update

Issue No. 2
January 1999

The Newsletter of Prostate Research Campaign UK

Prostate Cancer Man Seeks Marathon Sponsorship

Rex Willoughby, 55, from Cobham in Surrey, will be the first person to be sponsored to run in the London Marathon on Sunday April 18 wearing a **Prostate Research Campaign UK** T-shirt.

Rex was Finance Director of Mobil UK, when he went for his company's routine annual medical four years ago. He had heard about PSA testing for Prostate Cancer, so whilst they were about the business of taking a blood sample to test for standard substances such as cholesterol, he said "What about this PSA test?". "We do not usually include the test in the company medical, but since you ask, we'll do it" he was told. Rex had had no worrying symptoms and was therefore astonished that the result was a PSA of 9, the normal range being 0 to 4.

There then ensued a series of further tests which confirmed the presence of a rather aggressive cancer, which Roger Kirby FRCS removed in March 1995.

Up and running in 4 weeks

Rex was up and running again within four weeks of the operation. Last October, to confirm that he could complete the marathon next April, he ran with 30,000 other competitors in the Great North Run. This is a half marathon which he completed in 2 hours 19 minutes!

Now as well as training for next April's event he works during the week for a disabled persons organisation near Cobham called The Grange. His training has to be carried out in darkness. Fortunately he trains in daylight at weekends so we could get his photo for ***Update.***

The marathon is 26 miles 385 yards in length, commemorating Phidippides run to the city of Sparta to ask for help for the Persians in their famous battle against the Athenians 490 years before the birth of Christ, which they lost. In April, Rex will be running the same distance measured out from Greenwich to Westminster via the Cutty Sark, Docklands, Tower Bridge and Central London.

To sponsor Rex

Rex suggests that for sponsorship purposes he will run the first mile and 385 yards for nothing and his sponsors need only sponsor the remaining 25 miles. So 10p per mile is £2.50 and £1 per mile is a very useful £25.

Sunday Brunch for 4
at the London Hilton
to be won in Prize Draw

Sponsor Rex
to sponsor research funded by
Prostate Research Campaign UK

For details of both see the coupon on page 5

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Editorial

The first edition of Update was well received. We hope that our readers like the second one as much. There is so much of interest to write about that we have expanded from four to six pages. The sponsorship which the newsletter receives, means that its publication and distribution is not at all a financial drain upon the charity's resources. Nor does this welcome support impose an editorial policy.

Thanks to those who sent us donations in response to the first newsletter. Thanks also to those who wrote to us. Please, keep those letters coming.

One of our objectives for 1999 is to create a **Prostate Research Campaign UK** web site. On this we shall put our information leaflets, the newsletter back numbers, general news, links to other relevant web sites and have space to register new supporters and receive e-mail. If you have internet access, look out for our web site sometime in March.

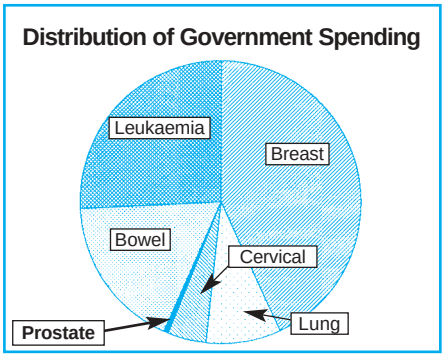
Finally - A Happy New Year to all our readers!

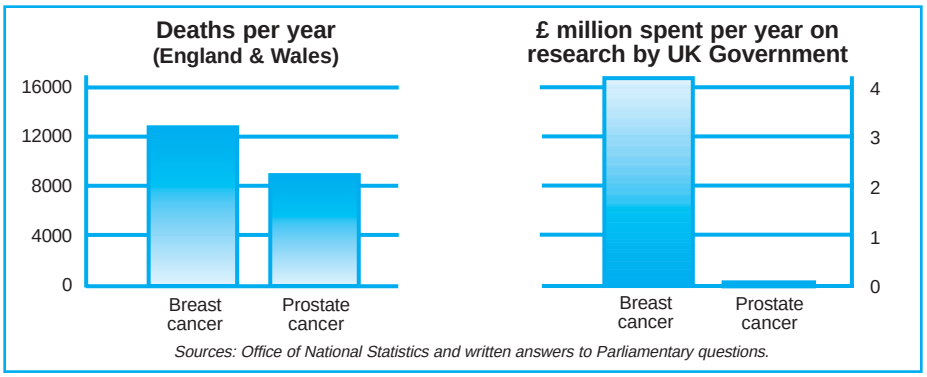
88 to 1 - Is the balance wrong?

