

# Norfolk & Waveney Prostate Cancer Support Group

Registered Charity No. 1108384

Newsletter no. 25 January 2009

Patron: Martin Bell OBE

## Chairman Ray Cossey explains why we are offering free PSA tests



Our long-term aim is to persuade the NHS that in common with breast and bowel cancer, there should be a national screening programme for prostate cancer.

Where such programmes exist, such as Austria and Ontario, early identification of the disease has led to vastly reduced rates of mortality compared with the UK.

However, persuading the NHS to change its current stance looks like being a long job.

In the meantime, we can give 200 men an opportunity to learn about prostate cancer, and have a free PSA test, and at the same time contribute data to an important national trial.

We are aiming at men who are unaware of symptoms which should encourage them to seek a PSA test, or who have symptoms but ignore them. Should the PSA result be normal, the individual will have a baseline for comparison against a future test.

This is very valuable, as the rate of increase in PSA readings gives a reliable indication that further tests, watchful waiting, or early treatment may be necessary.

So I urge group members to tell their friends and relatives over 45 get in early with a booking by ringing one of the numbers in the box on the right.

## A free PSA test for 200 men over 45 at our next Open Meeting

Norfolk & Waveney Prostate Cancer Support Group is offering 200 men over the age of 45 a free PSA test at an open evening in March.

The event will take place at the John Innes Auditorium, Colney Lane, Norwich on Thursday 5<sup>th</sup> March from 7-9p.m.

The evening has been organised in conjunction with the Graham Fulford Trust as part of a nationwide screening trial.

The Trust and Kidderminster Prostate Cancer Support Group have between them held 68 similar events across the country since 2005. In all 6788 men have had PSA tests, resulting in a "find rate" of cancers of about 3 per cent.

The aim of the sessions is to obtain data from 10,000 men. The results will be given to the NHS to help it to decide whether to introduce a national screening programme.

Men who book a place will be advised on the pros and cons of having a test - following NHS guidance - before deciding whether or not to give a blood sample for testing.

Retired consultant urologist, Mr David Baxter-Smith, president of the Kidderminster Group, will write to men telling them the result and advising on appropriate action in letters described as "green", "amber" or "red".

A Green letter tells a man that his PSA is in the normal range, but if he suffers from frequent voiding by day or night, or other symptoms he should see his GP.

An Amber letter tells man his PSA is borderline and he should have a further test in three months time.

A Red letter suggests that the PSA is significantly elevated and the man should see his GP.

Approximately 90 per cent of men tested so far have been in the normal range, 5 per cent borderline and 5 per cent significantly elevated.

Men in the "red" group are written to, within twelve months, and asked about the outcome. The majority of this group are found to have had early prostate cancer.

Speakers during the evening will include David Baxter-Smith and Graham Fulford. Our Patron, Martin Bell, hopes to attend.

## Tell your relatives and friends

The meeting will be publicised on radio and in newspapers from early February - including a slot with our chairman on Radio Norfolk's Morning Show between 10 and 11 a.m. on Thursday February 5<sup>th</sup>.

Men who are interested in having a test will be invited to ring 01603 - 881213, 01603-260539 or 01603-737588 to book a test. (People who want only to attend the meeting do not need to book - just turn up.)

Group Members have the opportunity to encourage relatives and friends to book a place before the event is more widely publicised.

For members of our Group this an important opportunity, as their close relatives are more at risk of getting the disease than the general population. For example, for the brother of a man with prostate cancer the risk is 2.5 times higher. Men from families with a history of breast cancer are also at greater risk.

## Scandinavian Trial shows Combination Therapy cuts death rate for locally advanced prostate cancers

Combination therapy that adds radiation to a standard medication for localized but aggressive prostate cancer results in longer survival and fewer signs of relapse than treatment with the drugs alone, Scandinavian scientists have reported in *The Lancet*.

