

# Prostate Matters

## Newsletter

ISSUE 2 AUTUMN 2008

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It is intended to publish this newsletter 4 times a year.

*Winter - Spring*

*Summer - Autumn*

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Charity No. 1123373

Worried or concerned about prostate cancer?

**National Help Line**  
**0845 601 0766**

## Federation - The Way Ahead

The Federation was launched at the Inaugural Conference in London (April 2008) and it is necessary to maintain momentum. This requires a modus operandi and prior to this meeting a working party proposed the following points to be included in outlining a role for the Trustees.

### The role of PCSF Trustees:

- 1) Provide a focus for the views of all member charities and groups
- 2) Coordinate at the national level: - Helpline, Newsletter, Website
- 3) Organise/coordinate meetings and events at national and international levels
- 4) Interface, network and liaise at the national level with Politicians, Government Agencies/Bodies, Health Professionals, and also with appropriate international institutions, with a view to emphasising prostate cancer awareness advocacy by:
  - Raising public awareness of PCa, and raising the awareness with health professionals of our concerns
  - Noting changes in the pattern of funding of research into the causes and treatment of PCa
  - Becoming involved in shaping the research agenda
  - Fostering good relations between charities and groups within the Federation, and between the Federation and other bodies mentioned above
- 5) Provide assistance in the development and nurturing of new support groups
- 6) Become involved in appropriate fund raising
- 7) Be accountable to the membership

We have made some progress with regard to points 1-3, in that a website is available, the Newsletter has been established and our national helpline 0845 601 0766 is now operational. Additionally, we have, with the aid of sponsors, organised national meetings.

However, in order to meet all of the above mentioned objectives, we need to improve links between members. One way to achieve this is to hold meetings around the Country (point 3) and our second meeting, a 'workshop' will be in Leamington Spa on October 16th 2008. This meeting, supported by the Graham Fulford Trust, has been organised by the PCSF and the GF Trust (see page 3). We will seek sponsors for further meetings and will look to groups in other regions to liaise with the Committee in this process. Where groups express a desire to provide a venue, and have views about content, this could be raised and discussed at committee meetings.

Although meeting annually, or biannually, will help with communication, it will hardly be sufficient. Consequently, we need to consider other means of communication and interaction between the Committee and the general membership.

*Continued on back page >>>>>>*

# Inaugural Conference of the Prostate Cancer Support Federation

28th April 2008 - a full report can be found on the Federation website

The Inaugural Conference of the Prostate Cancer Support Federation (the Federation) was held at Imperial College, London, on 28th April 2008. It was attended by approximately 55 representatives of 24 patient-led support organisations.

The conference was opened by John Dwyer, Chairman of the Federation, and Professor Mustafa Djamgoz, Professor of Cancer Biology, Neuroscience Solutions to Cancer Research Group, at the Imperial College, London, who were hosting the conference.

John Dwyer briefly outlined the background to the formation of the Federation and explained the purpose of the conference, which was to broaden the membership and establish a *modus operandi* for the Federation to act as a voice for all prostate cancer patients across the UK.

Mustafa Djamgoz then explained his department's interest in prostate cancer and why they were supporting this conference.

## Morning Session

The first speaker of the morning was (**Brig**) **John Anderson**, Chief Executive of Prostate UK, the sponsors of the conference. He emphasised the strength of groups 'coming together' and he explained that Prostate UK not only promote awareness of prostate diseases through a range of leaflets, but give money for research, pay for medical training and fund seminars to educate GPs and nurses in all matters relating to the prostate. He felt support groups play an important role in helping newly diagnosed men come to terms with a diagnosis and because of this, Prostate UK are offering grants to support groups who are members of the Federation, and have a particular expense that needs funding.

The second speaker was **Dr Chris Parker** from the Institute of Cancer Research, Royal Marsden Hospital, whose talk was entitled **Advanced Prostate Cancer: Recent Developments and Future Prospects**. He kicked off with a discussion about the most appropriate terminology to be used for that stage of the disease commonly referred to as "hormone refractory prostate cancer", which is not an accurate term for a

complicated situation which may be amenable to a number of hormone related treatments. He suspected that a more accurate term might be "castration independent" disease; it was made clear by the audience that this would not be a popular term with patients.

He stressed the importance of the 'multi-disciplinary team' meetings that now take place to discuss the care and treatment options available to patients. This *team* approach is of great benefit.

