

# Another drug ruled “too costly”

The Cancer Drugs Fund has ruled that it will no longer pay for the prostate cancer drug Cabazitaxel (trade name, Jevtana) because it is too expensive and the fund is not satisfied that the benefits justify the price tag. This follows the earlier crackdown on the availability of Abiraterone and Enzalutamide for men who have already had either of the drugs or chemotherapy.

The good news is that anyone already on any of these treatments will not be taken off them. And we have the further reassurance that the CDF decision to ration treatments for advanced (metastatic) prostate cancer will not affect “first line” treatments such as radical prostatectomy, radiotherapy, HIFU and cryotherapy, and hormone treatments such as Zoladex.

Cabazitaxel is one of 25 cancer drugs deleted from the CDF approved list to save about £80 million a year. The fund’s budget is growing from £200 million in 2013-14 to £280 million this year and £340million from April. But without the cutbacks costs would have risen to £420 million. The fund says this would have meant cuts in other aspects of cancer treatment such as radiotherapy, cancer diagnoses, cancer surgery and other services.

Professor Peter Clark, the fund chairman, says: “We have been through a robust, evidence-based process to ensure the drugs available offer the best clinical benefit, getting the most for patients from every pound.

“There were drugs that did not offer sufficient clinical benefit so we simply cannot go on funding those.

“There were others that offered some benefit but were costly and I am pleased that a number of pharmaceutical firms worked with us to make prices more affordable, saving millions of pounds that can now be reinvested in other treatments.

“These are difficult decisions but, if we don’t prioritise the drugs that offer the best value, many people could miss out on promising, more effective treatments that are in the pipeline.”

Owen Sharp, chief executive of Prostate Cancer UK, says the CDF decision is “just another symptom of a drug appraisal system in meltdown. It underlines yet again the critical need for a more effective overall solution to the commissioning of cancer drugs. Those at the very top of the Department of Health have pledged to make reform to the commissioning of cancer drugs a priority but we are yet to see action. We are determined to hold those responsible to account on this pledge. We won’t stop until we get the system that is right for cancer patients now and in the future.”

■ There’s a chance for us to add our voice to the campaign against the CDF ruling by signing an on-line petition to Prime Minister David Cameron urging him to keep his promise made at the last election that “... if your doctor thinks that you should have a cancer drug that will help you to live a longer and better life you should get that drug.” The petition asks the Prime Minister to intervene and halt the removal of the 25 drugs from the CDF list. The link to the petition is: <https://you.38degrees.org.uk/petitions/keepyourpromise> – but you need to act quickly because the decision is imminent.

## Mine’s a pint (several)

Ah, the pleasure of being chairman! Noel Warner receives a cheque for £327.60 – 10p for every pint of a special beer brewed by Wolf Brewery. And Noel admitted to contributing 60p to the total.

Staff of the micro-brewery at Besthorpe, founded at the Reindeer pub in Norwich and owned by Kay Edwards, have friends or colleagues who have been diagnosed with prostate cancer and wanted to do something to help.

Last November they decided that they would brew a beer to coincide with the “Movember” moustache-growing campaign and brand it as “Wolf Whiskers”. This special brew was introduced into 40 Norfolk pubs and for every pint sold 10p was donated to help the work of our group.

With 3,276 pints drunk by Norfolk’s charity-minded drinkers, £327.60 was raised. Thirst quenched, Noel was only too happy to receive the cheque from Wolf sales manager John Smith and thanked the brewers and all the landlords who helped to raise awareness of prostate cancer.



# Would limit close door on new drugs?

Some of us are costing too much and depriving others of treatment, according to economists at York University. The NHS should not be spending more than £13,000 a year on drugs for individual patients because higher spending does "more harm than good", claim researchers at the Centre of Health Economics.

But NICE has hit back and warned that imposing a £13,000 limit would mean "closing the door" on most new drugs.

Currently, NICE rarely backs drugs costing more than £40,000 a year but treatments such as the breast cancer drug Kadcylla which costs about £90,000 can be funded by the Cancer Drugs Fund.

The economists based their study on "Quality-Adjusted Life Years" (QALYS) – a measurement which makes one year in very poor health worth less than one in good condition. They concluded that each QALY gained by patients benefiting from the Cancer Drugs

Fund meant five years lost by other patients on whom the money could have been spent. "The threshold used by NICE when gauging the cost-effectiveness is too high. This means the approval of new drugs is doing more harm than good to patients overall."

