THE NEWSLETTER OF
Prostate Research Campaign UK

update

ISSUE No. 14 APRIL 2003

Royal Support for Prostate Research

Duchess of Gloucester becomes our Patron

Update joins the Trustees and members of their Advisory Council in expressing warm thanks to Her Royal Highness The Duchess of Gloucester GCVO who, with effect from 3rd March 2003, has become Patron of **Prostate Research Campaign UK**.

Within days of Her Royal Highness granting us her Patronage, our Chairman, Professor Roger Kirby and the charity's founder, Anthony Kilmister, called at Kensington Palace to discuss plans with The Duchess of Gloucester and members of her Household. It was clear from the outset that it is her wish to be seriously involved in furthering the work of our charity.

Only days after the Court Circular recorded the visit to Kensington Palace of our representatives, the Duchess crossed the Atlantic and was shown American prostate facilities in New York. Dr E. Darracott Vaughan escorted Her Royal Highness on a tour of Cornell University's New York Presbyterian Hospital and Memorial Sloan-Kettering Cancer Center. Dr Vaughan pointed out to The Duchess of Gloucester not just some of the latest work on prostate cancer but also their Charter from King George III thus demonstrating a common bond between our two nations and a common urological cause.

HRH The Duchess of Gloucester GCVO

In a message for all ***Update*** readers Her Royal Highness said: "I am very pleased to have been invited to become Patron of **Prostate Research Campaign UK** and look forward with particular enthusiasm to furthering the charity's important work. Since prostate cancer has become the most common cancer in men it may be helpful to underline the initiative that many women take in confronting this major concern for men. **Prostate Research Campaign UK** is to be commended for supporting work on benign as well as malignant prostate disorders. Until the charity launched its campaign this area had been somewhat neglected and I look forward to joining the assault on these serious medical conditions. I send my warmest good wishes to all the charity's supporters and readers of ***Update***."

Already The Duchess of Gloucester has plans to visit laboratories supported by **Prostate Research Campaign UK** and in particular those directed by Professor John Masters. Subject always to the unexpected, Her Royal Highness plans to be present at our Annual Luncheon to be held at the Savoy in October.

'I am very pleased to have been invited to become Patron'

All of us will join in thanking The Duchess of Gloucester for her close interest and will re-double our efforts to expand the campaign by raising the funds necessary to push forward the frontiers of knowledge.

IN THIS ISSUE

Bench to bedside and back to bench

The Royal Marsden pioneers a unique clinic in London for people with genes that predispose towards cancer

This is a story about Karen, whom we thank for allowing us to use her name. She is shown here with her husband, son and daughter. All apparently very normal; but she is, in fact, very special. She herself has breast cancer. Her mother and four aunts died of the disease as did one of her cousins. In addition to that, she is one of the patients who are contributing to *cutting edge* research and at the same time benefiting from it.

Karen with husband and children

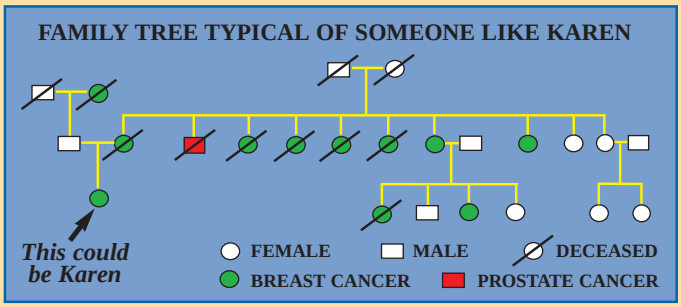
The study of how our genetic make up can cause us to be more or less likely to contract certain diseases is still in its infancy. There have however already been some very important discoveries. Two genes linked to breast cancer have been found in recent years and named unsurprisingly BRCA1 and BRCA2. Further research has now revealed that men who have either of these genes in their genetic code are much more likely to develop prostate cancer than the general population.

