

# Norfolk & Waveney Prostate Cancer Support Group

Registered Charity No. 1108384

Newsletter no 30 February 2010

Patron: Martin Bell OBE

## The View from the Chair

On 20<sup>th</sup> October, at the Imperial Hotel in Great Yarmouth, our Group organised its second mass PSA testing session, at which 205 men were given a free test.

A great deal of planning goes into these events, and everyone involved is to be congratulated on a job well done.

188 of the men were found to have a normal, PSA level; another 6 had an elevated reading, but not so high as to be of immediate concern.

The 11 men found to have very elevated readings have since been advised, by our consultant-urologist advisor, Mr David Baxter-Smith, to seek an early consultation with their own GP. Incidentally, at our first mass PSA testing session, on 5 March, 10 men were found to have very elevated readings, 6 of whom have since advised that they or are having, treatment for prostate cancer!

The most disturbing statistic, revealed at the Great Yarmouth session, was that 7 of the men, with a highly elevated PSA level, had been declined a test by their own GP. This was despite the fact that they each had a history of prostate cancer within their family.

By no means are all GPs so unenlightened, but there are a

few who need to be reminded that, under Health Department guidelines, all men over the age of 50, are entitled to have a PSA test if they ask for one.

Having now conducted sessions in Norwich and in east-Norfolk, at Great Yarmouth, your committee has decided to hold a final session, to cover the west area of the county, later in the year.

### Help us to help you

With your help we can save the Group a great deal of money. Currently just over 100 of our 350-plus members have agreed to view and, if they wish, print our Newsletter from our website, [prostatesupport.org.uk](http://prostatesupport.org.uk) rather than have a printed copy posted to them.

Members who do this receive an e-mail telling them when the latest Newsletter is available and directing them to the Group's website, to view it.

The more members avail themselves of this service the more money we will save.

If you would like to get the newsletter in this way please send an e-mail to our webmaster, Harvey Meadows, at [nwpcsg@hotmail.co.uk](mailto:nwpcsg@hotmail.co.uk) asking him to add you to the email list.

### The Group Needs You

The very existence, and continuation, of this Support Group depends on members volunteering to get more

involved, mainly by serving on the Committee.

Our fellow members do not get welfare and other support, receive regular Newsletters, have meetings arranged for them, have accounts and minutes kept, as well as many other things, without the unselfish dedication of the dozen blokes who serve on the Committee.

Unless members are willing to become more involved there is always the danger that the Group could fold.

There is no immediate threat of this but it is something which we must guard against - it would be such a hurt to those who founded this Group

Whilst most of the present Committee have indicated their willingness to offer themselves for re-election at the forthcoming AGM, some will not, reluctantly, be seeking re-election.

All have given freely of their time and energies to keeping our Support Group going.

The best 'thank you' you can give them is to step forward and offer to take their place. Details of how you offer yourself for committee membership appear at the foot of the AGM Agenda

I am now in my second year as Chairman and will be offering myself for re-election for just one more year, at the forthcoming AGM.

That will give plenty of time for someone else to consider



**The AGM of the Norfolk and Waveney Prostate Cancer Support**

**Group**

Will take place on Monday 12 April 2010 at 7 p.m in the Benjamin Gooch Lecture Theatre at the N&NU Hospital

**AGENDA**

- 1 - Apologies for absence
- 2 - Minutes of the 5th AGM, 6/4/09
- 3 - Matters arising
- 4 - Chairman's report
- 5 - Secretary's Report
- 6 - Treasurer's report
- 7 - Amendments to Clauses 6.1, 6.4, 8.1 and 9.8 of the constitution
- 8 - Appointment of new Trustees - Harvey Meadows and Brian Williams
- 9 - Election of Executive Committee
  - 1 - Chairman
  - 2 - Vice-chairman
  - 3 - Secretary
  - 4 - Treasurer
- 10 - Election of Committee
- 11 - Appointment of Bankers and Auditors
- 12 - Any other business
- 13 - Date of 2011 AGM

**Note** - The following are offering themselves for re-election to the Executive Committee: - Ray Cossey (chairman) Edward Hare (vice-chairman) Brian Smith (Secretary) David Kirkham (Treasurer)

The following seven members are offering themselves for re-election to the Committee:- Bernard Farrant, Chuck Lyons, Harvey Meadows, John Newman, Stan Thompson, Paul Whitehouse and David Wiseman.

**Note** - The Constitution allows for there to be 12 Committee members, and nominations, with the name of a member-seconder, should be submitted in writing to the Secretary, Brian Smith, 81 Nightingale Drive, Taverham, Norwich NR8 6TR, to be received no later than 15th March 2010. Nominations may also be made from the floor, subject to nominees' agreement.

Chairman Ray Cossey explains the thinking behind proposed changes to the Constitution. The current wording (abbreviated) of the relevant clauses are as follows in black. The proposed amendments or amended versions are shown in red.

**Clause 6.1** Current wording with proposed amendment in red. At the AGM ..... the members shall elect .... a Chairman, a Vice-Chairman, a Secretary, and a Treasurer....who will form the Executive Committee .....together with not more than twelve additional elected Committee members. From these Committee members will be appointed a Publicity/Press Officer, an IT Officer (Website), a Membership Secretary, a **Welfare Officer**, an **Editor** a Social Secretary .....

**Reason** -To have a member of the committee responsible for **Welfare** matters. We have such an officer, in David Wiseman, but this position was overlooked in the original Constitution. It is also desirable for the newsletter editor to be a committee member.

**Clause 6.4 - Current** - Elected Officers and Committee Members shall hold office for a maximum term of one year, after which they may offer themselves for re-election for a further ... year.

