

NICE guilty of U-turn on new drug

... and now for the bad news! In our last issue, we reported ("Golden age for prostate cancer drug discovery") that NICE was on the point of licensing the latest "last chance" drug, Enzalutamide (Xtandi). But NICE has now had what has been described as "a blatant U-turn". Men with advanced prostate cancer will be able to be treated with Enzalutamide after they have had chemotherapy – but only if they have not had Abiraterone first.

"This decision is very unfair," says Prostate Cancer UK, "and will mean that men and their doctors will have to make a really difficult decision about which treatment to try at an already very difficult time. Men with advanced prostate cancer do not have a lot of treatment options and we don't think NICE should be placing this restriction on men."

In a letter to the *Daily Telegraph*, PCUK's chief executive Owen Sharp, Professor Alan Ashworth, chief executive of The Institute of Cancer Research, and Professor Jonathan Waxman, of Imperial College, London, wrote: "A breakthrough drug which could give men with advanced prostate cancer extra time to live is going to be snatched away from them based on a technicality..."

"Only months ago, NICE gave hope to men with advanced prostate cancer by initially recommending Enzalutamide for use without this stipulation ... Since NICE's recent announcement, we've heard heartbreaking stories of men who have been waiting for Enzalutamide to become available as a last hope to prolong their life, only to have this hope taken away from them.

"This illogical decision has been made with a lack of transparency and puts a huge burden on clinicians to choose one treatment over the other without knowing which would most benefit the man. NICE has a duty to those men to revert to its initial recommendation and make Enzalutamide available on the NHS to all who need it."

Hundreds of men have taken the opportunity to respond to NICE's consultation process and urge that the rationing body think again, reverse the decision and bring England into line with Scotland where the new drug will be available without restriction.

For Hugh Gunn, treasurer of the Prostate Cancer Support Federation and editor of its magazine, *Prostate Matters*, the new drug has been a life-saver. "Having had six months' chemotherapy, the benefits of which only lasted about two months ... and with a rapidly rising PSA, I was one of the first patients to be given Abiraterone," he says. "Abiraterone worked really well for my cancer, but after about nine months, it was affecting my liver so I had to come off it. Life was bleak; I thought that this is the end.

"At the time, as it hadn't yet received its UK licence, the manufacturers of Enzalutamide (then called MDV3100) were giving it away, free of charge to patients for whom Abiraterone had failed. That was 14 months ago! I am now fit, healthy and living a totally normal and productive, busy life. My PSA is between 0.5 - 0.9 and my liver is now fine.

"What NICE has done is to pass Enzalutamide for use, but made it totally unusable. Nearly everyone who needs Enzalutamide at the moment has been given Abiraterone and unless the caveat is taken out, they are all going to die.

"I was given this life-saving treatment under circumstances which no longer exist and it is disgraceful that this situation has arisen."

Are we oldies being neglected?

Dr Tom Stuttaford OBE has got something in common with a lot of us, apart from prostate cancer – he does like a glass of red wine! In fact, he's the author of *To your good health: the wise drinker's guide*.

He obviously also has strong feelings about the subject of the talk he will be giving us at our open meeting on Monday, April 7: "Are we neglecting our old veterans?" And as we know from when he spoke to us before he is "a great raconteur", as the *Norwich Evening News* described him last year.

Dr Stuttaford, best-known in recent years as the medical columnist of *The Times* and now *The Oldie*, is very much a Norfolk man and for more than 20 years has lived in a house in Elm Hill, Norwich, parts of which date back to the 13th century. He was born at Horning, the son of a doctor, went to Town Close School, then Gresham's School where he was head boy and captain of rugby. After medical training, he was a GP in Norwich for 11 years and ran a drugs clinic which helped to change the way addicts were treated.

After spells as a councillor, he was MP for Norwich South from 1970 to 1974. When he lost the seat, it was back to full-time medicine at several London hospitals while establishing himself as an informative and entertaining medical columnist.

The meeting – at 7pm in the Benjamin Gooch lecture theatre at the NNUH – is also our AGM but we have a promise from our chairman that that part of the evening will be very brief.

From where I sit – the Chairman's view

Taking the Pee

Well, actually it's a case of giving, not taking. At long last scientists at Surrey University have been able to develop a PSA test using urine. It is deemed to be much more accurate than the blood sample test because it finds the amount of EN2, which directly relates to the size of the tumour, in the patient's prostate and therefore can lead to faster and more effective treatment. It also does away with the need for the DRE procedure. The test should cost about £10, and is initially being introduced in the private health sector.