*Dr Ros Eeles (right) and Zsofia Kote-Jarai demonstrate the technique used to colour chromosomes for genetic research in a project supported by **Prostate Research Campaign UK***

How does one carry out such research? Only by finding and working with families like Karen's. She and some of her relatives have given blood samples for the research programme from which it is possible to try to identify the genetic differences they exhibit which predispose them to a higher risk of these cancers than the rest of the population.

The Institute of Cancer Research and Royal Marsden Hospital, which is the centre where the research is carried out, has established a unique multi-disciplinary clinic for the management of cancer predisposition gene carriers. The Carrier Clinic set up by the Royal Marsden differs from the NHS model in that it is multi-disciplinary containing oncologists as well as geneticists. When the few NHS genetics centres that do exist were established, they mainly worked on genetic diseases that threaten children.

Clinicians can, of course, learn from the potential carriers whom they see and feed what they learn into multinational research projects (bedside to bench). At the same time, the Carrier Clinic helps patients and their families to deal with the higher risks of cancer that they run and provide them with rapid feedback of relevant research findings (bench to bedside). The Clinic is a place where advice can be given about the patient's lifestyle and help which may be needed by the family in the future. For example, it is already planned that Karen's daughter will be offered breast/ovarian cancer screening from the age of thirty whilst her son will be offered screening for prostate cancer from 45 years.



New treatment a when cancer has s

When cancers spread to the bone painful and debilitating complications often occur including severe pain, bone fracture and damage to the spine and even compression of the spinal cord. Since last September, a new Novartis Oncology drug, Zometa is available to mitigate these problems.

Endocrine drugs are the standard treatment for patients with advanced prostate cancer. Drugs such as Zoladex work to inhibit the action of testosterone, which otherwise would stimulate the growth of the cancer. Radiotherapy can be useful for pain relief. So too can chemotherapy, pain killers and on occasion orthopaedic intervention. But now there is Zometa as an addition to the armoury.

How does Zometa work?

Bone is alive. Cells die and break down and new cells are laid down in the bone to replace them. Once cancerous cells are present in bone, they cause abnormal dissolving or wearing away of the bone. In so far as new bone is formed, it is dense and poor quality and laid down not where cells have been removed but somewhere else, thereby deforming the bone structure. These two actions of bone erosion and abnormal bone creation in the wrong place are the root cause of the nasty complications which occur in patients with cancer which has spread to the bones.

Zometa operates by binding to bone surfaces and working directly against the cells that cause bone breakdown. It is important to understand that Zometa, as far as is known, is not treating the underlying cancer. It is treating the bone to strengthen it and prevent complications.

' treating bone to strengthen it and prevent complications'

How is Zometa given to the patient?

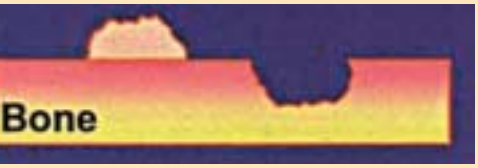
It is given via an intravenous drip for fifteen minutes or so every three weeks. At least half the patients report an immediate reduction in pain so their quality of life rises from the first injection. Receiving it is typically accompanied by the prescription of vitamin D and Calcium to maintain or increase bone density.

available to help spread to the bones

What can Zometa achieve?

Zometa has been shown to reduce the risk of bone complications by some 40% over a two year period. It is licensed for prescribing in the UK but has not been assessed by the National Institute for Clinical Excellence (NICE) nor is it on their agenda until after 2005. It costs some £120 per month.

n normal healthy bone breakdown occurs and eneration occurs to the same extent and in the e places



n bone attacked by prostate cancer, breakdown occurs but regeneration may occur to the same nt but in the wrong places...

.or not to the same extent but still in the wrong ces. These effects can lead to both bone pain and e fracture

The problems in getting Zometa prescribed include the fact that to some urologists it is not yet well known. Cost may also be a problem. There is also the practical problem that outpatient intravenous facilities are within oncology rather than urology departments.

