

Fundraising Successes

Since we last reported in *Update*, your charity has organised and run many diverse and highly successful events worthy of front page coverage.

We staged *Music Fit For a King* in Spencer House before an audience of 100 guests that included our patron Her Royal Highness The Duchess of Gloucester. A Champagne Reception was held prior to moving into the Great Room for the Recital. Once again we were delighted to welcome Rupert Gough, conductor of the Wells Cathedral Chamber Choir supported by select choristers and *Ricercare Musica* who are amongst the country's finest early music specialists. We were very fortunate in having internationally renowned soloists Emma Kirkby and James Bowman performing for us. With its rich tapestries, magnificent pictures and beautiful chandeliers the Great Room provided the perfect setting for a memorable evening. As a result of many generous donations, some from donors who were unable to attend, the charity banked in excess of £21,300.

At the other end of the spectrum, perhaps, there was our fun run *Pants in the Park*. Eighty people ran or walked 5km with their underpants on the outside of their running shorts to help raise awareness of prostate diseases. The sight of Union Jack emblazoned, striped, spotted, Y-fronts, boxers, lacy underwear running round Battersea Park on Father's Day was not for the faint hearted. The event was a great success, not only increasing awareness (15,000 leaflets were distributed) but over £7000 was raised by the participants. Thanks to all who took part and helped, notably Stuart May, Sir Bill Morris, the McIntosh family and Tom Anderson on the hottest day of the year. We look forward to repeating the event with many more of you on Father's Day 18 June 2006.



Alison Midgley and son next to sister Sharon McIntosh and their 'other halves' at *Pants in the Park*. The families travelled from Nottingham and Nuneaton to commemorate their father who had died of prostate cancer

A third front page event was the *Round the Island Race* where, thanks to the *Ignorance Isn't Bliss* Campaign and Kit and Susie Hobday's initiative we were made the official charity.

This well established spectacular race of 60 miles around the Isle of Wight was supported by 1648 yachts, involving some 14,000 sailors, who enjoyed wonderful sailing after a delayed start.

Thanks to Kit and Susie's unflagging efforts almost £10,000 was raised for **Prostate Research Campaign UK**.

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Trustee, Roy Kendrick and new adviser, Anthony McLelland with their wives aboard *Tuppenny Blue*. The sponsorship message was displayed to all taking part in the *Round the Island Race*.

Consequences of misdiagnosis

Ted Clucas's story by Professor Roger Kirby

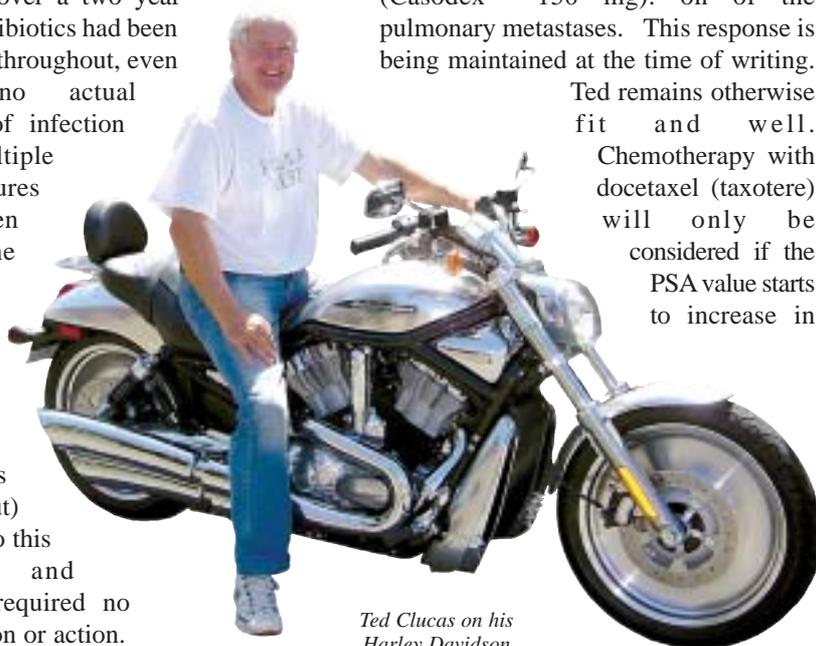
Ted Clucas, one of the most effective and dynamic supporters of the **Prostate Research Campaign UK**, first presented to his GP in 1995 with symptoms incorrectly diagnosed as a urinary tract infection. He also had a mildly elevated PSA. The symptoms continued over a two year period. Antibiotics had been prescribed throughout, even though no actual evidence of infection in multiple urine cultures had been found. The raised PSA had for two years been assumed (quite wrongly, as it turned out) to be due to this infection and therefore required no investigation or action.