The sums spent on prostate cancer research are low by any measure. Last July, Tessa Jowell told Parliament that the Government spend on Prostate Cancer Research in 1997/98 was just £47,000 . We do not think it unfair to compare this with the sum spent on breast cancer. Both diseases are the number two killer cancer of their sex after lung cancer. The number who die from each disease per year is quite similar - more from breast cancer, rather less from prostate cancer. The breast cancer figure has been falling over the past few years and is expected to fall further - a welcome outcome of well spent research funding and a national screening programme. Would it not be good to be able to say the same about prostate cancer, a disease which is forecast to rise very significantly over time?

Whereas the threat from the two diseases is comparable the spending on research is in the proportion of 88 to one. So, we ask, is the balance wrong?

Is breast cancer a special case? Are the sums spent on other cancers also so dramatically out of line with the sums spent on breast cancer research? The figures suggest not. When compared with any other cancer, the sums spent on prostate cancer research are self evidently extremely low.





Facts and Figures on Research Funding

We look at the three sources of money to fund research, development and trials relating to cancer treatment.

Industry

First, there is industry, the major drug companies, whose primary motive for carrying out research is simple. They want to make a profit through selling the products which derive from their research activity. We live in a 'market economy' society which, without the commercial risk taking and investment of the drug companies, would be in a sorry state when it comes to the treatment of cancer. In deciding which research topics to back, a drug company will consider the potential market, the investment needed, the competition and the likelihood of success. It will not, in the first instance, have to consider questions of political or social significance such as whether to prioritise treatments for children over those for adults or whether to prefer women to men.

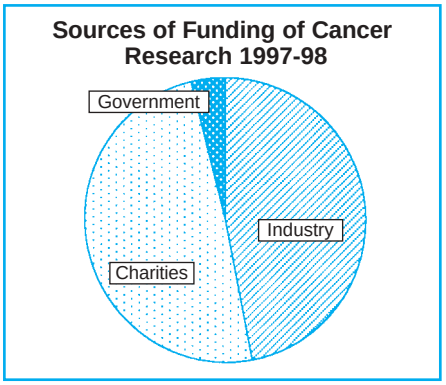
The total spent by industry on cancer research in 1997-98 was about £115 million.

Cancer Charities

Second, there are the cancer charities, to which a generous British public subscribes enormous sums every year. Collectively, the charities are very important players in the determination of what research is carried out. They support specialist laboratories, university and hospital-based research. They are able to take a slightly less commercial view than the drug companies of what should be done. Longer term research can more easily be fitted into the range of subjects they finance. They do, however, obtain their money from the public via legacies or donations and any specific wishes expressed need to be respected as far as possible.

The National Lottery is becoming an important source of funds with £2 million, 0.04 per cent of awards, going towards cancer research projects.

The amount spent by cancer charities in 1997-98 totalled about £122 million. Two charities account for a high proportion of this sum. The Cancer Research Campaign, now in its 75th year spent £49 million last year. The Imperial Cancer Research Fund spent a comparable amount. There are a number of smaller charities like the **Prostate Research Campaign UK** which focus on, and make a significant contribution to, specific research areas or teams.



Government

Third, there is Government. The Government pays for research directly from Department of Health funds and through the Medical Research Council. A small amount is also paid for by the Scottish Office. The total amount spent via these three Government sources on specific cancers during 1997-98 was just over £10 million.

Government funding, by comparison with that from industry and the charities, is a small sum indeed. But it understates the actual influence of Government in two ways.

There is a great deal of co-operation between the various funding bodies to ensure that there is complementary work being done which is proceeding according to agreed priorities and towards mutually agreed goals. The key personalities who make the decisions in all three areas know each other well and listen to each others' advice and recommendations. The Government's strategy tends, therefore, to be mirrored by the large charities and to influence the priorities of industry.