I know we are all past that point, but the men who will need to be tested in the coming years should get the benefit of this breakthrough. However, Prostate Cancer UK are saying that, although the Surrey results were encouraging, large-scale, long-term trials are needed. So, don't hold your breath.

Member survey

I mentioned in the last newsletter that I would be asking members to help with a survey. Regrettably we ran out of space in this issue so we will try again later. However, please don't be shy – if you want to suggest changes about the format and timing of meetings you have my contact details below.

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.

When help is needed

The "side effects" of prostate cancer are not just medical. We can find ourselves facing a range of financial and practical problems on top of the fear and confusion that can follow diagnosis or worrying news about the progression of the disease. We might need help and advice about grants, travel expenses, housing, benefits, blue badge applications, and so on.

Welfare advice is available from Citizens Advice Bureau advisers at Big C's centres and the main hospitals. "If all the financial and practical things are taken care of, it means people can concentrate on what really matters – getting better," say Big C in their newsletter.

In the six years since the project has been running, advisers have found more than £2million in additional income for people who need it – and the scheme has now been extended to May 2015.

If you or someone you know could benefit from talking to a welfare adviser, phone 01603 619900 and you will be put in touch with a local adviser.

Targeted Radiotherapy Appeal

The very latest figure for money raised by the Fund Raising Office is £356,000 so the appeal is now on the other side of the climb toward £600,000. We are holding an event with the TRA team on Sunday June 22 in the Bishop's Garden.

A must to visit if you are a keen gardener, otherwise just come along and spend some money – all proceeds, including admission, going to the TRA. Put it in your diary/gardening calendar!

Newsletter

This publication comes to you courtesy of David Paull, our Editor, numerous contributors and Chuck Lyons who knocks it into shape for the printer.

As of this issue it also comes at a lower postal cost thanks to Aviva, who kindly donated money to purchase a franking machine. This means we save 30% compared with the cost of stamps – which are going up soon to 62p and 53p for first and second class respectively.

By the way, if you no longer wish to receive the newsletter, or can now access it on-line, please let us know – noel.windfall5@btinternet.com or **01508 488088**.

Noel Warner

Not yet, he isn't!

We have reported several times on the problems of getting travel insurance – and we are not alone. In the final volume of his diaries, Tony Benn tells the tale of trying to get insurance for a trip to a conference in South Africa in 2007. Told that he had leukaemia and a pacemaker, insurance companies didn't want to know. "In the end [my son] found an insurance company that would give me year-long insurance for £1800... but wouldn't cover me if I had a heart attack or died of cancer.

"So I am now uninsurable! It was what you might call a reminder, by means of market forces, that I am legally almost dead." He went to South Africa none the less.

Quiz Corner

Q. Who coined the expression "Big C"?
A. John Wayne!

TEN YEARS & COUNTING!

Some Reflections by David Haines

It is difficult to believe that it is ten years ago on April 26, 2004, that a small group of 17 volunteers met with Sallie Jermy and Claire Fullalove to form the Norfolk & Waveney Prostate Cancer Support Group. This followed an earlier open meeting at the NNUH, organised by the specialist urology nurses and urology consultants, inviting prostate cancer patients and their partners to discuss the need for such a group and assess the level of interest and support.

We were fortunate to have as members of that first committee a dedicated team who laid the foundations for the success and development of the group we see today. Three of them are still serving. Over the years, we have lost many of our former friends and colleagues but other equally motivated people have come forward and made great contributions in achieving our key aims, and our present committee remains strong and committed under the energetic leadership of Noel Warner, Ray Cossey and their hard-working team.

However, we cannot stop the clock and, with several long-serving members now in their eighties, Noel was right to appeal in our last Newsletter for new active volunteers to share the load. We have found friendship, interest and motivation, and without doubt have made a difference in understanding, and our individual approaches in dealing with, prostate cancer.

The situation today is very different from that prevailing in 2004. From little public access to information in those days, there is now probably an information overload from the myriad sources on the internet; more media speculation (and hype); and an increase in the number of charities now involved with prostate cancer. It is sometimes difficult to sort the wheat from the chaff, particularly when faced with opposing reports, and one of our tasks is to offer patients reliable sources of information, and to arrange a programme of credible speakers to keep us up to date on new diagnostic and treatment



developments, together with our growing and ever-popular "Meet and Chat" events with nurses and surviving patients.

