update

Issue No.7
February 2001

THE NEWSLETTER OF
Prostate Research Campaign UK

Promises, promises – easy to make but hard to deliver

It would be most improper for the newsletter of a charity such as **Prostate Research Campaign UK** to take political sides. Nevertheless, all patients in the UK are affected by what facilities are provided under the NHS. As we approach the next general election the Government's health record may be perceived and presented in a promising light. 'Much has been achieved', a politician might say. In the realm of the prostate, however, we are, unfortunately still in the era of promises rather than delivery.

We have been promised that all urgent urological cancer patients will see a consultant within two weeks, a new standard set to be achieved from last December. We expect, as part of a general improvement in service levels at the consultant level, for integrated teams to be set up in hospitals. We have been led to believe that the new money which is in the process of being spent will become visible as more of the best equipment, more staff and more research.

In the euphoria of hearing of significantly increased health spending and new targets, one should not lose sight of the fact that very little has yet reached the patient. Where is this new equipment? Where are the integrated urological teams in hospitals? When can we hope to see the much needed increases in staff in this desperately under resourced area?

Let us hope that whoever is elected in the next general election, our political leaders will focus upon delivery of what is already being anticipated rather than upon 'spin' and promises.

But even that will not be enough for long suffering prostate patients as the letter reprinted alongside illustrates.

Even if all the Department of Health's present targets are met, the quality of treatment received may still fall a long way short of what we should like to see as the norm.

The letter from Charles Dutton of Bridport, was first published in *The Daily Telegraph*. The tone of the letter is bitter. The treatment received (or lack of it) makes that wholly understandable. And yet, had the date when Mr Dutton was seen by the consultant been just six days earlier, the DoH would have been able to record that his treatment had been up to the current best practice standards. For today the only measure of the quality of care is the time between a GP referring a patient and his being seen by a consultant.

So now when we write to our MPs we should be asking for their support for two things. First of all, delivery on existing promises and, secondly, some further work to be carried out urgently to set, and find ways of implementing, new standards to greatly reduce the time which elapses between seeing a consultant and treatment beginning.

Dangerous Waiting

Sir - I am amazed at the naivité of your recent correspondent who was surprised that the Government allocated £1 million to research into prostate cancer but £47 million to the Dome.

Prostate cancer is a most convenient way of culling male old age pensioners. Eugenics always seemed to be an important part of the socialist agenda. Pensioners not only do not contribute to the state's economy but are also a positive drain upon it.

I am 69 and first went to my GP complaining of the symptoms of the disease on Jan 25 2000. I had a blood test on Jan 28 and the result (positive) on Feb 9.

The consultation with the surgeon was on Feb 29, the biopsy on May 31. The consultation with the GP was on June 5 when I was told the biopsy was positive.

Then there was the MRI scan July19 and the bone scan July 28 before the consultation with the specialist on Sept 6 which showed that the cancer had spread.

I still await radiotherapy.

Charles Dutton of Bridport, Dorset.

(Daily Telegraph September 23 2000)

In this issue

First familial prostate cancer gene identified

American geneticists claim to have pinpointed the first prostate cancer gene that runs in families. It is suggested that mutations in the gene may account for as many as 5 percent of all human prostate cancer cases.

The gene was spotted by analysing the incidence of mutations in the gene in several extended Utah families that had a high frequency of prostate cancer. Its position (on the long arm of chromosome 17) was indicated by what is called a linkage analysis which measures how often the disease is inherited together with so-called marker genes whose location has already been mapped on the chromosome. Genes that lie close to each other on the chromosome tend to be inherited together. Many of the ill-fated members of the Utah families had inherited a particularly lethal variant of the gene, which has been dubbed HPC2, for Human Prostate Cancer gene 2.

Risk increased tenfold

Men who carry that mutant gene, which encodes a protein with a single altered amino acid, appear to have a 60 to 80 percent likelihood of developing prostate cancer over their lifetime - a ten-fold higher risk than the average man. (Researchers are in the midst of a hunt for another prostate cancer gene, HPC1, but they have not found it yet.)