Ted approached me for a second opinion in September 1997, when his PSA level was found to be 9.8 nanograms per millilitre (ng/ml). After the usual tests and discussion of the available treatment options, Ted underwent radical prostatectomy. Pathological examination revealed extensive disease within the gland and several positive margins. Moreover, his post-operative PSA level never fell below 0.5 ng/ml and started to rise within three months of surgery. Second-line radiotherapy (70 Gy over six weeks) stabilized his PSA level for two years at <0.2 ng/ml. It then began to rise again. When the PSA rose above 1 ng/ml, he chose to start hormone therapy with the antiandrogen bicalutamide (Casodex™) 50 mg. This lowered his PSA level to <0.1 ng/ml within 3 months; however, after two years of starting Casodex™, Ted decided to discontinue this therapy as he wished to try alternative treatments. Subsequently, his PSA level gradually increased to 23 ng/ml and, in May 2004, he developed breathlessness and blood in the sputum. Computed

tomography scan and a bone scan revealed that he had developed lung metastases in the absence of bone metastases. A lung biopsy was performed, revealing adenocarcinoma of prostatic origin. Because of this, he elected to restart hormonal monotherapy (Casodex™ 150 mg) on of the pulmonary metastases. This response is being maintained at the time of writing.

Ted remains otherwise fit and well.

Chemotherapy with docetaxel (taxotere) will only be considered if the PSA value starts to increase in



Ted Clucas on his Harley Davidson

spite of treatment with Casodex™. Ted is a uniquely positive individual and he is optimistic about the prospects of a prolonged continuing response to bicalutamide and the possibility of subsequent chemotherapy producing a further remission.

Ted's story has recently been recorded on a teaching video and published in both the Daily Mail and the medical journal Prostate Cancer and Prostatic Diseases to illustrate the dangers of ignoring a raised PSA and urinary symptoms which were wrongly ascribed to infection rather than prostate cancer. In an attempt to make a difference to prostate cancer awareness and treatment, shortly after his operation in 1999 Ted ran a half Marathon for the **Prostate Research Campaign UK** raising £47,000, a sum equal to the total amount of money the Government were spending on prostate cancer research at the time! This encouraged me to run my first London Marathon in 2000. Ted remains an inspiration to us all, as well as one of our most trusted and effective advisors.

Passage to Antigua

Jonathan Shingleton (58) was diagnosed with prostate cancer in 1997. Thankfully, due to the alertness of his GP, the cancer was in its early stages and a course of radiotherapy was successful in terminating its growth.

'It was a shock' recalls Jonathan. Diagnosis was made three days after his 51st birthday and two weeks before the birth of his son, Rupert. 'If I hadn't been booked to have a medical with my GP... If my GP hadn't decided to do a quick check of my prostate which wasn't a requirement of the medical... If the cancer had not been discovered until it become more widespread...'

Jonathan, a self-confessed workaholic, decided enough was enough. He decided to sell his business which he achieved in 1999 and set himself the goal of sailing the Atlantic.

Jonathan's objective is about to be realised this year. He has signed up for the Atlantic Rally for Cruisers which leaves Lanzarote in the Canaries for Antigua on 19 November. Now he is looking for crew. 'I have in mind crewing the boat with prostate cancer



Jonathan Shingleton

survivors/sufferers like myself and hopefully that way we can get some publicity and raise money for the benefit of the **Prostate Research Campaign UK**.

Anyone interested in joining Jonathan on his voyage and helping raise money can contact him at jpsingleton@aol.com. You need to be able to sail and you need to be able to be away for 4-5 weeks starting from mid-November. And for the yachties among you, Jonathan's boat is a brand new Oyster 47.

Better than PSA?

The search for a test that is better than the PSA test for detecting prostate cancers is hotting up.