He went on to discuss the treatment of *advanced disease* and some of the newer drugs coming through the trials system - *Dexamethasone*, a steroid, has been given to men whose PSA has started to rise after the standard treatment with Zoladex and Casodex has failed, and some have experienced dramatic improvements using this drug.

Two chemotherapy drugs, *Docetaxel* and *Mitoxantrone* are now in more common use. The former has been shown to improve quality of life even in older patients thought to be 'too old'. An example was shown of an 86 year old who responded well. *Strontium 89* trials, held 15 years ago, have proved the benefits of this treatment; back then it was thought to be expensive at £1000 a shot, but now that is cheap and can have dramatic effects on quality of life.

Dr Parker concluded his talk with news about new drugs which will hopefully become recognised as standard treatment for advanced prostate cancer - *Abiraterone* has had good response in trials, most men experiencing a drop in their PSA and bone density improvement. *Alpharadin*, *Radium 223* is showing early evidence that it improves bone marrow, and a phase 3 trial is recruiting patients now. These are all entering clinical trials, and one of the problems that he continues to see is difficulty in recruiting men, particularly to randomised trials, where the common belief is that those randomised to the control arm of a trial (i.e. those who do not receive the intervention being trialed) are somehow missing out. He emphasised that in all cases a

trial participant who does not receive the drug or procedure under trial will nonetheless still receive the best **proven** treatment. He asked the audience to encourage men to participate in these trials.

The third speaker of the morning, offering a *neuroscience solution*, was **Prof. Mustafa Djamgoz**, Professor of Cancer Biology, Neuroscience Solutions to Cancer Research Group, at the Imperial College, London, who reported on his research into gene therapy and his quest to identify at diagnosis whether a disease is indolent or dangerous (the '*pussycat or tiger*' dilemma). He showed a gene map, which immediately identified how difficult the task is when it comes to looking at cells and genes.

A simple equation was shown - *gene > protein > signal > function* and the professor said that if one of these goes wrong it results in disease. His research had been looking at electrical *signalling* to identify cells that show metastatic progression compared to those showing non metastatic. His *gene* research has identified embryonic cancers and, in passing, he observed that it can be seen why salt is very bad for prostate cancer sufferers. He finished his presentation by thanking all the charities and companies involved in the funding of his research, two of which were present, PCaSO and Prostate UK.

## Business Session

After lunch the conference got down to the business part of the day with **John Dwyer**, the current Hon Chairman, in the Chair.

A roll call of organisations represented at the meeting was taken by **Sandy Tyndale-Biscoe**, the Acting Hon Secretary. He explained that, for the purposes of this inaugural meeting, and pending any decisions about membership fees and other constraints that might deter organisations from joining, the assumption being made was that any eligible organisation present wished to be treated as a member. Representatives of each attending organisation had received copies of the Constitution and Rules, which stated that, as currently implemented, there was no effective distinction between Full Members and Associate Members, and that, in particular, each such member had exactly one Delegate with one vote. Voting cards had been issued to the nominated Delegate for each

member organisation.

#### **Chairman's Review**

The Chairman then reviewed the history of the Federation and outlined the kind of issues that he hoped would be taken up and progressed by the Trustees. Although the Federation will be run by a *central committee* of Trustees voted in annually by group votes, it was hoped to form regional committees made up of representatives from member groups, who could then provide feedback on specific issues

obtain small grants (of the order of £250), for such purposes as equipment purchase, advertising, web space design and purchase, etc. An application form for these grants will be made available on the Federation website. Election of Honorary Officers and Trustees, then took place.

#### **Immediate Work Programme**

There was a brief discussion on the immediate work programme, which will concentrate on the following:

establishing a membership



and identify targets and direction.

**Finance - Mike Lockett**, Acting Hon Treasurer, gave an overview of financial issues, explaining how money from a fund raising event at Dummer Golf Club, several years ago, had been 'ring-fenced' to provide initial funds for the Federation to be launched. There was now around £5,250 left, which will shortly be transferred into a Federation account newly opened following achievement of charity status.

A discussion ensued about membership fees payable by groups, with several options put forward. It was decided to form a sub-group of volunteers to look into and recommend to the main committee the best format for membership. The following volunteered to form this group: Brian Cooley (PCSA Central), Keith Hobby (PCS Cheadle), Philip Barnard (PSA).

