Norfolk & Waveney
Prostate Cancer Support Group

Registered Charity No. 1108384 | Newsletter no 32 November 2010 | Patron: Martin Bell OBE

The View from the Chair.....

When I took the chair of your group, in June 2008, I promised the Committee that one of the principal things I would attempt to do would be to generate more public awareness and interest in prostate cancer, by raising its profile, throughout Norfolk & Waveney.

As we now head into the final six months of my tenure of office I think I am justified in claiming that this objective has been achieved; mainly due to the dedicated work of the committee and others, all of whom share my aims and objectives.

The 'others' include the Graham Fulford Trust, which first inspired the Committee to undertake our own local, mass PSA testing sessions.

Then there's Mr. David Baxter-Smith, the Kidderminster-based urology consultant surgeon, who has supported our work in a most hands-on fashion. He has also, single-handedly, interpreted all the laboratory test-results and has written personal letters to over 13,000 men, tested by the Graham Fulford Trust, over the past two years. The man deserves a medal.

The statistics from our three sessions, held in Norwich (March 2009), Great Yarmouth (September 2009) and at Fakenham (October 2010) have revealed that this region has a greater than the national average percentage of men with a higher-than- expected PSA level. There appears to be no apparent reason for this anomaly.

Each of the 642 men we tested at our three sessions was sent a 'green', 'amber', or 'red' letter, from David Baxter-Smith. 'Green' - if there was nothing abnormal about their PSA level reading; 'Amber' - if it was above normal; 'Red' - if it was at such an elevated level as to suggest the need for further investigation, by their own GP.

Overall, there were 563 green, 32 amber and 47 red letters sent out and, from information volunteered by some of the men tested, we know of 12, (from the first two sessions at Norwich and Great Yarmouth), who have been, or are now being, treated for prostate cancer.

At these two sessions the youngest man to receive a 'red' letter was aged only 48 and the oldest was 81. As might be expected, the vast majority of the 'reds' were within the 65-75 age range.

It is too early for us to have received any follow-up advice from the 218 men tested at Fakenham, on 23 September this year, but it is likely there will be a similar ratio found to have prostate cancer, as with the earlier two sessions.

With 21 reds being found at Fakenham, as against Norwich (15) and Great Yarmouth (11) we have to anticipate that there will more than likely be a greater number of instances of prostate cancer being diagnosed, from those tested at that session.

Over the next few weeks we will be undertaking a more detailed analysis of the results of our three sessions and, in due course, we shall be seeking a meeting with the management of the local PCTs and Anglia Cancer Network, to present our findings to them.

We will also be highlighting the many identified instances of men had been previously refused a PSA test by their GP; some with a family history of prostate and/or breast cancer. This has to be matter of some real concern to them.

The Fakenham session was the final one we intend to undertake for the foreseeable future. The net cost to the Group is of the order of £1000-£1,500 for each session, so it is not possible to underwrite the costs of any more sessions at this time.

I and your committee feel that our aim, to create a greater awareness of prostate cancer throughout Norfolk and north Suffolk, has been achieved.

From hereon we intend to concentrate on and, where necessary, extend our involvement with support and information; these being the two principal aims and objectives of this Group when it was set-up some seven years ago.

At last month's committee meeting I suggested that we carry out what I call an 'audit' of the Group's way of operating. We need to review both what we are doing and the way in which we are doing it? This will involve reviewing such matters as Open Meetings' – their frequency and venues; the Newsletter – the frequency of editions and the format; a review of the Membership and the resultant mailing lists. These are just a few of the things we need to take a good look at. Procedures which were first adopted some seven years ago may now need to be reviewed and reassessed, to see if they still serve us as well as they might?

I have already told the committee that this will be the third and final year of my chairmanship and I feel most strongly that I have a duty to ensure that I leave the Group's affairs and procedures in good order, so that it has the best chance of continuing for many more years. This is, I hope you will agree, the best legacy I can leave behind me.

In the meantime, is there any member out there prepared to take over from me as chairman, in April next year?

If you are even slightly interested, please call me to have a chat about it, without any commitment at this time. You can call me on 01603 720980, anytime.