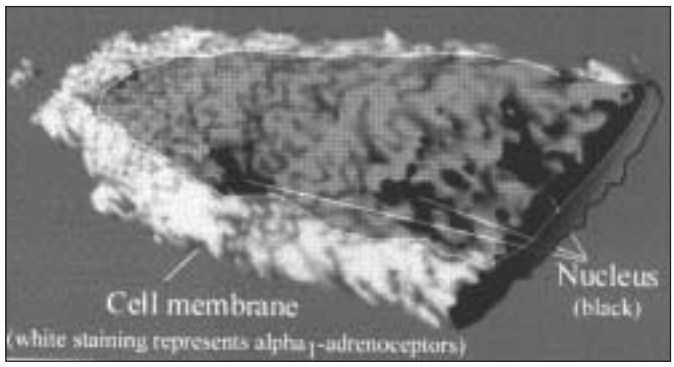
The Government, through the Medical Research Council, supports a large amount of basic research which underpins the more focused work into specific diseases. In 1996-97, for example, it spent £63.5 million on the study of molecules and cells, £39.8 million on the study of genetics and health and £55.6 million on the study of infections and immunity.

Research to improve treatment of benign enlargement

Dr Janet Mackenzie, of the University of Glasgow, is carrying out research, funded by Prostate Research Campaign UK, which could lead to improvements in the treatment of benign enlargement of the prostate (BPH).

One of the symptoms of the condition is slower urinary flow. This is due to constriction of the urethra by the enlarged prostate. This problem is currently alleviated by the patient taking alpha-blocker drugs which inhibit the contraction of the smooth muscle in the enlarged prostate. Dr Mackenzie's work is increasing our understanding of the "alpha-receptors" at which these drugs work. Better understanding of the mechanisms involved should lead to improved targeting and efficacy of the drugs used to treat patients with BPH.

Dr Mackenzie has been working with human cells taken from patients undergoing surgery for BPH. She has developed new methods of studying the receptors on such cells. The technique involves making the alpha-blocker fluoresce so that its behaviour with human prostate cells can be seen and photographed at reasonably high magnifications. The visualisation can also be carried out in real time so that the kinetic properties of receptors and their role in the cellular activation process may be studied.



The photograph shows the 3-dimensional distribution of the alpha-receptors on a live cell. The actual cell is shaped like a short fat cigar and in the photograph one quarter of a cell is shown after cutting the cigar lengthways and then cross ways. It reveals that the receptors are mostly on the cell surface. Detailed analysis also reveals sites within the cell which could be associated with the growth inhibiting effects of alpha-blockers of the type used, which might represent another beneficial action.

Increasing availability of radioactive seed therapy

The Cookridge Hospital in Leeds was the first in the UK to offer brachytherapy as a treatment for prostate cancers which have not spread outside the gland itself. The procedure, as pioneered in Seattle, involves the insertion of small pellets of radioactive material into the prostate gland where the radioactivity burns away the cancerous tissue. It was described briefly in our first issue in the article about Andy Groves of Intel.

Its acceptance is clearly on the increase, which is not surprising as it exhibits fewer side effects than either radical surgery or conventional external beam radiotherapy. Its long term results are less clearly established, as it is a newer procedure, but indications are that its effectiveness is comparable to the best figures achieved with the other two treatments.

Kings College Hospital in London was the second to offer brachytherapy starting to do so last October. Other Hospitals who will be offering a service in the near future include the Royal Surrey - Guildford, Christie Hospital - Manchester, the Middlesex, the Central Paddington, the Western General - Glasgow, Clatterbridge - Liverpool/ Wirral and Mount Vernon in Northwood, Middlesex.

Prostate Research Campaign UK thanks

Nycomed Amersham

and

ZENECA Oncology

who have financed this issue of ***Update*** *as a service to the community. The views expressed are not necessarily those of our sponsors. The companies are not responsible for any inaccuracies or statements made. Any queries or comments to the charity, please.*

Why the Tax Man parts with money.

Covenanting with this charity explained

The Inland Revenue offices in Merseyside are not wholly occupied by grasping individuals, as Alex May, the volunteer who acts as Honorary Covenant Administrator for **Prostate Research Campaign UK**, has discovered. Indeed Alex has found that they very speedily send us a cheque when he applies to them for a refund of tax on donations which supporters have made under the terms of a Deed of Covenant.

