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# Norfolk & Waveney Prostate Cancer Support Group

Registered Charity No. 1108384

Newsletter no. 26 March 2009

Patron: Martin Bell OBE

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## The view from the Chair



The results of the the mass screening event in Norwich on March 5th raise two matters of concern.

One is that the 31 results found to be abnormal was 40 per cent higher than the average found at other similar sessions elsewhere in the country.

The second is that of the 219 men 68 told us they had been refused a test by their GP.

One of them was a man whose father and grandfather had died from prostate cancer and his younger brother had been diagnosed with it.

Yet, still his GP refused a PSA test - despite reputable medical studies showing that a man with a family history of prostate or breast, cancer is 2.5 to 3.5 times more likely to contract prostate cancer than a man with no family history of these cancers.

It beggars belief that there are still a few GPs who are so anti PSA-testing that they are, unwittingly, exposing their patients to serious, potentially life-threatening, risks.

They are just not following Health Department guidelines, which state that any man over 50 who requests one should be given a free PSA test.

This does not preclude any GP from *advising* against a test, but I contend that no GP has the right to refuse one. I believe there is an urgent need for the local PCT to remind all GPs of this.  
*Continued on page 2.....*

## Mass PSA test session three times over-subscribed

Two hundred and nineteen men aged from 40 to 89 gave blood samples for PSA tests at our mass screening session in Norwich on March 5th.

The demand for PSA tests was such that over 700 telephone call were received from men wanting to book tests. Sadly, only a few over 200 were available.

The results were as follows:-

Fifteen men were found to have a significantly raised PSA and have been advised to see their GP as soon as possible, for further investigation. A further 16 were found to be borderline and have been advised to see their GP for another test in three months time.

The remaining 188 were found to have a normal PSA level for their age. The Norwich screening session was staged in conjunction with the Graham Fulford Foundation Trust, which is holding similar sessions throughout the country, with the aim of getting 10,000 test results.

So far over 7,500 men have had PSA tests at these sessions.

The results of the tests were analysed by Kidderminster-based, consultant urologist, Mr. David Baxter-Smith, who supervised the Norwich session. He reported that the 31 abnormal PSA readings found was 40% higher than the average found at other sessions around the country.



Norwich North MP Ian Gibson and North Norfolk MP Norman Lamb attended the screening session. Here Ian Gibson gives his blood sample for testing.

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## Thanks for a Job well done

In all some 40 people - committee members and some wives and nine nurse-phlebotomists - assisted with the planning and implementation of the mass screening session at the John Innes Centre in Norwich on March 5th.

To everyone who contributed, I say a big 'thank you'. I think we can congratulate ourselves on a job well done.

Ray Cossey - Chairman

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## View from the Chair *continued...* Screening session findings “cause for concern”

*Continued from page 1*

Surely, no one denies that the earlier a cancer is detected, the better the chance of effective, often life-saving, treatment.

Why then do a few GPs refuse PSA tests, when their patient has none of the classic symptoms of *possible* prostate cancer?

Are they unaware that it can take 12-15 years to fully develop?

And that when it does manifest itself, by the usual classic symptoms, it may well be too late for the patient?

If symptoms are to be a pre-requisite for screening, why are all women over 50 invited to have a mammogram to diagnose the possible presence of breast cancer?

Not for one moment do I advocate the withdrawal of one single penny of the funds allocated to breast and any other cancer-screening services.

The question for the health authorities is “Where is the expenditure on a national prostate cancer screening programme?”

You all know the answer, as well as I do....there is none!

Many in the medical profession will say the PSA test is imperfect; it gives false positives and false negatives.

Are they claiming that there are no such imperfections with breast-screening?

Of course there are and they know this only too well. Yet, still they turn a deaf ear to advocates of a national screening programme for prostate cancer.

I accept that the PSA test is not totally reliable, but it's the best we have. If it is so useless why are we still given regular PSA tests to see if our cancer is giving any indication of returning, or showing increased activity?

Recently I have seen a draft document which shows that the 5-year survival rate from prostate cancer in the Anglia Region is around 70%, in line with the national average.

This is way behind Austria (87%) where PSA testing is offered to all men over 50. If ever there was an emphatic case for national PSA screening there it is – in Austria.

While I have been concerned by the negativity of some in the medical profession towards what this Group is doing to raise the profile of prostate cancer and the benefits of PSA testing, I emphatically do not include in this any consultant, or nursing staff, at our local hospitals' urology departments.

