

# Norfolk & Waveney Prostate Cancer Support Group

## NEWSLETTER

Issue No 38

August 2012

### Abiraterone: a success story

After repeatedly refusing to recommend Abiraterone – the breakthrough treatment for advanced prostate cancer – the National Institute for Health and Clinical Excellence (NICE) has backed down and agreed that the drug should be available on the NHS in England and Wales.

NICE had argued that the high cost of the drug – £3000 for a month's treatment – could not be justified when it could bring about only a few months' extra life. But the drug also eases pain and improves quality of life, and some patients have lived far longer than expected, including Britons who have survived on the drug for almost five years.

A fine example of how effective the drug can be is one of the leading campaigners, Hugh Gunn, treasurer of the Prostate Cancer Support Federation to which our group is affiliated. Our president, David Haines, reports that Hugh "has responded amazingly to Abiraterone treatment".

Welcoming NICE's decision, Owen Sharp, chief executive of Prostate Cancer UK, said:

"This announcement represents a resounding triumph for each of the thousands of men with advanced prostate cancer in England and Wales who know just how much the prospect of precious extra time with their loved ones really means.

"We are delighted that NICE has overturned its earlier decision after reviewing the evidence.

"We are also pleased that the manufacturer responded to our call for a further reduction in price.

"We picked up the baton for these men – for whom other treatment options have run out – and led this campaign with a strong conviction that NICE's decision had to be changed ...

"We are grateful to the politicians, clinicians, media, partners, and men, who joined us in championing the rights of men with this disease, which has suffered a legacy of neglect for decades. If the past few weeks have taught us anything, it is that accepting the status quo is just not acceptable.

"The rates of prostate cancer diagnosis are rising in the UK – against a backdrop of imperfect tests, complex treatment options that risk unnecessary side-effects, and a postcode lottery when it comes to support and information.

"Nothing short of strident action is needed for the fathers, grandfathers, husbands and best friends this disease affects all too regularly. The victory around Abiraterone in England and Wales has to be the beginning – not the happy ending".

### A warning for eight

Eight of the 97 men who took part in our fourth and probably final PSA testing session at Thetford on May 24 have received "Red" letters from David Baxter-Smith to alert them to the fact that their result was at such an elevated level that they should seek further advice from their GPs.

A further three have received "Amber" letters to say that their result was above normal.



Consultant urologist David Baxter-Smith "in action" at the Thetford PSA testing session

The remaining 86 have been sent "Green" letters stating that they are within the "normal" range.

Of the 97, 81 men came from Thetford, nine from Brandon, four from Norwich and three from Diss.

The age breakdown of the 97 was: 45-49, 9; 50-54, 17; 55-59, 15; 60-64, 24; 65-69, 12; 70-74, 8; 75-79, 11; 80-84, 1.

David Baxter-Smith has also recently conducted a similar testing session in Ipswich where the number of "Reds", 8.9%, very much reflected the Thetford results. Vice-chairman Ray Cossey says that the results at Thetford and Ipswich seem to confirm the real benefits of "targeted screening". "Like us, Ipswich appealed for men with a family history of prostate and/or breast cancer or who had been refused a PSA test by their own GP.

"The comparative age breakdown showed that Ipswich had a far higher proportion of men in the 65-69 age band – which we already know from our past results is the "dangerous age-band".



# From where I sit – the chairman's view

## Meetings

I believe, and am sure you will agree, that getting the whole group membership together benefits all concerned. It was encouraging to see the turnout of just under 100 members and partners for the talk by Professor Colin Cooper on June 11.

It was also good to know that, thanks to an article in the EDP and our own publicity, some 20 new men turned up. Of these probably half will join us.

I'm sure that everyone hearing about Colin's research hopes that he and his colleagues can find an answer to the earlier diagnosis and successful treatment of this disease.

With regard to our open meetings next year, would you like to comment on the type of speaker that we have and the subject matter presented?

