Zeolite alongside chemotherapy and he assured me that he uses it all the time during conventional treatment at his clinic and drew me a graph in order to explain why! When I said that oncologists are not happy for supplements to be used at the same time as their treatment he told me to tell them to read the research! I leave *that* decision to you!

If you wish to try the Zeolite it can be bought from The Really Healthy Co. (020 8480 1000) or the Nutri Centre (020 7637 8436) and quote ZZ ARS 001 as you will get a 15% discount. Needless to say it is not cheap but if you use the liquid form called Z Natural then this will not be too much. The detox recommendation is 10 drops 3 times a day and maintenance 3 drops 3 times a day. One of the best sources of curcumin (Curcumoin 98) is from Lemonburst (01273 558112), it is cheaper than the one from The Really Healthy Co. but still a very good product, several capsules a day is fine.

It is also possible to listen to Professor Pfeifer's 2005 lecture about his protocol in connection with prostate and breast cancers if you go to www.clearfeed.com/pfeifer and you have a broadband connection. The site is waiting to be updated with his 2007 information on Zeolite.

Ann Rowland Dip ION January 2008

Broccoli - *super veg*

Broccoli is well publicised and well known for its anti-cancer qualities, but now has been reported to possibly help slow ageing too.

New research shows that sulforaphane which is found in broccoli activates antioxidant genes and enzymes in immune cells. Oxidative damage is thought to be the main cause of ageing. Antioxidants prevent free radicals (supercharged oxygen) from causing this damage.

The professor leading the recent studies commented that "in particular, our study shows that a chemical present in broccoli is capable of stimulating a wide range of antioxidant defence pathways and may be able to interfere with the age-related decline in immune function."

Clinical Trial

ALPHARADIN - Radium 223

Phase III Randomised Study in the treatment of Patients with Hormone Refractory Prostate Cancer

Study Design

This is a double-blind, randomised, multiple dose, international Phase III pivotal efficacy and safety study of Alpharadin - Radium 223.
The study treatment consists of 6 intravenous administrations of Alpharadin or placebo (normal saline) each separated by an interval of 4 weeks (total 24 weeks).
Alpharadin (radium 223) is very similar to calcium, so that when it is injected into the blood, the body takes it up in the bones, and especially in bone secondaries. Because radium-223 is radioactive it then delivers radiotherapy to the bone secondaries.
So far, Alpharadin has been compared with placebo in a trial of 64 men with advanced prostate cancer who were all receiving standard treatment in addition. The drug was very well tolerated with more adverse effects in the placebo group. A large trial, involving hundreds of men, is now needed to confirm these exciting results. All men will receive best standard treatment for prostate cancer. In addition, they will either get Alpharadin or placebo, and will then be followed up for several years.

Eligibility Criteria

Males greater than 18 years of age who:

- Have a confirmed diagnosis of or clinical history consistent with adenocarcinoma of the prostate.
- Serum PSA progression defined as two consecutive increases in PSA.
- Have multiple skeletal metastases (>2 hot spots) on bone scintigraphy within previous 12 weeks.
- Are taking regularly any analgesic medication for cancer related pain (>level 1) or had treatment with EBRT for bone pain within previous 12 weeks.
- No intention to use cytotoxic chemotherapy within the next 6 months.
- Willing and able to comply with the protocol, including follow-up visits and examinations.

Study Centres

Bristol > Southampton > Taunton > Manchester
Cardiff > Plymouth > Guildford > Leeds + others
450 patients will be randomised in a 2:1 ratio

Co-ordinating Investigator (contact)

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Seven New Prostate Cancer Genetic Risk Factors Identified

Cancer Research UK funded scientists have found seven new sites in the human genome that are linked to men's risk of developing prostate cancer. Their findings are published in *Nature Genetics today*.

The scientists from *The institute of Cancer Research* and *University of Cambridge* found one gene called MSMB which could possibly be used in screening for prostate cancer and disease monitoring. Another of the sites harbours a gene called LMTK2 which might be a target for new treatments. The data suggests these newly identified genetic alterations are present in over half of all prostate cancer cases. They each increase a person's risk of the disease by up to 60 per cent.

There are probably many different factors that influence the development of prostate cancer, but particular combinations of genes are thought to play a major part. These results represent the largest number of genetic risk factors found in one genome-wide cancer study to date.

Dr Ros Eeles, who led the study at The Institute of Cancer Research, said: "These exciting results will help us to more accurately calculate the risk of developing prostate cancer and may lead to the development of better targeted screening and treatment."

The team, collaborating with scientists in the UK and Australia, studied the differences in the genetic make up of over 10,000 men in total. They started by scanning the DNA of men who were thought to be at higher 'genetic risk' of prostate cancer because they had been diagnosed with the disease before the age of 61 (1,171 men) or had a family history of prostate cancer (683 men). They then compared these results with a control group of men who did not have the disease (1,894 men) but lived in similar areas.

