

## Golden age for prostate cancer drug discovery

In the wake of Abiraterone comes another "last chance" drug created by the Institute of Cancer Research and the Royal Marsden Hospital: Enzalutamide (Xtandi). It has been found to extend life by at least five months for men who have ceased to respond to hormone treatments and chemotherapy, with almost half the men on a trial experiencing a better quality of life.

NICE is recommending the treatment for hormone relapsed metastatic prostate cancer and is due to make a final announcement in February on whether the drug should be licensed. If it is licensed, it should become available on the NHS in England early this year for patients who have had at least one cycle of Docitaxel-based chemotherapy.

The new drug costs about £25,000 for an average course of treatment but the manufacturer, Astellas Pharma, has cut the price through a patient access scheme which makes it cost-effective, according to NICE.

Professor Carole Longson, director of NICE's centre for health technology evaluation, said: "There are few treatments available for patients at this stage in their cancer so we are very pleased that we are able to produce draft guidance recommending Enzalutamide. It is an effective treatment and it also allows patients to be treated at home as it can be taken orally."

Professor Alan Ashworth, chief executive of the ICR, says: "Advanced prostate cancer is very difficult to treat, and it's taken a co-ordinated effort to finally bring new drugs into the pipeline after decades when there were no options once old-style hormone treatment stopped working.

"What we are seeing now is an unprecedented period of success for prostate cancer research, with four new drugs shown to extend life in major clinical trials in just two years, and several others showing promise. It truly is a golden age for prostate cancer drug discovery and development."

Enzalutamide was assessed in a trial involving 1,199 patients with advanced prostate cancer who had previously received chemotherapy. Survival averaged 18.4 months, compared with 13.6 months for men receiving a placebo. More than 40 per cent reported an improved quality of life compared with 18 per cent on the placebo. The trial was so successful that it was stopped early so that the placebo patients could be given the new drug.

Owen Sharp, chief executive of Prostate Cancer UK, said: "This is great news for men. We fought long and hard to have Abiraterone, which works in a similar way, available on the NHS. It isn't successful for every man, and we need clinicians to have options at their disposal to do what counts – extend the lives of men with this disease when other options have run out."



*Do you remember these cars from the 1970s – the iconic Triumph Stag, a British-built Grand Tourer with a unique three-litre V8 engine? They are now a rarity and their owners cherish them. There is a thriving Stag Owners Club in Norfolk – and they have been raising money for our group. To find out how, turn to page 3.*

### Share your worries

As they say, "Been there, done that ..." - and a lot of us have and are only too willing to talk about our experiences with those who have recently been diagnosed or are being offered different forms of treatment. If you think it would be helpful to share your concerns with those who have "got the T-shirt", why not come along to our next "Meet and chat" evening at the Big C centre at the Norfolk & Norwich Hospital on Monday, February 3? There'll be a cup of something and a warm welcome any time after 7pm.

## Broccoli – the wonder veg!

Is there no end to the wonders of broccoli? Not only is Beneforté broccoli thought to protect against prostate cancer and heart disease but scientists have found that it produces metabolic changes that are the biological equivalent of a car's 12,000-mile service. Tiny energy generators in cells called mitochondria, which become less efficient with age, were given a new lease of life and their performance improved.

Elsewhere, researchers have found that a chemical

called glucoraphanin which is present not just in broccoli but also in Brussels sprouts and cabbage is taken in by our body and turns into sulforaphane, a compound that can protect our joints. Volunteers will eat the super-broccoli every day before surgeons repair their badly arthritic knees.

Not content with that, other scientists are testing a cream made from broccoli as a sunscreen to ward off skin cancer!

# From where I sit – the Chairman's view

## WE HAVE A PROBLEM

I am hoping that the saying "A problem shared is a problem halved" is true. If that is not the case, then we do have a potential problem.

Your Support Group has been running for very nearly ten years now – and for the simple fact of not finding a volunteer to take over from our secretary we could face extinction. Allow me to explain. Our long-serving secretary, Brian Smith, has been trying to retire for the last couple of years. He now brings his good lady, Margaret, along to committee meetings so that she can be his back-up ears. Brian has made it clear that he will not be seeking re-election this year at the AGM on Monday, April 7. The Charity Commission would rightly take action against us if we tried to operate without a secretary – hence the threat of extinction.

The role can be filled by a man or a woman, with or without experience. The person who volunteers for the job will get all necessary help. The commitment is to take notes at six committee meetings a year, plus the AGM. Access to e-mail would be essential. There is no other involvement unless you wish it.

IF I RECEIVE 10 PHONE CALLS OR 20 E-MAILS ENQUIRING ABOUT THE JOB I WILL BE VERY HAPPY.

IF I GET NO RESPONSE AT ALL... BUT THAT'S NOT GOING TO HAPPEN, IS IT?

