

## New drug approved – but will we get it?

Yet again the National Institute for Health and Care Excellence (NICE) has changed its mind on the latest drug treatment for advanced prostate cancer – and left us in limbo!

NICE has issued final draft guidance stating that men with hormone-relapsed prostate cancer that has spread to other parts of the body (metastasis) should be given access to Enzalutamide through the NHS after they have undergone a course of chemotherapy with Docetaxel. The ban on men receiving Enzalutamide if they have already been treated with Abiraterone appeared to have been dropped after NICE was presented with a petition signed by 13,500 people, including a number of our members.

But in a statement announcing the change NICE says that studies showed that a proportion of patients might benefit from treatment with Enzalutamide after Abiraterone but there were too many uncertainties in the evidence and it was therefore not possible at this stage to make a recommendation on clinical and cost effectiveness. "Therefore the use of

Enzalutamide in this context is no longer covered by this guidance" – a statement that has left even the experts baffled.

Professor Carole Longson, director of NICE's centre for health technology evaluation, commented: "We now know that, at the moment, evidence on the effectiveness of Enzalutamide when given after Abiraterone is too uncertain to make a definitive evidence-based recommendation, so we have not done so. We know that the manufacturer is currently collecting data ... and we look forward to seeing the results of the ongoing trials."

NICE says that, until final guidance is issued, NHS bodies should make decisions locally on funding.

Owen Sharp, chief executive of Prostate Cancer UK, said: "We are pleased that overall Enzalutamide has been approved in England and Wales and that the long-contested blanket restriction around use after Abiraterone has been lifted. By removing the outright ban, NICE has stated that there is no clinical reason for Enzalutamide not being prescribed after Abiraterone.

"However, we are not currently clear as to what this ruling will truly mean in reality for the men across the country who have exhausted all other options and are grappling with the final stages of this cruel disease. The bottom line is: Will these men be given the potential of extra time with their loved ones or not?"

"We strongly expect that after eight long months of dithering NICE has done the right thing, and that men across England and Wales can access this vital drug now. If it transpires in reality that this is a de facto restriction thinly veiled by complex prose, we will be holding relevant parties to account and will continue our fight to ensure men are not denied Enzalutamide after Abiraterone."

- One of our members who was being treated with Abiraterone and is about to start chemotherapy at the NNUH has been told that, as things stand, he will not be eligible for Enzalutamide post-chemotherapy because the hospital's current interpretation of the NICE guidance is that the ban still applies.

## And for short?

There's a clinical trial under way under the acronym Stampede. It stands for – take a deep breath – Systemic Therapy in Advancing or Metastatic Prostate Cancer Evaluation of Drug Efficacy. You could do quite a lot of research in the time it took to work that one out!

### Terry on song again

Last year fellow prostate cancer patient, octogenarian Terry Chappelle, staged a highly entertaining, sell-out show at Sheringham in aid of our support group. Terry and his friends are promising an equally entertaining evening this year on Saturday, September 13, again in Sheringham,

There are only 150 tickets and, like last year, we expect it to be a sell-out. See the advertisement on page 4 for details as to how you can obtain your tickets for "Sing As We Go".



*A day at the Bishop's Garden – see inside...*

# Diet and lifestyle after prostate cancer

Professor Robert Thomas, consultant oncologist at Bedford and Addenbrooke's Hospitals and professor at Cranfield University, spoke at our June meeting about how we can help ourselves by the way we eat and live after we are told that we have prostate cancer. Here is a summary of his advice:

Exciting new evidence has revealed more proof that lifestyle can influence the course of prostate cancer and help with many of the side-effects of cancer treatments:

**Exercise:** 30 minutes a day or 3-4 hours a week reduces fatigue, improves mood, psychological well-being and body composition – and any level of exercise is better than none. Other trials have linked exercise with a reduced rate of PSA progression and risk of relapse.

**Diet:** Two large studies have linked colourful fruits, berries, tomatoes, beans, pulses and legumes with a lower risk of prostate cancer. The Ornish study showed that a healthy diet and exercise regimen slowed PSA progression.

**Mineral and vitamin supplements:** Some studies actually showed an increased prostate cancer incidence with vitamin E, selenium and zinc despite deficiencies being linked to an increased risk. This prompted development of an online testing service which measures blood micro-nutrient levels, then provides bespoke dietary advice ([www.cancernet.co.uk/nutritional-tests.htm](http://www.cancernet.co.uk/nutritional-tests.htm)). Prof. Thomas is editor of the website.

**Whole food supplements** are a convenient method to boost daily polyphenol intake. The largest completed evaluation of their benefit was the UK's Pomi-T study, sponsored by the charity, Prostate

Action. Two hundred men, with prostate cancer managed with active surveillance or experiencing a PSA relapse following radical interventions, were randomised to receive, blind, an oral capsule containing pure pomegranate, green tea, broccoli and turmeric, or placebo. The full presentation at the American Society of Clinical Oncology conference was seen as a major breakthrough for nutritional research because there was a 64% reduction of PSA progression which was linked to disease status seen on MRI.