In the next stage, they looked to see if these genetic variants could be found more frequently in men with prostate cancer than in men without the disease. They studied 3,268 men with prostate cancer from the UK and Australia and 3,366 men who did not have the disease.

Fellow study author, Professor Doug Easton, director of Cancer Research UK's Genetic Epidemiology Unit at the University of Cambridge continued: "In comparison with other cancers such as breast and lung cancer, we understand little about how prostate cancer develops. These results will greatly improve our knowledge of this important disease."

Harpal Kumar, chief executive of Cancer Research UK, said: "These results are a breakthrough in our efforts to understand men's susceptibility to prostate cancer. Thanks to the international collaboration of so many scientists, and this huge advance in technology, we can now trawl through the human genome to discover so much more about prostate cancer – the most common cancer to affect UK men.

"We hope these findings will help us illuminate some of the main difficulties faced by doctors and researchers in diagnosing and treating prostate cancer, so in combination with other advances we can eventually beat it."

Older men with prostate cancer can Watch and Wait

Men in their 70s and older who are diagnosed with early stage prostate cancer can safely "watch and wait" because they are not likely to die of it.

Research findings at the Cancer Institute of New Jersey were presented by Grace Lu-Yao, They confirm the widely held belief that prostate cancer rarely kills men if it strikes late in life, something else will kill them first. Her study of more than 9,000 older men with prostate cancer that had not spread showed that just 3 to 7 percent of the men with low or moderate-grade tumours died of it after 10 years.

"Because prostate cancer therapies are associated with significant side effects, our data can help patients make better informed decisions about the most appropriate approach for them and potentially avoid treatment without adversely affecting their health," Lu-Yao said in a statement.

…..prostate cancer rarely kills men if it strikes late in life…..

She stressed that ‘’men who choose not to undergo treatment should be carefully watched to make sure their cancer does not spread or become more aggressive’’.

Whether to treat men with prostate cancer, because the disease often comes in a slow-growing form, has been debated by doctors for some time.

Eventually 2,675 of the men in her study, did get treated for the cancer, with either surgery, chemotherapy, hormone therapy or radiation, but they waited on average more than 10 years before treatment.

Salvage Radiation Therapy

A second study presented at the meeting showed radiation therapy can help save the lives of men whose PSA has begun rising following a radical prostatectomy, a sign the cancer has come back.

The team at the Johns Hopkins University School of Medicine in Baltimore said ‘’So-called salvage radiotherapy reduced the risk of dying from prostate cancer by more than 60 percent’’.

Prostate cancer is the second leading cancer killer of men after lung cancer. Globally, some 782,600 men will be diagnosed with the disease and 254,000 will die from it.

ERECTILE DYSFUNCTION

Daily Cialis should soon be available

The Indianapolis drug company, Eli Lilly, has recently had US and European approval to market a once-daily formulation of Cialis, in dosages of 2.5 milligrams and 5 milligrams, that will allow men to attempt sexual activity any time between doses.

Lilly said the low-dose daily formulations "may be most appropriate for men with erectile dysfunction who anticipate more frequent sexual activity (e.g. twice weekly) and without regard to timing of sexual activity"

The widely used treatment has been sold world-wide since 2003 in dosages of 5 mgs, 10 mgs and 20 mgs, and taken as needed. Those dosages provide effectiveness for up to 36 hours.

‘’In clinical trials, when taken without restrictions on the timing of sexual activity, Cialis for once daily use improved erectile function over the course of therapy," Lilly said in a release.

Levitra suitable for men with High Cholesterol

Bayer, the drug company who market Levitra, says that its impotence pill could be suitable for use in men with dyslipidaemia, based on data presented at the European Association of Urology Congress in Milan.

The 12-week placebo-controlled study involving about 400 men who were also taking statins, "provides further support that Levitra can successfully treat ED, even in men with a serious underlying condition like high cholesterol," commented Ian Eardley, honorary senior lecturer at St. James University Hospital in Leeds, UK.

3 Drugs - Dosages & Results

Viagra: 25 mg, 50 mg, and 100 mg tablets. Most patients begin using the 50 mg pill and either increase or decrease the dosage based on drug tolerance and / or effectiveness. Recommended taking Viagra 1 hour prior to sexual activity – lasts approx. 4 hours.

Cialis: 5 mg, 10 mg, and 20 mg tablets + new 2.5mg. It is recommended that you start out using 10 mg tablets and either increase or decrease the dosage depending on the results achieved.
Traditionally, Cialis tablets can be taken anywhere from 30 minutes to 12 hours prior to sexual activity – lasts approx. 17 to 36 hours.