The results were presented in the American Journal of Human Genetics last September by Sean Tavtigian, vice president for cancer research at biotech company, Myriad Genetics, based in Salt Lake City, Utah.

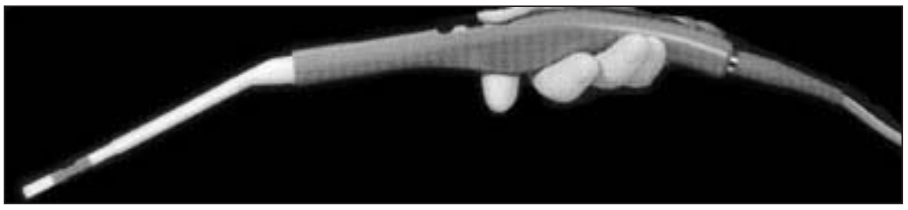
At this point, the researchers are almost positive they've got the right gene but they still do not know what, precisely, HPC2 does.

'We're about 99 percent sure that it's a prostate cancer susceptibility gene,' Tavtigian says. 'Researchers will need to check for HPC2 mutations in more large families with a high incidence of prostate cancer before we can be sure the gene is truly a prostate cancer susceptibility gene'. He compared his results with the better established work which identified the breast cancer genes BRCA1 and BRCA2.

Genetic testing

Myriad Genetics' results open the door for developing a genetic test for prostate cancer susceptibility, similar to the tests for BRCA1 and BRCA2 and breast cancer susceptibility. Tavtigian predicts, with the natural optimism of US start up companies, that reliable test will be developed within the next two years.

Advance in Nerve Sparing Technology



No its not an answer to fuel shortages but the probe of the CaverMap system in a surgeon's hands.

The Gold Standard treatment in the USA for prostate cancer confined to the gland is radical prostatectomy - removal of the entire prostate and the cancer within. The most common complication of this surgery is impotence caused by damage to the nerves around the prostate during the operation. Most surgeons currently use a technique known as nerve sparing with results which vary widely depending upon the skill of the surgeon and the age of the patient.

Now, a new technology is helping surgeons navigate around the vital nerve bundles. The CaverMap surgical aid can assist the surgeon in locating and mapping the cavernosal nerves around the prostate that control a man's erectile function. By knowing where the nerves are, the surgeon is better able to decide where to cut in order to keep the nerves intact. In this way the key nerves which take messages from the brain to the penis during male arousal can be safeguarded. Further, at the end of the operation CaverMap can be used to confirm that the nerves have indeed not been damaged

The CaverMap has been evaluated over the past four years at several centres. Of 61 men who had normal erectile function before surgery, 92% continued to have erections a full year after surgery. This represents a dramatic improvement over previous unaided results.

CaverMap is now being used and highly spoken of by surgeons in this country.

How does it work? The idea is very simple. An electrical signal is applied and one sees whether the key organ twitches or not. More scientifically, the nerves are stimulated via a probe with a tip as small as 2mm in width. Attached to the penis is an ultra sensitive strain gauge which can detect very slight tumescence. The whole is attached to a box of electronics which provide audible and visible response indications.

More information can be obtained from the UroMed Corporation at www.uromed.com.

In Memory of Jeremy Fermo

It is inevitable that a charity such as ours receives donations from time to time in memory of someone who has died from a prostate disease. Jeremy Fermo, from Stockbridge in Hampshire, had no warning signals at all until, in November 1999, he suffered a collapsed vertebra - a sign of the advanced prostate cancer which had taken hold in his bones.

His artistic wife, Shirley started organising an exhibition of paintings to raise money for **Prostate Research Campaign UK**. The exhibition evenings were to be accompanied with music and singing, Jeremy's hobby. He was practising some French songs for the event when, sadly, he became very ill and died last September.

The exhibition by five local artists went ahead over the first weekend in December. Some fifteen hundred pounds worth of paintings were sold and with the commissions from these plus some generous donations, **Prostate Research Campaign UK** is the richer by £571.

