

Our gift to new radiotherapy unit

A big occasion and a big cheque – a very big cheque. The occasion was our annual meeting on April 13 and the cheque was our contribution to the Norfolk and Norwich Hospital's Targeted Radiotherapy Appeal.

In fact, it was a joint cheque combining our donation of £20,000 and the £30,000 raised by the Brundall Cancer Community Chest towards the cost of equipment for treating prostate cancer.

And we gave the honour of presenting the cheque to someone who plays a leading role in both organisations – Adrienne Capp, one half of our welfare team and trustee and shop committee chairman of the Community Chest.

The cheque was received on behalf of the N&N by the hospital trust chairman, John Fry. Also present was Daniel Williams, chief executive of Big C which has contributed £50,000 to the appeal.

Between the three charities we have raised 18% of the £600,000 needed to build and equip the new brachytherapy unit. It will mean that men can receive the treatment locally instead of having to travel to London or Cambridge.

Our chairman, Noel Warner, said: "We were delighted to be involved with the appeal from the beginning and to make a difference. Our group continues to raise awareness of prostate cancer and is determined to provide support and help to those living or diagnosed with the disease."

So, what is brachytherapy? Alison Vinall, head of radiotherapy physics, writes:

Brachytherapy is the insertion or implantation of radioactive sources into or close to a tumour for the purpose of treating the cancer over a short distance (from the Greek word "brachy" meaning "short"). With high-dose-rate (HDR) prostate brachytherapy we will be using a high activity iridium source on the end of a long wire to treat the prostate.

The process involves first inserting needles into the prostate under ultrasound guidance. The patient will then be taken to the CT scanner in the department to image the needles in position and these scans will be used to plan the dwell positions of the source and the times that the source will stay at each dwell position, in order to build up the dose distribution around the prostate "from the inside out".

This type of treatment will help to improve our efficiency by enabling some patients to have fewer attendances, may help to reduce some of the side-effects of prostate radiotherapy, and enable us to give higher doses with the possibility of improving cure rates.

We are enormously grateful to all three charities involved for enabling us to purchase equipment which includes the ultrasound unit and transducer, so that we can provide this additional treatment technique within the department.



Presenting the £50,000 cheque. From left: Alison Vinall, head of radiotherapy physics, John Fry, hospital trust chairman, Adrienne Capp, welfare officer and Community Chest trustee, chairman Noel Warner, and Big C chief executive Daniel Williams

Dave's second chance

We make no apologies for devoting much of this issue to an article by our treasurer, Dave Kirkham, because it is a story full of hope and with a powerful message. Dave was first diagnosed in 2007 with aggressive prostate cancer. Conventional external beam radiotherapy was his only hope but by 2013 it had failed and his PSA was rising. He was, however, lucky enough to qualify for salvage treatment and to be referred for HDR brachytherapy, very much a second chance in the last chance saloon.

Three Journeys

The talk at our next open meeting will be the prostate cancer journeys of three of our members:

- David Paull – radiotherapy, hormone therapy, abiraterone, chemotherapy, etc.
- Dave Kirkham – hormone therapy, radiotherapy, salvage brachytherapy (see his story in this issue).
- Chuck Lyons – prostatectomy, salvage radiotherapy, hormone therapy.

There will be Q&A after the three presentations, followed by refreshments.

Monday 1 June at the Benjamin Gooch Theatre, East Atrium, NNUH from 7pm to 9pm.

Another chance for Dave

I was first diagnosed back in 2007, at the tender age of 54, with an aggressive variant of prostate cancer. At the time my options were extremely limited. The cancer at Gleason 9 was too aggressive for surgery. Furthermore at T stage 3, it was advanced, pressing against the edge of the capsule, and just to make matters worse I had swollen lymph glands.

I consider myself fortunate to have been put under the care of Mr Edwin Ho. He pulled no punches and told me what I needed to know. Gleason 9 was not good, and he told me I was likely to die of prostate cancer. However, he said he would do his best to confound nature, and I have to say it is a case of so far so good. Eight years on, and under his stewardship, I am still surviving.