Such malignancies make up roughly 10 to 20 percent of prostate cancer cases. Doctors call these growths locally advanced prostate cancers — tumors that are marked by fast growth and can even be felt by a doctor during a routine prostate examination. And although the cancer hasn't spread to lymph nodes or organs beyond the prostate, it has often expanded to the outside of the gland and can be lethal.

For such patients, doctors can use radiation treatments to kill cancer cells, or prescribe drug therapy to suppress the testosterone that fuels prostate cancer growth.

The benefits of using both had not been ascertained until now.

Researchers at 47 medical centers in Sweden, Denmark and Norway enrolled 875 men with this form of prostate cancer, average age 66, into a trial lasting from 1996 to 2002.

Half were randomly assigned to get drugs only, while the others also received radiation treatments, says study coauthor Anders Widmark, a medical and radiation oncologist at Umeå University in Sweden.

After an average follow-up of 7 ½ years, 79 men in the drugs-only group had died of prostate cancer or related causes, compared with 37 in the group that received radiation and drugs. Deaths from other causes were roughly equal between the groups.

Furthermore, 285 men assigned to the drugs-only group — but only 77 men getting the combined therapies — experienced warning signs of a return of their prostate cancer as evidenced by an increase in their prostate specific antigen (PSA) score. This measurement, obtained by a blood test, is a proxy for cancer and a jump in the score reveals “a very early relapse stage,” says Widmark.

“[This] is a pivotal trial, and is the first to show an overall survival advantage for radiotherapy in the primary treatment of prostate cancer,” according to Alex Tan of the Noe Valley Clinic in San Francisco and Chris Parker of the Institute of Cancer Research in Sutton, U.K., writing in the same issue of *The Lancet*.

“The results should change current practice, making long-term hormonal therapy plus radical radiotherapy the standard of care for men with locally advanced prostate cancer.”

Whether dual therapy would help prostate cancer patients who have slower-growing malignancies, the vast majority, remains unclear, these researchers say.

“Watchful waiting” may be best for elderly, frail men in that situation, whereas young or middle-aged men with slow-growing cancer have other options such as surgery or implantation of highly localized radioactive capsules.

In the new study, some well-known side effects of prostate cancer treatment showed up, and men getting the combined treatment experienced more of them than those on drugs alone. For example, five years into the follow-up period, roughly twice as many men in the combined therapy group than in the drugs-only group — 7 percent versus 3 percent — reported urinary incontinence. And roughly 9 in 10 men receiving the dual therapy reported erectile problems, compared with 8 in 10 men getting drugs alone.

On a more positive note, Widmark says radiation therapy has advanced since these men were treated and can now deliver more specifically targeted doses that are 10 percent greater than those used in much of this trial. Research has shown an added clinical benefit from the higher doses, he says.

*By Nathan Seppa - from Science News Web edition December 15th, 2008*

Note - Combination hormone and radiation therapy is a standard option at the Norfolk and Norwich University Hospital, and many members of our Group have been treated in this way.

### Hormone therapy survey

The Prostate Cancer Charity is developing an area of policy work around hormone therapy, its side effects and the support and information available to men and the partners of men who have received the treatment.

It wants to ensure that men who receive this treatment (and their partners) have access to the information and support they need.

They have asked invited members of our Group who have had hormone treatment, and their partners, to tell them about their experience of the treatment by completing one of two surveys. One survey is aimed at men who have received hormone therapy and the other is for their partners and spouses.

This is an important piece of work and the Charity would like as many people as possible to complete the surveys, which will help them to develop a comprehensive understanding of the impact of this treatment and its side effects on men and their partners.

It will also enable them to find out what support and information is available to help people cope with, or manage these side effects and identify gaps in the services available.

**So if you have received** hormone therapy treatment, or are the partner of a man who has, and would like to contribute, if you are on the internet, you can complete both surveys online at the Prostate Cancer Charity's website

[www.prostate-cancer.org.uk/campaigning/tellus.asp](http://www.prostate-cancer.org.uk/campaigning/tellus.asp).