#### **Prostate UK Grants**

Sandy Tyndale-Biscoe outlined a scheme, to be funded by Prostate UK, whereby Full and Associate Members of the Federation can

register;

getting the National Helpline up and running;

development of a Federation Newsletter – Prostate Matters, an evolution from Prostate Matters South, a collaborative newsletter produced by patient groups across the South Coast of England;

development of a regional structure, based around the catchment areas of the four founder members, viz: PSA: South East; PCaSO: South coast & West; PCSA: Midlands; PCS: North West; to which could be added Wales and the North East.

Details will be worked out by the new committee. There was comment from the floor that the Federation should not become just a talking shop. Action is needed, e.g. on advocacy regarding the lack of any prostate cancer screening programme. The Chairman noted this, and promised that the Federation, under his leadership, will be very active.

There being no further business the Chairman closed discussion at 3pm.

## **'Promoting Patient Power' Workshop**

at

**Leamington Spa  
16<sup>th</sup> October 2008**

**Sponsored by the Graham Fulford Charitable Trust**

One of our 'Organisation' members – Graham Fulford of the Graham Fulford Charitable Trust – has very kindly offered to sponsor a mid-term workshop with the aim of consolidating the very positive response to the Inaugural Conference in April, and moving the Federation forward. This has the full backing of the Federation Committee and the workshop will be held on 16th October in Leamington Spa. The venue address is - **Wright Hassall Solicitors, Olympus Avenue, Leamington Spa, Warwickshire, CV34 6BF.**

The workshop is themed 'Promoting Patient Power' and is very much geared to getting the thoughts and views of members. There is no cost for the day, lunch will be provided free of charge and the venue is only a mile from Leamington Station. Graham has also kindly offered to organise a pick up and drop off service from the station if needed. The venue has plenty of parking.

The full programme, an invitation letter and booking form can be downloaded from our website. This should be completed and sent to: Graham Fulford - 3 Mill Street, Warwick, CV34 4HB. His email address is [gfcharitabletrust@tiscali.co.uk](mailto:gfcharitabletrust@tiscali.co.uk), and his phone number is 07831 156071. Please feel free to contact either Graham or the Secretary, Sandy Tyndale-Biscoe on 01243 572223 if you want further details or a booking form sent by post.

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



# Searching for the perfect diet

by Rod Lane

I am a man of 65 diagnosed with locally advanced prostate cancer in 2002, I was given conventional treatment with goserelin (Zoladex) to suppress testosterone production and prevent progression of cancer. Hormone treatment can be effective for several years particularly when 2<sup>nd</sup> and 3<sup>rd</sup> line hormone treatments prove to be effective when goserelin ultimately ceases to be able to prevent disease progression. The conventional view is that hormone treatment cannot offer a cure because ultimately cancer progression will occur due to the formulation of hormone independent cells, which are unaffected by hormone treatments. In my case hormone treatments had become ineffective by Dec. 2006. At this stage only moderated increase in life expectancy was considered possible employing steroid treatment and chemotherapy.

The position that I had reached by Jan 2007 was extraordinary: while my PSA was rising alarmingly, my general health had never been better in my life. Ailments that I had suffered from since birth, which had begun to be particularly troublesome in my 50's, had all but vanished. My eczema and asthma had virtually gone, problems with allergies and infections, particularly chest infections, were greatly reduced. Both my GP and I attributed these health improvements to the healthy diets that I had been using since 2003. The diets responsible for these improvements in health were a mixture of vegan and vegetarian recipes and supplements.

The general effect of the diets were very encouraging, yet what I wanted most of all was some indication that it was improving my cancer prognosis and despite my persistent search for such an indication between 2003 and 2007, there was no objective indication whatsoever. During this period I had searched in vain for some indication that diet could hold down the PSA reading or, at least, that changes in diet could be seen to have some effect on

the PSA. While feeling and looking well might be encouraging, my GP, my Oncologist and I were focused on the PSA reading. By contrast any change in hormone treatment during these years was accompanied by unmistakable change in PSA reading. The message seemed clear, hormones affected the PSA and cancer progression, diet did not. This conclusion accorded exactly with the conventional view and came as no surprise to my GP and my Oncologist. I tried to console myself that the diets had greatly increased my quality of life during these years even if it seemed unlikely to provide any increase in life expectancy.