I was put on hormone therapy, I had my pelvic lymph nodes dissected, and then had to nip in and out of hospital dealing with post-operative infections, so all in all 2008 was a fun year.

However, hope springs eternal and after that year of tests the doctors finally agreed that I could have radiotherapy as a curative treatment. I was, of course, overjoyed but at the same time I realised that I was lucky. This really was the last chance saloon. I was referred to Dr Gaurav Kapur, and told that I could only have radiotherapy once. If in later years I developed bowel cancer or bladder cancer, it would be too bad, because the risks of collateral damage to healthy tissue were too great. You could only ever have the one blast of radiotherapy below the diaphragm.

I had my external beam radiotherapy in January 2009. All went well, the side-effects while unpleasant weren't as bad as I feared. My radiotherapy had been given alongside three years of hormone therapy, so it was not until January 2011 that I had my last shot of Zoladex.

During 2011 and 2012 I started to slowly recover from the hormone therapy, my muscles got stronger and I regained a bit of vigour. My PSA bumped along at 0.8, 0.6, 1.8, 1.4, well within the target I had been given of keeping PSA under 2.5 in the first two years.

I really did start to believe that I had been cured, but as we all know, pride goes before a fall, and in 2013 my PSA started to grow: 2.0 in January, became 3.6 in March, so I breathed a huge sigh of relief when it dropped back to 2.6 in May. But by September it was 4.9, and by November 6.1.

It was at that time that the doctors called me in and put me back on hormone treatment – no longer curative, I was now firmly in the palliative camp. While I asked about all sorts of new treatments I had heard about or seen on the Internet, my doctors were gently suggesting that I should focus less upon miracle cures and direct my efforts into enjoying the time I had left.

I did however write to Mr Ho, a polite letter asking whether I might be suitable for some of the latest treatments I had read about such as cryotherapy or cyberknife.

This led to an appointment with Dr Kapur, who referred me to Professor Hoskins at Mount Vernon hospital in Hertfordshire for salvage high dose rate brachytherapy.

I had to go through all the usual tests, MRI scans, bone scans etc, but once they were sure that my cancer was still contained within the prostate gland I qualified for the HDR Brachytherapy, only the second patient referred from Norfolk.

The first phase of this is a template biopsy, which involves a three-day stay in hospital, while they drill a series of holes into your prostate in a grid pattern.



(It is like the game of Battleships we used to play as kids, complete with the A1, B2 grid.)

Fortunately, this is performed under a general anaesthetic, but you awake from the biopsy with intravenous drip and a large bore catheter still in place. It took me several weeks of convalescence to regain full composure.

A few weeks later it was back to Mount Vernon for the actual brachytherapy. To some extent this was a repeat performance, and you are again anaesthetised while they insert the matrix of tubes into your prostate. However, they need you to be conscious for the treatment, so I awoke lying on a trolley, legs akimbo, and spent the afternoon being wheeled around the hospital. Firstly they need to be sure the matrix is in exactly the right position, so it's an MRI scan which needs metal marker rods inserted into the matrix. Then for the actual brachytherapy a series of tubes are attached, and radioactive rods are passed in and out of the prostate. It was all quite painless. I kept drifting in and out of consciousness, and I was back on the ward in time for supper.

That is about it. We won't know whether this salvage treatment has been a success until next year or the year after. I do however draw the following points from my treatment.

Firstly it pays to do as much research as you can, read all that you can, and gain as much knowledge as you can, from books, papers and the Internet.

This allows you to understand your treatment, and ask pertinent questions. For example, when my PSA rose in 2013, had I been an ignorant and acquiescent patient, I would have been consigned to hormone therapy on a palliative basis. However, because I had read up on cryotherapy and cyberknife, this allowed me to ask relevant questions about salvage treatment, which in turn led to my referral to Professor Hoskins and the HDR Brachytherapy.