Professor Robert Coleman of the Cancer Research Centre, Weston Park Hospital Sheffield is an authority on Zometa. He suggests that patients on long term endocrine treatment should have their bone density monitored (since the treatment itself causes slow bone loss). This too can cause an interdepartmental problem in hospitals because the x-ray machines which measure bone density are typically within rheumatology departments.

Details of the trials of Zometa can be found in the Journal of the National Cancer Institute Vol 94, no 19, October 2002.

Keyhole Surgery - Declan Cahill describes experience gained in Paris

Laparoscopic radical prostatectomy (LRP) is the removal of the prostate using keyhole surgery. The small access sites through the abdominal wall afford patients a procedure with a low complication rate and an accelerated return to normal activity. Importantly this is not at the expense of cancer clearance or the patient's functional capacity post-operation. The views under significant magnification allow more precise surgery of the prostate, neurovascular bundles and urethra. This translates into less blood loss, better negative margin rates (cancer clearance), preservation of potency (erections) and, probably, better continence. It is an important and worthwhile addition to the selection of treatments for clinically localised prostate cancer from which patients may choose.

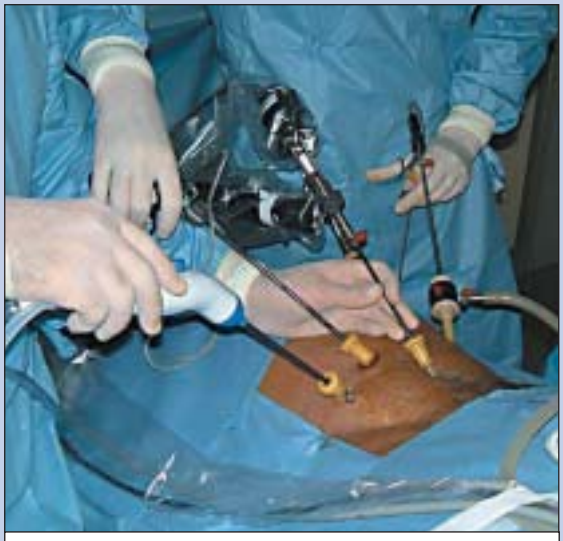
'a lifetime experience for many surgeons'

This is technically challenging surgery. Sufficiently intense training in this procedure is not available in the UK. The premier centre for this operation is Institute Montsouris in Paris where LRP was developed, standardised and popularised by Professor Guy Vallancien and his team. Thanks to the generous support of the **Prostate Research Campaign UK**, I was able to spend 6 months dedicated to learning this operation 5 days a week. This was a recipe for success.

The backbone of my training in Montsouris was *pelvitrainer* work every day, Monday to Friday. This involves performing laparoscopy in a small wooden box. I carried out procedures to reconnect simulated severed urethras, using segments of expired dacron vascular grafts that had been scrounged from various London Hospitals. This gave me the dexterity and hand/eye coordination to operate on people, and made laparoscopic suturing second nature.

It is perceived to be a very difficult procedure. I do not believe this is entirely true. Yes, it has proved beyond many surgeons that have tried to take it up, and has deterred others. However, this is due to inadequate opportunities for training in this country and embarking on this venture unprepared. With training I think LRP is very realistic. During my time at Montsouris there were 250 prostatectomies performed. This is a lifetime experience for many surgeons. This large volume of work allowed me to become *experienced* in a short time, see most of the possible complications, learn how to avoid them or manage them efficiently so that they did not translate into patient harm.

I have had an invaluable 6 months of training. In this country special experiences such as this are made possible thanks to organisations such as the **Prostate Research Campaign UK** and I am extremely grateful to them.



A laparoscopic prostatectomy in progress: There are five ports. In the middle the camera is directed by a voice controlled robot. The two on the left are for the instruments of the principle surgeon, those on the right for his assistant.