Alternatively, if you would like to receive a paper copy of the survey call Katie Matheson Policy Officer

## Black men three times more likely to get prostate cancer

A new study has confirmed that black men in the UK are three times as likely as their white counterparts to develop prostate cancer.

The study, published in the British Journal of Cancer, shows that black men are diagnosed on average five years younger than white.

It also showed that the majority of black men do not know that they are at a greater risk of developing prostate cancer than white men.

Anna Jewell, Head of Policy and Campaigns at The Prostate Cancer Charity, said "The study is significant in that it shows that black men have a comparable knowledge of prostate cancer and experience of symptoms and are no more likely to delay visiting their GP than white men.

This gives greater weight to the theory that a genetic difference between black men and their white counterparts could explain the increased incidence."

She said the study produced very helpful information about why both groups may delay seeking medical attention.

It highlights that in black men it is more likely to be because they find the symptoms embarrassing or are scared it might be something serious. The research showed that a significant proportion of all men in the study delayed seeking medical attention.

"We would encourage all men to visit their GP if they are experiencing any possible symptoms of such as problems when urinating," she said.

She added "We would like to see further research into whether there are any differences in access to treatment or care between black and white men."

## UK prostate cancer initiative fails to influence PSA referrals

Research shows that the UK's Prostate Cancer Risk Management Programme has not significantly altered patterns of urologist referrals following PSA testing.

The guidelines were sent to UK family physicians in 2002 and recommended PSA levels at which further urology examination should be made.

Jane Melia and colleagues, from the Institute of Cancer Research in Sutton, Surrey, UK say "The referral rate was lower than expected if the guidelines had been followed. The influence of the guidelines seems to have been low."

They say this may have been because only 56 per cent of doctors participating in the study knew of the Prostate Cancer Management Programme.

The guidelines give PSA levels in men with no symptoms at which GPs are recommended to refer them for further examination. The levels vary with the age of the men.

To determine the impact of the PCRMP, the researchers compared the number of urologist referrals for men with no symptoms but with a PSA of 3 or above between December 2001 and May 2002 - before the initiative - and between December 2003 and May 2004 - after the PCRMP was launched.

They looked at information for 200 family physicians in 48 practices that tested 709 men before and 898 men after the PCRMP guidelines were issued.

Around 20% of the men tested in both the time periods had PSA levels which warranted further tests, but the proportion were referred to a urologist did not change significantly after the PCRMP - rising from 24% to 29%.

Reasons given for not referring men with an elevated PSA level included PSA being too low for referral, that the patient was asked to return for a second PSA test, comorbidity that should have excluded testing.

"Without routine, standardized data on reasons for PSA tests in general practice, it will be impractical to monitor trends in use of the PSA test, and its impact on general practitioner workload and detection of prostate cancer," the researchers observe.

They add: "There is an urgent need for evaluation to ensure future, effective implementation of guidelines."

Source - Br J Cancer 2008; 98: 1176-1181

**The Prostate Cancer Charity's annual Prostate Cancer Awareness Week has been extended to Prostate Cancer Awareness Month this year.**

**The month will be March and Support groups are being encouraged to join the Charity in its efforts to raise awareness of prostate cancer during the campaign.**

**You can keep up to date with the Charity's plans for Prostate Cancer Awareness Month by visiting its website - [www.prostate-cancer.org.uk](http://www.prostate-cancer.org.uk).**

## A Big Thank you.....

### **Our thanks for donations made in memory of:**

Mr Donald Carey  
Mr Ronald Cunningham  
Mr Neville Donmall  
Mr Leslie George  
Mr Roy Hider  
Mr Kenneth Laud

**And in celebration of the 70<sup>th</sup> Birthday of Mr John Drew.**

### **Thanks also for donation from:**

Bowers Chapter;  
Costessy Park Golf Club Senr Section;  
Diss Bowls Club;  
Feltwell Golf Club Senr Section;  
Freemasons Blakeney Lodge;

