Norfolk & Waveney
Prostate Cancer Support Group

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Raising funds – and awareness

More than 30 prostate patients together with their wives and partners went along to another highly successful meet and chat morning at the James Paget Hospital, Gorleston – and our chairman of trustees Ray Cossey came away with donations to the group totalling more than £3000.

Graham Manning had a nasty shock when he was diagnosed with cancer in March but fortunately it was discovered early enough to be treated successfully. He had the operation and has since been given the all-clear.

"It really was such devastating news," said Graham, who at 54 is one of the younger men to fall foul of the disease. "You are just full of emotion and you just don't know what is going to happen next. It was a roller coaster of emotions, not just for myself but also for my wife and three children."

Graham and his wife Trudy are now campaigning to make men – and their partners – aware of the threat. "Many men don't have a choice of treatment but they could have done if only they had known about, asked for, or been offered a PSA test at the doctors," said Graham. "Don't ignore the fact or the symptoms. All men over 50 are entitled to a free PSA test which won't say whether you have cancer but it will show up any irregularities that need to be checked further."

After getting the good news about her husband, Trudy decided that she wanted to help by raising money and awareness, so she organised a "coffee and cake" event at their home in Bradwell. Combined with a £500 donation from Graham's Angel Masonic Lodge, the couple were able to present Ray Cossey with a cheque for £2074.

In our last issue, we reported how Jill Siely, whose husband George had had surgery for prostate cancer, decided that, rather than receiving farewell gifts from clients when she retired from the Haven Veterinary Surgery at Yarmouth, she would invite them to make donations to the group. She and George then raised more money by holding a party at their Happisburgh home and asking guests to make donations. The total contributions amounted to £1370 and George took the opportunity of the meet and chat morning to present the cheque to Ray.

Big C – New Chief Executive

The new Chief Executive of Big C, Dr Chris Bushby, will give the talk at our next open meeting on Monday 7 December (7pm-9pm at the Benjamin Gooch Theatre, NNUH).

His subject will be ***"Big C Dynamics"***.

Big C was set up 35 years ago "to improve the lives of those affected by cancer in Norfolk & Waveney".

Mass testing: yes or no?

To test or not to test. That was the question posed in our last issue. Should we organise further mass PSA testing sessions like the four we ran several years ago?

The question arose from a discussion at a meeting of our committee. A decision on whether to go ahead with more tests was deferred for further consideration and, to get the debate started, Ray Cossey, chairman of our trustees, set out the pros and cons in an article in the newsletter.

There are strongly held opinions for and against. Dave Kirkham is so adamantly opposed to mass testing after researching the scientific arguments that he felt he should resign as our treasurer. He presents his reasons in an article on page 3.

In an attempt to achieve some balance in the debate, others were shown Dave's article in advance and invited to comment on it, so on these two pages, you will find their views.

Tim Farnham, former committee member who nobly raised a lot of money for the group by walking round Norfolk, is also firmly against mass testing.

On the other hand, our president and founder chairman, David Haines, is strongly in favour.

So too, hardly surprisingly, is David Baxter-Smith, the consultant urologist who carried out the testing for us and wrote letters to all the men who were tested – red, amber or green letters depending on the outcome of the test.

David Haines is firmly in favour

I am sure both Dave and Tim have strong and sincere views on this question, both from their own experience and from browsing the net. However, I cannot share their views. I too have read a great deal on the subject and I am sure that three of the top urology surgeons in the UK who I have discussed this question with cannot all be wrong, plus Mr David Baxter-Smith, Dr Tom Stuttaford and my own GPs, all of whom advocate an early PSA for all men over 50.

Dave suggests that men have died as a result of a PSA test. I would ask: Are specific numbers of such cases available, for comparison against the great number who have died because they did not have an early PSA test? During my time as your Chairman, I personally was told of over 20 such instances locally where diagnoses were too late.

We are fully aware that the PSA itself is not a diagnostic tool. It is one indicator of a possible problem. Before a biopsy decision is taken, which may or may not reinforce or discard the PSA indicator, further preliminary tests are undertaken, including the mandatory DRE examination, a computer recorded flow test, and in most cases, a repeat PSA.

I feel I owe my life to the elderly GP who sent me for a PSA test as a routine check. He himself had prostate cancer and died some time ago. I was told last Monday by a patient who now has multiple metastases that he wished he could have had an early PSA test, but his medical practice were lacking in knowledge and motivation at the time to make him aware that such an opportunity existed.

The debate will continue to divide both the medical establishment and the men at risk. I am sure that Ray Cossey would agree that our Awareness and Test programme did contribute to saving a number of lives in Norfolk. I am not aware of anyone losing their life or suffering severe anxiety as a direct result of our activities.

I note that there is a similar campaign emerging against routine testing for breast cancer. To this I would say that my late wife enjoyed a further ten years of life as a result of successful treatment for her breast cancer which was found as a result of an early routine mammogram.