My phone number is **01508 488088**, and my e-mail is [noel.windfall5@btinternet.com](mailto:noel.windfall5@btinternet.com)

## MEMBER SURVEY

Just because we have a membership of more than 200, have been active for ten years, and can be arguably praised for being one of the best and most pro-active Support Groups in the UK, that is no reason to delude ourselves into thinking that we are doing what **YOU** want us to do.

In order to be certain of that, we are going to send out a survey with the March newsletter. The first question we will ask is: "Do you wish to remain a member of our Group, and continue to receive the newsletters?"

Those of you who reply **yes** to that question will then be asked a number of other questions, along the following lines:-

- Do you value the Open Meetings at the NNUH, and have you an opinion on the subject matter for the speaker?
- Are these meetings held at the best venue for you, and would day-time be better than evening?
- Would you prefer the meetings to have an "open forum" format instead of having a formal speaker so that a wide variety of subjects could be discussed?
- Do you feel the bi-monthly newsletter keeps you informed about our work and prostate cancer matters? Are there other subjects you would like to see covered?

Please give these matters some thought ahead of the survey form and pre-paid envelope arriving in March.

Noel Warner

## Life expectancy doubles

Men with advanced prostate cancer have seen their life expectancy more than double in a decade – from less than a year and a half to almost four years.

Research conducted by the Institute of Cancer Research and the Royal Marsden found that the introduction of new drugs has had such an impact that the system used to predict how long patients will live now needs to be revised.

Professor Johann de Bono, professor of experimental cancer medicine at the ICR and honorary consultant in medical oncology at the Marsden who led the clinical trials of Abiraterone, says: "This highlights the remarkable benefits we are seeing from new treatments for men with advanced prostate cancer. Put simply, men are living for much longer with incurable disease than a few years ago."

The number of people dying from prostate cancer is on course to almost halve within three decades. In 1992 only 28 per cent of men survived for at least five years. Macmillan Cancer Support now forecasts that by 2020 the survival rate will rise to 64 per cent.

Professor Malcolm Mason, a Cancer Research UK prostate cancer expert, says: "We have come a long way in improving the treatment of prostate cancer over the last couple of decades. Improvements in how we treat prostate cancer have been key to reducing deaths from the disease."

But Owen Sharp, chief executive of Prostate Cancer UK, comments: "The raw truth is that there are simply too few options for men with advanced prostate cancer and even life-saving treatments can have life-changing side effects."

## Tiger-spotting

A prostate cancer test has been developed that could avoid unnecessary treatment for thousands of men by predicting whether a tumour will be aggressive or slow-growing.

The Polaris test, developed by Professor Jack Cuzick, of Queen Mary University, London, and other Cancer Research UK scientists, measures the activity of a set of genes known as cell cycle genes, which help drive the division of cells in the body.

Professor Cuzick said: "Overtreatment of prostate cancer is a serious issue, so it's essential that we have an accurate way of spotting those cancers that pose an immediate risk."

For patients with slow-growing tumours, it's far safer and kinder to watch and wait – only acting if the situation starts to change."

# Stag owners' £300 tache cash

*So how did those devoted owners of Triumph Stags support our group?*

They took on the challenge of the nationwide Movember campaign and grew moustaches. Top lips became fur-encrusted during November and typically, if friends or work colleagues poked fun at a Mo-Bro, they retaliated by requiring a donation. A total of £300 was raised.

Featured in the Mo-Bro photo are (left to right) Peter O'Neill, Paul Girling, Stu Holman, David Barker, Alan Betts, Ross Holman, Chris Liles, Don Mickleborough, Paul Fenner, Simon Wilkinson, Tom Rix and Peter Herwin. Mo-Bro Dean Barker was unable to make the photo-shoot but he sent a "selfie" photo to prove his achievement.

Such was the support from within the club that some members who could not/would not grow a moustache still chose to partake in the event.

"The Pretenders" are (left to right) front row, Su (Mo-Brows) Dunkerley, Pam Fenner, and Chrissy Rix, and, back row, Barry Dunkerley, Richard Fereday, Mike Peters, and Ted Ramsey

It's not the first time that the Stag



Owners Club's Norfolk Area has raised money for N&WPCSG. In 2009 the club raised £500 which was generously doubled to £1,000 by the Imperial Hotel in Yarmouth. The hotel has been host to SOC's annual parties for 18 years and owner Nick Mobbs has had family experience of prostate cancer.

You can learn more about Stags and the international Stag Owners Club (SOC) via [www.stag.org.uk](http://www.stag.org.uk) or by contacting Norfolk Area Co-ordinator and national Honorary Vice President, Chris Liles at [chris@liles.co.uk](mailto:chris@liles.co.uk)

## And The Pretenders...



## Problems getting to those never-ending appointments?

Some of us seem to spend half our lives travelling to hospital for yet another appointment – and some have a major problem making those journeys. Wendy Marchant, Big C information lead nurse, told us at our open meeting at JPH Gorleston that there have been many changes recently to who can and cannot qualify for hospital transport.