A new blood test may provide a much more effective way of detecting early prostate cancer. Researchers at John Hopkins University in Baltimore found that the test for a blood protein called EPCA, early prostate cancer antigen, can spot the disease with a 94% accuracy rate. This promising result, albeit with a relatively low number of patients, is a lot better than one would expect from the PSA test.

Yet another line of research is based on a recently discovered gene PCA3 that has been shown to be over-expressed only in malignant prostate tissue. The company developing the new blood test has evaluated it amongst over 400 men and found it to be significantly more accurate than what is currently achievable with PSA screening

The widespread use of the PSA test has led to increased tumour detection rates, particularly among those at early stages of the disease. This has led to a clinical dilemma, since standard analysis of biopsy samples often cannot distinguish which tumours are going to spread and which are not. Many men live for years with slow-growing prostate tumours before they die of unrelated causes, and treating such patients could cause more harm than good. So finding a better way to determine which patients need aggressive treatment and which can try active surveillance has become a major challenge.

Magnetic resonance spectroscopy, which provides detailed information on the chemical composition of tissue samples, may be the answer. Researchers from Massachusetts General Hospital believe that it can determine a tumour's prognosis better than standard pathological studies. Now they wish to evaluate their techniques with a much larger sample of men.

All these new approaches show promise but all are some considerable way from clinical use. **Prostate Research Campaign UK** looks forward to seeing the results of larger trials. We hope they are successful and we shall certainly publicise promising results as they are reported.

BPH Research among Bangladeshis

Gillian Bentley is carrying out research, funded by the **Prostate Research Campaign UK**, into the prevalence of Benign Prostatic Hyperplasia (BPH) amongst Bangladeshi men. The study aims to compare five groups of men - Bangladeshis who arrived here as adults, those who came as children, those born here of Bangladeshi parents, men still living in Sylhet, Bangladesh and lastly, white, UK born men.

Gillian reports that, while some of the groups are still in the recruitment phase, some interesting results have emerged. Compared to published values of lower urinary tract symptoms among UK men, values do appear to be higher among Bangladeshi immigrants. About 10% of UK men over 50 report severe symptoms of BPH whilst among Bangladeshi men it is over 40%. The incidence of moderate to severe symptoms appears to occur at an earlier age as well (under the age of 40).

It remains to be seen whether these preliminary results are upheld in comparison with the reference group of



white men from whom Gillian is collecting data. They should be better matched for residential neighbourhood and socio-economic status.

Useful tips from supporters

Sir Bill Morris, past leader of the Transport and General Workers Union whose fund raising jog in Battersea Park



Vince (left) and Alwin Williams

raised £2,000 for the charity says 'I am very aware that the incidence of prostate cancer in the general population is on the increase, and today it has almost as much impact on the male population as breast cancer has on women. And statistics show that Afro-Caribbean men like me are disproportionately affected. The key to prevention is early diagnosis'.

Vince Williams, whose brother **Alwin** died of prostate cancer in 1997 reports 'I went to see my GP citing my brother's situation but he was very reluctant to agree to my having a PSA test. It was just as well I insisted because the PSA was 13.4. Six years after my operation the PSA is a comforting 0.1. It is clear that, where there is a family history of prostate cancer, other male members of the family can also be vulnerable. I would therefore urge that such men undergo PSA tests and not be put off by their GP. If there is a problem and it can be caught early enough, it can be dealt with and lives can be saved'.

Support group

Would any of our readers who live within 50 miles of Oxford and who would like to help set up a Support Group for those suffering from Prostate Cancer, and specifically the after-effects, please contact us

Fund Raisers

Our volunteer fund raisers continue to work wonders. We would like to say a huge **THANK YOU** to all of them and those who generously sponsor and support them.

Among our fundraisers were:

Guy Woodford who is in the middle of his three year project to walk from Geneva to the Mediterranean along the highest paths has now raised in excess of £46,500.

Ronald Hurren completed his Kilimanjaro climb last year. We are pleased to announce his final total of £15,349.

17 year old **Sarah Kennedy** with her friend, **Elizabeth Martin** supported her Dad by cycling 55 miles from Godalming to Portsmouth, raising £500.

Mike Hancock cycled from Beckley in Kent to Santiago de Compostela last year. His final total is just over £5,000.

