

Norfolk & Waveney Prostate Cancer Support Group

Registered Charity No. 1108384

Newsletter no. 27 May 2009

Patron: Martin Bell OBE

Meet Our First President



David Haines, founder chairman of our Group, has been elected as its first President, in recognition of his service as chairman until he stood down on medical advice last year.

David was one of 17 prostate cancer patients who attended the inaugural meeting in April 2004, and established the Group's aims:-

- To increase awareness of prostate cancer,
- Provide information
- Provide patient-to-patient support, and support for wives and families.
- Support local research.

He was elected chairman of the first Patients Steering Committee, and subsequently of the Norfolk and Waveney Prostate Cancer Support Group.

The Group now has 350 members.

David is 78 and is a retired Chartered aeronautical Engineer. He has lived in Norfolk for the past 36 years, and has been involved in voluntary work for the last 20.

He and his wife, Yvonne, are both cancer patients, and say they owe their survival to early diagnosis and prompt and effective treatment by the clinical and nursing staff of the Norfolk and Norwich University Hospital.

Prostate Cancer Support Federation produces test guidance for GPs

The Prostate Cancer Support Federation - the UK organisation of prostate cancer support groups, of which our group is a member - has established a website and produced a leaflet for for GPs to use to help patients decide whether to have a PSA test

The Federation says it has done this because it fears that out-of-date information may continue to be given to patients who request a PSA test.

The Federation is calling its website and leaflet

"The Real' Prostate Cancer Risk Management Programme".

It says they update the 'official' Prostate Cancer Risk Management Guidance Pack produced by the Department of Health, which was produced in 2002 and has not been updated since.

That guidance advises GPs on how to advise a man without symptoms who asks for a PSA test.

This guidance is acknowledged to be out of date, and the Department of Health initiated a revision programme in 2006.

However, in March this year - when publication of the Department's new Guidance was imminent - the New England Journal of Medicine published interim results from two major studies into PSA-based screening for prostate cancer.

One, the European Randomized Study of Screening for Prostate Cancer, showed significant reduction in mortality.

The other, the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial in the US, showed no benefit. This completely opened up the arguments for and against screening, and rendered the revised guidance obsolete.

As a result the Department of Health announced that it would not publish the revised Guidance.

GPs are now being referred back to the 2002 version, with its acknowledged flaws.

All men over 50, but over 45 where there is a family history of prostate cancer or other higher risk factors are entitled to a PSA Test on the NHS every year.

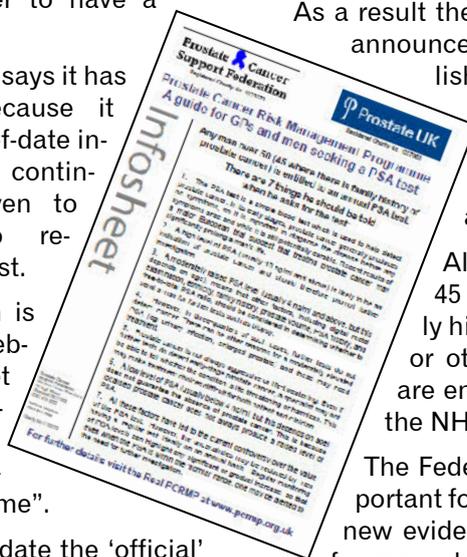
The Federation believes it is important for GPs to be aware of the new evidence, of its implications for men who are deciding whether to have a PSA test, and of the need for men to make up their own minds about it.

Because it is concerned that out-of-date information may continue to be given to patients who ask for a PSA test, it has printed enough copies of its simple leaflet to allow for a copy to be held in every GP's surgery throughout the United Kingdom.

The text of the leaflet has been produced by members of the Federation, and has been reviewed and approved by eminent clinicians.

Publication of the leaflet is supported and approved by Prostate UK, the UK's leading charity concerned with prostate diseases.

The full text of the leaflet is reproduced on page 2



This is the guidance in the leaflet which the Prostate Cancer Support Federation has produced for every GP in the country

“There are 7 things a man should be told when he asks for the PSA test:

1 - The PSA test is a simple blood test which is used to help detect prostate cancer. In its early stages, prostate cancer generally produces no symptoms, so it is important to diagnose the disease before any symptoms arise and while it is still potentially curable. Recent results of a major European trial suggest that treating prostate cancer may significantly prolong a man's life.

2 - A high level of PSA (usually 10 ng/ml and above) is likely to be an indication of prostate cancer and should therefore prompt further investigation.

3 - A moderately raised PSA level (usually 4 ng/ml and above, but this

depends on age), means that other factors, including digital rectal examination, ethnicity, family history, prostate volume, PSA history, and free-to-total PSA ratio, should be considered in determining whether to send a man for further tests such as biopsy.