As always , the final choice to take a test for either condition rests with the individual, after being made aware of the pros and cons.

Life is short.

Urologist David Baxter-Smith responds

Dave Kirkham is wrong to think that PSA testing is "internationally recognised as a mistake". He must be unaware of the Scandinavian results and also the Austrian Tyrol results. You and maybe he may be interested to review on Google The Melbourne Consensus in which many internationally recognised experts advocate screening.

"PSA cannot detect prostate cancer", he quotes. We recently had a man come to one of our events with a PSA of 800. What else could it be? We have never said that it will diagnose prostate cancer but can act as an indicator of prostate problems.

The earliest and most important symptom of prostate cancer is to have no symptoms at all; that is when it may still be curable. The first symptom could be back pain due to metastatic disease and then it is quite incurable. I have seen this presentation on several occasions and it breaks my heart.

"A proper medical examination" by which I suspect he means a DRE. I can feel a T3 or T4 tumour on rectal examination but I cannot feel a T1 or T2 tumour and these are the ones that are potentially curable. Perhaps the GPs in Norfolk have more sensitive fingers than me but I doubt it. Rectal examination is a very poor substitute.

Yes – very occasionally a man may die as a result of complications following prostate biopsies but let's just remember that 10,000 men a year are dying because they did not have a P.S.A. early enough. Men occasionally die following colon biopsy as a result of screening for bowel cancer, which is accepted.

Short-changed!

Thanks to a slip of the finger on the keyboard, a donation from Kathy Bell was reported in the last issue as £60. It should have been £80. Sorry – and again many thanks, Kathy.

Dave Kirkham argues the case against mass PSA testing

Science learns from its mistakes and moves on. The use of PSA as a screening tool for prostate cancer is now internationally recognised as a mistake.

Dr Richard Ablin, the man who discovered PSA back in the 1970s, has described PSA screening as a "public health disaster".

He says: "…the test is hardly more effective than a coin toss. As I've been trying to make clear for many years now, PSA testing can't detect prostate cancer and, more important, it can't distinguish between the two types of prostate cancer — the one that will kill you and the one that won't…"

This view is shared by the BMA, the NHS, and major charities such as Prostate Cancer UK, and Cancer Research UK. The latest research by the Canadian Government Health Task Force concludes that PSA screening does more harm than good. Overtreatment results in the premature death of men who would never have died from prostate cancer.

We should be advising men with symptoms of prostate cancer to have PSA tests done by their GPs as part of a full range of examinations to determine precisely what ails them. There are many other serious illnesses such as bladder cancer and kidney cancer which produce similar symptoms, but will not raise the PSA. PSA screening is not a valid substitute for a proper medical examination.

Most men who are diagnosed with prostate cancer in Norfolk and Waveney do not contact our group or attend our meetings. We should be asking ourselves why, and coming up with initiatives to meet their needs. We should not be worrying men who have no symptoms of prostate cancer and are otherwise living fulfilling and care free lives.

My sources include: http://www.nytimes.com/2010/03/10/opinion/10Ablin.html?_r=0 and http://canadiantaskforce.ca/news/2014-10-27/canadian-task-force-recommends-against-screening-for-prostate-cancer/

Tim Farnham offers a personal viewpoint

The issue of PSA testing at a population level remains controversial. There appear to be few, if any, medical bodies advocating mass or routine PSA screening currently. Much of the enthusiasm for PSA screening in the USA appears to be driven by drug companies and medical insurance schemes.

The evidence surrounding the effect of routine PSA testing on men's chances of dying of prostate cancer and of their general mortality rate is conflicting. It would be simple to cherry-pick studies to support an existing viewpoint and this temptation should be resisted.

There are specific risks associated with PSA testing that men should be aware of. These include: Unnecessary treatment; false reassurance due to 'false negatives'; complications resulting from trans-rectal biopsy; incontinence and erectile dysfunction following treatment.

Men over 50 should be made aware that they are eligible for a PSA test, but any test should be preceded by detailed unbiased counselling. There is a view that the DRE is just as effective as PSA testing as an initial screening approach, though men universally find it an unpleasant experience.

There may be a case for testing men over 50 who are at higher risk due to ethnicity or a close relative who has had prostate cancer. This should only be following detailed counselling. Men who have symptoms or who are anxious should consult their GP to discuss the appropriate course of action.

Logically there may be a case for the use of PSA testing to provide a baseline for ongoing monitoring. The danger is that there is a tendency to move straight from a higher-than-normal PSA test result to biopsy and potential treatment when monitoring over a period of time might be more appropriate.

There should be shared decision-making between GP and patient about the risks of prostate cancer and the appropriate course of action.