It may be that you would like to take a break from medical matters and have someone talking about income tax.....only joking, but for example your ex-chairman Ray has an excellent talk about wartime Norwich.

## Thetford PSA Test Results

We have received preliminary results from David Baxter-Smith for the test session held in May. A total of 97 men attended, following a targeted ad campaign.

This resulted in eight men being identified as needing further investigation. This is the highest percentage of "reds" so far from our four sessions.

Thankfully, 86 men will receive "green" letters, whilst three men have "amber" letters coming.

Ray will be producing a much more detailed analysis later when all the figures are available, but in the meanwhile my thanks to all involved with the Thetford session, and let's hope that our help in the early detection of possible PCa means that the men concerned are treated quickly and effectively.

## What did he say?

It might be a function of age, it might be that we are scared of learning the facts, but when a doctor or consultant tells us what is wrong with us we don't always take it all in – well, I don't, anyway!

We have heard of an initiative launched by the Edinburgh & Lothian PCSG who have funded a recording device which is used at the diagnosis discussion to record the conversation.

The patient can then take a CD home (only one copy is made) and play back the conversation later when he has recovered from the shock – or, better yet, he can let his wife/partner listen to it and therefore get a proper understanding of the situation.

You are all past that point, but I would welcome an opinion from you if you feel that it would benefit newly-diagnosed men in our county if we made that facility possible at the N&N.

## Big C Centre

Those of you who have attended previous "Meet & Chat" sessions at the Big C know that they offer a quiet, friendly place to rest and have a cuppa and relax. Internet connection is available, along with a comprehensive library. If you haven't visited yet I can recommend it.

The Big C allow us to use their facilities for meetings, etc, and I have had a request from their head of marketing, Jamie Cooper, for as many of our members as possible to take a look at their web site [www.big-c.co.uk](http://www.big-c.co.uk) and give an opinion as to its degree of interest for men in particular. Jamie feels that the content may be perceived to be too female-oriented.

"Any feedback would be appreciated, even if you have strong feelings either way," says Jamie. "We would like our services to be seen to be open to everyone but can't do it without your help and advice. Anonymity will be respected."

Email: [Jamie.cooper@big-c.co.uk](mailto:Jamie.cooper@big-c.co.uk).

## Fitness & You

We have obtained a DVD which sets out a number of gentle exercises that can be carried out at home using everyday items such as a staircase, chair, table top, etc. The beauty of this DVD is that the instructor shows all the moves and encourages you to do only as much as you feel capable of.

Furthermore, it is produced by NHS Norfolk Health Trainer Service who will assess you in a brief meeting to ensure that the programme is suitable. Committee member Stan Thompson, and Nurse Sallie Jermy and I have viewed the DVD and we all think that it is suitable for gentle "limbering up" and because it can be done at home you wear what you like!

If you would like to comment on "Meetings", "What did he say?" or this item please email me at [noel.windfall5@btinternet.com](mailto:noel.windfall5@btinternet.com), or get in touch with our editor, David Paull, either by email at [DavidLPaull@aol.com](mailto:DavidLPaull@aol.com) or by post to 8 Lindford Drive, Eaton, Norwich, NR4 6LT.

## Nasty or NICE?

I am sure that we could not be hard hearted to a fellow PCa sufferer, Abdelbaset al-Megrahi, even if he had been convicted of one of the worst terrorist acts ever to be inflicted on this country.

But to hear, as we did from Colin Cooper, that when he was returned to Libya – ostensibly to pass away quietly within months – he lived for another 36 months because he was treated with Abiraterone, I expect that we must have felt a sense of injustice.

Our (founder) member Ray Allen – and fellow committee members – had to fight, cajole and argue the case for him to be given a course of Abiraterone, but when NICE finally gave way it was too late for Ray Allen. Nasty.