Professor Karl Claxton, co-author of the research, said that funds were better spent on cheaper treatments which benefited larger groups of patients. "If we stopped spending money on drugs that cost more than £13,000 per QALY, we would improve outcomes overall."

Sir Andrew Dillon, chief executive of NICE, said it was always necessary to balance cutting edge treatments with more routine care. "Unless you think that drug companies will be prepared to lower their prices in an unprecedented way, using a threshold of £13,000 per QALY would mean the NHS closing the door on most new treatments."

## Handbook for new patients

This is the splendid new handbook that newly diagnosed prostate cancer patients are now given.

It has been compiled by specialist nurse Sallie Jermy and we have contributed £200 towards the cost of the initial print run.

The handbook lists the "people involved in your care" – consultants, nurses, and other members of the support and care team – with their direct line phone numbers.

The role of the multi-disciplinary team is explained and the fact that patients can ask questions about their treatment at any time is stressed.

Other sections of the handbook cover spiritual care and holistic assessment.

A two-page "spread" tells patients about our group and what we can offer by way of help.

There is information about the Urostomy Association, It's On The Ball (testicular cancer), and Big C.



## M & C @ JPH

For members living in the east of our "patch", there's a further opportunity to discuss medical and welfare problems at a Meet and Chat gathering at the James Paget Hospital, Gorleston, on Saturday, April 25. The meeting will be in the Louise Hamilton Centre from 11am-1pm and will be a chance to talk to the hospital's oncology team and to group members who have experienced a variety of treatments.

## No charge!

It'll come to us all eventually but in the meantime we can have a quiet chuckle courtesy of Kingsley Amis:

*Death has this much to be said for it:  
You don't have to get out of bed for it.  
Wherever you happen to be  
They bring it to you – free.*

## Chemotherapy unit is set to expand

Members who have reached the stage of needing chemotherapy will be pleased to have read in the *Eastern Daily Press* that the rather cramped Weybourne Day Unit at the Norfolk and Norwich Hospital is to be expanded, subject to planning permission.

The hospital wants to add a single-storey extension to the unit in the Colney Centre to provide bays for 10 more patients because of increasing demand.

"We are investing £1million to add to and

improve the space available, increasing the number of chemotherapy bays from 14 to 24," a hospital spokesman said.

"This will mean we can treat more patients and will improve the environment for all our patients undergoing chemotherapy."

Joanne Beven, operational director for cancer services, said that as research developed so would cancer treatments.

"Over the last five years there are more and more treatments available to patients.

"In the past there may have been one course of treatment but there are now two or three.

"The increase in bays doesn't mean there are significantly more people with cancer but there are more treatments available to them."

Provided planning permission is granted by South Norfolk District Council, the extension should be finished by late autumn.

# Breakfast club's £1,000 gift

Yaxham Breakfast Club, a monthly gathering of local small businesses, kindly chose our group as their charity for last year and we were presented with a cheque for £1,030.00 by Anna Stevenson, the owner of Yaxham Mill, who runs the club with Sarah Daniels. Sadly, Anna lost both her father and grandfather to prostate cancer.

Part of the money raised was from the sale of bottles of wine donated by local winegrower Peter Ross. His vineyard is called Babu's Vineyard, because Peter's daughter wanted to know what to call her grandfather who was living in East Africa at the time. He asked her to call him Babu – Swahili for grandfather. As Peter himself became a grandfather, and by this time his father had passed away with prostate cancer in Kathmandu, Peter decided to carry on the tradition of being called Babu.

Our chairman Noel Warner, pictured with Anna Stevenson and Peter Ross, said that we were grateful to Anna and Sarah for the donation. We have added this to the many other donations which we have received, all earmarked for the Targeted Radiotherapy Appeal.



## Don't ignore it – get it checked

It's a bit late in the day for those of us who already know that we have a major health problem but it's advice that might help our families and friends. A study by Cancer Research UK has found that, because of that classic "British stiff upper lip", half of people over 50 are ignoring potential symptoms of cancer.

The research showed that because of our reluctance to go to our GPs for fear of wasting their time – and for fear of what we might be told – health complaints such as persistent heartburn, which seem trivial but could indicate cancer, are being ignored.

Some participants told the researchers that they assumed that changes in their body were a natural consequence of ageing. They were also frightened that they might be told they have cancer.