I now had a difficult problem. Since my PSA was rising, the conventional wisdom dictated that I should receive steroid treatment and eventually chemotherapy. However, both of these treatments would be likely to seriously impair the immune system with the prospect of a deterioration in my general health, the recurrence of all of the health problems that I had experienced formerly and, consequently, a marked deterioration in my quality of life. Since I was not experiencing any serious symptoms, it was agreed with my Oncologist that I should defer steroid treatment and chemotherapy until I experienced significant discomfort. In early 2007, I began yet another search of complementary and alternative therapies to see if I could find some more dramatic treatment that might influence the progression of the prostate cancer. I briefly considered the Gerson Therapy. I had experimented with this therapy in 2005, but rejected it, mainly because with prostate cancer there would have been serious problems in consuming the large quantities of juice.

I now began further searches, using the Internet, and almost immediately identified a treatment by Ralph Breuss (Ref. 1)

that I had not seen previously. The brief description on the web page suggested that this was quite unlike the diet treatments, involving consumption of vegetables and fruits that I had been employing for the last 4 years. It was scarcely a diet at all, but could more correctly be defined as a **juice fast**. The rationale was also very different from the earlier diets that I had been employing. Rather than attempting to introduce nutrients that would have a beneficial effect on cancer progression, the idea here was to remove nutrients and effectively to starve the cancer cells. The *Breuss* diet focuses on fasting. Obviously this would also involve starving all of the vital organs of the body. The question was: 'could the body endure the fast long enough for the deprivation of nutrient to the cancer cells to have a significant effect on disease progression'?

Breuss reported very impressive anecdotal results for large numbers of patients with a wide variety of cancers. It appeared, therefore, that this might be a general treatment for all cancers. Breuss specified that his juice fast relied on depriving the cancer cells of protein. He considered that if the cancer cells could be deprived of protein for 6 weeks they would not survive. With assistance from a limited amount of vegetable juice

and certain herb teas, Breuss indicated that the body could easily endure the 6 weeks of the juice fast. The Breuss 'diet' appealed to me for a number of reasons:

- ✦ The rationale was simple and could be readily understood.

- ✦ The 'diet' itself was also comparatively simple, and did not involve the great complexities of the other diet treatments.

- ✦ The timescale for the diet was short – 6 weeks.

- ✦ The cost of the diet was very



Rod Lane

modest compared to the other diet treatments.

✦ Breuss provided a book giving very specific instructions - and all for the trivial cost of £10.

✦ Breuss came across as a modest, self-effacing, almost monk-like character who I found impressive and very human.

Breuss clearly based his diet on the very ancient concept of the fast, a tradition well known on the continent and elsewhere, but little known, used or respected in the English-speaking world.

The Breuss diet also very much appealed to my scientific curiosity (I was a career scientist). Would it really be possible to endure for 6 weeks with no solid food without harmful effects? What would be the effect on the cancer cells? Could it really be possible that the cancer could actually be cured as Breuss implied? Did the diet work by deprivation of protein, as Breuss postulated, or were the herb teas and vegetable juices playing some active part? The questions were endless and could only be answered by experimentation. Attempts to contact others who had tried the diet provided no information specific enough to be useful.

I applied the diet very strictly according to the instructions of Ralph Breuss that required the diet to be conducted over a period of 6 weeks (42 days). After completing the diet, you are allowed to return gradually to 'normal eating'. For me 'normal eating' had for many years become some form of vegan or vegetarian diet according to the recommendations of a variety of complementary or alternative health practitioners, each with their particular favoured foods and supplements.

- 1 Breuss R, 'The Breuss Cancer Cure' (1995, Alive Books, Burnbury BC, Canada). ISBN 0-920470-56-4.

*The next issue of PM will describe my experience using the Breuss diet.*

*Rod Lane*

## Diets and Cancer by Rod Lane

So far as cancer is concerned it is now generally accepted that diet can play an important role in cancer prevention and that diet therapies might be beneficial as a complimentary therapy to conventional cancer treatments.

During my searches I identified many different diet therapies that had been advocated for cancer prevention or treatment, some going back to ancient time. After exploring a number of diets, I came to realize that the most important features of virtually all the diets were similar, stressing the need to consume vegetables and fruit while excluding animal produce, meat, dairy and even fish. Essentially all advocates of diet therapies were stressing the need for a vegan diet.