When we receive donations of this sort it makes us realise the responsibility we have to spend the money as wisely as we know how. Knowing that test methods exist but are not widely used that could provide much earlier warning than Jeremy had, makes the story poignant indeed.

NHS Cancer Research Network launched

The NHS Plan published last July dealt with investment and reform throughout the NHS. Most of us are aware that the amount of money being spent is set to rise but, in areas of interest to our readers, what is it being spent on?

Cancer Services were identified as high priority and three targets set.

1. To address socio-economic gaps, the 'post code' lottery and the disproportionate disadvantages caused by poverty. Smoking is still the biggest preventable risk factor for cancer. In twenty areas with the highest smoking rates the aim is to reduce the rate from one in three people to one in four by 2010.

Alan Milburn, Secretary of State for Health, on a visit to the QEII Hospital in Birmingham where he announced the launch of the new NHS Cancer Research Network

2. To establish and meet targets to reduce waiting times for diagnosis and treatment. We wrote about the steps to reduce diagnostic waiting times in September's ***Update*** and consider the wait for treatment in this edition.

3. By 2004, to actually match what the voluntary sector spends on hospices and palliative care services. (What a shaming target! And why wait four more years for its achievement?)

Within the overall NHS plan, there is a specific and wide ranging cancer plan which includes elements to

- Address healthy lifestyles,
- Raise public awareness of dangerous signs and symptoms
- Extend screening services (including making PSA testing available),
- Increase staff numbers. By 2006 there will be approaching 1000 extra cancer specialists, a 32% increase in the number of urologists and a 20% increase in the number of general surgeons.
- Invest in new equipment. The next three years should see 50 new MRI and 200 new CT scanners to increase diagnostic capacity and 45 new linear accelerators for radiotherapy.
- Strengthen the research base by setting up and funding a new National Cancer Research Network that will co-ordinate research into cancer genetics and oversee the doubling of the number of cancer patients entering clinical trials in the next three years. It will also advise on spending the £4.2 million for directly commissioned research which will be available by 2003/4. This funding is a twenty fold increase over the 1999/2000 figure.

New Awards *you* made possible

In addition to our funding of work by Professor John Masters (*see Tigers and Pussycats story*) **Prostate Research Campaign UK** last October awarded substantial sums to Dr Moray Campbell at the University of Birmingham for his work on the Dysregulation of Vitamin D3 signalling by histone deacetylation in prostate cancer and to Dr Jane Melia and Dr Connie Parkinson for investigating observer variability in the pathological grading of prostate cancer at the Institute of Cancer Research. Also funded by us will be work by Dr Andrew Baranowski on prostatitis and chronic pelvic pain syndrome - a rather neglected subject - that will be centred on the National Hospital at London's Queen Square.

Richard Wilcox Charity tackles Prostate Cancer

Prostate Research Campaign UK is delighted to have become the catalyst for two major new projects which will be financed by the *Richard Wilcox Welfare Charity* at a cost of £100,000. In the larger of the two projects the plan is to produce a detailed database of the very large number of patients treated for prostate cancer at St George's Hospital in South West London. The expenditure involved will be £80,000 over a two year period beginning this February.

At the same time a parallel bank will be set up of patients' DNA, serum and, where possible, tumour tissue. Currently there is a large, multi-disciplinary team on site involved in a number of aspects of prostate cancer research and this database together with the bank of material will greatly expand the usefulness of the work being undertaken and of future projects also. Once the scheme is fully operational it is hoped to widen its possibilities by including other UK hospitals.

In the second project being financed by the *Richard Wilcox Welfare Charity* (with a further £20,000) genetic immunotherapy for prostate cancer will be worked upon at St George's also. The central part of the research will be to analyse the *in vitro* immunological effects of vaccination.The grant will enable a scientific officer to be employed there for a year together with provision of the necessary 'consumables'.