4 - However, in three-quarters of such cases, further tests do not detect cancer. There can be other reasons for a moderately elevated PSA (eg urinary infection, enlarged prostate) and these may need treatment.

5 - Prostate cancer is not always aggressive or life-threatening. Even if further tests do detect early-stage prostate cancer, a specialist may not be able to tell whether the condition is life-threatening or harmless. This may

make treatment choices difficult for both patient and clinician.

6 - A low level of PSA (usually below 4 ng/ml, but this depends on age) does not guarantee the absence of prostate cancer. This is because localised prostate cancer does not always produce a raised level of PSA.

7 - All these factors have led to the controversy over the value of the PSA test. However the uncertainties may be reduced by men having a regular test, ideally on an annual basis. Regular monitoring of PSA levels can highlight any significant or gradual increase, so even when the PSA is within the 'normal' range, one may be alerted to the need for further investigation.

The view from the Chair

Since this Group was founded some five years ago one man, perhaps more than any other, has been responsible for what it has achieved.

David Haines has been very much the driving-force, in leading the N&WPCSG, as its founder-chairman and trustee.

When I took over the reins from David, in June 2008, he stayed on, as vice chairman and has helped me settle-in as chairman and, when asked, has given both his wise counsel and experienced advice.

With the transition period complete, David decided that it was now time for him to take a back-seat and so, at our AGM, did not offer himself for election to any executive, or committee, role.

Nevertheless, I believed that David's talents should not be entirely lost to us and suggested to the committee that we should offer him the presidency.

We were all delighted when he accepted this new, non-executive, role, with a standing invitation to attend all, or any, committee meetings.

David Haines will be a difficult act to follow, but I will do my best, content in the knowledge that, if ever I need advice, he is only a phone call away.

Well done and thanks, David, for all you have done for us.

The AGM also saw another founder member of the Group, Stan Thompson, retire as treasurer.

I would like to also thank Stan for all his hard work. I am delighted that Stan is staying on the committee. Stan is also a trustee.

We are fortunate to have Dave Kirkham, to take over from Stan. I know that Dave will do a fine job.

We have a new vice-chairman, Edward Hare. Ted has many contacts in local health concerns and the cancer-charities sector and his help and support will be invaluable.

To have Brian Smith continue in the role of secretary is a real bonus for me. He represents continuity on the executive committee and is a real asset to the Group.

The remaining committee members are all as last year. They are a great bunch, carrying out their delegated roles efficiently and without fuss. Last, but certainly not least, I must thank our specialist oncology nurses and staff – Angie, Elizabeth, Sallie and the two Wendys. Ladies we all owe you a debt of gratitude for all the support and advice we all receive from you, on our cancer journeys.

Ray Cossey Chairman

Trial Volunteers Needed

If you have had prostate cancer and have had radiotherapy at least 12 months ago you may be eligible to volunteer for a trial looking at a treatment for people who have long-term side effects after radiotherapy.

A recent clinical trial of high pressure oxygen therapy (the kind used in divers who get the 'bends' and elite footballers after injury), suggests that radiotherapy side effects can be improved.

A multi-centre research collaboration led from The Royal Marsden Hospital aims to repeat this work in a randomised trial comparing high pressure oxygen treatment with sham treatment.

They are looking for volunteers to join in this research programme."

One of the centres at which the treatment will be given is Great Yarmouth.

A number of conditions have to be satisfied before anyone can be accepted for the trial, but if you are interested in finding out further details about what is involved in the trial, please contact Sue Martin, Trial Coordinator to Tel: 020 8661 3273 Fax: 020 8661 3107 Email Sue.Martin@icr.ac.uk

Call for end to postcode lottery for Brachytherapy

A group of leading healthcare professionals – the Prostate Brachytherapy Advisory Group - is calling for the eradication of the postcode lottery for prostate cancer patients seeking treatment by low dose-rate brachytherapy.

Brachytherapy involves implanting tiny radioactive seeds through fine needles into the prostate to destroy the cancer cells.

The procedure normally takes less than an hour to perform under anaesthesia and most patients can go home the next day with minimal disruption to their day-to-day life.

Currently, 1 in 6 patients are denied access to this therapy despite the fact that the National Institute of Health and Clinical Excellence (NICE) has approved it and the Department of Health has issued advice supporting increased usage.

The Prostate Brachytherapy Advisory Group says studies show that brachytherapy is a proven and well-tolerated therapy. The 10-year cancer free rate following LDR brachytherapy is similar to that with conventional external beam radiotherapy and surgery (radical prostatectomy).

Reported rates vary between 66% and 92% depending on the initial severity of the disease², but they say this is achieved with a lower risk of the complications associated with surgery and external beam radiotherapy.