Ray Cossey - Chairman

As prostate cancer sufferers are well aware, the issue of prostate cancer screening and its potential for saving many of the 10,000 men who die of the disease in the UK each year, has been stalled because of the very well documented shortcomings of the only currently practical test that could be used, the PSA Test.

Prostate cancer, in its early, curable,stage, normally has no symptoms. It is in a harmless form extremely common and many men are never aware that they have it.

Patients, have for years been calling, if not for full PSA-based screening, at least for a programme to encourage men at risk to take the test.

However, clinicians, concerned about the harm that would be done by the diagnosis and treatment of irrelevant cancers that will never trouble a man, are largely sceptical about the benefits of such a course.

So, official policy about PSA testing has been, at the very least, equivocal, with a strong bias towards not encouraging men to have the test.

It is the belief of the vast majority of patients that this is leading to late diagnosis and in March last year, results of a large European trial were published that, for the first time, showed clear a reduction in mortality from PSA-based screening.

Unfortunately, it also showed that this was accompanied by a large measure of over-treatment, and did nothing to resolve the controversy – if anything it fuelled it.

Last November, the Prostate Cancer Support Federation, held "The Great PSA Debate".

Led by acknowledged experts from both sides of the argument, we achieved a remarkable 100% consensus that what is needed is a more sophisticated, risk-based, approach to early diagnosis, in which a number of factors, including PSA, are taken into account before a man is recommended for invasive biopsy..

Directly as a result of that consensus, a trial is now being proposed, with widespread support from some of the top clinician-researchers in the country. That's Patient Power!

A serum PSA test, on its own, is a poor measure of the likelihood that a man has prostate cancer, unless the reading is very high.

Approximately 20% of dangerous prostate cancers show no significant raise in PSA levels, and in more than 75% of the cases where it is raised, subsequent biopsy does not show the presence of cancer.

So, as a screening test it fails on both the key counts: it is not specific (abnormal results indicate cancer in only a third of cases) and it is not sensitive (cancer can exist without raised PSA).

The Group has contributed £3000 towards the cost of setting up a trial aimed at bringing about a major improvement in the way the risk of a man developing prostate cancer is assessed.

The proposal for the trial is a direct result of a The Great PSA Debate staged by the Prostate Cancer Support Federation (of which your group is a member).

Here the chairman of the Federation, Sandy Tyndale-Biscoe, explains the thinking behind the trial.

With our contribution the target amount for this phase of the project has been reached.

The reduction in mortality shown by the European Trial was bought at enormous cost in needless painful and occasionally dangerous biopsies.

It is estimated that, for every 1000 men screened the number of biopsies would rise from 192 to 368 and the number of cancers discovered would rise from 48 to 82 - but only a single life would be saved.

The problem, of course, lies not in the PSA test per se, but in the way the results are handled. Automatic referral for biopsy, against some notional agerelated threshold value, is never going to work.

Recent research, however, has shown that when you factor in a number of other indicators, such as ethnicity, family history, urinary symptoms, and, significantly, the ratio of free-to-total PSA, you can get an accurate assessment of the risk that a man has a dangerous cancer.

The aim of our proposed trial is to show how use of such a technique, could significantly reduce the number of biopsies, without reducing the number of significant cancers discovered.

If such were demonstrated, it would be a major step on the road to the change in clinical practice that would save lives.

To change clinical practice needs evidence, and that doesn't come cheap. Randomised trials represent the "gold" standard for evidence, otherwise, advocacy or pessimism can have strong effects.

A large, "well-powered" study is required to provide robust evidence and change clinical practice.

The risk based screen would be employed in General Practice as this represents the first point of contact for most patients.

GPs' practices would be randomised, some to deliver an active intervention using a risk based assessment (the Sunnybrook risk calculator) and others to use the current threshold based PSA test, with no active encouragement.