Mr Richard Oury, Administrator of the *Richard Wilcox Welfare Charity* explained to ***Update*** that it liked to support specific projects where performance could be monitored and tangible results could be seen. It was for this reason that he looked so favourably on the prostate cancer proposals put to him by Mr Brian Barnes of **Prostate Research Campaign UK.**

Mr Nick Sargent, a Trustee of the *Richard Wilcox Welfare Charity*, said that the charity recognised the serious Government under-funding of research into prostate cancer in recent years. He added that he was pleased to be associated with something which would help towards redressing the balance.

Tigers or Pussycats?

Research to identify men who will benefit from radical treatment

Prostate Research Campaign UK is funding important research being carried out at University College London. Professor John Masters, who leads the team, explains his research to ***Update***.

'The way in which prostate cancer develops in an individual depends both on environmental factors (diet, geography) and more personal factors (age, family history, race, hormonal balance). Consequently, the prognosis of the disease is very variable. Some cancers are aggressive and fast growing. Others grow very slowly and may require no treatment at all. Differentiating the tigers from the pussycats is difficult and we need more research in this area. The prognosis is known to depend on the stage and grade of the tumour at the time of diagnosis. Only localised cancer, that is cancer confined to the prostate, can be reliably cured and this requires radical treatment.

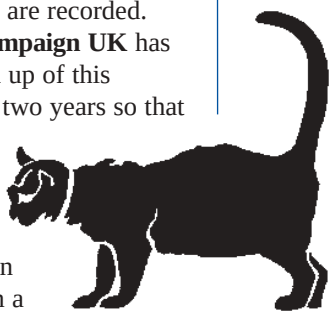
Currently, there are a number of tools which help to predict the stage of the cancer at the time of diagnosis - blood tests, digital rectal examination, biopsy, and various scanning techniques. Whether used singly or together, they do not, however, do a particularly good job of predicting the future on a case by case basis.

Many genetic changes associated with prostate cancer have been identified, but their clinical significance is, as yet, unknown. In the research we are undertaking at UCL, we will examine the three most common types of genetic change; deletion of genetic material, duplication of genetic material and gene inactivation by a process called methylation. The aim of our study is to identify which genetic changes are related to the outcome of patients with prostate cancer. Our hypothesis is that by identifying specific genetic changes we will be able to provide more accurate markers to predict prognosis. This will enable more appropriate selection of treatment for patients with prostatic carcinoma.'

Professor John Masters and his colleagues already have a database on which details of 712 radical prostatectomy patients are recorded. **Prostate Research Campaign UK** has been funding the build up of this database over the past two years so that it now represents the largest series available in the UK.

'The next step' explains Professor John Masters, 'is to perform a number of outcome studies using this data including pre and post operative staging, the effect of radiotherapy on subsequent PSA recurrence, positive urethral margins compared with other positive surgical margins and subsequent PSA rise. The research will also examine data on those patients who have undergone radical prostatectomy and who had repeated negative prostate biopsies before the correct diagnosis was made'.

The plan for the research is to select a subgroup of patients (30 in the first instance) who relapsed after surgery and match these with controls who have been untreated and disease-free for at least 3 years since surgery. The cases will be selected from those who relapsed within 2 years of radical prostatectomy. Normal and cancerous tissue, obtained at the time of the operation is available from these patients. The DNA samples will be examined to identify genetic differences between the relapsed and the control group of matched patients. The hope is that there will turn out to be sufficiently large differences that examination of DNA at the time of diagnosis may become an additional (and more effective) staging tool than those the medical profession has today'.



'While you wait' PSA test now available

Although the Department of Health position is currently against screening for prostate cancer, there is growing interest in the early detection of the disease. In both Germany and the USA, there is already an effective screening and diagnostic service.

The most sensitive test available is the prostate specific antigen (PSA) blood test. The value of the PSA test lies in its simplicity, objectivity, reproducability, lack of invasiveness and low cost.

The present method of carrying out a PSA test in the UK is to take a blood sample and have it analysed in a pathology laboratory. It typically takes about a week for the results to become available and the cost of the laboratory work is at least £10.