Levitra: 2.5-mg, 5-mg, 10-mg, and 20-mg. Most people start out on the 10 mg pill and either work their way up or down depending on the results achieved.
Levitra should be taken anywhere from 25 minutes to 1 hour prior to sexual activity – lasts approx. 5 hours.

and relate to the efficacy of diagnosis and the characterisation of the type of prostate cancer (particularly the recognition of aggressive cancers) and the identification of procedures for satisfactory prediction of outcomes. New "markers" and new "predictors" are periodically reported in the literature, but there seems to be little translational research aimed at their evaluation and subsequent translation into clinical practice. This applies both to predicting the need for biopsy, and identifying the most appropriate type of treatment (including palliative treatment) for a particular patient. What are our views on research priorities? We must define our views and express them.

Treatments and their Availability

We constantly hear of differences in the availability of treatments in different regions of the country, and differences in interpretation of guidelines within different GP practices. As a Federation we should be in a position to collect information, and express our views.

It will take time for the Federation to establish sufficient credibility and momentum to achieve optimal treatment for our prostate cancer community. The inaugural meeting marks a first step. By acting in concert with organisations having similar aims we can, together, increase the pace of change. John Dwyer, chairman of PCSF

Advocacy by Sandy Tyndale-Biscoe of PCaSO

It is a key aim of the Federation that it should act as a channel for Advocacy – to represent the considered, collective voice of the million or so patients throughout the country, whilst in no way inhibiting the rights of individual groups to express their own opinions.

There are many channels by which patients' voices might be heard. Formal examples include the Prostate Cancer Charter for Action, the Prostate Cancer Advisory Group, representations to NICE, participation in the National Cancer Research Institute user panels, and in the anticipated consultation in the revised Prostate Cancer Risk Management Programme, and representation at the European level in organisations such as Europa Uomo.

At present, patients' voices are heard in these fora on an ad hoc basis. A classic example is in the Charter for Action, where I, representing PCaSO, because it was originally the only signatory that was a patient-led organisation, find myself representing, or assumed to represent, the views of patients throughout the land. This is not only unfair, it is quite dangerous. I could get it horribly wrong. Naturally, I feel that the views of patients are safe in my hands, and so long as the only people objecting are those whose actions we wish to change (e.g. the Dept of Health, and the major cancer charities), I'm confident that nothing is basically wrong. On really controversial issues, such as PSA based screening, I, as a mild sceptic, try to steer a middle line ("a man should know his PSA – it's an instrument on the dash-board of life"). But I'm conscious that I'm basically self-appointed, and at any point someone could stand up and say "What gives you the right to claim that you represent me on this subject?" And I'd have no answer.

Further, the ad hoc nature of this form of representation could result in more than one conflicting view being peddled as the patients' position in different fora.

The Federation should provide a partial answer to this dilemma. Details will have to be worked out, but it is at least feasible that we could devise a process whereby one or more members of the prostate cancer patient community, whose views are trusted, could be "elected" to represent the Federation, and thus UK patients, in these various fora. It can't be worse than the current situation. Join, and you'll help work out the system.

Europa Uomo by Mike Lockett of PCS

Europa Uomo (European Man) is a coalition of (currently) twenty national patient led support organisations from within the European Union. In their own countries these organisations operate independently from Europa Uomo, but subscribe to the view that cooperation and partnership with other patient organisations will strengthen their voices at both a national and European level. Its full manifesto can be found on its website: www.cancerworld.org/cancerworld/home.aspx?id stato=1&id sito=4

Among its aims are patient advocacy, appropriate early detection, quality of life, individualised treatment and personalised care.

To this extent Europa Uomo is almost a blueprint of how the Prostate Cancer Support Federation (PCSF) is looking to operate by bringing the combined voice of our individual support groups to bear at a national level.

Europa Uomo is beginning to have an impact at the European Parliament level which in turn will help our efforts nationally. Many medical organisations have shown their direct support by looking to work with Europa Uomo. Prominent among these are the two leading professional pan-European societies EAU (European Association of Urologists) and ESMO (European Society for Medical Oncology), which have many UK clinicians among their membership. Europa Uomo has established a Scientific Committee drawing on experts from EAU and ESMO whose function is to keep us up to date, provide advice and to act as a "sounding board".

PCSF has close ties with Europa Uomo. Both PCaSO and PSA (Central England) have been involved with Europa Uomo since its inception (legally established in 2004). More recently as PCSF has developed, I have, as a steering committee member and Chairman of my local group, PCS, been elected Vice Chairman of Europa Uomo at their March 2008 General Assembly in Milan.

The Secretary, and a driving force behind Europa Uomo, is Prof. Louis Denis, an eminent urological oncologist who is author or co-author of over 40 books and more than 300 publications in scientific journals. Significantly he is also a prostate cancer patient and we welcome him as one of our guest speakers at the inaugural conference.