Norfolk & Waveney
Prostate Cancer Support Group

NEWSLETTER

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NICE shuts the door on vital drugs

The battle over two life-extending prostate cancer drugs goes on. Rulings by the National Institute for Health and Care Excellence (NICE) will mean that Abiraterone (Zytiga) and Enzalutamide (Xtandi) will not be available to many patients who could benefit from them – but there is hope in the shape of a decision by the Health Secretary Jeremy Hunt to pour more money into the Cancer Drugs Fund (see page 3).

In its final draft guidance issued on August 15, NICE confirmed its refusal to let men with advanced prostate cancer have Abiraterone before chemotherapy even though it has been shown to improve quality of life and delay the need for chemotherapy with all its unpleasant side-effects.

"There is clear evidence that use of Abiraterone before chemotherapy is beneficial for patients and gives them longer, healthier lives," said the Institute of Cancer Research which discovered the drug.

"We urge NICE and the drug's manufacturer (Janssen) to get back to the table and explore every option for making Abiraterone available to these men at a price that is affordable for the NHS."

NICE has approved the use of the drug on the NHS only after men have been through a course of chemotherapy with Docetaxel. But the irony is that many men (your editor among them) have had Abiraterone pre-chemotherapy via the Cancer Drugs Fund. "It has been the second most requested drug on England's Cancer Drugs Fund, suggesting clinicians and patients have great confidence in its benefits," says Prostate Cancer UK.

The NICE decision is based on a strange end-of-life formula involving a two-year cut-off. Because some men can survive more than two years on Abiraterone, NICE says no one can have it pre-chemotherapy. "We know how important it is for patents to have the option to delay chemotherapy and its associated side-effects, so we are disappointed not to be able to recommend Abiraterone for use in this way," said Sir Andrew Dillon, NICE chief executive. "But the manufacturer's own economic model demonstrated that the drug does not offer enough benefit to justify its price."

(Continued on page 2)

Another big cheque from the little shop

That tiny charity shop that punches so far above its weight – the Brundall Cancer Community Chest – has done it again! On Friday, August 8, the chairman of the trustees, Christine Buchanan (left), handed over a cheque for £20,000 to Keith Simpson, MP for Broadland. Keith in turn handed the cheque to Adrienne Capp (right), who is chairman of the shop committee but also one half (with husband David) of our group welfare team.

Members may recall (see issue No. 45) that back in October last year we reported that the shop had presented chairman Noel Warner with a cheque for £10,000.

This money is being held by us until the Targeted Radiotherapy Appeal at the Norfolk and Norwich University Hospital reaches its target of £600,000 – this is expected toward to end of 2014. At that stage we will hand over £40,000 to the TRA, £10,000 of which is our own contribution. The money is earmarked towards the cost of equipping the new centre to provide a new radiotherapy service for patients known as high dose rate brachytherapy. The N&N will be one of the few hospitals able to offer the procedure, currently only available for Norfolk patients if they travel to Cambridge or London.

All the staff at the Cancer Community Chest are volunteers, and many are ladies "of a certain age". They work in an incredibly small space and are very much at the centre of the community. If you have goods – clothes, books, etc – that could be sold by the charity, why not take them along to Brundall? They have done us proud. Let's support them in turn.

- Keith Simpson is an avid reader and one of his tasks is to provide his fellow MPs with a holiday reading list. Noel presented him with a book by our patron, Martin Bell, entitled In Harm's Way, an account of his time in war-torn Bosnia.

To test or not to test

Routine screening of older men for prostate cancer could reduce deaths by about a fifth but researchers who conducted a Europe-wide study concluded that universal testing should not be introduced because the current test – the PSA – is so unreliable that two out of five men told they had cancer would be "over-diagnosed" and subjected to unnecessary treatment.

The study, which covered eight countries, showed that over time the group of men who were regularly screened had a 27 per cent lower chance of dying from prostate cancer than those in the unscreened group. But study leader Professor Fritz Schröder of Erasmus University Medical Centre in the Netherlands said: "PSA screening delivers a substantial reduction in prostate cancer deaths, similar or greater than that reported in screening for breast cancer. However, over-diagnosis occurs in roughly 40 per cent of cases detected by screening, resulting in a high risk of over-treatment and common side-effects such as incontinence and impotence.

"The time for population-based screening has not arrived. Further research is urgently needed on ways to reduce over-diagnosis, preferably by avoiding unnecessary biopsy procedures, and reducing the very large number of men who must be screened, biopsied and treated to only a few patients."

Dr Iain Frame, from Prostate Cancer UK, said: "These results highlight yet again the urgent need for a test which can distinguish between dangerous cancers that could go on to kill and those which may never cause any harm. Without a reliable test, the introduction of a screening programme could mean an enormous rate of over-diagnosis and therefore over-treatment of potentially harmless cancers – outweighing any benefits that a screening programme might bring."