There will be 3 main phases -

- **Trial protocol** approved and ethics committee and other governance approvals obtained
- **First practices recruited** - Oct 2010 – Mar 2011.
- **Full recruitment** and main body of work and analysis Mar 2011 – Jun 2014

The trial will be run by some very eminent researchers and clinicians, including, Prof John Anderson (president-elect of the British Association of Urological Surgeons), Prof Kenneth Muir (Warwick University), Dr Chris Parker (Royal Marsden) and David Baxter-Smith (Prostate Cancer Support Federation Medical Adviser)

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Total costs for the trial are estimated to run to about £2M, with nearly £200,000 needed in the first twelve months.

Because the trial is in tune with general medical trends towards risk-based approaches to screening, the principal researchers are confident that the major funders will be supportive.

But getting our hands on their money takes time, and we are at the wrong point in their budgeting cycles.

From patient's perspective, time is of the essence.

If we get this trial started now, there is a reasonable hope that clinical practice could be changed significantly for the better by 2014.

This is why the Prostate Cancer Support Federation, a charity with very small resources, is committed to raising, over the next two or three months from its member organisations between £10,000 and £20,000 to provide seed corn funding to get the work started.

We have other potential sources we are approaching to cover the rest of the first year's work.

Please give it your backing, and make patient power a reality.

Sandy Tyndale-Biscoe

HORMONE TREATMENT AND DIABETES?

A member of the Group who has had hormone treatment has written the following for the information of other members ......

Dear Friends,

There is some relatively new material on the Internet (2008 & 2009 research results) linking diabetes, particularly Type 2 Diabetes with low testosterone levels in general terms and specifically with Hormone Therapy in Prostate Cancer Treatment.

Your GP may not be aware of this, but Astrazenica who manufacture Zoladex, are recommending that men treated with Zoladex have their blood sugar levels regularly monitored.

The Internet links are as follows:

ttp://www.netdoctor.co.uk/medicines/100002862.html

"Your doctor may want to monitor your blood sugar levels while you are being treated with this medicine…"

http://www.medsafe.govt.nz/profs/Datasheet/z/Zoladex10implant.htm

"…A reduction in glucose tolerance has been observed in males receiving LHRH agonists. This may manifest as diabetes or loss of glycaemic control in those with pre-existing diabetes mellitus..."

http://www1.astrazeneca-us.com/pi/zoladex10_8.pdf

Recent major changes"

Warnings and precautions, hyperglycemia (5.3), 09/2008

Adverse Reactions, Post-Marketing, Glucose Tolerance (6.5) 09/2008

5.3 Hyperglycemia

Hyperglycemia has been reported in patients receiving GnRH agonists including ZOLADEX.

Hyperglycemia may manifest as diabetes mellitus or worsening of glycemic control.

Monitor blood glucose in patients receiving ZOLADEX and manage with appropriate medical care."

N&WPCSG is not able to comment on the validity, or otherwise, of this information, but feels members should be informed so that they can mention it to their GPs if they wish.

Holiday Insurance

A member has drawn attention to a newspaper article about travel insurers AllClear Travel.

AllClear Travel is reported to offer insurance for people over 65 with medical conditions which other insurers often refuse to consider.

They say they will give cover for people with almost any condition as long as they have persmission to travel from their doctor. This includes people with cancer still receiving treatment.

Again - no endorsement, but members can get more information from AllClear's website - www.allclear.co.uk (where they are offering a 20 per cent discount for online customers.)

Bladder Scanner handed over to N&NUH

The bladder scanner which the Group has given to the Norfolk and Norwich University Hospital was handed over to consultant oncologist Dr. Robert Wade at the August open meeing.

Dr. Wade told members how essential it was for a patient undergoing radiotherapy of the prostate to have a full bladder before the start of a treatment session. The scanner enables oncologists to be certain of this.

Costing just under £8,000, the scanner is being used specifically for patients with prostate cancer.

Ray Cossey, (right), presents consultant oncologist, Dr. Robert Wade, with the bladder scanner.

Dates for your Diary

Monday 6 December

In the Benjamin Gooch Lecture Theatre, East Atrium Norfolk and Norwich University Hospital at 7 p.m.