The research committee are now working with the Institute of Preventative Medicine to evaluate its impact on other stages of prostate cancer and symptoms including joint pains, tinnitus and prostatitis. To aid the calculation of PSA doubling time in response to lifestyle interventions, an "app" has also been developed – available on the iPhone app store (PSAcal). There is also a helpful website about Pomi-T which links to all its publications ([www.pomi-t.com](http://www.pomi-t.com)).

■ Prof. Thomas is the author of a very helpful book, *Lifestyle and Cancer – The Facts: Learn how to live stronger for longer*. We have a supply of copies of the revised 2011 edition to give, free, to members who might find it helpful to take a close look at their exercise and diet regime – or lack of it!

## Men who are 'ticking timebombs'

Four out of five men at higher than average risk of prostate cancer aren't aware of their risk and are therefore not having the vital conversations with GPs that could save their lives, according to new research commissioned by Prostate Cancer UK. This could mean that thousands of men may miss out on being diagnosed at an early stage when treatment for the disease is most effective.

The majority of early cases are symptomless and a lack of accurate tests for life-threatening forms of the disease means there is no national screening programme. As a result, awareness of risk and speaking to a doctor about it is a man's main defence

against the disease. But, alarmingly, the survey showed that more than four in five men (83%) at increased risk of prostate cancer do not grasp that their chance of developing the disease is higher than average. It also showed that three quarters (75%) of men at greater risk admit that, even if they were aware but didn't have any symptoms, they wouldn't go and speak to their GP about it.

Owen Sharp, chief executive of Prostate Cancer UK, said: "Black men, men who are over the age of 50 and those with a family history of the disease must wise up to the cruel fact that they face a higher than average risk of prostate cancer than other

men. They need to know this so that they can instigate potentially life-saving conversations with their GPs about the next steps. This isn't happening and as a result men are walking around like ticking timebombs, completely oblivious to the danger they face."

PCUK's aim is to transform the way risk is calculated so that the most vulnerable can be diagnosed early enough to survive, while those at low risk are spared invasive testing or sometimes unnecessary treatments. "Our plan is to fund research that we hope will revolutionise how we diagnose and treat prostate cancer."

## Urine test to aid diagnosis?

A new licence between the University of Surrey and Randox could bring to market a urine test that will help with the early detection of prostate cancer. According to scientists at the university, the test is a more reliable way of detecting cancer.

Dr Matthew Hobbs, deputy director of research at Prostate Cancer UK, said: "The diagnostic tests currently available to doctors can't easily differentiate deadly forms of prostate cancer which require immediate radical treatment from less harmful cancers that may require no treatment at all. This lack of clarity means that many of the 40,000 men who are diagnosed with the disease each year are faced with making difficult decisions on which treatment path to take

without all the information they need. There is a desperate need for better tests that can immediately identify men in need of urgent treatment, whilst saving others from having to endure treatment unnecessarily.

"The results of research into the EN2 biomarker are encouraging ... However, much larger trials that involve a broader sample of men and follow their health for several years are needed before we can say for sure that a test for this marker is one that will work in clinical practice. Even then, it is unlikely that this test on its own will give a reliable enough result to be used on its own and will most probably be used in addition to current tests."

# From where I sit – the Chairman's view

Summer's here at last – so to spend a Sunday afternoon in the Bishop of Norwich's garden was a very pleasant affair. We were there in force on June 22 to raise money – £1,700, since you ask – for the Targeted Radiotherapy Appeal, which as of early July has reached £480,000. The fund manager, Louise Cook, is confident of reaching the target of £600,000 by the end of this year.

We were entertained by the Creakes Choral Group, who sang for a couple of hours and could be heard all around the garden – a setting in which they utterly belonged! The raffle tickets were drawn by Julie James, the Bishop's wife.

On Saturday, April 12, we held our first "Meet & Chat" event at the Louise Hamilton Centre in Gorleston. The venue was first class, with free parking for all our visitors. Refreshments were provided by the centre staff, and our two dedicated nurses, Angie and Wendy, were available to talk to newly diagnosed patients. Around 30 newly diagnosed men turned up, many with their partners.

We had a briefing by our welfare officers, David and Adrienne Capp, then split into smaller groups. There was also a big demand for the Lifestyle book by Professor Robert Thomas (see page 2) and many wanted the Sitting Room Circuits DVD as well.

There will be another "Meet & Chat" at the Louise Hamilton Centre on Saturday, August 9, starting at 11am and finishing at about 1pm.

Incidentally, those of you who receive our newsletter in the post, as well as books, etc, may have noticed that the packaging has a franking machine logo printed on it. It mentions our charity and also acknowledges Aviva who very kindly funded the purchase of the machine.