Prostate cancer is my special interest and by undertaking this fellowship I have greatly strengthened the service I can provide my patients. They will now have increased choice and security in the knowledge that I have been properly trained.

On my return to the UK I am taking up a consultant post at Guys' and St Thomas' NHS Trust and will be utilising my new skills in this area. Once the service is established I hope to be able to train other surgeons in this technique.

Welcome to a new Vice President

We warmly welcome Baroness Gardner of Parkes who has joined Sir Timothy Hoare as a Vice President of **Prostate Research Campaign UK**. Lady Gardner, a dental surgeon, has shown great interest in prostate disorders and has asked parliamentary questions on prostate subjects in the House of Lords on several occasions. She served as a member of Westminster City Council for ten years and was Lady Mayoress in 1987-88. Baroness Gardner, an Australian, takes her title from Parkes in New South Wales.

Among former Vice Presidents of **Prostate Research Campaign UK** have been the one-time Archbishop of Canterbury the late Lord Runcie and the late Sir Julian Critchley author, journalist and MP

Benign prostate enlargement An improved drug treatment

A new drug, Avodart, has recently been introduced for the effective treatment of moderate to severe symptoms of benign prostatic hyperplasia (BPH).

Commenting on the launch of Avodart by GlaxoSmithKline, Tom McNicholas, Consultant Urological Surgeon, Lister Hospital, Stevenage, said "This is good news for BPH sufferers as it provides patients with an effective treatment option, which addresses more than just symptom control. Clinical trials have proven that Avodart is not only effective with a good safety profile, but reduces the risk of acute urinary retention by 57 per cent, and BPH-related surgery by 48 per cent, over two years."

BPH is one of the most common health problems in ageing men. It is estimated that over 20 million European men suffer from BPH. Current worldwide sales of treatments for BPH are over £1.5 billion

For the technically minded, Avodart is a novel 5-alpha reductase inhibitor which inhibits the enzyme responsible for converting testosterone to dihydrotestosterone (DHT) in the prostate. DHT is the primary hormone causing prostate growth and BPH progression. Avodart has been shown to suppress DHT levels by 90 per cent at two weeks and shrinks the prostate continuously over the two year study period.

'This is good news for BPH sufferers'

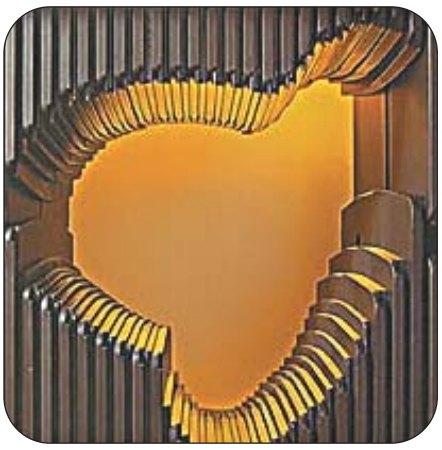
A new treatment technique in Radiotherapy

Radiotherapy is frequently prescribed as a means of curing or, at least, reducing the size of cancers of the prostate. The intensity of the radiation is what kills the cancer cells. Unfortunately the same level of radiation will also kill normal cells. Standard radiotherapy involves two or more beams of radiation striking the body from different angles. Only where these beams meet is the radiation of sufficient strength to destroy cancerous and, regrettably, normal cells.

Conformal radiotherapy uses the same radiotherapy machine (called a Linear Accelerator) as the normal treatment but uses metal blocks placed in the path of the x-ray beam to alter the shape of the beam. This means that the metal blocks can be carefully planned for each patient to shape the treated area more precisely and so reduce the amount of bowel and bladder tissue that is irradiated. A number of centres in the UK now offer conformal radiotherapy. In theory, it is more effective in providing a high dosage of radiation to the tumour while keeping radiation to normal tissue to a minimum.