Although the group has made headway in increasing awareness, there is a new generation joining the ranks of those at risk who need to be informed, and the group is this year widening its programme of contact and talks with organisations across Norfolk and Waveney.

Over these ten years, there have been some great advances in survival rates and the outlook now is that, within the foreseeable future, the disease will become more a chronic treatment condition that will allow most people to carry on with their lives, in much the same way as those living with diabetes. Our latest Newsletters illustrate some of these latest treatment advances.

We, with the unfailing help of our supporters and donors, have raised over £100,000 to fund new treatment trials (such as Cryotherapy), and to provide essential items of equipment to our local Pathology and Radiology departments, all for the benefit of prostate cancer patients. We are giving our full support to the NNUH TRA (Brachytherapy) appeal, for which we have been able to pledge over £20,000 to date.

As long as people come along to our meetings we are meeting a need. Our audiences vary, but with a hard core of 200 members, we are doing something right. David Baxter-Smith, one of our medical advisers, told me he has travelled around the country talking to Prostate Support Groups, on one occasion addressing an audience of just six people, but those six would go on to tell at least six others, and so on. We have some way to travel before everyone is aware, and David does it to great effect, as all who have heard him speak agree. We must continue to "spread the word".

Finally, I would extend sincere thanks to all our volunteers, past and present, our supporters, donors, nurses, clinicians, and speakers. If we have helped to save one life, (and from the letters I have had, I am sure we have), then it has all been very worthwhile.

Happy birthday, N&WPCSG! I wish you continuing impact and success over the next ten years.

David Haines
Chairman 2004-2008
Vice-Chairman 2008-2010
President 2010 -

Hospital transport arrangements

The report in our last issue on "Problems getting to those never-ending appointments" needs clarification.

The statement that "hospital transport is now booked by patients themselves" may be misleading in some circumstances. It's correct – but not for patients receiving radiotherapy or chemotherapy at the NNUH who need hospital transport because they have no other way of getting to the hospital for their appointments. To make transport arrangements, patients having radiotherapy should contact the Radiotherapy Scheduling Team on 01603 288756 and patients having chemotherapy should contact the Chemotherapy Scheduling office on 01603 287213.



From being the “hidden killer” that we didn’t mention because it involved the unmentionables, prostate cancer has become front page news. And it’s very much in the news now following the launch of Prostate Cancer UK’s “Men United” campaign, fronted by comedian Bill Bailey (also pictured on the cover of PCUK’s *Progress* magazine) and supported by a host of celebrities such as TV veteran Michael Parkinson, actors Damian Lewis and Charles Dance, and rugby legend Will Carling.

What’s it all about? As Parkinson puts it: “Men United aims to save lives. It’s a team I’m proud to be part of and I urge you to join me. By acting as a team we will have more impact and improve the life of every man with prostate cancer.”

The aim of the campaign is to build a united front to get the message across, to support men affected by the disease and to raise funds to find more reliable tests and treatments.

To find out more about the campaign and sign up to Men United, go on-line to menunited.prostatecanceruk.org.

Soaring costs

The cost of treating prostate and breast cancer patients is likely to rise by more than a fifth within a decade, warns Macmillan Cancer Support. The hospital bill is expected to be at least £790million a year by 2020. Macmillan says the surge in costs is being driven mainly by increasing numbers of people getting and surviving cancer, many of them with complications.

Dates for your Diary

Wed 5 Mar & 2 Apr. . . . 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

Dr Tom Stuttaford OBE
 GP, long-term prostate cancer patient, ex-MP, medical correspondent of *The Oldie*, previously of *The Times*
‘Are we Neglecting our Old Veterans?’

Sat 12 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

Taches for tea

Money comes to us in the strangest ways. One of our members, Michael Woodcock, won a raffle at an event at the John Innes Centre. The prize: a “Movember” cake decorated with icing moustaches in several colours.

But rather than gorge himself he passed on the cake to his daughter Johanna who works for the Victory Housing Trust. She raffled it among her colleagues – and we’ve now received a cheque for £40.40.

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- **Help or Advice – Our Welfare Team:**
We have over 30 members available to help. There is probably one near you.
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