Now, products are becoming available which make the test simpler, quicker and cheaper. Near Patient Technologies, based in Suffolk are exclusively distributing a PSA testing kit which is designed to be used in a GP's surgery. The blood sample is derived from a finger prick. Colour changes on a special paper indicate one of three conditions; a PSA less than 4 - the patient does not appear to have prostate cancer; a PSA between 4 and 10 - it is possible that the patient has the disease, further tests are required; and a PSA greater than 10 - it is rather likely that the patient has the disease and should be seen as a matter of urgency by a consultant urologist.

It is likely that we shall see products such as this one being used in doctors' surgeries in the near future. There are cost savings with the immunographic paper test costing about £2. There are time savings both for the doctor and the patient. The test can probably be administered in two or three minutes and, of course, the week's delay in waiting for a result can be eliminated.

Biggest and Best Annual Luncheon

The Wellington Ballroom at the London Hilton on Park Lane was 'bursting at the seams' for a packed event on 18th October. So great was the demand for tickets for the Annual Luncheon that a 'waiting' list was created and thoughts turned to a bigger venue in 2001. The vastly amusing television celebrity Ronnie Corbett was the star after-lunch speaker and his performance on this occasion was as good as any he has made. It would be impossible to retell any of his hilarious anecdotes but we do remember the one about his cooking prowess (cordon noir) and his cat called Lord Irvine who lives rent free and in the lap of luxury.

*From left to right, representing **Prostate Research Campaign UK,** Brian Barnes, Donald du Parc Braham and Tony Kilmister receive the £93,000 sponsorship cheque from marathon runners Andrew Etherington, Roger Kirby and Doug Davidson.*

There was a packed programme at the lunch which included a report to supporters by Mr Neil 0'Donoghue FRCS on research grants recently awarded, an auction conducted by Mr Clive Turner and the presentation of a giant sized cheque for £18,000 by former Patent Attorney Mr Arnold Watkins who completed his long distance walk that day in time to take a shower and change into a suit for lunch. Mr Andrew Etherington and Mr Doug Davidson who had accompanied Mr Roger Kirby FRCS as competitors in the London Marathon also brought on a colossal cheque for the spectacular sum of £93,000. The applause resonated around the Ballroom and the enthusiasm and excitement was palpable. 'Follow that' as they say…..

The 2001 event is expected to take place on Wednesday 17th October and already Tony and Sheila Kilmister who made the Luncheon arrangements have opened a list (at 36 The Drive, Northwood, HA6 1HP) for those keen to be at this year's Luncheon and who will be notified as soon as details are finalised.

Fun Day at Llanfair Caerinion

TV personality Ronnie Corbett handed a cheque for £1,000 to Anthony Kilmister at the annual luncheon on behalf of a Select Caravan and Chalet Park – Dolgead Hall – at which its owner had organised a 'Fun Day' to aid **Prostate Research Campaign UK**.

Ronnie Corbett presents Welsh caravaners cheque to Anthony Kilmister

Set in extensive farmland near Welshpool in Powys, this award winning, family managed park, sports twenty Swiss style chalets. The owner, Mrs Marjorie Pryce, whose late husband had prostate cancer, held the 'Fun Day' in August with many caravaners taking part. Among the many attractions were a dog show (live), a duck race (plastic), golf and bowling competitions. Also adding to the fun and the funds raised was a car boot sale and the provision of teas with home made cakes. Well done and thank you!

Arnold Watkins' Walk to London

The warmth and security of the Hilton Hotel could not have contrasted more with wide open spaces as patent attorney Arnold Watkins witnessed a fierce thunderstorm during his sponsored walk to London. With thunder and lightening raging overhead he worried about the metal struts in his back pack. Fortunately their properties as lightening conductors did not become an issue. His journey from Kidderminster in Worcestershire took him along the Severn path, the Gloucestershire and Oxfordshire Ways and into Henley. Thereafter the Thames path led to central London.