### The Metabolic Diet (References 1 and 2)

Developed by Ernsto Contreras in the 1970's and 1980's and has been referred to as a Metabolic Diet. The group of diets referred to here as Metabolic Diets have one particular characteristic feature, the use of a naturally occurring substance, amygdalin, that was claimed to have anti cancer properties. Opposition focused particularly on the use of amygdalin in its synthetic form, Laetrile, which was viewed as an unlicensed drug and has been banned from sale. Natural amygdaline is present in many foods, which are not subject to control, and therefore it is still possible to follow a Metabolic Diet although no clinics providing Laetrile can now operate (legally) in the UK. In addition, these Metabolic Diets insisted on fruit and vegetables, which should be consumed raw, the elimination of salt, sugar and avoidance of salted or pickled foods.

### The Gerson Diet (Reference 3)

Dr Max Gerson was a German medical practitioner who experimented with diets to cure a number of medical conditions during the 1920's and 1930's. Many of the principles underlying other diet therapies were originated by Gerson who might justifiably be regarded as the founder of the concept of diet treatments for disease in the context of modern medicine. He brought ancient traditions of naturopathic, holistic medicine into the modern scientific age.

Gerson groups still exist in many countries today led by Charlotte Gerson, Max Gerson's daughter, who has ensured that approved Gerson groups keep rigidly to the protocol originated by her father. It is claimed that the Gerson approach offers a 30% cure rate for all cancers even when treatment commences at a late stage. For some cancers, particularly those with a high growth rate, greater success is claimed, although for others, particularly those with a slower growth rate, it is suggested that the success rate is lower.

The Gerson Group provides detailed instruction for the approved protocols, which again focused particularly on raw vegetables and fruit, much of it consumed in the form of juice to maximize nutrient intake. The use of coffee enemas, a practice later adopted by others, such as Contreras, was introduced by Gerson, as an essential part of the protocol. Unlike many other diet therapies however, Gerson used virtually no supplements, believing that all nutrients are available in the diet and are best obtained in their natural form. Vitamin C supplementation, used by most cancer diets, is not considered necessary under Gerson where large quantities of vegetable juice, fruits, salads and some cooked vegetable dishes should supply vitamin C in abundance in its natural form.

### References

- 1 Contreras F. 'The Coming Cancer Cure' (2002, Siloam Press, Florida) British Library Catalogue Record 1-86024-285-5.
- 2 Brinzel P.E. Jr. 'Alive and Well' (1994, American Media, Westlake Village, California) ISBN 0-912986-17-4.
- 3 Gerson M. 'A Cancer Therapy' (1958, Whittier Books, New York) ISBN 0-88268-203-2).

*A further article on 'Diets and Cancer' will appear in the next issue of PM*

## Tests may predict Prostate Cancer Spread

Clinical Cancer Research

U.S. researchers have found seven biomarkers in blood tests that may help doctors predict if prostate cancer will recur or spread.

Researchers at the University of Texas Southwestern Medical Centre in Dallas have identified a 'panel' of seven biomarkers - proteins in the blood specific to a disease - for prostate cancer.

"We found that a combination of independent yet complementary markers may provide a more

accurate prediction outcome compared to single markers" lead study author Dr. Shahrokh Shariat said in a statement. "This could help physicians provide individualised care and targeted therapy for patients. It will also allow us to design clinical trials to target these individual biomarkers."

The study, published in Clinical Cancer Research, measured the levels of seven biomarkers in 423 patients subsequently treated surgically.

Of the study participants, 75 had a recurrence of their cancer. All 75 had levels of at least several of the seven

biomarkers. Shariat's seven-biomarker model was able to accurately predict the risk for recurrence 86.6 percent of the time, the study said.

## Clinical Nurse Specialists

Report by Roger Bacon

One of the *recommendations* published in the NICE guidance on Prostate Cancer 2008 is – *Men with prostate cancer should be offered individualized information tailored to their own needs. This information should be given by a healthcare professional, for example a consultant or specialist nurse.*

Urological Clinical Nurse Specialists play an important role, as a *keyworker*, in caring for a prostate cancer patient. They have specialist knowledge which can be invaluable to a patient or his family, enabling them to ask detailed questions which they may feel uncomfortable posing to a consultant with whom they will generally spend less time. Similarly, Clinical Nurse Specialists should be on hand to help manage more complex or challenging symptoms or side effects associated with prostate cancer. In most Urology departments they have specialist nurses dealing with incontinence and erectile dysfunction problems.