There are some who are not entirely enthusiastic about our PSA testing campaign, but they have respect for it, and have been open to persuasion towards our point of view.

For this I, your committee and I hope all members of this Group are most grateful.

As to the unexpectedly high number of elevated PSA levels found at the test session, I feel that this is a reason for real concern.

There may be some local influence which has revealed this greater-than-expected number of men with an elevated PSA.

I do know that the Anglia Cancer Region is 23<sup>rd</sup> out of 30 regions for the survival rate for prostate cancer patients, of all ages.

It is cause for concern that the Anglian Region is in the fourth quarter of this particular league table.

I hope the local Primary Care Trust and the ACN will now be willing to enter into a dialogue with our Support Group to discuss the results of our PSA screening initiative.

Finding what we have from this first session, I shall be recommending to the committee that we give serious consideration to having another session, to offer tests to some of the over 400 men we had to refuse tests on 5<sup>th</sup> March.

**Ray Cossey - Chairman**



Left to right, David Baxter-Smith, Ray Cossey, Graham Fulford and David Haines with the 219 blood samples taken at the session.



The medical team who took 219 blood samples in two hours on March 5<sup>th</sup>.

**Don't forget - Ray and Vera Allen's Barn and Car Boot Sale at Hingham on May 9<sup>th</sup> - see last page**



# State of the Art radiotherapy equipment at N & N

Prostate cancer patients are expected to benefit later in the year from new state of the art radiotherapy equipment at the Norfolk and Norwich University Hospital.

The hospital is one of the first in the country to use intensity-modulated radiotherapy, or IMRT.

This uses computers to give a specific dose of radiation more targeted at the exact size and shape of the tumour than conventional radiotherapy. The treatment means there are fewer side-effects and could ultimately increase survival rates.

At the moment it is used for some head and neck cancer patients - about 30 a year -

However later this year it will be expanded to some men with prostate cancer, expected to be 50 to 100 people a year.

In future there are plans to expand it to gynaecological cancers such as cervical cancer.

Not all patients will benefit any more than from conventional radiotherapy, and because it is more labour-intensive, some hospitals do not use it at all. It is thought it could be beneficial for about a third of people who have radiotherapy.

In prostate cancer, side-effects can be damage to the bowels, causing incontinence, and rectal bleeding.

The more precise targeting used in IMRT means that side-effects are reduced. In future this could mean that a higher dose can be given, resulting in better survival rates.

The N&N has four of the linear accelerators used to give radio-therapy, each costing £1.5m and paid for through a PFI deal.

*From the Eastern Daily Press*

## Sponser Neil to support Prostate Cancer Research

Group member Neil England will be climbing Mount Snowdon on 16th May to raise money for the Prostate Cancer Research Centre.

He writes to Group members "You can help me to make a difference by sponsoring me to complete the challenge So please sponsor me now"

The easiest way to sponsor Neil is through his Justgiving web page. It is

quick, easy totally secure, and if you're a UK taxpayer, Justgiving makes sure 25% in Gift Aid, plus a 3% supplement, are added to your donation to the Prostate Cancer Research Centre.

Neil's web page is at <http://www.justgiving.com/neilengland> (where there is also a picture of him standing in a lake half way up Ben Nevis)

## Free Prescriptions for cancer patients from April 1st

Cancer patients will be able to receive all their prescriptions for free, even if the medicines are not related to treating the disease or its side effects, saving them around £100 a year.

Forms can be collected from GPs and cancer specialists during appointments and those received before March 24th should be processed in time for the April 1st implementation date.

The certificates will mean patients will be entitled to free prescriptions for five years even if they are declared free of cancer before then and they can be renewed as many times as necessary.

Estimates suggest that exemptions for cancer patients will cost the NHS around £15m a year in lost revenue.

Eventually the exemptions will be extended to all patients with long term conditions, such as heart disease, asthma and arthritis, and a consultation is being carried out by Prof Ian Gilmore, president of the Royal College of Physicians.

Public Health Minister, Dawn Primarolo said: "This new scheme gives people living with cancer one less worry at such a difficult time.

"Everyone undergoing treatment for cancer, the effects of cancer, or the effects of cancer treatment is entitled to free prescriptions from 1st April.

I would urge patients to make an appointment with their GP to talk about applying for their exemption certificate."