*The Creakes Choral Group in full flow*

Finally, we have set up the facility for people to make donations via the internet. For example, many of you offered to pay the postage for books.

To do so, go to our website page – [www.prostatesupport.org.uk](http://www.prostatesupport.org.uk). Click on the link to [www.mydonate.com](http://www.mydonate.com) and make a donation. Simple!! But for those of you who still prefer good, old-fashioned cheque books, just write a cheque to N&WPCSG and send it to our treasurer, Dave Kirkham, at 3 The Coppice, Attleborough NR17 2PY.

**Noel Warner, Chairman**

## Another battle with NICE

In another draft ruling that will affect men with advanced prostate cancer, NICE is proposing to refuse approval for Abiraterone for general use before chemotherapy.

At the moment, Abiraterone, which can significantly postpone chemotherapy, is available on the NHS only for men who have already had both hormone therapy and chemotherapy but some patients have received it before chemotherapy as a result of individual applications by consultants to the Cancer Drugs Fund. If NICE confirms its ruling, chemotherapy will be the first treatment option for men with advanced cancer who are no longer responding to hormone therapy.

NICE says it has not been able to approve Abiraterone for use before chemotherapy because the manufacturers, Janssen, have not provided enough data on its benefits.

Mikis Euripides, director of policy and strategy at Prostate Cancer UK, said: "This news is a huge blow to those with advanced disease who have long hoped for the chance to delay chemotherapy and the debilitating side effects and incessant hospital visits which come with it. In the sixteen months since it became available on the Cancer Drugs Fund in England, pre-chemotherapy Abiraterone has become the fund's second most requested drug,

indicating great confidence from clinicians about its benefits at this stage of the disease and great value from patients who, with input from their clinicians, are opting to delay or avoid having chemotherapy.

"It seems unforgivable that such a powerful and beneficial treatment should be left tantalisingly out of reach. We implore Janssen and NICE to work together to do everything in their power to make this vital treatment available as soon as possible for all in England and Wales who need it. This decision has been delayed once before and it is more than frustrating that still we seem to be no further forward. Men should not be forced to wait a moment longer."

## UEA genetic discovery

Researchers at the University of East Anglia and the Institute of Cancer Research in London have made an important breakthrough in understanding genetic changes associated with terminal prostate cancer. In a study funded by the Association for International Cancer Research, Colin Cooper and Jeremy Clark have shown how a genetic mutation in untreated patients is linked to aggressive cancer

later in life. It had been thought that the mutation occurred only in response to therapy.

The research has highlighted why relapses can happen in some men following hormone therapy. Key to implementing the discovery will be finding ways to identify for early intervention patients who will develop aggressive cancer.



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St. Andrew's Church  
Cromer Road, Sheringham**

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and the popular artistes who sang them!*

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Please enclose a stamped & addressed envelope and make cheques payable to "N&WPCSG"  
Also on sale at the door on the night - subject to availability.*

## Hitting the target

How do powerful prostate cancer drugs get to the seat of the problem without causing major damage on the way? Backed by £750,000 career development fellowship awarded by Prostate Cancer UK, a researcher at the University of East Anglia is setting up a laboratory to find new ways of drug delivery.

Dr Wafa Al-Jamal will be exploring better ways to deliver chemotherapy to patients. She will be aiming to evolve incredibly small drug delivery devices, called nano-carriers, that will take drugs directly to prostate cancer cells, reducing the side-effects of treatment.

Dr Al-Jamal says the award, made with support from the Movember Foundation, is enabling her to set up her own lab and build a strong team.

"Thanks to my fellowship, I have the confidence to develop my lab, knowing that my work will be supported for the next five years. I aim to develop a way to get drugs to prostate cancer cells that have spread around the body and so prolong patients' survival while reducing side-effects."

## Our thanks

We are most grateful for the following donations we have received recently:

£172.50 from Mrs Carole Williams in memory of her husband, David Williams, who died in February.

£50 from Mrs Kathy Bell, a regular donor, in memory of her husband Alan who died last year.

£390.70 in memory of Mr Ellis Henry George Kiddell

£104 from the Maids Head Lodge

£100 from R Wharton, for and on behalf of Thurton & Berghapton Players

£300 from Jackie and Steve Mitchell

£370 from Steve Baker.

## Dates for your Diary

Wed 6 Aug and 3 Sep. . . . . 5.30-7pm

**Radiotherapy Department**

*Open Evenings, Big C & Colney Centre,*

*NNUH. Meet at Big C.*

*Call 01603 288779 to book.*

Sat 9 Aug . . . . . 11am-1pm

**"Meet & Chat" at Louise Hamilton Centre, James Paget Hospital, Gorleston-on-Sea NR31 6LA**

An opportunity for newly diagnosed patients to chat with members who have already been through the same journey.

## How to Contact Us

### Specialist Nurses:

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**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*