Jane Dawoodi and **Bernard Wills** ran for us in the London marathon this



Jane Dawoodi and Bernard Wills show their finishing medals

year and we thank them both for their efforts before during and after the event. Together they raised in excess of £13,000

Will Rowson plans to cycle to Amsterdam with 22 others on September 22/23. He is also organising the *One Off Ball* on March 2 next year to benefit **Prostate Research Campaign UK**.

Mike Baker raised awareness at the Hayling Island Sailing Club by organising a pursuit race which also made a useful profit.

Malcolm walks the Pilgrims Way

Of his long walk from Winchester to Canterbury Malcolm Ridley writes 'The main news is that I made it without any blisters or broken limbs!! Although my legs were aching and my feet were very sore, it was a wonderful feeling finally to see the great Cathedral. I had walked 140 miles in 8 days, averaging 17.5 miles per day.

My son John and I left Winchester bright and early. The first two days, walking with John, were very hot and it was important to end the day with a long soak in the bath to restore aching joints. In fact this became an essential feature of each day of the walk. On Day 2 when we walked 19 miles, I made a quick recovery after my

host introduced me to arnica pills, which are very good at relieving stiffness.

I only had one afternoon on my own when I had to make my weary way past the paper mills and industrial grot of the Medway Valley. I had company the rest of the time; my wife Bridget, her friend Judy, Brian, a fellow cancer sufferer, a school friend Roger and on the last day my three daughters and my brother, Tom. I do not know how I would have coped without my walking companions who were all delightful.

It was an emotional time for me. I had

time to reflect on the good fortune I had enjoyed when my prostate cancer was diagnosed in time for a successful operation and the warmth of the people who have helped me when I needed it most. But the lasting memory will be of the people who made this walk possible. My family have been 110% behind me.



Malcolm Ridley and son, John setting out from Winchester

I have received encouragement from those who walked with me and gave me food and shelter on the way. And I have received an enormous boost from your generosity and all those who have given money to **Prostate Research Campaign UK**. Donations received and promised have already exceeded £20,000, before the charity has claimed back tax on those donations qualifying for relief. This is a wonderful result and I am very grateful to you and to all those who gave so generously to such an important cause.'

Duncan Miller is walking and cycling in the Alps on our behalf.

Andrew Kneen, who lives in Worcester, was offered hormone treatment after his PSA started to go up following radiotherapy. He explored alternatives and eventually had a salvage prostatectomy: two years on he is fit and well. He was recently asked to write a guide to walks in his area and decided to donate the fee to us – a very hefty £3,200 - as a practical way of showing his gratitude to those who saved his life. It will go towards saving the lives of others.

The **Rotary Club of Langley and Iver** hosted their annual charity golf day on June 9

at Richings Park Golf Club. 17 teams competed for the Mark Foley shield. **Prostate Research Campaign UK** was one of the beneficiaries of the day and received a cheque for £1,000 from organisers, Roy Bain and John Rees.

Paul Norris was fortunate to have his prostate cancer picked up by his cardiologist who was investigating his irregular heartbeat. Now after successful radiotherapy treatment he has embarked on a 750 mile backpacking venture from Northern France to Montpellier.

We hope this long list of committed people working hard for the cause may inspire others to follow in their footsteps.

Annual Luncheon

Our Annual Luncheon in the new setting of the Dorchester Hotel, Park



Lane, London is always a splendid occasion - full of fun, good food and good company. We are hoping that our Patron, Her Royal Highness The Duchess of Gloucester, will be present

so the demand is likely to be heavy. If you have not already booked your tickets don't delay.

The ticket price of £95 per person is an all inclusive, covering both the Reception which begins at 12.15pm and the Lunch itself at 1 pm - as well as wine at the table.

Auction lots donated so far include a portrait to be painted by Johnny Jonas, whose official 100th birthday portrait of The Queen Mother, is shown above. As Johnny supports just one charity a year we are fortunate indeed.

Events Diary

September 2 -11 2005

Walk the Wall

Our big fund raiser along Hadrian's Wall

October 19 2005

Dinner and Wine tasting

at the Vintner's Hall.

Organised by Tony Lea

October 21 2005

Annual Luncheon

at The Dorchester Hotel

Tickets £95

See our website for details

December 16 2005

Performance of Handel's Messiah

at Marylebone Church.