But Professor Roger Kirby, director of the Prostate Centre, London, says in an article in the Daily Mail: "What could rule out such 'over-diagnosis' would be to tackle screening this way: let every man over 50 ask for an annual PSA test. Anyone with a raised level should then demand a detailed 3 Tesla MRI scan, a form of magnetic imaging that can identify the presence and extent of the cancer.

"Biopsies miss one tumour in two, while a high-quality MRI scan can rule out tumours that don't require urgent treatment in 95 per cent of men with prostate cancer. If an MRI shows a biopsy is needed, it will also pinpoint where in the prostate this should be carried out.

"That way, the damage to normal tissues during subsequent treatment can be minimised.

"Doing this, we could eradicate the scattergun approach with biopsies that causes so much anguish as a result of side-effects, physical discomfort and expense."

NICE shuts the door on vital drugs – continued

The clinical evidence submitted by the manufacturer came from one trial which showed that, while Abiraterone could delay the progression of the disease, it was not clear how much it actually extended life. "It was clear that the drug is not cost-effective at its current price," said Sir Andrew.

"Abiraterone maintains patients in a better state of health during the course of treatment than chemotherapy and the increases in median survival it offers include much larger benefits for life expectancy in some men," said Professor Paul Workman, ICR chief executive. "Now men will have to wait until they are in the final stage of their lives before they can access this treatment, and men who are too frail to receive chemotherapy face not being able to receive Abiraterone at all.

"It is critical that patients are able to benefit from innovative new treatments that make use of the latest genetic and molecular advances in cancer. We believe that the current NICE system for drug appraisals takes too little account of how innovative a treatment is and we worry that the new rules under consideration could make this situation even worse. It is likely that many modern targeted therapies will be more effective in patients when used earlier in treatment or in combinations but it will be impossible to provide treatment in these ways if innovative drugs first fail to clear the hurdle of NICE approval."

Owen Sharp, Prostate Cancer UK chief executive, said: "It's a fiasco. This decision is a kick in the teeth for men with advanced prostate cancer. An inflexible NICE process plus the drug company's inability to produce all the requested data has led to this being just the latest in a string of hugely disappointing rulings. Once again men in England will have to take their chances with the Cancer Drugs Fund. The current system is flawed. It is not fit for purpose and it is the very people it is supposed to serve who are bearing the brunt. This decision is unjust and it needs to be overturned so that men in desperate need can receive the most effective drugs. We urge Janssen and NICE to get their act together and do whatever is necessary to get Abiraterone pre-chemotherapy across the line without delay."

In July, NICE published its final guidance on Enzalutamide, confirming its ruling that it will be available on the NHS to men who have been treated with the chemotherapy drug, Docetaxel – but not if they have already had Abiraterone. PCUK's Owen Sharp said: "We are extremely disappointed that NHS England has interpreted NICE's guidance to mean that they are not obliged to fund Enzalutamide for men who have had Abiraterone. We have heard many heart-breaking stories of men and their families now left with nowhere to turn, with some resorting to raiding their savings or fundraising to pay for Enzalutamide privately.

"The system has given with one hand and taken with another. As these drugs are both relatively new there is not currently a huge volume of evidence to prove the efficacy of sequential use. However, in this situation the default position should not be to deny access. Doctors should be enabled to prescribe whichever drugs they feel clinically appropriate and learn from the outcome, without having to worry that their decision may mean another door is closed further down the line."

- PCUK is urging men to write to the NHS chief executive, their MPs and the chief executive of their local hospital asking them to take action on the NICE ruling on Enzalutamide. Draft letters, which can be found on PCUK's website, www.prostatecanceruk.org, point out that the cost would be small and time-limited because relatively few men will have had Abiraterone before chemotherapy.

Big boost for Drugs Fund but ...

The prostate cancer drug Enzalutamide (Xtandi) is one of the new drugs which can be paid for through the Cancer Drugs Fund as a result of a big increase in funding – but under the new plans it will be up to clinicians to examine whether the drugs on offer are the most effective to ensure that "this extensive additional funding is spent in the best way for patients". The Government has made it clear that pioneering drugs will not be made available via the fund if they do not represent good value for money.

The Health Secretary, Jeremy Hunt, has announced that he is increasing the fund by £80million to £280million a year which should give thousands more cancer patients access to cutting-edge drugs which would otherwise be deemed too expensive for the NHS. The powers-that-be hope that the new arrangements will give the NHS more bargaining power and help to bring down the price of drugs.