LDR brachytherapy scored highest in a recently published health related quality of life study with regard to urinary incontinence and preservation of sexual function. The Data was collected from 625 patients through self completed questionnaires following treatment by LDR brachytherapy, external beam radiation and radical prostatectomy.

Recently, 15-year survival figures have been published for men who received brachytherapy combined with external beam radiotherapy for the treatment of localised prostate cancer. The overall PSA progression-free survival

rate in 223 patients at 15 years was 80% in intermediate risk patients.

The key objective of The Prostate Brachytherapy Advisory Group is to support the development of LDR brachytherapy services nationally in line with the Department of Health expectations and to improve patient coverage by Primary Care Trusts (PCT) through educational initiatives. The Group, which was formed in March 2007, consists of medical and NHS representatives with an active



The campaign is supported by
Norwich North MP Dr. Ian Gibson

interest in the commissioning of services and the provision of care for brachytherapy patients.

Stephen Langley, Professor of Urology at St Luke's Cancer Centre, Guildford, is Chair of the Group and a leading expert in the field.

"There is a clear disparity in the provision of LDR brachytherapy for prostate patients across the UK," says Professor Langley. "We are calling on healthcare purchasers and providers to improve access to LDR brachytherapy by four-fold in line with Government expectations and patient's choice; to create a better understanding of brachytherapy amongst healthcare commissioners; and to empower patients."

To help the commissioning of LDR brachytherapy services, The Prostate Brachytherapy Advisory Group has launched a new website www.prostatebrachytherapyinfo.net which provides current information on brachytherapy and practical resources to help decision-making.

John Anderson, CEO of the Prostate Research Campaign UK supports the initiatives of The Prostate Brachytherapy Advisory Group and hopes that it will drive more patients to seek appropriate treatment.

"Prostate cancer is equivalent in many ways to breast cancer", says John Anderson, "both are hormone linked, and yet the patient journey that men undertake is very different. Prostate cancer is still perceived as a less important cancer and quality of life issues are not taken into account"

One of the issues with prostate cancer treatments is the risk of incontinence and impotence, particularly for younger men.

Continues John "We get hundreds of calls from men who, quite simply, are not being given the information they need to make an informed choice. One of their greatest fears, which can sometimes delay them seeking treatment, is that they may no longer be sexually active after therapy which, of course, is much less of an issue with treatments such as LDR brachytherapy"

The campaign has the support of Dr Ian Gibson, MP for Norwich North and Chair of the All Party Parliamentary Group for Cancer.

He said "I welcome the plans of the Prostate Brachytherapy Advisory Group to widen access to brachytherapy for men with prostate cancer. This reinforces the practical advice for healthcare commissioners on brachytherapy, published by the Department of Health in November last year. All cancer patients must have access to the right choice of treatment for their condition and their circumstances".

Brachytherapy is available to appropriate patients in this area at Addenbrookes Hospital at Cambridge.

Dates for Your Diary

Tuesday June 7th

Burrage Centre, James Paget Hospital 7 p.m. Talk
by
David Baxter-Smith FRCS
Consultant Urology Surgeon

Sunday June 7th

Waveney Motorcycle Club are hosting a
motorbike Charity Ride in aid of Norfolk & Waveney
Prostate Cancer Support/
Start from Palgrave Community Centre, Diss at
11.30 a.m.

(Doors open 10.30 a.m. for refreshments), and
finish at the Ferry Inn Stokesby, Acle around 12.30.
For further information call Chummy on 01379
643528

Sunday August 2nd

At Lodge Public house North Tuddenham (off A47)
"Summer Soul" BBQ and music.
In aid of N&W Prostate Cancer Support

Monday August 3rd

NNUH Lecture Theatre Open Meeting 7p.m. Talk by
Jennie Nobes, Research Fellow
Royal Surrey Hospital

Monday October 6th

NNUH Lecture Theatre Open Meeting 7 p.m.
An inspirational talk on the life of
May Savidge, Engineer, by Christine Adams (BBC
Antiques
Roadshow and Bygones)
Christine Adams will tell the story of the remarkable
life of her aunt, May Savidge who lived in a
half-timbered house in Hertfordshire.....until the
council served her with a compulsory purchase
notice to make way for a roundabout,
May decided she had to move.
So she did - with her house, which she had
dismantled and shipped to the North Norfolk coast,
where she spent the rest of her life rebuilding it -
single-handed.

How to Contact Us

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NORFOLK AND NORWICH PROSTATE CANCER SUPPORT GROUP

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Trustees 2008/9 David Haines, Stan Thompson

Do you need help or advice?

Perhaps a friendly chat or a visit would be
welcome

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 David Wiseman,
our Welfare Officer on 01603 260539