...and a powerful message

Personally, ten years ago I was in a mess. A long marriage had ended in divorce, I was at a loose end, drinking and smoking far too much, and unbeknown to me prostate cancer had already kicked in.

I was fortunate enough to meet a new woman, who turned my life around and amongst other things got me on to the books of a new GP. She quickly identified my prostate cancer, referred me to Mr Ho and there is no doubt that the first blast of radiotherapy almost cured me. Seven years on and I am once again privileged to get an extra blast of radiotherapy, this time HDR Brachytherapy as a salvage operation.

We don't know whether it will work, but potentially it will give me another few years of life. The highlight of the last year was seeing my granddaughter star as Mary in her school's nativity play. Without the initial treatment I wouldn't have lived long enough to see it. Now I have had salvage treatment, I have a second drink in the last chance saloon, and who knows I may yet live long enough to see her or her brother graduate or get married.

The moral is that it pays to know about treatment options and politely ask pertinent questions.

Dave Kirkham

A vaccine to prevent recurrence?

A vaccine to help prevent the recurrence of prostate cancer is being tested at the US National Cancer Institute on 70 men who have had conventional treatments but whose PSA is rising again.

The vaccine is designed to teach the immune system to recognise compounds found in prostate cancer cells. It is made from pieces of a protein called TARP that is found in about 95 per cent of prostate cancers. The thinking is that the vaccine will prime the immune system so that it creates antibodies when it detects TARP-related cancers. Then, should the cancer reappear, the antibodies will be dispatched to attack the malignant cells. The antibodies, along with other immune cells, can then destroy cancer cells without harming non-cancer cells, so minimising side-effects.

Professor Raj Persad, urology consultant at the Bristol Urological Institute, said that the idea of boosting the body's own immune defences was an "excellent strategy" for preventing recurrence of the disease. "Toxicity studies will have to be done and then clinical effectiveness studies are needed ... but the research looks very promising indeed."

Sniffing out cancer

The sensitive noses of dogs could be a life-saver. They can detect prostate cancer in men almost every time.

In an Italian study, two German shepherd dogs sniffed the urine of 900 men – 360 with prostate cancer and 540 without – and got it right in about 98% of cases.

The dogs are able to detect specific volatile organic compounds in the urine but the researchers are still unsure of how a dog would perform in daily practice.

The results echo similar research by Dr Claire Guest, co-founder of Medical Detection Dogs, a Buckinghamshire charity, who said of the Italian research: "These results are spectacular. They offer us further proof that dogs have the ability to detect human cancer.

"It is particularly exciting that we have such a high success rate in the detection of prostate cancer for which the existing tests are woefully inadequate."

Dr Guest said there was "a reluctance to embrace this tested, time-old technology" but dogs could pick up a scent in a dilution of one to a thousand parts.

"Over the years, millions of pounds of NHS funding has been poured into the traditional test methods and yet there has been little improvement in their reliability," said Dr Guest.

"This has caused a huge waste of resources, not to mention the distress to impacted individuals. Moreover, the detection dogs provide an alternative solution that yields consistently accurate results. If our detection dogs were a machine, there would be a huge demand for them."

A good place to live

East Anglia has one of the highest five-year survival rates in the UK for prostate cancer patients.

Figures released by the Office for National Statistics show that 83.1% of patients in the region are still alive after five years.

That compares with the worst areas, Derbyshire and Nottinghamshire at 70.9%, South Yorkshire and Bassetlaw at 72.2%, Kent and Medway at 74.5% and Devon, Cornwall and the Isles of Scilly at 76.0%.

The best-performing region is Birmingham and the Black Country at 86.3%.

Drug test implant

An implant no bigger than a grain of rice could be injected into a cancer tumour to make chemotherapy more effective.

Researchers have developed a device which can carry up to 30 different cancer drugs into the heart of a tumour to tell doctors which will work best.