Dr Katrina Whitaker, a senior research fellow at University College London, said: "Many of the people we interviewed had red-flag symptoms but felt that these were trivial and didn't need medical attention, particularly if they were painless or intermittent." She said that many of those interviewed felt that they "shouldn't make a fuss or waste valuable NHS resources. The stiff-upper-lip stoicism of some who decided not to go to their doctor was alarming."

The researchers found that patients were more likely to get symptoms checked if they were encouraged to do so by family or friends.

Dr Richard Roope, of Cancer Research UK, said: "The advice we give is: if in doubt check it out – this would not be wasting your GP's time.

"Often your symptoms won't be caused by cancer but, if they are, the quicker the diagnosis the better the outcome."

Sara Hiom, director of early diagnosis at Cancer Research UK, said that British attitudes appeared to play a part in the reluctance to visit the doctor.

"International comparisons have already shown us that the British public are far more worried about being a burden on the health system or 'wasting the doctor's time' than in other developed countries."

Public Health England has launched a television and radio campaign to encourage people to go to their GPs to get symptoms checked out early before they develop into serious problems.

## Come and see where your money goes

Our annual meeting on Monday, April 13, will be one of the most important meetings in our ten-year history. We shall be handing over a lot of money!

Since the Norfolk and Norwich University Hospital launched its Targeted Radiotherapy Appeal, we have been squirreling away the money we have raised from a variety of sources with a view to donating it to the appeal to pay for some of the specialist equipment that is needed in the new unit which will enable Norfolk patients to receive brachytherapy treatment locally instead of travelling to London or Cambridge. Our contribution will amount to £20,000.

And, as we have twice reported, the remarkable Brundall Cancer Community Chest has raised first £10,000, then a further £20,000 to add to our contribution. And Big C is donating a splendid £50,000.

On April 13, at the Benjamin Gooch Theatre at the NNUH (7-9pm), the three groups will come together to present the money to the hospital trust chairman, John Fry.

And, as if that isn't enough for you, our vice-chairman Ray Cossey will be taking us back more than 70 years with his illustrated talk on The Norwich Blitz (see page 4).

# Monday 13th. April

( 7.00 till 9.00pm )

**Benjamin Gooch Lecture Theatre  
Norfolk & Norwich University Hospital**

**Illustrated talk by**

**Ray Cossey**

***The Norwich Blitz  
1940-43***

## Charities demand better funding system

Fifteen cancer charities, including the Support Federation, now known as Tackle, have put their names to a letter in the Daily Telegraph raising concern that the drug appraisal and funding systems are failing patients.

The charities say that the establishment of an additional Cancer Drugs Fund was a clear sign that the current system for the effective and efficient commissioning of cancer drugs in England was failing to achieve its objectives.

"Now even this additional pot is crumbling under demand and the high cost of cancer drugs, and the knee-jerk reaction has been to save money by re-evaluating the availability of these drugs, regardless of need.

"The harsh truth is that cancer patients are paying the price for a system in meltdown. We refuse to tolerate such an appalling situation," say the charities.

"The number of people living with cancer is predicted to reach a record level this year in the UK. A long-term plan for more sustainable and effective drug funding and appraisal systems in all parts of the UK is urgently required.

"Only this way, with the full co-operation of manufacturers, will the health service be able to cope with demand and meet the needs of people affected by cancer.

"Cancer charities are uniting behind this common goal and will be working closely with NHS England, the Department of Health, NICE and the Association of the British Pharmaceutical Industry (ABPI) over the coming months to develop a better process for commissioning cancer drugs.

"We will not rest until we get the system that is right for cancer patients now and in the future."

## Dates for your Diary

Wed 3 Mar and 1 Apr. . . . . 5.30-7pm

**Radiotherapy Department**

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

Call 01603 288779 to book.

Mon 13 Apr. . . . . 7-9pm

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

**AGM**

followed by

**Targeted Radiotherapy  
Presentations by Big C,  
Brundall Cancer Community  
Chest and our support group**

followed by

**Ray Cossey on**

**"The Norwich Blitz 1940-43"**

Sat 25 Apr. . . . . 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.

## A Poirot, perhaps?

Stuart Malone, technical skills laboratory manager at the NNUH, sported what he describes as "silly hair growth" during the Movember campaign and raised £30 for the group for which we are very grateful.

Sadly no one took a photograph, so we shall just have to use our imagination.

### 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](mailto:noel.windfall5@btinternet.com)

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#### ■ Visit our website:

[www.prostatesupport.org.uk](http://www.prostatesupport.org.uk)