

Keep taking the steroids

Are the steroids some of us are given as part of our treatment potentially harmful because they can lead to drug resistance in cancer cells?

After some rather scary reports in national newspapers, the Institute of Cancer Research and Prostate Cancer UK have put the record straight.

Researchers found that some treatments, while initially effective at controlling prostate cancer, not only stop controlling the disease but actually start driving tumour growth. They showed that use of glucocorticoids – steroid drugs often given alongside hormonal therapy – coincided with the emergence of mutations that resulted in the drug becoming an activator of the disease rather than an inhibitor.

The findings suggested that in future men with advanced prostate cancer could be carefully monitored for circulating tumour

DNA, allowing doctors to spot the emergence of dangerous mutations and alter treatments before they drive the disease into more aggressive forms.

The vital message from PCUK: "This is early stage work and men should not stop taking any treatments as a result of these findings. In particular, glucocorticoids are widely used with much success in a large number of men. Men with advanced prostate cancer that is progressing who are taking steroids and are worried about these results should speak to their oncologist. The most exciting aspect of this work is that it suggests that analysing circulating DNA from tumours could be used to personalise treatment based on how each man's cancer develops."

Study leader Dr Gerhard Attard said: "In future we hope to routinely monitor genetic mutations in patients with advanced disease

using just a blood test, enabling us to stop treatments when they become disease drivers and select the next best treatment option. We need to confirm these findings in larger numbers of patients but using these types of blood tests could allow true personalisation of treatment."

Professor Paul Workman, head of ICR, said: "Drug resistance is the single biggest challenge we face in cancer research and treatment, and we are just beginning to understand how its development is driven by evolutionary pressures on tumours. This important discovery reveals how some cancer treatments can actually favour the survival of the nastiest cancer cells, and sets out the rationale for repeated monitoring of patients using blood tests, in order to track and intervene in the evolution of their cancers."

Dame Mary's survival story

Dame Mary Archer will be the speaker at our next open meeting on Monday, December 1 (7-9pm), in the Benjamin Gooch Theatre at the Norfolk & Norwich University Hospital. Her subject: "My battle with cancer", and she will be telling us how she underwent major surgery for bladder cancer at Addenbrooke's Hospital, Cambridge.

It is a hospital she knows well. For 20 years until 2012 she was a director of the Cambridge University Hospitals NHS Trust (formerly Addenbrooke's), the last ten as chairman.

As a scientist, she is a specialist in solar power conversion. From 1988-2000 she chaired the National Energy Foundation which promotes improving the use of energy in buildings, and is now its president.

She lives with her husband, author and politician Jeffrey Archer, at the Old



Vicarage, Grantchester, once the home of the poet Rupert Brooke, and is patron of the Rupert Brooke Society.

A sweet solution?

You couldn't make it up. Pectin, the substance that makes jam thick, could be a radical new treatment for prostate cancer. Pectin, which is found in the skin of apples, oranges, plums and berries, has been shown to reduce the size of tumours by blocking the effects of a harmful protein called galectin-3. Israeli researchers are testing a powdered form of the carbohydrate on 60 men whose cancer has returned after treatment and will monitor their PSA levels for six months. Just eating the jam won't help because it contains a lot less pectin!

Come and join us

It's time for our Christmas lunch once again and we look forward to your company. It is on Thursday December 11. The cost is £16.50 for a two-course lunch. For details, see back page.

Ton-up in the search for genes

Scientists now have a better understanding of the inherited risk of prostate cancer after an international study identified another 23 genetic variants associated with increased risk of the disease.

The study brings the total number of common genetic variants linked to prostate cancer to 100 and testing for them can identify the one per cent of men with a risk of the disease almost six times as high as the population average.

Scientists at the Institute of Cancer Research and in Cambridge and California led a huge search for the new variants involving almost 90,000 men and for the first time combining populations with European, African, Japanese and Latino ancestry.

The research was jointly funded by Cancer

Research UK, Prostate Cancer UK, the EU and the National Institutes for Health in the USA.