The implant is removed with a tumour sample after 24 hours and analysed to establish which drug will be the most effective. It has worked on mice and scientists plan to launch a clinical trial with cancer patients next year.

The research was published in the journal *Science Translational Medicine*.

New centre is just Champion!

A new £19million research centre has been opened within a stone's throw of the Norfolk and Norwich University Hospital – and it will mean a major boost for the study and treatment of prostate cancer. The centre, opened by and named after top jockey and cancer survivor Bob Champion, whose charitable trust contributed £750,000 towards the cost of the centre, will bring medics and researchers together to work on diseases such as cancer and bone degeneration.

A significant feature of the unit is that it is creating greater collaboration between researchers and students at the University of East Anglia and the N&N. "We have brought together important groups that were disparate," said Professor Bill Fraser, who is leading the bone research unit. "We have scientists working with clinicians and it also means we can provide better opportunities for graduate students."



Professor Colin Cooper

The prostate cancer research is being led by Professor Colin Cooper, cancer geneticist at Norwich Medical School. He said he hoped that the involvement of Bob Champion would bring the work being done to combat age-related diseases to the public's attention.

He said there were only two genome research centres of this kind in the UK – the Sanger Institute in Cambridge and Norwich Research Park. "There are all these jewels in the crown here – the John Innes Centre, the Institute of Food Research, the Genome Analysis Centre, the Sainsbury Laboratory – and now this new unit."

It was, he said, important that they worked more with each other to get the message out to the public.

Professor Cooper said that this was the age of genome – "I decode the DNA in cancer." He said that patients in the UK were currently being given the same treatment for prostate cancer – hormone withdrawal – no matter how different they were genetically. But everyone's genes were different. The work they were doing would enable them to find out the drugs that worked best for certain genes. The future was personalised treatment.

Breast cancer risk

Women who have a father or brother with prostate cancer are at greater risk of developing breast cancer, according to an American study. Scientists believe both diseases are caused by the same inherited faulty gene.

The study of 78,000 women over a 16-year period showed that those with a first-degree male relative were 14% more at risk of developing breast cancer but the risk rose to 78% if their mother or sister also had breast cancer.

Dates for your Diary

Wed 6 May and 3 June... 5.30-7pm

Radiotherapy Department

Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C.

Call 01603 288779 to book.

Mon 1 June... 7-9pm

Open Meeting at Benjamin Gooch Theatre, NNUH

"Three Journeys"

Three of our members describe their individual prostate cancer journeys, discussing their symptoms and treatments.

followed by

Questions & Answers

For him the risk is greater

In its remoteness from the great conurbations, Norfolk is home to relatively few black men but if you happen to have one among your friends and family you can do him a big favour by pointing out that black men are about 35% more likely to die from prostate cancer than white men – but they are less willing to be tested.

Researchers at Exeter, Bristol and University College London found that only 44% of black males deemed to be at low risk opted for investigation compared with 91% of white males. Overall, 94% of white men agreed to be investigated but only 70% of black men. Tanimola Martins of Exeter University medical school who led the study said: "GPs should be aware of the reduced appetite for testing in black males, which may be linked to fear and a perception that treatment may lead to severe complications."

How to Contact Us

Specialist Nurses:

Sallie, Wendy, Helen & Rachel

NNUH

01603 289845

Angie, Wendy & Simon

James Paget

01493 453510

Sally, Clare & Anne-Marie

QEH, King's Lynn

01553 613075

Lizzie, Macmillan Info & Support Radiographer

01603 289705

Help or Advice – Our Welfare Team:

We have over 30 members available to help.

There is probably one near you.

For more information please call our Welfare Team, David and Adrienne Capp, on 01603 712601

E-mail us:

Noel Warner, Chairman, noel.windfall5@btinternet.com

Letters to the Editor:

David Paull, Editor, DavidLPaull@aol.com

Visit our website:

www.prostatesupport.org.uk