The Improving Outcomes Guidance for Urological Cancers, which sets out how prostate cancer services should be organised and delivered, is explicit on the importance of Clinical Nurse Specialists: "*All patients with urological cancers should be managed by multidisciplinary urological cancer teams. These teams should function in the context of dedicated specialist services...Nurse specialist members of urological cancer teams will have key roles in these services.*"

Prostate cancer is by far the most common form of tumour for which a urological Clinical

## Clinical Trial STILL RECRUITING

### RADICALS - Radiotherapy and Androgen Deprivation In Combination After Local Surgery

In several other types of cancer, such as breast cancer, for example, surgery is typically used in combination with radiotherapy and drug treatment. This approach has been shown to lead to better outcomes than treatment with surgery alone. In prostate cancer, surgery alone is a standard treatment and the role of additional radiotherapy and drug treatment is uncertain. The RADICALS trial aims to identify the best way to use radiotherapy and androgen deprivation in men who have had surgery for prostate cancer.

It has already been shown that immediate post-operative radiotherapy is better than late salvage radiotherapy ie. when the patient has clinical progression. RADICALS will test whether giving radiotherapy routinely, within a few months after surgery, rather than waiting for the PSA to rise, will reduce the proportion of men who die from prostate cancer.

RADICALS will also test whether men receiving radiotherapy after surgery also benefit from the addition of androgen deprivation treatment. We don't know if such treatment may reduce the proportion of men who eventually die from prostate cancer, and, if it does, whether 2 years androgen deprivation is better than 4 months.

RADICALS has two separate randomisations. The first randomisation, performed immediately after radical prostatectomy in patients where there is clinical uncertainty about the timing of radiotherapy, is defined as '**Radiotherapy timing randomisation**'. The second randomisation, performed shortly before the administration of radiotherapy, is between none, short-term (4 months) and long-term (2 years) androgen deprivation and is defined as '**androgen deprivation duration randomisation**'.

All patients who are about to undertake surgery should discuss the possibilities of joining this trial with their consultant. You will have the benefit of being monitored regularly and, if you feel so inclined, you can always leave the trial at any stage.

ISRCTN40814031 <> Funding Body: CRUK (C7829/A6381)

**Chief Investigator:** Dr Chris Parker, The Academic Unit of Radiotherapy & Oncology, The Royal Marsden NHS Trust and The Institute of Cancer Research

**CTU Lead:** Matthew Sydes <> **Contact:** radicals@ctu.mrc.ac.uk



Nurse Specialist will be responsible. A major national survey of the NHS experience of over 1,100 men affected by prostate cancer, carried out by The Prostate Cancer Charity in 2005, showed that when asked the question, "Who was the most helpful in providing you with emotional support," specialist nurses were ranked the highest around the time of diagnosis and treatment decisions. Yet, 38% of men did not have the opportunity of speaking to a specialist nurse about these issues.

The National Audit Office 2005 survey of newly diagnosed men with prostate cancer showed > 66% had not been given information about support or self-help > 50% had no named nurse in charge of their care > 30% did not fully understand the explanation of how their treatment had gone.

**A Clinical Nurse Specialist can play a vital role in your cancer journey - make sure one is looking after you!**

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## Rusty Surgeons put Patients at Risk

*Reported in TimesOnline*

Prostate cancer patients are being put at risk by surgeons who lack regular practice and expertise, a leading consultant has claimed.

Many surgeons perform only a small number of keyhole operations a year, leaving patients vulnerable to complications such as incontinence and impotence as a result. Christopher Eden, of the Royal Surrey County Hospital in Guildford, said that surgeons needed to carry out hundreds of operations before perfecting their technique for the complete removal of the prostate. Writing in the British Journal of Urology, Mr Eden, who has completed a thousand such operations, said: "The learning curves demonstrate that it takes 100 to 150 cases to achieve proficiency. It

takes 200 to 250 cases for complications and continence but 700 cases for potency. Given that most surgeons will not do 700 prostatectomies in their entire career, this makes a powerful argument for limiting complex surgery to high-volume surgeons."

His claims are backed up by the National Institute for Health and Clinical Excellence (NICE), which insists that radical prostatectomy should not be done by teams who carry out fewer than 50 a year, and surgeons who do fewer than five a year should stop altogether. But NICE reported in February that this "key recommendation" was frequently ignored and that more than half still did fewer than ten operations annually.

"Patients need to be aware of how proficient their surgeon is," said Mr Eden, who also operates at the BMI Hampshire Clinic in Basingstoke.