# Tim goes walk-about

Tim Farnham, group committee member and publicity officer, is going for a walk. In September, he is going to walk around Norfolk – for 240 miles! It's a big county. Much of his route will follow the county's long-distance national trails such as Peddars Way, the North Norfolk Coast Path and Wherryman's Way. He hopes to average about 12 miles a day and the route and where he plans to be each day can be found on his web site:-

[www.walknorfolk.wordpress.com](http://www.walknorfolk.wordpress.com).

Why is he doing it? Let Tim explain: "I am a farmer from near Dereham ... and have in recent years been diagnosed with chronic lymphocytic leukaemia and prostate cancer.

"Thanks to early diagnosis and the NHS I am in good shape and would like to raise some money as a way of giving something back." It's also an opportunity to raise awareness of the importance of exercise to improve our chances of living to a ripe old age.

How can we help? First and foremost, by sponsoring Tim. The money he raises will be shared between our group and Big C.

If you haven't already got a sponsorship form to thrust in front



Tim – Right foot forward!

of your friends, family and colleagues, you can contact Tim by email at:- [rookfarn@googlemail.com](mailto:rookfarn@googlemail.com).

"The second thing is much better fun and will help me even more," says Tim.

"What I want is for you to do a section of the walk with me and get as many people as possible to sponsor you to do so – a couple of days or just one day, just a few miles or even the whole thing if you have the time and energy. This way you enjoy walking in the Norfolk countryside, I get some company on my travels and you raise some money for a good cause."

Tim's web site will be updated regularly and you will be able to read his blog to find out where he is and expects to be in the next few days.

*Tim's picture is by Angela Sharpe, a freelance photographer (formerly with Archant) who took it as part of a 10,000-photo challenge to raise money for a national prostate cancer charity. Her father died of the disease last year. She has just completed the challenge and will be having an exhibition of the photos at The Forum in Norwich later this year.*

## A big thank-you

An anonymous benefactor who has been a patient at the Spire hospital in Norwich has made a donation to the group of £1,000. Chairman Noel has written to him via the hospital director, Dan Cyprus, to thank him for his generosity.

We have also received £180 given by mourners instead of flowers in memory of George Henry Coleman, of Toftwood; £110 collected by Robert Drew during pig farming presentations; and £10 from VG and FM Allum.

These donations – together with £647 from collection boxes on the night – will help to offset the cost of the Thetford PSA event. The total bill was £2,050, nearly half of it accounted for by the cost of the laboratory tests of the samples.

## Come for mardle

We know from the feedback we receive that members – especially those who have been recently diagnosed – have found our Meet & Chat evenings very helpful and reassuring.

The next is on Monday, October 1, in the relaxed setting of the Big C Support and Information Centre at the NNUH between 7 and 9pm.

If you know of any members who are perhaps reluctant to come to our lecture meetings but might welcome the chance of an informal natter, why not try to persuade them to come along?

And if you know of anyone who is undergoing treatment or might be soon and is not (yet) a member of the group ... even better if you can bring them along with you.

## Not just hormones!

A chance for our Yarmouth and Waveney area members to hear an excellent talk that members who attend the Norwich meetings heard last December.

On Monday, August 6, Dr Jenny Nobes, a consultant oncologist at the Norfolk and Norwich Hospital, will be speaking about **"Drug treatment for prostate cancer: It's not just hormones"**. The meeting will, as usual, be in Burrage Centre lecture theatre at the James Paget Hospital, starting at 7pm.

Do note that the free parking area is now slightly different from before. You can find a map on our website:-

[www.prostatesupport.org.uk](http://www.prostatesupport.org.uk) under "How to find us – at James Paget Hospital".



# They're after your money!

Ever been had? It's all too easy to find yourself the victim of con-men, whether it's the roving rogue who offers to do some minor repair work, "finds" a lot more wrong and demands a lot of money, or the highly sophisticated share-dealing fraudsters who can clean out your savings.