**6.4 Proposed** - **Members of the Executive Committee shall not serve in excess of three consecutive years in any one executive post, except if there is no nomination to replace them**

**Reason** - The main part of this amendment was proposed by David Haines, to keep the committee fresh, with 'new blood'. However, if no new volunteers came forward the continuation of the Group might be threatened. I, therefore, added the last nine words so that if serving committee members are willing to continue if there is no one to replace them, they should be able to.

**Clause 8.1 - Current wording, with proposed change in red** :- The Management shall consist of the Chairman, Vice-Chairman, Secretary, Treasurer, and eight (**twelve**) members .....

**Reason** - To correct an error in the drafting of the original Constitution .This brings this clause into line with clause 6.1.

**Clause 9.8** The Charity will appoint three Trustees from the Officers of the Charity, in compliance with the rules laid down by the Charity Commission.

**9.8** The Charity will appoint a minimum of three Trustees, two from serving Committee members ..... and others ... from the wider membership or from the general public.

**Reason** - This clause means Trusteeship is only open to the chairman, the vice chairman, the secretary and the treasurer, they being the only 'officers' of the Group. I have the strongest anti-feelings about officers also being Trustees, as this means you have the same persons as managers and governors. This change opens up Trusteeship to any committee member and to others, if necessary, to outside persons. Most of the charities I have been connected with follow this policy and I commend it to you.



### **Good news from American Survival Rate Study**

An American study has shown that of 12,677 men who had a radical prostatectomy – removal of the prostate – only 12% died of prostate cancer within 15 years of surgery, compared with 38% for death from other causes.

This indicates that the majority of men can expect to survive for many years following surgery for prostate cancer.

The study was carried out by the American Memorial Sloan-Kettering Cancer Centre.

The Prostate Cancer Charity's Head of Research Management, Dr Helen Rippon, said: the study was the first large scale research to look at survival rates after a radical prostatectomy since the PSA test became available.

She said it highlighted the need for to find the key characteristic that will enable clinicians to identify which cancers are most dangerous.

These new findings emphasise the need for medical research to find a biological marker that accurately predicts, from initial diagnosis, how risky a prostate tumour is and identify men who need immediate and life-saving treatment.

### **The Great PSA Debate**

Over a hundred representatives of prostate cancer patient support groups – including ours, represented by President, David Haines – went to Leamington Spa in November to join with six distinguished experts in The Great PSA Debate, organised by the Prostate Cancer Support Federation and sponsored by the Graham Fulford Charitable Trust and Prostate UK.

This is a summary of the Federation's newsletter's report of the event.

The main aim of the day was to get the prostate cancer charities to speak with one voice on the issue of testing for prostate cancer. The meeting debated the following motion:

*"Every man at risk of prostate disease ... should be encouraged to check his PSA every year."*

As expected, the open debate session was lively and views were passionately expressed. However, it emerged that the two sides of the argument were actually much closer than had been thought. In particular, there was agreement by all that:

- men should be aware of the PSA test, its benefits and limitations, and of their right to have it;
- GPs need education;
- research is urgently needed to identify and get consensus on how to use risk factors to govern follow-up action.

A final vote was taken on an amended motion, as follows:

*"Every man at risk of prostate disease ... should be made aware of the PSA test, its benefits and limitations and should be able to freely exercise his right to have it",*

On this there was total agreement, with one abstention. So for the first time, the major charities are agreed on a need for raising awareness of all men at risk of the availability of PSA testing.

Two streams of work needed have been identified.

First, we must build on the consensus that men should be made aware of the test. The Prostate Cancer Charity are taking the lead on this and the Federation, are involved in their work. The goal is to ensure that the NSC reflects this in recommendations it makes about prostate cancer screening in the Spring.

Second - the risk assessment approach needs to be developed further.

### **"Living with Hormone Therapy" Booklet**

Peter Montgomery, our literature and display officer, now has a stock of the booklet entitled 'Living with Hormone Therapy.' If you would like a copy telephone or e-mail him His phone number is 01603 737568 and his e-mail address is pmcolt@tiscali.co.uk.



## Dates for your Diary

**Monday April 12th - 7 to 9 pm**

Talk by Hashim Ahmed, MRC Research Registrar in Uro-Oncology on

### **Focal Therapy of Prostate Cancer - The Male Lumpectomy?**

In the Benjamin Gooch Lecture Theatre,  
East Atrium,  
Norfolk and Norwich University Hospital

**Tuesday June 1st 7-9 pm**

A talk by Julie Hayward of  
The Really Healthy Company on  
Complimentary

**Nutrition Therapy for Cancer**  
in the Burrage Centre, James Paget  
Hospital Gorleston

**Friday April 16th - 7-30 at UEA**

### **Concert in Support of the new Blue Ribbon Foundation**

Group member Mel Lacey is organising a concert to raise funds to launch the Blue Ribbon Foundation, which aims to become the 'brother' of the breast cancer charity, the Pink Ribbon Foundation.

Mel says "We hope blue ribbons will do for prostate and testicular cancer what the Pink Ribbon Foundation has done for Breast Cancer. Funds raised will go to charities such as the Norfolk and Waveney group."

Music will be provided by two local bands, Hollow Earth and The Harvs. Compere will be BBC TV's Stewart White. There will be a licensed bar.

Tickets are £10 - with every penny going to the charity. For information or to order tickets email [mel.lacey@talktalk.net](mailto:mel.lacey@talktalk.net) or call Mel on 07976 901 442.

#### How to Contact Us

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#### NORFOLK AND NORWICH PROSTATE CANCER SUPPORT GROUP

Registered Charity No. 1108384

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#### **Do you need help or advice?**

Would a friendly chat or a visit 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.