No patients will have any current treatments terminated and patients with rare conditions who have no other options will continue to get access to the most effective drugs. NICE has been ordered to review its system for approving drugs following complaints that it bases its trials solely on patients with no other underlying health conditions. It is being asked to include evidence from patients with other conditions, a move that could see more drugs bring approved. At present NICE says it makes no sense to fund drugs that can extend life for a few weeks or months but cost tens of thousands of pounds when the money could be better spent on other treatments. But critics point out that it rejects almost two-thirds of the cancer treatments it assesses, meaning that patients in England are denied drugs that are available in other parts of the world.

The fund has helped more than 55,000 cancer patients since it was set up more than four years ago. Last year it was extended until at least 2016. Mr Hunt said: "It's vitally important that as many people as possible have access to these pioneering, life-enhancing drugs, and we need to continue to focus our efforts on increasing access to these innovative treatments, while ensuring all patients continue to receive the effective drugs which are right for them.

"By protecting the NHS budget, we have been able to create this fund which has given hope to many thousands of people, their families and friends, and has an essential role in helping realise our ambition to be the best place in Europe to survive cancer."

But NICE chief executive Sir Andrew Dillon told MPs on the Commons Health Select Committee that it was illogical that the Cancer Drugs Fund paid for medication that NICE ruled was not cost-effective. The fund made no sense because it was irrational that it approved drugs which NICE had already turned down. Sir Andrew said the fund should be brought under the remit of NICE, because funding for drugs had become "misaligned". They would like to move away from a situation where they applied their correct threshold to say they could not support routine use of treatments, and in most cases the Cancer Drugs Fund then said yes to the treatments they had said no to.

"I don't think that makes any sense. It's not a criticism of the decision to allocate more money to cancer. It's about an alignment of processes and methodologies that we need to get sorted out. There is no reason at all why we can't provide the basis for NHS England's decisions on cancer treatments just as we do for all other treatments."

Sir Andrew also warned that devoting money to cancer risked diverting funds from other diseases. "It's inevitable if you choose to spend money on one thing you can't spend it on something else. If you allocate more money to one condition, other conditions are getting less."

Meeting and chatting at JPH

Our second Meet and Chat gathering at the Louise Hamilton Centre at the James Paget Hospital, Gorleston, was held on Saturday, August 9, and was another worth-while event. About a dozen existing members turned up and six newly diagnosed men, most with partners, also attended.

Considering it is only four months since we held the first event in Gorleston, the turnout was very encouraging. One gentleman very bravely came along, having had surgery only two weeks before, and was evidently still in some discomfort.

As well as our committee members, specialist urology nurses Angie Fenn and Wendy Keenan gave up their time to be there. Angie is pictured above talking to one of the newly diagnosed patients.

Another man had just been diagnosed and was anxious to learn about radiotherapy treatment combined with hormone treatment. David Capp, one half of our welfare team, pictured back to camera wearing his distinctive gold sash, came to the rescue, having had these treatments.

The staff at the centre looked after all of us very well – they also raffled some large cakes left over from a previous event and managed to raise over £60 for the centre. We also donated £50 for the use of the centre and the refreshments.

This event will be a regular fixture from now on, and for 2015 we hope to hold two meetings – in April and September.

A chat might help

Newly diagnosed? Facing up to a change of treatment? A bit worried about what it all might mean? We've all been through it, so why not come along to the next Meet and Chat evening on Monday, October 6, at the Big C Centre at the NNUH and share your concerns with someone who might be able to offer information and reassurance.

The Church Hall
St. Andrew's Church
Cromer Road, Sheringham

FREE PARKING

Interval refreshments available

Saturday 13th. September

(Curtain-up 7.30pm)

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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.

Dates for your Diary

Wed 1 Oct and 5 Nov. 5.30-7pm
Radiotherapy Department
Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C.
Call 01603 288779 to book.

Mon 6 Oct 7-9pm
"Meet & Chat" at Big C Centre, NNUH
An opportunity for newly diagnosed patients to chat with members who have already been through the same journey

Mon 1 Dec. 7-9pm
Open Meeting at Benjamin Gooch Theatre, NNUH
Dame Mary Archer, OBE

A welcome donation

We are delighted to acknowledge a handsome donation of £1317 from the Eliel Community First Revenue Fund via the Norfolk Community Foundation. Our warmest thanks for your generosity.

If members would like to make a donation to the group or, for example, pay for postage on publications we have sent you, here's how to do so:-

Go to our website page:- www.prostatesupport.org.uk.

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

Alternatively, you can still send a cheque to N&WPCSG to our treasurer, Dave Kirkham, at 3 The Coppice, Attleborough NR17 2PY.

More survivors

Deaths from some of the most common cancers have dropped by up to a third in the last 20 years. Prostate cancer has dropped by some 21 per cent.

Cancer Research UK points to innovative drugs, advances in surgery and improvements in radio and chemotherapy.

Critically important earlier diagnosis, as well as improvements in treatment, have contributed to the reduction in prostate cancer deaths.

How to Contact Us

- ***Specialist Nurses:***
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  James Paget
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  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
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