Tickets available from 3 October.

March 2 2006

One Off Ball

at Marriott Hotel London

Organised by Will Rowson.

March 12 - 19 2006

Hike for Hope

Jordan Desert Trek

from the Dead Sea to Petra

June 18 2006

Pants in the Park

Fun Run in Battersea Park

on Father's Day.

Xmas Messiah

On Friday 16 December 2005 The Sheldon Consort, formally The Wells Cathedral Chamber Choir, under the leadership of Rupert Gough will be performing Handel's Messiah at Marylebone Parish Church, Marylebone Road, London. Two renowned soloists,



St Mary the Virgin by the Bourne church (corrupted over time to Marylebone) where Charles Dickens and Lord Nelson once worshipped.

Richard Rowntree, tenor and Malin Christiansen, soprano will be performing for us.

A reception will be held in the Crypt before the performance. We are hoping that our patron Her Royal Highness The Duchess of Gloucester will attend.

Tickets will be available from Music Box on 3 October.
01272 349010

Walk the Wall

At present we have a good number of walkers registered for our Hadrian's Wall event, led by Professor Roger Kirby. We can accommodate more walkers each prepared to raise as much sponsorship as possible. There will be three groups arriving at Wallsend on 2nd, 3rd, and 4th of September to start walking a day later. Arriving, all being well, at Bowes-on Solway on the 7th to 9th and leaving the following day. Join any of these groups or come and walk for just one day.

Desert Challenge

Anyone who likes a challenge is invited to take part in a unique charity trek in Jordan called *Hike for Hope*.

Funds raised by the five-day hike from the Dead Sea to Petra will support the work of two charities - WellBeing of Women and **Prostate Research Campaign UK**.

So far 60 people are registered, including our chairman. We hope that 100 people from across the UK will join the doctors in the fundraising challenge which takes place from 12-19 March 2006. To take part you need to raise at least £2,500.

For further details:

email events@actionforcharity.co.uk or phone 01462 634646

Please contact us if you are interested in any of these events or if you are inspired to run your own.