Much of the foregoing lies outside the remit of a patient support group. Given the workload of most GP's the most appropriate role for the group might be the support of existing patients and the dissemination of unbiased information to the general male population. The balance of scientific and medical opinion suggests that advice given directly by the group should be neutral and balanced on the subject of PSA testing. At the present time my personal view is that promoting mass PSA testing sessions is not the best way forward for the support group.

For the future, hopes rest on the two-pronged approach of finding a more accurate diagnostic test and being able to distinguish the cancers that need prompt treatment from those that don't. In the meantime a cautious approach would seem to be indicated.

A cautionary tale!

Newsletter editor David Paull writes:

For some time now I have been having injections of Decapeptyl. It does exactly the same thing as Zoladex and similar injections other members are having.

For various reasons and because I failed to make a note in my diary, I was late booking my latest injection. Too late! What I hadn't realised is that, if you are more than a week late booking your treatment, you can't have it. If you did, you would get tumour flare sparked by a rise in testosterone. Not nice!

The result was that people whose time is more valuable than mine had to waste some of it checking the correct procedure to get me back on track. The outcome was that, in a sense, I had to start all over again – on Cyproterone acetate (remember that, those of you on Zoladex, etc?) before I could resume Decapeptyl.

The moral of this story? Make a clear note in your diary – paper or electronic – to book your next injection in good time, then you won't feel a complete idiot like me.

Yes for Scotland but not for England

Scientists are doing a splendid job in creating wonderful new drugs to help men with advanced, incurable prostate cancer that has spread to other parts of their bodies. But whether you can have them may well depend on where you live – and the best place to live is in Scotland.

The Scottish Medicine Consortium (SMC) has ruled that Abiraterone and the latest treatment to come on stream, Radium-223, will now be routinely available to all men, regardless of whether they have had chemotherapy.

But in England Abiraterone is normally available only for men who have had chemotherapy although, until April next year, it can be available pre-chemo through the Cancer Drugs Fund.

Radium-223 has only recently been approved but was almost immediately struck off the Cancer Drugs Fund list, even before the final appraisal which is not due to be completed until January. And the treatment has not been available in Norfolk. The handful of patients who were placed on the treatment before it was struck off have to make a monthly trip to Addenbrooke's Hospital, Cambridge.

Now that Scottish patients have had the good news Prostate Cancer UK is stepping up its campaign to get both treatments made routinely available to all men in the rest of the UK.

Heather Blake, UKPC's direct of support and influencing, said: "Delighted though we are for men who are able to routinely access these drugs in Scotland, our work will go on until the National Institute for Health and Clinical Excellence follows SMC's lead and approves these treatments as the next step towards delivering full access for men throughout the whole of the United Kingdom."

£10 test a life-saver?

Could a simple urine test costing no more than £10 help to save thousands of lives? Early trials show that the test not only picks up signs of prostate cancer but also shows the size of tumours and appears to be twice as accurate as PSA tests.

It would enable patients to know within minutes whether they had cancer based on levels of EN2 in their urine, a protein that is produced by tumours, and allow doctors to determine more quickly what treatment, if any, is needed.

But don't hold your breath because, contrary to a national newspaper report, it will be some time before it is ready for routine clinical use.

So far the test has been trialled on only about 1000 men and is only now moving on to a much larger clinical trial involving many thousands of men. It must also be approved by regulators before it can be adopted by the NHS.

However, this field of biomarker science is seen as a hugely important area of research. "Knowing what to look out for between men at high risk and low risk of prostate cancer, between aggressive prostate cancers, cancers that are responding to treatment and cancers that aren't responding, will make an enormous difference to men with, or at risk of, prostate cancer over the next five years," says Prostate Cancer UK.

Dates for your Diary

Wed 2 Dec and 5 Jan. 5.30-7pm

Radiotherapy Department

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

Call 01603 288779 to book.

Mon 7 Dec. 7-9pm

Open Meeting at Benjamin Gooch Theatre, NNUH

Dr Chris Bushby

Chief Executive of Big C on *"Big C Dynamics"*

Mon 1 Feb. 7-9pm

"Meet & Chat" at Big C Centre, NNUH

An opportunity for newly diagnosed patients to chat with members who have

Dogs with very sensitive noses

Dogs appear to be able to sniff out cancer with remarkable accuracy and the NHS is to take part in first UK trials using dogs to detect prostate cancer. The Medical Detection Dogs charity will be taking urine samples from 3000 patients at Milton Keynes University Hospital as part of a three-year trial.

Nine dogs – six Labradors, two spaniels and a Hungarian Vizsla – which have had six months' training to detect cancerous odours will assess the samples for prostate cancer as well as kidney and bladder tumours. When they suspect that a sample is cancerous, they have been taught to sit up straight, still and alert. Tests run so far by Medical Detection Dogs have shown a 93% accuracy. If the trial is a success, screening will be offered at clinics funded by charities in Cheshire and Warwickshire.

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- ***Help or Advice – Our Welfare Team:***
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