'This can give even more precise shaping'

More recently a device called a multi-leaf collimator has been produced as an alternative to the metal blocks. This consists of a number of layers of metal sheets which are fixed to the Linear Accelerator. Each layer can be adjusted to a different position and so alters the shape and intensity of the beam of x-rays reaching the patient. This means the settings of the multi-leaf collimator can simply be changed for each patient's treatment and there is no need to make special metal blocks.



A multi-leaf collimator used in intensity modulated radiotherapy

A further development to move the collimator during the radiotherapy treatment gives even more precise shaping of the treatment areas. This is called intensity modulated therapy.

As far as we know there are no centres in the UK that yet offer intensity modulated radiotherapy. Dr Roger Macklis at the Cleveland Clinic Foundation in Ohio is one of a number of physicians in the US who are now treating prostate cancer patients with this technique.

At the moment although conformal therapy has theoretical advantages over standard treatment the case for its routine use remains to be proven. The Medical Research Council has a trial under way to clarify this issue but it will be some years before the results are available. Recently issued national guidelines for the use of radiotherapy in the management of prostate cancer make no specific recommendations for the use of conformal or, indeed, intensity modulated therapy.

We are grateful to Cancer Bacup for some of the information in this article.

The Newsletter of *Prostate Research Campaign UK*

update

Mad Marathoners to attempt mighty mountain

This is our top fund raiser of the year

Three London Marathons completed, and last year's event raising over £170,000 for the **Prostate Research Campaign UK**, we were looking around for a fresh challenge. Here, Roger Kirby describes the venture.

"Kilimanjaro with its gleaming glaciers and wreathing veils of clouds is an awesome and magnificent mountain. Standing so solidly and majestically amidst the vast open plains, it beckons you closer to experience it yourself; to ascend through the farms, forest and giant heather, to cross moors and highland desert up to the eternal snows of Kibo, the highest point in all Africa."

That's it I thought, the perfect fund-raising event and a chance for the *fit fourteen* to test their mettle against the acute mountain sickness that prevents more than half of all climbers from reaching the top of this famous mountain.

On the first day of the climb there is an idyllic tramp up through the National Park to 8,500 feet where the team stay in four berth huts in lush rain forest. The following day it all starts to get harder. A 6.30 am start presages a seven hour hike up much rougher terrain reaching Horombo camp at 14,000 feet.

On the next day, another early start will take the team over chilly, heathery moorland that soon gives way to desolate windswept lava where the Kibo hut can be found . Many of the team will by now be affected by the altitude. Five hours of rest inside sleeping bags until the 11.30 pm start for the summit. Out into a starry frosty blackness knowing it is no picnic. The effort is now immense. 15 steps and then a rest. A biscuit, a Mars bar before the path clinging perilously to the iced rim of the volcano's crater. A 360 degree sunrise at the summit, which few fully appreciate because they feel so grotty. A few quick photos and then a day long, knee aching hike down to the Horombo camp for night five.

'The following day it all starts to get harder'

Finally another long slog downhill and back to the hotel for a well earned beer and a bath.

Undaunted by the horror stories, the team, including as usual a combination of doctors and patients, is now making preparations for their trip starting on 3 September 2003. This year we are aiming to raise over £200,000 for the work of the **Prostate Research Campaign UK**. So please support us and think of us at the Uhuru peak at 19,340 feet!

All looks lovely from the bottom...

... but nearer the top...?

Please send your sponsorship donation immediately to Professor Roger Kirby at the Eastcote Office

Our web site

www.prostate-research.org.uk

The web site is for anyone seeking trustworthy information on all diseases of the prostate - patients, health professionals and those thinking about a PSA test. It tells you how we spend the money you raise and is invaluable for keeping in touch.

Do visit it and recommend it to others who might benefit.

In Memoriam

We are most grateful for the generosity of those who have supported **Prostate Research Campaign UK** through legacies and donations in memory.