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## Novel Chemo Drug Helps Treat Prostate Cancer

*ScienceDaily (May 30, 2008)*

Men with a certain type of prostate cancer have been shown to respond to a new chemotherapy drug, Sagopilone, plus prednisone in an international trial led by Oregon Health & Science University Cancer Inst. researchers.

The research involved men with androgen-independent prostate cancer that has metastasized, meaning their cancer has spread beyond the prostate and is no longer responding to hormonal therapies. This is the most advanced form of prostate cancer.

"We are showing solid activity that this drug shows promise," said Tomasz Beer, M.D., principal investigator. He is the Grover C. Bagby Endowed Chair for Cancer Research, director of the Prostate Cancer Research Program at the OHSU Cancer

Institute and associate professor of medicine (hematology/medical oncology), OHSU School of Medicine.

Of the 37 study participants taking the Sagopilone and prednisone long enough to be evaluated, the majority showed positive results in the reduction of their prostate specific antigens, or PSA. PSA is often elevated in the presence of prostate cancer.

During the three-month trial thirteen study participants had a more than 50 percent reduction in their PSA; 23 showed a 30 percent reduction; one who had radiographic measurable disease showed complete response; and four had unconfirmed prostate response. A 30 percent reduction in PSA levels in three months is a strong indicator of survival.

Sagopilone, a fully synthetic derivation, is a new class of drug that inhibits growth and the spread of malignant cell, similar to docetaxel, which has been the gold standard for this type of hormone independent prostate cancer. Docetaxel, however, it is not a cure and not all patients benefit from it. For this reason, Beer and colleagues are committed to searching for new drugs that will be effective against advanced prostate cancer.

"We look forward to completing this study and to the further investigation of Sagopilone as a new treatment option for men with advanced prostate cancer," said Beer.

The study was carried out in collaboration with members of the Prostate Cancer Clinical Trials Consortium, as well as a number of collaborating institutions in the United States and Argentina. Sagopilone is an experimental drug made by Bayer Healthcare Pharmaceuticals, which has funded this research.

*Adapted from materials provided by [Oregon Health & Science University](#), via [EurekaAlert!](#), a service of AAAS.*

*continued from front page >>>>* How can we establish routes to provide views, and inputs (point 1), which are more representative of the National picture? We might better achieve this by agreeing to form sub-groups, each dealing with specific issues for example: *Advocacy, Fundraising, Education, Awareness* etc. Such sub-groups could include volunteers from around the country, linked by email or by tele-conference. It would be appropriate to include a member of the Committee in such groups to maintain awareness within the Committee. However, sub-groups may well wish to elect their own chairman.

From time to time we are asked to comment on proposals, for example by *NICE* or (recently) on the *Prostate Cancer Risk Management Programme*. It would be helpful if we could garner wider based opinions on such matters and, perhaps, provide information on disparities in access to treatment across the country.

In the short term we are limited by resources, making it difficult for us to realise our inherent potential. Consequently, we should endeavour to achieve funding to employ a manager. Most major charities reach this point and we should.

At this time the Committee would like to know more about the concerns of support groups around the country. Perhaps we could clarify the position by asking members to list, in order of importance, the points they feel should be addressed.

John Dwyer, Chairman PCSF

## MANIFESTO OF THE PROSTATE CANCER SUPPORT FEDERATION

1. To promote and encourage the formation of patient support groups and to provide a single voice for the prostate cancer patient community across the Country.
2. To argue for change in the approach to and treatment of prostate cancer by championing the combined expectations of patient support groups.
3. To promote prostate awareness and appropriate diagnosis and prognosis.
4. To emphasise the need for appropriate early detection.
5. To campaign for provision of and access to optimal treatment for all men.
6. To assist men to fully understand all proposed treatment options including their benefits and risks.
7. To promote the dissemination and exchange of evidence-based and/or best practice information on prostate cancer.
8. To find ways and means to promote quality of life for prostate cancer patients and their families.
9. To emphasise that men have the right to a second opinion on treatment options and the right to receive details on entry into clinical trials.
10. To advocate for quality supportive care throughout and after treatment.
11. To acknowledge good clinical practice and promote its development.
12. To promote multi-professional quality care and appropriate medical infrastructure.
13. To promote the advancement of prostate cancer research.

**General Disclaimer** This newsletter is providing news, information, personal memoir and opinion about prostate cancer. It also reports, quotes and cites published medical views and research findings about prostate problems. 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.