When, in the Spring of last year, Mr Watkins relinquished the post of Senior Partner in Frank B. Dehn & Co., the London patent attorneys, he asked that instead of the usual retirement gifts colleagues and clients should sponsor

Retired Patent Attorney Arnold Watkins ends his journey at the Hilton

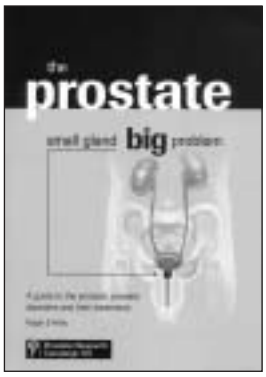
him on a walk from Kidderminster to Park Lane in London in order to raise funds for **Prostate Research Campaign UK**. He and they were delighted when over £18,000 resulted.

It was in September 1989 that Mr Watkins successfully underwent a radical prostatectomy and his obvious good health eleven years later was the cause of the beaming smile on the face of Mr Neil 0'Donoghue FRCS as he watched Mr Watkins hand over his giant cheque at the Campaign's Luncheon last October.

The Prostate: Small Gland, Big Problem

The best book of its kind

No thoughtful family or Primary Care Practitioner should be without the superb new book, *The Prostate: Small Gland, Big Problem*. Lavishly illustrated in colour throughout its 100 pages, the book has the latest angles on all three prostate diseases. A consultant urologist on seeing it for the first time hailed it as 'the best you will find on these subjects'. The new book is four times as long as its predecessor which, in its day, was given five stars on the nhsdirect web site. It includes sections on 'Frequently Asked Questions' and is complete in its coverage, up to date and user-friendly. A bargain at £8.95 inc p&p.



Verdi Centenary Concert at Albert Hall to aid our funds

The celebrated writer and broadcaster Humphrey Burton will be 'celebrating' in several senses on Sunday 18th March when he plans to make the dream of a lifetime come true. He will be conducting the Verdi Requiem at the Royal Albert Hall 125 years after it was first performed at this self same location. 2001 is also the centenary year for the Italian composer Guiseppe Verdi (1813-1901) whose works include Rigoletto, La Traviata and Aida.

In 1996 Humphrey Burton discovered, through a routine PSA test, that he was suffering from prostate cancer. After successful treatment in Seattle using brachytherapy he conceived the idea of turning his 'dream concert' into a charity gala to aid **Prostate Research Campaign UK** so as to raise public awareness of the need both for more research and for early diagnosis and treatment of prostate cancer.

Humphrey Burton's Verdi Requiem performance promises to be a spectacular musical occasion. Taking part will be the world renowned Philharmonia Orchestra, a huge chorus of more than 500 voices (combining no less than five of the country's best known choirs) and a solo quartet of exceptionally gifted young singers from English National Opera.

Further details can be seen in the leaflet circulated with this issue of ***Update***. Tickets at prices ranging from £8.50 to £35 are obtainable now from the Box Office at The Royal Albert Hall, Kensington Gore, London SW7 2AP on telephone number 020 7589 8212. Come and enjoy yourselves while supporting us at the same time.

Guiseppe Verdi 1813-1901

Our Other Publications

Prostate Problems? An introduction

Brand new. 8 pages. Recently brought right up to date.

FREE of charge, but please send a C5 SAE and donation.

How you can help us...

A folded leaflet explaining ways in which you can help this charity, including Gift Aid Declaration and Bankers Order. FREE of charge.

Mailing list changes

- ❑ Amendment
- ❑ Deletion
- ❑ Addition

Publications orders

Please send me the following publications: .....

.....

.....

Name .....

Address .....

.....

.....

Post Code .....

£ *Amount enclosed*

Support research and information dissemination with a donation

Prostate Research Campaign UK

Prostate Research Campaign UK cannot function nor do the work it wants without your help. £20 per year from each of our readers would make a big difference. So please do your best.

If you would like to make suggestions or comments write to the address below or e-mail us at info@prostate-research.org.uk

Name .....

Address .....

.....

.....

Post Code .....

£ *Amount enclosed*

Visit our web site at http://www.prostate-research.org.uk

Please make cheques payable to **Prostate Research Campaign UK** and send to:
36 The Drive, Northwood, Middlesex HA6 1HP Telephone enquiries: 01923 824278