Researchers found that assessing the top 100 variants identified ten per cent of men with a risk almost three times as high as the population average and said that this was high enough to investigate whether targeted genetic screening was merited. They intend to lead a new clinical trial to test whether genetic screening can be effective.

In European men, scientists had previously found 77 genetic variants which were known to increase the risk of prostate cancer.

Dr Matthew Hobbs, deputy director of research at Prostate Cancer UK, said: "There's no doubt that genetic testing for prostate cancer is an exciting area of

research. The results of this study could take us a step closer to targeted screening by allowing us to identify those most at risk of the disease, based on the genes that they possess. However, this is not the end of the story and the challenge now lies in translating this knowledge into a reliable test that can be used on a large scale through the NHS to find those men at highest risk.

"It is also absolutely vital that researchers build on this work to discover which of these genetic variants can tell us whether a man's cancer is aggressive and likely to go on to kill him, or one that may never cause any harm.

"This would save those men with non-aggressive disease from undergoing unnecessary treatment."

Terry the Trouper

Look! It's Marlene Dietrich! No, it's not. It's that great entertainer Terry Chappelle in one of his favourite rôles.

Terry may be 80 and a long-term prostate cancer patient but that didn't stop him strutting his stuff for the second year running in a revue in aid of our group and raising another £1,000-plus on top of the £1,250 he raised last year.

All the money will go to the N&N's Targeted Radiotherapy Appeal.

In the show called "Sing As We Go" which he also produced and directed, he and his team brought back to life singing stars including Gracie Fields, with Vera Lynn also making an appearance.

Terry said: "The show was about the Second World War and the Blitz and how people kept up their spirits with songs. It was a very merry show which people seemed to very much enjoy. This is not surprising with so many people now into 1940s events.

"It was somewhat physically demanding for me as I didn't just leap from costume to costume, but from gender to gender.

"I wanted to give something back to the cancer charity, having had prostate cancer myself, and I wanted to make it easier for other people. Unfortunately it is sometimes a silent disease that just creeps up on you."

In paying tribute to Terry, our chairman, Noel Warner said: "Terry is quite incredible, with his boundless energy and having such a wonderful talent to entertain. I am truly amazed how, at his advanced age, he does it all.

"Terry has fought and won his own prostate cancer battle and now dedicates himself to helping others with the disease. What a great inspiration he is to others. Terry has told us that he is already making plans for a third show next year."



The cost of staying alive

A man who has been refused the "last resort" drug Enzalutamide and is spending £100 a day to get it privately has some harsh words to say about the bureaucrats and administrators who have left him in what his oncologist calls "an Orwellian nightmare".

Peter Smith, a 74-year-old Open University associate lecturer from Teeside, was diagnosed with prostate cancer ten years ago and went through the usual treatments ending with Abiraterone. When that stopped working, the next option was Enzalutamide but the NHS and the Cancer Drugs Fund will not pay for it for any patient who has already had Abiraterone.

The experts claim that there is not yet sufficient evidence that Enzalutamide is effective in that situation. But, as Peter points out, he is living proof that it is because he is feeling well and able to work and pay taxes! And so is Hugh Gunn, treasurer of the Prostate Cancer Federation, who joined Peter in a discussion with Adrian Chiles on BBC Radio 5 Live.

The Cancer Drugs Fund was set up in 2010 to pay for treatments that are seen as not cost-effective enough to be prescribed on the NHS but can prolong life, if only for a matter of months and at considerable cost. The fund has already helped 55,000 people but it is a victim of its own success. It spent £200,000 last year, and will be spending £280,000 in each of the next two years, and is having to refuse more and more applications.

Peter says that NICE should review its stance on Enzalutamide and NHS England and the Cancer Drugs Fund should look at their processes and procedures. "I have been really quite upset about the lack of transparency and openness. They are not patient-friendly," he says. He is horrified by the extraordinary language they use in letters and communications. He appealed when he was refused funding. The response was "most unfriendly" and in convoluted language that was almost untranslatable. His only course was to buy the drug - £3,000 for 28 days, even after haggling a small discount. By the time of the Radio 5 Live programme he had already spent £15,000 and will run out of money unless he sells his house.

