

Norfolk & Waveney Prostate Cancer Support Group NEWSLETTER

Issue No 11

August 2006

Support Contact Network

Our key aim this year is to establish a Support Contact Network for Prostate Cancer across the County and the Waveney Valley. This is in response to a growing number of calls for information and help we have received, and requests to widen our scope from members of the Group and the General Public. The Committee feels that we have now gained sufficient local credibility and support to introduce this project, which will aid those unable to attend our meetings or the Big C Family Cancer Support Centre at NNUH.

Our target is to attract 30

volunteers, who will offer their services from home in their own locality, and possibly within a ten mile radius. So far we have 9 names from those who would like to be considered, and we are seeking others from areas outside Norwich, Lowestoft and Yarmouth.

We are currently working on the ground rules, screening, training, and insurance requirements, but would like to hear from anyone who could offer an hour or two each week. Those interested should preferably have either personal experience of Prostate Cancer, or as a carer.

It is difficult to launch a county-wide network all at once, and we will probably start with a few "trial" locations, to learn lessons we can apply on a larger scale.

We intend to have a "brainstorming" session for those who would like to help in setting up the network. This will be arranged in the autumn, and details published in the next Newsletter. If you would like to register your interest, please contact any Committee member.

Thank you,

David Haines – Chairman.

Focus on Levitra – Oral Drug for Impotency

LEVITRA (Vardenafil) has become one of the mainstream drugs for the treatment of impotency. It is a phosphodiesterase 5 inhibitor designed specifically to be an effective and safe oral treatment for erectile dysfunction.

Levitra is an oral tablet and it is recommended to start with 10mg once a day and move up to 20mg if required. It has been shown to start working as quickly as after 10 minutes in some patients and lasts up to 6 hours. Levitra has proven to be effective in both the short and long term treatment of men with erectile dysfunction of various causes and of varying severity, including patients who have undergone nerve-sparing radical prostatectomy.

In a trial of patients who underwent bilateral nerve sparing retropubic prostatectomy 71% of patients reported improved erections on Levitra compared to 12% on placebo. And in another study of 231 patients who had not responded to Viagra, 46% did respond to Levitra. It is available on prescription.

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Letter to the Editor

Shortly after being diagnosed with prostate cancer John and I were in an art gallery in Holt. There we saw a notice regarding a meeting to be held at the Norfolk & Norwich University Hospital – for all interested or concerned about prostate cancer.

This we attended and regularly thereafter. We enjoyed the meetings (very well attended, even the first one), found friends and some help and information in what could have been a lonely situation – for which I thank you. Sadly John's cancer had spread and developed into his bones – a different scenario re his treatment. We were most impressed and helped by the doctors and nurses at the N&NUH Hospital on John's various stays and visits for treatment.

This last year has been difficult and because John was unable to drive we became housebound, and not able to get about much. Our only son died unexpectedly before Christmas, a great blow, and John himself died (peacefully) on 3rd May 2006. I am enclosing a small donation for the Prostate Cancer Group, and returning the last letters received.

I am somewhat surprised that such a well organised group (with registers, signing in etc) has no facility to pick up, and contact members no longer attending meetings or, if deceased, to acknowledge and/or delete from records. This is not said in anger on a personal basis, but as a point to consider in future. It rather seems that being a member ceases (as indeed it must) when no longer able to participate in events.

Sad – as many members, unable to get to meetings, would possibly appreciate a note or visit.

Such a pity that so much effort is put into raising money (although admirable) and so little into serving or helping those for whom the money's treatments are too late.

Yours sincerely,

Margaret Lefevre

*Thank you very much for your letter. As a result of your comments, the Committee reviewed how the mailing list system might be improved, and as a start we have produced a Mailing List Survey, which is inserted in this Newsletter. **Could readers please take a few minutes to fill in the Mailing List Survey.***

Following our successful appeal to raise money to support the Cryo-Ablation trial, the Committee had already decided to focus this year on our third core aim – "Support" (see previous page).

We have been concerned that some people were unaware of the help available with transport and visits, which have helped a number of patients in recent months.

If you need these services, do not hesitate to contact one of our Committee members. We will be happy to do our best to help you. – Ed.

Men's Cancer Month – Big C Family Cancer Centre NNUH

It's Men's Cancer Month – Prostate and Testicular – at the new Centre for the whole of August. The Centre is now open Monday to Friday. Big C would welcome any of our members and friends – so do drop in for a coffee and chat.

That Programme on BBC Radio – Prostate Therapy Benefits Doubted

Many of you will have heard – or heard about – the BBC radio programme on doubts voiced about prostate cancer treatments. Here are the main points covered.

A study published in the British Journal of Cancer suggests that many men diagnosed with low-grade prostate cancer do not benefit from radical treatment.

The researchers calculated that, even without treatment, only about 1% of men aged 55-59 with diagnosed low-grade disease would die within 15 years. Prostate cancer is the most commonly diagnosed male cancer in the UK. Nearly 32,000 new cases are diagnosed, and around 10,000 men die from the disease, each year.