Getting the tax man to add to your generosity, without costing you anything, is a straight forward matter. If you will sign a form pledging a specific amount which can be paid monthly, quarterly or annually to our charity then, providing that the pledge covers a period of not less than four years (or one's lifetime if shorter) the rest is easy. The form (i.e. the Deed of Covenant) can be obtained from Prostate Research Campaign and accompanying it is a Banker's Order form which donors can complete to enable payments to be made under the terms of the Deed. There is one proviso which is that the donor must be paying UK tax on at least some of his or her income.

*Alex May, Honorary Covenant Administrator for **Prostate Research Campaign UK***

The Inland Revenue will, once our claim is made, give us the tax which you have previously suffered on the sum donated to our charity. To take an example: if you covenant £5 a month then we can recover income tax at 23% (which, in this case would be £17.93 a year) so your gift would be worth £77.93 a year and over the four year period of the Deed the gift would be worth £311.72 to us. Of course there are correspondingly greater sums obtainable from larger donations and more for the tax man to "cough up".

Please send a stamped addressed envelope to Prostate Research Campaign UK with your request for a Covenant Form.

Your letters

P = Peace (or piece) of mind

Dear Sir,
There is a serious need to tell people going through the prostate cancer decision process what are the implications, and who better than those of us who have been through it? Not medical, not treatments just practical comments. If the breast cancer devotees can wear a ribbon what about a lapel badge for us?

John Grove, London N1

Increased awareness is of great importance, an idea for the future. Ed

Need for better health education

Dear Sir,
Health Education from whatever source is failing men with prostate cancer. If I had known what I know now, I am convinced that I would have been treated earlier.

There may be resistance in the medical profession to giving PSA tests, but this means that nothing is done unless the man (future patient) knows sufficient to ask for some other way to safeguard his health. Few Consultant Urologists would quarrel with the idea that all men over 50 should ask their doctors for a digital rectal examination annually. So that is what men should ask for.

Norman Bryan, Cardiff.

Agreed. Should you ask your GP for a check up - suggest he/she measures your PSA as well. Ed.

PROSTATE RESEARCH CAMPAIGN UK

Support research and information dissemination by sponsoring Rex Willoughby's marathon and entering the prize draw.

I am happy to sponsor Rex's London Marathon on 18 April 1999 and look forward to receiving confirmation of his finishing time.

£ .....
Sponsored sum

Name .....

Address .....

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..... Post Code .....

£ *Amount enclosed*

Prize draw for
Sunday Brunch for 4
at the
London Hilton, Park Lane,
to be enjoyed during 1999.

Tickets £5 each

I should like ..... *tickets*

Draw to take place on Sunday 28 March 1999.

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

Prostate cancer vaccine treatment trial started

A trial is just starting into the benefits of a vaccine which has the potential to harness the body's own immune system to better fight prostate cancer.

Throughout 1999, about 60 volunteer patients at St George's Hospital, London will receive a monthly injection of the vaccine. The patients concerned all have somewhat advanced disease, with PSA levels over 30 which are no longer being held in check by androgen hormone therapy.

How the vaccine works

The vaccine is derived from human prostate cancer cells. These have, first, been 'immortalised' so that they can multiply indefinitely outside the body. Those to be used for the vaccine are then 'inactivated' by radiation, so that they are no longer able to divide and, hence, grow in number. They are then injected into the patient whose body will very likely recognise the cells as foreign. The patient's own immune system will then try to reject the foreign cells and kill them The behaviour is much the same as when a transplanted organ is rejected. Once the body's immune system is stimulated by the vaccine in this way, it should also set about destroying the live cancer cells which are already within the patient's body.

First time in humans

Such a procedure has been tested in rats but with a vaccine derived from prostate cancer in rats. This trial will be the first time the actual vaccine has been used with human patients. Its effectiveness will be measured through the indirect marker of changes in the PSA level and through scans of the patients. The trial will also assess the impact of side effects such as inflammation of the injection site and feverish flu type symptoms.