John Wilson MBE
Angler, TV personality and prostate cancer survivor
"Angler's Yarns, TV Anecdotes and my Prostate cancer Experience"

Monday 7 February

Julia Hayward of The Really Healthy Company
Complementary Nutrition Therapy for Cancer.

Many Thanks for the following donations since the last Newsletter

VG & FM Allum	£10
J Whetter	£20
DL & IJ Paull	£30
S & J Mitchell	£572
Royal George (Chapter 52) Masons	£500
V Allen (Cake Sales)	£50
V King (The Lodge North Tuddenham)	£20
Wroxham & Hoveton Lions	£500

How to Contact Us

Write to : Norfolk and Waveney Prostate Cancer Support Group, c/o Urology Dept Norfolk and Norwich University Hospital, Norwich NR4 7FP

Telephone: Specialist Oncology nurses: Norfolk and Norwich University Hospital- Sally, Wendy or Helen on 01603 289845. **James Paget Hospital** - Angie or Wendy on 01493 45310. **Committee/Help**: 01603 713463 - 01603 881213 or 01328 862972. Email: David.haines@btinternet.com. **Newsletter editor:** Bernard Farrant 01603 664515. **Website:** www.prostatesupport.org.uk - email nwpcsg@hotmail.co.uk

The Newsletter

You can get the newsletter via the internet, where it can be read or downloaded from our website; www.prostatesupport.org.uk.

You get it sooner, and it saves us printing and postage costs.

If you would like to do this please email Harvey Meadows at **nwpcsg@hotmail.co.uk**

NORFOLK AND NORWICH PROSTATE CANCER SUPPORT GROUP

Registered Charity No. 1108384

Committee members

Medical Advice/Help (Specialist Uro-Oncology Nurses)
Norfolk and Norwich University Hospital 01603 289845

Sallie Jermy - sallie.jermy@nnuh.nhs.uk
Wendy Baxter - wendy.baxter@nnuh.nhs.uk
Helen Walker- helen.walker@nnuh.nhs.uk
Rachel Matthews - Rachel.matthews@nnuh.nhs.uk

James Paget University Hospital 01483 453510

Angie Fenn - angie.fenn@jpaget.nhs.uk
Wendy Keenan - wendy.keenan@jpaget.nhs.uk

President - David Haines 01603 881213 david.haines2@btinternet.com The Corner House 2 Peacock Close, Easton NR9 5JD

Chairman - Ray Cossey 01603 720980 ray@thecosseys.co.uk 73 Blofield Corner Road Little Plumstead Norwich NR13 5HU

Vice-Chairman - Edward Hare 01603 400424 Mobile: 07787124143 edwardhare@btinternet.com 84 The Warren Old Catton Norwich NR6 7NN

Secretary - Brian Smith 01603 860954 smiths.online@virgin.net 81, Nightingale Drive, Taverham, Norwich, NR8 6TR

Membership - Stan Thompson 3 Skedge Way, Blofield Corner. NR13 4RY. sa.thompson31@talktalk.net 01603 713463.

Membership - John Newman 01603 744581 john.newman990@ntlworld.com 62 Jerningham Road New Costessey Norwich NR5 0RF

Website Editor - Harvey Meadows 01603 737588 nwpcsg@hotmail.co.uk - 31 College Close Coltishall Norwich NR12 7DT

Treasurer - Dave Kirkham 01953 456858 Mobile: 07799 074372 dsdavekirkham@yahoo.com

Newsletter editor - Bernard Farrant 01603 664515 bernardfarrant@norwich.clara.co.uk 161 Rupert Street Norwich NR2 2AX

Welfare Officer - David Wiseman 01603 260539 david@wisemandav.go-plus.net 14 Manor Chase Taverham Norwich NR8 6UB

Display/Literature Mel Lacey 7976 901442 mel.lacey@talktalk.net

Chuck Lyons - 01328 862967 charleswlyons@aol.com 71 Norwich Road Fakenham NR21 8HH

Trustees: Harvey Meadows, Brian Williams, David Wiseman,

Do you need help or advice?

We have 29 Group members available at the end of a telephone ready to help.

There is probably one near you.

For details please ring our Welfare Officer, David Wiseman, on 01603 260539.