The Institute of Cancer Research team found that radical treatment was only effective for men with high-grade disease. In those cases they calculated that, without treatment, up to 68% could die from prostate cancer.

Difficult decision

Researcher Dr Chris Parker said: "Most men with prostate cancer detected by PSA screening will live out their natural span without the disease ever causing them any ill effects. The decision whether to have radical treatment can be tremendously difficult for the patient. The results of trials looking at the long-term survival benefit of radical treatment are several years away. So, this new information on the potential impact of treatment on overall survival will be of great interest to men faced with this decision."

Dr Parker said his team was trialling a new prostate cancer management technique called active surveillance. This aims to target treatment only at those who need it by closely monitoring patients for signs of disease progression. Preliminary results of this technique have been encouraging.

Types of cell

High-grade prostate cancers are made up of undifferentiated cells, which can reproduce quickly, speeding growth of the tumour. Low-grade tumours are made up of differentiated cells which do not reproduce at the same speed.

Chris Hiley, from the Prostate Cancer Charity, said: "Decision making on treatment for prostate cancer is not straightforward for anyone involved, but we hope that these results might make explaining options and possible outcomes to patients easier for doctors. Clearly, some men with a prostate cancer diagnosis will always prefer an operation to cut it out or radiotherapy to treat the cancer. This new evidence shows men mustn't be left to overestimate the survival advantage that such an option would give them."

Dr Emma Knight, of Cancer Research UK, said: "It is important to stress that these results are only predictions. Data from ongoing clinical trials should, in time, portray the pros and cons of treatment versus monitoring more accurately."

The Department of Health said the findings would be considered by its Prostate Cancer Advisory Group.

And Now for Something Completely Different – Pomegranate Juice ... Pomegranates May Slow Prostate Cancer

The bottles of pomegranate juice flown to Germany to stop England's football players wilting in the stifling heat could have other health benefits, according to a study that suggests the juice can combat prostate cancer.

Drinking a daily eight ounce glass of pomegranate juice could significantly slow the progress of prostate cancer. It is so effective that it might help older men to outlive the disease. According to a team from the University of California, Los Angeles, this would increase – by nearly four times – the period during which PSA levels in men treated for prostate cancer remained stable.

The three-year study published in *Clinical Cancer Research* by Dr Allan Pantuck and colleagues involved 50 men who had undergone surgery or radiation but quickly experienced increases in PSA.

Pomegranate juice is known to have anti-inflammatory effects and has high levels of anti-oxidants, which are believed to protect the body from free-radical damage.

... or Beer

A main ingredient in beer may help to prevent prostate enlargement and cancer, according to an Oregon State University study. There is only one catch: the ingredient is present in such small quantities that a man would have to drink more than 17 pints a day to benefit.

A Big Thank You

The following donations have been received since our last newsletter:

	£
Project 2001 Ladies	1,500.00
South Norfolk Council – Newsletter sponsorship	600.00
John Jarrold Trust	500.00
Suffield Park Bowls Club	430.00
Mr & Mrs Spindler and Mr & Mrs Willgoss	55.00
Norwich Aviation Society	40.00
Mrs Margaret Lefevre, in memory of John Lefevre	25.00
Mr Mike Forster	30.00
Mrs Yvonne McCann	20.00
Mr C Watson	15.00
James Paget Meeting	28.50
Inland Revenue (Gift Aid)	1,525.00

South Norfolk Council are sponsoring our Newsletter costs this year, for which we thank them.



Presentation of cheque for £430 from the Suffield Park Bowls Club in Cromer, who made our Support Group their charity for this year. Front left: Roger O'Leary, President of the Club, gives the cheque to Chuck Lyons of our Support Group.

Dates for your Diary

Friday, 15 September – 7pm
Norwich Accordion Club
concert, Methodist Church, Chapelfield, Norwich. All proceeds to our Support Group.

Monday, 2 October – 7pm
Open Meeting, NNUH
Details of Speaker to be advised.

Friday, 3 November
National Prostate Cancer Conference Olympia Conference Centre, London.

Friday, 1 December
Gala Lunch – Big C / Norfolk & Waveney Prostate Cancer Support Group – Maids Head Hotel, Norwich with Martin Bell
(Please note this event will now be at lunchtime, not in the evening).

Monday, 4 December – 7pm
Christmas Open Meeting & Raffle, NNUH
Details of Speaker to be advised.

How to Contact Us

- **Write to:**
Norfolk & Waveney Prostate Cancer Support Group,
c/o Urology Department,
Norfolk and Norwich University Hospital,
Colney Lane, Norwich, NR4 7FP
- **Telephone the Specialist Nurses:**
Sallie, Claire or Wendy,
Specialist Uro-oncology Nurses,
Norfolk and Norwich University Hospital
01603 289845

Angie or Wendy,
Specialist Uro-oncology Nurses,
James Paget Hospital
01493 453510
- **Committee / Help:**
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