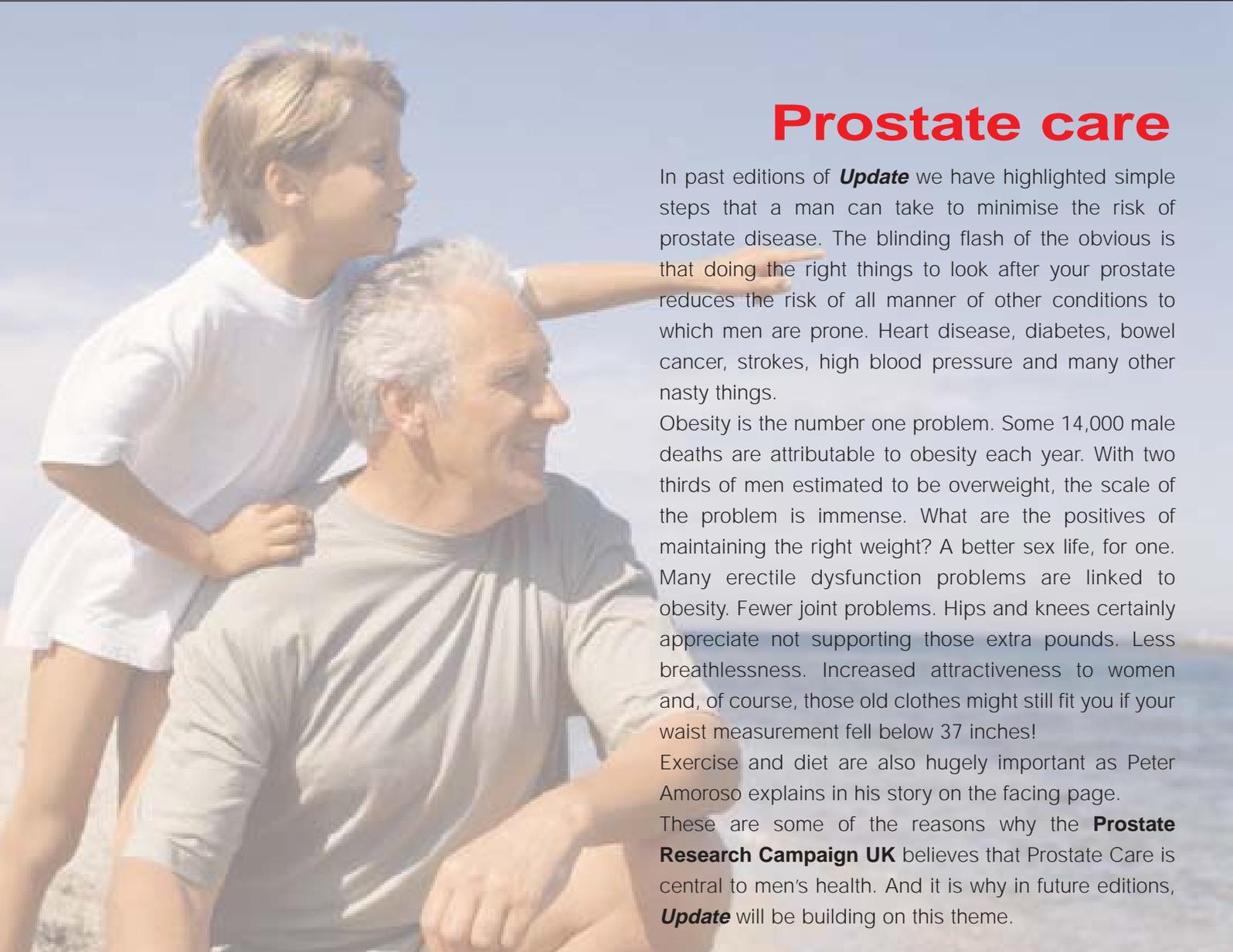
As always we need your support

Dinner & Wine Tasting

Tony Lea, a **Prostate Research Campaign UK** supporter is organising a Diner and Wine tasting in the Vintner's Hall on 19th October 2005 to raise awareness of Prostate Cancer. Five Winemakers from France will talk guests through the wines as they enjoy them. Tony is still looking for sponsors for programme, entertainment, flowers and auction lots. If you are interested in supporting Tony you can contact him at lea_tony@hotmail.com



Prostate care central to good health



Prostate care

In past editions of **Update** we have highlighted simple steps that a man can take to minimise the risk of prostate disease. The blinding flash of the obvious is that doing the right things to look after your prostate reduces the risk of all manner of other conditions to which men are prone. Heart disease, diabetes, bowel cancer, strokes, high blood pressure and many other nasty things.

Obesity is the number one problem. Some 14,000 male deaths are attributable to obesity each year. With two thirds of men estimated to be overweight, the scale of the problem is immense. What are the positives of maintaining the right weight? A better sex life, for one. Many erectile dysfunction problems are linked to obesity. Fewer joint problems. Hips and knees certainly appreciate not supporting those extra pounds. Less breathlessness. Increased attractiveness to women and, of course, those old clothes might still fit you if your waist measurement fell below 37 inches!

Exercise and diet are also hugely important as Peter Amoroso explains in his story on the facing page.

These are some of the reasons why the **Prostate Research Campaign UK** believes that Prostate Care is central to men's health. And it is why in future editions, **Update** will be building on this theme.

Poacher turned gamekeeper

Five years ago, weighing almost 19 stones and measuring 5 foot 9 inches I was not at my best! Aged 40 years, my waist was 44 inches, my chest 52 inches and my collar size 18 inches. As a doctor, my motto was *Do as I say not as I do!* It occurred to me one day as I puffed up one flight of stairs that I was not a good advert for my profession. A friend of mine, Frank Xavier, had recently been diagnosed diabetic. He was three years older than me and less overweight. His doctors encouraged him to ward off the diabetes by slimming down. As a hospital theatre orderly, Frank was setting a fine example to his consultant anaesthetist colleague (me). Enough was enough. I decided to shed weight and change my ways.



Lifestyle

The key to losing weight and keeping it off is *lifestyle*. I had to change my eating habits, the type of food, the timing of meals and the type of food consumed. I added exercise to my daily routine and I increased the amount of water that I consumed every day.



The saying *Eat breakfast like an emperor, lunch like a king and dinner like a pauper* is spot on. The body needs a kick start in the morning and a constant supply of energy through the day but does not need fuelling up at night.