Our treasurer, Dave Kirkham, knows a lot of people who have been had. In his working life until a few weeks ago, he was Detective Sergeant Kirkham of the Norfolk Police economic crime unit. But, even as he joins the ranks of the retired, Dave is still concerned that some of our older – and perhaps not-so-old – members might fall foul of, for example, share scams. "Legitimate financial advisers and stockbrokers will never, ever, cold-call potential investors in the UK because cold-calling to sell financial products in the UK is against the law," he says. "So if you get a phone call from stockbrokers claiming to be calling from New York, Tokyo, Zurich or wherever, they cannot be genuine because no genuine firm would risk heavy fines for mis-selling."

Dave also warns us to beware of "posh" names that the villains make up to sound impressive. At random, pick any two of the following: Berkeley, Burlington, Cavendish, Carleton, Dupont, in fact, anything with "de" in front, such as de Montfort, Grosvenor, and so on, then add Advisors, Associates, Investments, Partners ... See how easy it is to come up with the very convincing Carleton de Montfort Associates. Add a mail-drop address in Geneva or some other money-laden location and you are in business.

The rogues don't target youngsters who are mortgaged to the hilt. They are after our nest-egg that we have spent years building with a view to "leaving something for the children" – and they know that we come from a generation that was rather more trusting and naïve.

While we men fall for this sort of scam, our ladies can be strangely susceptible to lottery frauds. "I don't know why but they can't resist the approach that you have won a prize in an Australian, Brazilian, Canadian, Irish or, most often, a Spanish lottery and must pay a 'registration fee' in advance to collect your winnings. Just remember the Camelot National Lottery catchphrase: *You've got to be in it to win it*. If you haven't bought a ticket, how can you possibly have won that fantastic prize?"

The final word from Dave: "If it sounds too good to be true, it almost certainly is. Just don't touch it with a bargepole."

## Dates for your Diary

Wednesday 4 August &  
5 September

**Radiotherapy Department**  
Open Evenings, Big C & Colney  
Centre, NNUH. Meet at Big C  
5pm (optional). Tour 6-7pm

Monday 6 August 7-9pm  
Open Meeting at James Paget  
Hospital, Great Yarmouth

**Dr Jenny Nobes**  
Consultant Oncologist  
**"Drug Treatment for Prostate  
Cancer: It's not just  
Hormones"**

Monday 3 September & 5  
November 7-9pm

**Committee Meetings, Big C**

Monday 1 October 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.**

Monday 3 December 7-9pm  
Open Meeting at Benjamin  
Gooch Theatre, NNUH

**Martin Bell OBE**  
**Our Patron, former MP and  
war correspondent**

## The Yorkshire Three Peaks Challenge

Mark Sayer is taking part in this event on September 1 with four friends. They will be raising funds for – and awareness of – the NWPCSG. His father, Peter Sayer, a member of our group, nominated us when asked to choose one of the charities he would like his son to support. 50% of funds raised by Mark will be given to us.

More information on [www.thethreepeakschallenge.co.uk](http://www.thethreepeakschallenge.co.uk).

## How to Contact Us

- **Telephone the Specialist Nurses:**  
**Sallie, Wendy, Helen & Rachel**  
Norfolk and Norwich University Hospital  
01603 289845  
**Angie & Wendy**  
James Paget Hospital  
01493 453510  
**Lizzie – Macmillan Info & Support Radiographer**  
01603 289705
- **Help or Advice:**  
**We have 29 members available at the end of  
a telephone ready to help.**  
**There is probably one near you.**  
For more information please call 01508 488088,  
01603 720980 or 01328 862927
- **Letters to the Editor: David Paull**  
[DavidLPaull@aol.com](mailto:DavidLPaull@aol.com)
- **E-mail us: Noel Warner, Chairman**  
[noel.windfall5@btinternet.com](mailto:noel.windfall5@btinternet.com)
- **Visit our website:**  
[www.prostatesupport.org.uk](http://www.prostatesupport.org.uk)