### A Big Thank You...

Our thanks for donations made in memory of:

Mr Frederick Steward

Mr Frank Jones

....And in Celebration of the 80<sup>th</sup> Birthday of

Mr P Solomon

Thanks Also for donations from:

Mr K Oldrey

Mrs L Winter

Mr J Hayward



*Our appeal for a new treasurer has been answered by Dave Kirkham (above). Dave is a Police officer - head of the Economic & Computer Crime Unit ( otherwise known as the 'Fraud Squad' . Subject to the formality of election, he will take over from Stan Thompson after the AGM. One of Dave's first jobs was helping Stan count the contributions from men tested at the John Innes Centre session - over £1500.*

On  
**Saturday May 9th**  
Ray and Vera Allen are  
holding another  
**Giant Fundraising  
Barn and Car Boot Sale**

K.W. Eaglen's Yard,  
Seamere Road,  
Hingham, NR9 4LW

8am - 2pm (Set up from 7am)

Pitch Fee: £5 (please take all rubbish away)

If you have any unwanted items and would like  
to donate to the Group's funds, we would be  
very grateful.

Phone 01953 850863 for further information

### 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:

Angie 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)

### Dates for your Diary

**Monday 6th April**

. Open Meeting

Talk by Matthew Sydes, Medical Research Council, ,  
"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.

**May 9**

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

**Tuesday 2nd June**

James Paget Hospital Gorleston

Open meeting Burrage Centre 7-9 p.m.

Talk by Mr. David Baxter-Smith, Consultant Urologist  
and Chairman of the Kidderminster Prostate Cancer  
Support Group

### NORFOLK & WAVENEY PROSTATE CANCER SUPPORT GROUP

Registered Charity No: 1108384

Committee Members 2008/9

Medical Advice/Help: (Specialist Uro-Oncology Nurses)

Norfolk & Norwich University Hospital 01603 289845

Sallie Jermy-sallie.jermy@nnuh.nhs.uk

Wendy Baxter - wendy.baxter@nnuh.nhs.uk

James Paget University Hospital 01493 453510

Angie Fenn - angie.fenn@jpaget.nhs.uk

Wendy Keenan-wendy.keenan@jpaget.nhs.uk

Elected members (Patients):

Chairman - Ray Cossey 01603 720980

ray@thecosseys.co.uk 73 Blofield Corner Road Little  
Plumstead Norwich NR13 5HU

(Acting Vice-Chairman) David Haines 01603 881213

david.haines2@btinternet.com The Corner House 2

Peacock Close Easton NR9 5JD

Secretary - Brian Smith 01603 860954

smiths.online@virgin.net 81 Nightingale Drive

Taverham Norwich NR8 6TR

Treasurer - Stan Thompson 01603 713463

thompson31@tiscali.co.uk 3 Skedje Way Blofield

Corner Norwich NR13 4RY

Treasurer-elect - Dave Kirkham 01953 456858

Mobile: 07799 074372 dsdavekirkham@yahoo.com

Membership Sec - David Winter 01603 868967

davidandlesleywinter@yahoo.co.uk 5 Woodside Close

Taverham Norwich NR8 6LH

Newsletter editor - Bernard Farrant 01603 664515

bernardfarrant@norwich.clara.co.uk 161 Rupert Street

Norwich NR2 2AX

Welfare Officer - David Wiseman 01603 260539

home@wisemandav.go-plus.net 14 Manor Close

Taverham Norwich NR8 6UB

Website editor - Harvey Meadows 01603

737588rvmcolt@hotmail.com 31 College Close Coltishall

Norwich NR12 7DT

Big C Liaison - Edward Hare 01603 400424 Mobile:

07787124143 edwardhare@btinternet.com 84 The

Warren Old Catton Norwich NR6 7NN

Display/Literature - Peter Montgomery 01603 737568

pmcolt@tiscali.co.uk 33 Kings Road Coltishall NR12 7DX

Chuck Lyons 01328 862967 charleswlyons@aol.com

71 Norwich Road Fakenham NR21 8HH

Paul Whitehouse 01263 825989

whitehouses@1orchid.fsnet.co.uk 1 Orchid Drive

Sheringham NR26 8UU

John Newman 01603 744581

john.newman990@ntlworld.com 62 Jerningham Road

New Costessey Norwich NR5 0RF

Trevor Watson 01603 437291

trevor.watson@mypostoffice.co.uk 59 Vincent Road

Norwich NR1 4HQ

Trustees: 2008/9 David Haines, StanThompson,

David Wiseman

### 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.