Exercise

Exercise is essential. I recently asked a patient before surgery whether he could walk in the park for an hour or so without stopping. 'Why?' was his response. He had never done such a thing! You should aim to walk 10,000 steps each day. Not every one needs to train for the London marathon as I did but I recommend it to all the readers as a life enhancing experience and one that you will remember forever. After shedding seven stones and training for eight months I completed the 2002 Marathon in just over five hours. If I can do it, anyone can!

I have continued to maintain a steady weight of 12 stones for five years. I feel more energetic, happier and healthier than ever before. My measurements? 40 inch chest, 34 inch waist and 15.5 inch collar. Happy Living !

Peter Amoroso

You may be interested in past issues of **Update** touching on lifestyle and healthy eating. We found the following subjects (issue number in brackets). Tomatoes (3), Selenium (4), Vitamin D (9), Healthy eating (10), Beans (11), Brazil nuts (15), Herbs (19) and preventing prostate cancer (20). All can be found on the website or in back issues.

Healthy tip

Selenium is *the* essential trace element as far as the prostate is concerned. Although found in grains, nuts and oily fish, the average intake in this country is well below the recommended amount. Evidence suggests that a supplement of 200µg (not more) per day reduces cancer risk by a third. It is also thought that taking selenium as a supplement may delay the progress of disease amongst those who already have it. Ask for it at your local health food store.

Congratulations

Professor Roger Kirby, chairman of the **Prostate Research Campaign UK** Trustees has been awarded the prized St Peter's Medal by his colleagues in British Association of Urological Surgeons. The Medal is the highest accolade the Association can bestow, and is awarded annually for outstanding work in the field of Urology. The award is in recognition of Prof. Kirby's lifetime of dedication to work in the field of prostate disease and in acknowledgment of his fund-raising activities for **Prostate Research Campaign UK** and the British Urological Foundation, which raises money for kidney, testicular and bladder cancer. He says: 'Naturally, I am delighted by it, and very honoured to have my work acknowledged by my peers.'

Anthony Kilmister OBE



Photograph: BCA Films

We reported on our President's well merited award of an OBE in the New Year Honours List. Now we have great pleasure in publishing the picture of Her Majesty The Queen presenting the award to Tony.

Support needed

Dr P Ambikapathy, a GP at Chadwell St Mary, Thurrock is training for the Windsor Half Marathon on 25 September 2005. He recently underwent surgery for prostate cancer. He will be running for



the **Prostate Research Campaign UK** and seeks the support of his colleagues and others in order as he says 'to promote cancer awareness and encourage further research into prostate cancer that has been sidelined for a long time'. Why not call him on 07956 394062 to sponsor him?

Recommend our Web Site

For trustworthy advice on all prostate diseases

www.prostate-research.org.uk
www.prostatecare.org.uk

Green light for green light laser

The National Institute for Clinical Excellence (NICE) has already approved the use of Holmium laser surgery for carrying out prostatectomies. It has now approved the use of a different laser (wave length 552 nm rather than 2100 nm) for carrying out operations to relieve the symptoms of Benign Prostatic Hyperplasia (BPH). This shorter wavelength KTP laser light is often referred to as *green light*.

BPH is a non-malignant disease of the prostate which may lead to gland enlargement that can cause prostatic obstruction. This obstruction can be managed medically or surgically. The gold standard surgical treatment has for many years been transurethral resection of the prostate (TURP). However, the relatively high morbidity for TURP has driven the development of less invasive techniques.

Green light laser vaporisation involves the insertion of a small flexible fibre-optic tube into the urethra. Light pulses are then sent through this fibre *vaporising* and removing the prostatic obstruction. The procedure can be conducted in an outpatient setting, and takes little more than half an hour.

Prof. Roger Kirby is one of the first surgeons in the country to use *green light* laser to treat BPH. He is also currently installing a £1.5 million robotic assistant to help him operate on his patients. The treatment is already available to NHS patients at Guys and St. Thomas' Hospital in London.

'Using laser surgery minimises bleeding and means that patients who suffer from non-cancerous prostate disease can be in and out of hospital in 24 hours, instead of almost a week as they would be using conventional surgery,' he says. 'The robot will minimise blood loss and ensure a much happier outcome and faster recovery for prostate cancer patients.'

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