He argues that everyone should initially be given the drug on the NHS, then the situation should be reviewed after only two months because the evidence is that, if it is going to be effective, it works very quickly. His PSA dropped by two-thirds in 25 days. The alternative is that those who are being refused the drug will go on to chemotherapy which is more expensive and has unpleasant side-effects, then they will go into hospital for palliative care which will be even more expensive.

NICE, the NHS and the Cancer Drugs Fund declined invitations to appear on the programme.



Hair today ...

Once upon a time, Howard Gardner had a full head of hair – lots of it. And then he didn't! As his wife Johanna put it, he was "volunteered" by three friends to have it shaved during the Worstead Festival.

The friends donated £50 each to a charity of Howard's choice – cheap at the price, one would have thought.

Howard, who lives at Westwick Road, Worstead, went on to raise a total of £1,250 of which he gave £800 to BreastcancerCare and £325 to our group.

On top of that his employer donated £500 to prostate cancer research.



"Crime" does pay!

Insult the club president? That's a £1.00 fine. If you argue, we'll double it. Wrong tie? Another £1.00. You're quibbling? Make it £2.00. And the fines mount up. By this light-hearted penalising of (mostly deliberate) misdemeanours, the North Sea Petroleum Golf Association, based at Gorleston Golf Club, has raised the astonishing sum of £100,000 for charity in ten years.

The association holds weekly golf matches during the summer and each is sponsored by a company servicing the offshore industry.

When it came to the turn of association member Donald Blair, managing director of Beccles-based Aquablast, to be the sponsor, the choice of charity was an easy one because he is one of us – a prostate cancer patient but fortunately being treated successfully, so it hasn't stopped him playing golf.

At our October meet and chat evening, Donald presented chairman Noel Warner with a very welcome cheque for £1000 - £500 from fines during the match day, topped up with £500 from association funds.





**Two Course
Traditional
Christmas
Lunch
with coffee
£16.50 per head**

**We invite you to join us at
NORFOLK & WAVENEY
PROSTATE CANCER
SUPPORT GROUP'S**

Christmas Lunch

THURS. 11th. DECEMBER

(12.30 for 1.00 pm)



*To obtain your tickets complete
& mail the Order Form below*

Dates for your Diary

Mon 1 Dec. 7-9pm

**Open Meeting at Benjamin
Gooch Theatre, NNUH**

**Dame Mary Archer DBE
"My battle with cancer"**

Wed 3 Dec and 6 Jan. 5.30-7pm

**Radiotherapy Department
Open Evenings, Big C & Colney Centre,
NNUH. Meet at Big C.
Call 01603 288779 to book.**

Making a point

Is your index finger shorter than your ring finger? That might account for why you are now reading this newsletter!

Scientists at Warwick University and the Institute of Cancer Research compared the hands of 1500 prostate cancer patients with 3000 healthy men and found that men with index fingers longer than their ring finger had a significantly lower risk of the disease.

Studies have shown that babies exposed to a surge of testosterone towards the end of pregnancy can end up with a ring finger longer than their index finger.

Reduced exposure to testosterone in the womb might have protected babies against a future risk of cancer – but the scientists don't appear to have come up with an answer.

If members would like to make a donation to the group, go to our website page:- www.prostatesupport.org.uk.

Click on the link to www.mydonate.com and make your donation.

To: R. Cossey, 73 Blofield Corner Road, Little Plumstead, Norwich, NR13 5HU

Please send me.....tickets for the Christmas Lunch, on Thurs. 11th. December, at Costessey Park Golf Club. I enclose my cheque for £.....


(Make cheque payable to 'Norfolk & Waveney Prostate Cancer Support Group')

Please include a stamped & addressed envelope

Name _____

Address _____

Post Code _____ Telephone No. _____



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- **Help or Advice – Our Welfare Team:**
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