The path to general availability

The trial has, of course, been cleared with the local medical ethics committee. Normally, when introducing a new drug, three stages of testing are gone through. First, the drug is tested on a low number of healthy volunteers, often medical students, to look at its safety, tolerability and the incidence of side effects. It is not until phase two that the potential new drug or treatment is tried in, again a low number, of ill volunteer patients. Phase two results include measures of the effectiveness of the new drug and allow assessment of what dosages would be most suitable. The prostate cancer trial starting at St George's is a combined phase one and two trial.

Finally, before the drug is licensed by the regulatory authorities, there must be phase three trials. These are large scale, randomised, trials (known as double blind) in which half of the recipients receive a placebo and half the actual drug without either the patient or the prescribing doctors knowing who is getting what. It is only when the results of these phase three trials are available that the new drug will reach the market. This is a very safe but also a very slow procedure typically taking five or six years from start to finish.

Who makes the vaccine?

The vaccine for the trial is being produced by a biotech start-up company called Onyvax, which currently employs just 20 people. It was formed in 1997 with the express aim of developing therapeutic vaccines for cancer. The use of the word 'vaccine' may be confusing since it usually implies something which is given to prevent the occurrence of a disease whereas, in this context, it refers to a treatment for the disease.

Hundred Holes in a Day

Hugh Blenkin achieved something few golfers of any age have done when he completed 100 holes of golf in a day to raise over £5,000 for Prostate Research and two other charities through sponsorship. He started just after four in the morning on 19 June on Rye golf course, East Sussex completing the five rounds, ten holes just before dark at 9.20 p.m. the same evening. He had five volunteer caddies (one per round) to carry his clubs and the other golf club members not only sponsored him, but let him through their games to speed him on his way. He spent 13 hours 49 minutes actually playing golf and took 451 strokes for the 100 holes without losing a ball. All this just 57 days after having his cancerous prostate removed at the hands of Neil O'Donoghue FRCS. Well done Hugh and thank you!

Golfer Hugh Blenkin(right) with his wife, Marilla and consultant urologist, Neil O'Donoghue FRCS.

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Huge Success of Annual Luncheon

There was a steady buzz of warm chatter as those present enjoyed the Campaign's Annual Luncheon held at the Hilton Hotel on Park Lane in London's West End. The atmosphere was happy and the financial outcome good. An onlooker from outside could wonder how the survivors of an air crash would react to a reunion yet the trauma which many of those at the Hilton Luncheon had been through as prostate patients, showed that one can rise like a phoenix from the ashes and enjoy a reunion - full of good cheer. Attendance was up 80% and the profit made was of the order of £7,400. This included donations from those who could not be present as well as an auction of a West End Theatre break including dinner at the Savoy and a night at Claridges, which

raised £1,000. This was 'knocked down' to Christopher Barnes from Jersey who is the son of the charity's Hon Secretary. Dr Thomas Stuttaford, that pillar of *The Times*, gave an after lunch address making interesting comparisons of life expectancies in the four major democracies, namely, the USA, Germany, France and the United Kingdom.

The next Annual luncheon is expected to be held on Wednesday 20th October 1999.

Helping You, the Postman and Us

Sheila Kilmister, the *Queen Bee* of our mailing list is keen to 'brush up' her database as she is sure that some who received the first issue of **Update** may have found themselves addressed in a less than perfect manner. She is anxious that all readers who found that their names were misspelt, whose addresses were slightly wrong or who received duplicate copies by mistake should let her know without delay. Also, if you know of others who might like to receive a copy, do let her know. This can help us spread the word or save us postage and save you 'aggro'.

Prostate Problems: The Facts

Described by a consultant urologist as 'Quite simply the best of its kind there is on the subject.'

Price £5.95 inc. p&p

You and Your Prostate

This comprehensive book is by Lee Rodwell, health editor of the popular weekly magazine Take a Break and writer for several national newspapers.

Price £10.95 inc. p&p

Prostate Briefs

No 1 Disorders of the Prostate
No 2 Benign Prostatic Hyperplasia
No 3 Prostatitis
No 4 Prostate Cancer

FREE of charge, but please send SAE and donation.

The Prostate and You

A brief leaflet pointing the way to further action.

FREE of charge, but please send SAE and donation.

How you can Help

A folded leaflet explaining ways in which you can help this charity, including Deed of Covenant and Bankers Order.

FREE of charge.

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❑ Addition

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