Sadly this is becoming one of our most important sources of revenue. In the past year we have received more than £68,000 in *in memoriam* donations.

Our New Office

On 1st March we opened an office in a fully-serviced Business Centre almost opposite Eastcote station. We warmly welcome Mrs S. Lesley Samuel as our Office Manager. The office at Swindon has been closed accordingly and the new office address is:

Canada House, 272 Field End Road, Eastcote, Middlesex HA4 9NA.
Tel: 020 8582 0246 Fax: 020 8582 0250

The Newsletter of *Prostate Research Campaign UK*

update

Diary for 2003

June 12
Golf Day at Richings Park Golf Club, Middlesex

July 9
Golf Day, Burnham & Berrow Golf Club, Somerset

July 11
Wells Cathedral Chamber Choir perform in Wiveliscombe Parish Church

September 24
7th World Congress on Urological Research

October 15
Annual Luncheon at the Savoy Hotel. For the last two years this has been a sellout. Tickets £80 available now from 36 The Drive, Northwood, HA6 1HP.

October 23
Fashion Show by "Kimberley" of Bath

For more information on any of the above please get in touch with **Prostate Research Campaign UK.**

Jennifer Sheldon to raise £100,000

Jennifer is the widow of Richard Sheldon, former High Sheriff of Somerset, who died of prostate cancer in July last year.

Jennifer has set herself the target of raising £100,000 for **Prostate Research Campaign UK** before the end of this year.

Jennifer Sheldon, in the foreground with five 'models' at her recent fashion show

She said: "In the early 1990s just £47,000 of Government money was spent on prostate cancer research. Now it stands at £4 million but it remains peanuts compared to funding research into other cancers."

"A screening programme and research would make all the difference. I want to make people aware and stop them feeling embarrassed about it. Men are not very good at talking about their own health problems and the trouble with prostate cancer is that, often, it presents itself when it is too late. Women have regular smear tests and breast checks after they reach a certain age and it should be the same for men. Wives or partners may have to push men to go for tests and they may grumble about it but it is certainly worth it. The figures are pretty frightening"

Many of the events Jennifer has arranged are listed in our 2003 Diary. Please do your best to support them and help Jennifer to reach her target.

Support Prostate Research Campaign UK with a donation

Title ..... Fore Name ..... Surname .....

Position and Organisation *(if applicable)* .....

Address .....

Post Town ..... Post Code .....

Tel No ..... E-mail .....

I enclose cheque made payable to **Prostate Research Campaign UK** ❑

Please debit my Mastercard ❑ Visa ❑ Delta ❑ Switch ❑

Card Number ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Expiry date ☐☐/☐☐ Start date/Issue no *(Switch Only)* ☐☐/☐☐

Signature

£ *Amount*

Gift Aid Declaration *(Please complete if you have not already done so)*

As a UK taxpayer, I want **Prostate Research Campaign UK** to reclaim tax on my donations now and in the future.

Name of taxpayer ..... Date.....

Signature

Publications

The Prostate: Small Gland, Big Problem.
Lavishly illustrated in colour, with over 100 pages, this book has all the latest angles on all three prostate diseases. Complete in its coverage, newly updated and user friendly.

New Edition

A bargain at £8.95 inc p&p.

Prostate Problems? An introduction
An excellent 8 pages.

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

Fundraising Pack
Ideas, posters and information to help anyone trying to organise an event to raise funds for ***Prostate Research Campaign UK***

Order any of these by post, e-mail, phone or fax

Printed by Heathprint & Associates 01296 614624

Prostate Research Campaign UK holds names and addresses on computer for the purposes of keeping supporters informed about its work but does not pass information to third parties. Please tick if you do not wish to receive further information ❑

Please make cheques payable to **Prostate Research Campaign UK** and send to:
Canada House, 272 Field End Road, Eastcote, Middlesex HA4 9NA Telephone enquiries: 020 8582 0246