Lowestoft Probus Club;  
Sprowston Methodist Church Badminton Club;  
Sprowston Sports and Social Club;  
The Lodge North Tuddenham;  
Tolver Taxis;  
Mr & Mrs. R Allen (car boot sale);  
Mr & Mrs. L Earl;  
Mr. K Gee;  
Mr. D Haines;  
Mr. E Hare;  
Mr & Mrs. J Sheward;  
Mr & Mrs. E Willgos;  
Mrs. L Winter (sale of cards)  
Mrs. J Wolton  
The December Raffle raised £176..65

## Dates for your Diary

### Monday 2nd. February

Open meeting  
Talk by Prof. Dylan Edwards, UEA  
"Advances in Genetic Research for Prostate Cancer".  
NNUH East Atrium. 7-9p.m.

### Monday 2nd. March

Committee Meeting NNUH Room 4 - 7-9 p.m.

### Thursday 5th March

Public Open meeting  
**"PSA Testing and need for Screening"**  
Speakers: David Baxter-Smith, Consultant Urology Surgeon, Graham Fulford, and our patron Martin Bell  
PSA tests available to men over 45  
John Innes Centre Colney Lane Norwich 7-9

### Monday 6th April

Open Meeting  
Talk by Matthew Sydes, Medical Research Council, London, "Clinical Trials for Prostate Cancer"  
Followed by AGM and Election of Committee 2009/2010.  
NNUH East Atrium 7-9p.m.

### Monday 11th May

Committee Meeting NNUH Room 4 7-9 p.m.

### Saturday in May

**(Date to be announced)**

Ray and Vera's Giant Fundraising Barn and Car Boot Sale - Hingham

### Monday 1st June

James Paget Hospital Gorleston  
Open meeting Burrage Centre 7-9 p.m.  
Speaker to be announced

## How to Contact Us

Write to:

Norfolk & Waveney Prostate Cancer  
Support Group, c/o Urology Dept,  
Norfolk and Norwich University Hospital, Colney  
Lane, Norwich, NR4 7FP

Telephone - Specialist Uro-oncology Nurses:

Sallie or Wendy at the Norfolk and Norwich University Hospital 01603 289845

Angie or Wendy at the James Paget Hospital 01493 453510

Committee / Help:

01603 713463 -01603 881213 or 01328 862927

E-mail- DavidHaines David.haines2@btinternet.com

Newsletter Editor: Bernard Farrant 01603 664515

Website: [www.prostatesupport.org.uk](http://www.prostatesupport.org.uk)

## Support Network - Do you need help or advice?

Perhaps a friendly chat or a visit would be welcome.

We now have 29 volunteer Group members, who are all Prostate Cancer patients or survivors, (with the exception of our ladies who are carers), available at the end of a telephone ready to help.

There is probably one near you.

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

There are still vacancies for contact volunteers for the following areas: Beccles, Bungay, Thetford and Swaffham. To find out what is involved please phone David Wiseman,

**The Group has two important - indeed vital - posts to fill. If you would like to be nominated for either of them please contact our Chairman, Ray Cossey, on 01603 720980**

### Vice Chairman

Currently David Haines. David is a founder-member of the Group, and was until this year chairman. He now needs to take a back seat.

So any volunteers please to take his place?

David defines the role as:

1. To assist the Chairman and to deputise for him when the occasion demands.
2. Charity Commission contact member. (Correspondence only).
3. Delegate to the Prostate Cancer Support Federation, London. (Two meetings per year).

For more details contact David on 01603 881213.

### Treasurer

Stan Thompson, who was a founder member of the Group, secretary for three years and treasurer for the last two, has decided that it is time retire.

So we need a successor.

Stan says the work involved takes him about three hours a month, and is straightforward book-keeping.

It involves receiving donations, sending letters of acknowledgement, banking money, paying bills and keeping the Committee informed of the Group financial position.

Stan says he will be happy to show his successor the ropes. To learn more contact him on 01603 713463