More people are failing to qualify now than in the past because of pressures on the ambulance service and volunteer drivers. She asked us, wherever possible, to use our own car or seek help from a family member, friend or neighbour.

There are drawbacks to this, however, the main one being cost, particularly for those living rurally and a long way from hospital. Some hospitals do have concessions for cancer patients and it is worth asking your hospital for more information (especially for radiotherapy appointments).

Hospital transport is now booked by patients themselves but do contact your nurse or doctor if you encounter problems. If you are in receipt of the mobility component of DLA (Disability Living Allowance – now PIP Personal Independence Payments) or AA (Attendance Allowance), you will not qualify for hospital

transport because the Government deems that you have already been paid to provide your own.

Claimants of some benefits can claim back the cost of travel to hospital but you will need to take receipts, tickets and evidence of being on benefits to the travel office or general office of the hospital in which you are treated to get this.

Please see the Macmillan booklet "Help with the Cost of Cancer" for more details. Some people qualify for a Macmillan Patient Grant or other grant to help cover the expense of travel to hospital. More information about this is also in the Macmillan booklet.

A good alternative is community transport. This needs to be booked in advance but is often cheap and efficient and the service is door to door.

Please check the NHS Heron website for local providers: [www.heron.nhs.uk](http://www.heron.nhs.uk)

If you want more information about travel or would like to talk about other topics relating to cancer and living with it please call into one of the Big C Centres (at the NNUH, the Millennium Library in Norwich on Monday mornings, in the Louise Hamilton Centre at the James Paget Hospital, at the Big C Centre in Great Yarmouth, and at the Big C Centre King's Lynn).

# Could you talk the talk?

ProstateCancerUK are trying to recruit volunteer male speakers to spread the word by giving short talks to groups/organisations in Norfolk/North Suffolk. Training is over two days (with a gap of about a month between each day) and would be in Norwich. You must be able to attend both dates to complete the training.

Giving talks and presentations about prostate cancer is vital in making more and more people across the UK understand the impact of this disease. With your help, thousands of men across the UK can find out:

- What the prostate is and what it does
- Facts and figures
- The risk of prostate cancer
- The signs and symptoms
- What to ask your GP about diagnostic tests

As part of PCUK's volunteer speaker team, you'll be representing the charity at a range of different events, giving talks about prostate cancer, your personal experience and the work of the organisation.

What you will get from volunteering?

- The opportunity to raise awareness of prostate cancer to a range of groups and at a range of events.
- Meeting new people and sharing your story with them.
- Knowing that you're making a difference to thousands of men – your talk on prostate cancer may be the reason a man decides to visit a GP or a wife notices potential symptoms in her husband. You could help save a life and also educate thousands of people.

Any members who would be interested should contact [brian.mitchell@premier-links.net](mailto:brian.mitchell@premier-links.net) or phone Brian on 01508 480883.

## High-tech diagnostic tool on trial

With the intriguing name of "BiopSee", new diagnostic equipment which can more accurately identify and analyse potentially cancerous areas in the prostate is on trial at Addenbrooke's Hospital, Cambridge.

The BiopSee, which is currently on loan to the hospital from the manufacturers, is new technology that combines two diagnostic tools – an ultrasound scan combined with an MRI scan – along with a new way of taking a biopsy, which can much more accurately identify cancerous areas and provide vital information on the grade and stage of the cancer.

Adopting this novel technique involves a detailed MRI scan being taken of the prostate to identify potentially cancerous areas. Any suspicious lesions are marked on the scans by radiologists and these images are imported into the BiopSee computer system. Under a short anaesthetic, the patient's prostate is then visualised using high precision ultrasound and a three-dimensional view is produced which guides the surgeon to the specific site of the cancer from which to take the biopsy.

This new approach has been evaluated on over 140 patients whose initial biopsy was negative. It has proved not only to be more accurate at detecting cancer but has also helped provide detailed information about the specific type of cancer to enable the most effective treatment plan to be developed for each patient. It has also resulted in significantly reduced side effects compared with a standard biopsy. The Addenbrooke's urology team are now aiming to raise £114,000 to buy the equipment.

## Research appeal

New facilities for expanding research and bio-medical expertise in musculo-skeletal diseases, prostate cancer and diseases of the gut are being developed by NNUH and UEA. The Norfolk bone and joint research centre will be sited in the new £19million medical research building being built next to the hospital. Keith Tucker, consultant orthopaedic surgeon, is seeking support from charities, trusts and former patients for a £3 million fund-raising campaign.

### Dates for your Diary

Mon 3 Feb. . . . . . 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*

Wed 5 Feb & 5 Mar. . . . . 5.30-7pm

**Radiotherapy Department**

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

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

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

*Speaker: to be announced*

### 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:**

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