# Norfolk & Waveney Prostate Cancer Support Group NEWSLETTER

Issue No 22

June 2008

# Support Network

### An Important Message from David Wiseman, our new Welfare Officer

For quite some time your committee has been discussing the idea of setting up a network of members, located throughout the Norfolk & Waveney area. Their purpose would be to act as local telephone contacts for both existing members of the Norfolk & Waveney Prostate Cancer Support Group and their families and friends. Also for newly diagnosed patients who may wish to speak with a fellow male to ask about what is involved with a particular treatment for prostate cancer.

It must be stressed, these Support Network Members would not be expected to answer questions of a medical nature, which would need to be referred to one of our team of Specialist Uro-oncology Nurses. Their time in clinics and consultations is scarce and expensive, for all the usual reasons connected with the provision of a universal health service. However, the time of a Prostate Cancer Support Group volunteer in a support network – on the other hand – is free. Also Prostate Cancer Support Group members are uniquely knowledgeable about the patients experience of the particular treatments they have undergone.

In the days and weeks after diagnosis, a new prostate cancer sufferer may want to talk a lot and find out about different forms of treatment, the degree of trauma involved, the after-effects, recovery times and likely effects on lifestyle etc. In general, GPs see very few prostate cancer patients in the course of a year (less than one on average), and have neither the specialist knowledge nor the time available to advise patients in detail.

There are lots of good information sources available, including:

- The Big C Centre at the Norfolk & Norwich University Hospital, 01603 286112, www.thebigccancercentre.co.uk
- Prostate UK (previously Prostate Research Campaign UK), 020 8877 5840, www.prostateuk.org
- Cancer Research UK, 020 7242 0200, www.icnet.uk
- The Prostate Cancer Charity, 0845 300 8383, www.prostate-cancer.org.uk
- CancerBACUP, 0808 800 1234, www.cancerbacup.org.uk

Patients may also want to speak with someone who has travelled the same journey – quite possibly someone of similar age, background and neighbourhood. They might wish to return to the clinic to have their queries answered, but this is simply not practical, though the nurses offer help by telephone.

The Support Network Members would not be expected to have detailed knowledge of all the various treatments for cancer of the prostate gland, which can be any one of the following:

- radical prostatectomy (both open and laparoscopic)
- radiotherapy
- chemotherapy
- HIFU
- brachytherapy
- hormone treatment
- cryotherapy (soon hopefully).

In time, it is hoped they would accumulate the knowledge of members of the Support Group within their locality, who have first hand experience of the various treatments – to enable concerned patients to be put in contact with these Support Group Members who have personal experience of a particular treatment.

Patron: Martin Bell OBE

Continued on Page 2

The following Norfolk & Waveney Prostate Cancer Support Group Members have agreed to be Local Contacts:

(01602) 100E20

| Norwich (North):              | Mike Mills      | (01603) 490528 |
|-------------------------------|-----------------|----------------|
| Norwich (South):              | David Paull     | (01603) 457270 |
| Norwich (East):               | Stan Thompson   | (01603) 713463 |
| Norwich (West):               | David Haines    | (01603) 881213 |
| Great Yarmouth:               | John Leadbeater | (01493) 730565 |
| Lowestoft:                    | Ronald Capps    | (01502) 562584 |
| Kessingland:                  | Richard Rolph   | (01502) 740329 |
| Cromer/Sheringham:            | Paul Whitehouse | (01263) 825989 |
| Suffolk Coast/Waveney:        | Dave Cole       | (01728) 684244 |
| Poringland/Framingham Earl:   | Mike Smith      | (01508) 493323 |
| Taverham District:            | David Wiseman   | (01603) 260539 |
| Hingham/Watton District:      | Ray Allen       | (01953) 850863 |
| Fakenham District:            | Chuck Lyons     | (01328) 862927 |
| Burnham Market/North Norfolk: | Peter Smith     | (01328) 738685 |
| New Buckenham District:       | Ken Gee         | (01953) 860221 |
|                               |                 |                |

Miles Mills

There are **VACANCIES** for the Districts of Dereham, Wymondham/Attleborough, North Walsham, Holt/Melton Constable, Wroxham, Beccles/Bungay, Thetford and Swaffham.

Volunteers are needed to fill the vacant Districts to ensure there are local contacts available to all existing Support Group Members and New Members. Would any member wishing to find out more about what is involved in becoming a local contact for the Support Network please contact David Wiseman, Welfare Officer on (01603) 260539, <a href="mailto:home@wisemandav.go-plus.net">home@wisemandav.go-plus.net</a>

The following Support Group Members will be available to answer questions concerning specific treatments:

Cryotherapy
 John Newman (01603) 744581 and Michael Beaumont (01603) 410899

HIFU Jack Avery (01953) 606107.

There will be regular updates in the Newsletter giving details of the progress of the Support Network.

"We are fully dedicated to improving the lives of those affected by cancer in Norfolk & Waveney"



# Big C Walk of Thoughts 2008

Walking Together to Support and Remember

Join in this year's Big C Walk of Thoughts on Sunday 29th June and raise sponsorship to help fund <u>cancer equipment</u>, <u>care</u> and <u>research</u> in Norfolk & Waveney.







The walk is approximately 6 miles long and this year it will take a new route around the circumference of Fritton Lake passing through the otherwise private woodlands of Somerleyton Estate in peaceful, picturesque countryside.

The <u>Big C Walk of Thoughts</u> takes place from 10.00am - 4.00pm (last departures at 1.00pm), starting from Fritton House Hotel.

Tributes and dedications can be left at the special Dedication Tree. <u>Click here</u> to read messages left by walkers in 2007 and see why so many people take part in this special walk to remember friends, family and loved ones affected by cancer.



For more details about the Walk of Thoughts, visit the <u>Big C Website</u>, call 01603 619900 or email <u>rachel.irvine@big-c.co.uk</u>.

#### SOCIAL OUTING TO DUNWICH

There are still places available for the coach trip to the historic Suffolk coastal village of Dunwich on **Saturday 7th June**.

10.30am Coach departs Notcutts Garden Centre (Daniels Road, Norwich,

NR4 6QP. 01603 453155).

Midday Arrive for lunch in the famous beach café. After lunch, members

can visit the fine museum (picture right).

2.30pm Dave Cole will lead a short walk around the village, which will

include a stop off at his house where 'free' tea and biscuits will be

provided. (Members who prefer to explore on their own do not

have to come on the walk).

4pm Return to the car park.

4.15pm Coach departs Dunwich, to arrive back at Notcutts by 5.30pm.



Total cost – which will include Fish and Chips (or some other choices), a sweet and tea/coffee – will be £15 per head. The executive coach will have a loo on board.

Please send a cheque for the appropriate amount, made out to Dave Cole at Middlegate Barn, Dunwich, IP17 3DP. For more information, please email him at <a href="middlegate@aol.com">middlegate@aol.com</a>, or telephone him on 01728 648244.

#### Here's an Idea - an Annual PSA Test

I caught an interesting programme about Prostate Cancer on BBC Radio 4 recently. Among the contributors was Professor Roger Kirby, whom I have met.

Apart from outlining the obvious points we have been promoting in Norfolk, (symptoms, testing, treatment decisions and options, etc), he also drew attention to the fact that in the USA 70% of men at risk knew their PSA and had an annual check to keep a graphical record. This compares with only 6% in the UK.

This adds weight to the suggestion that our Group consider funding a pilot scheme to encourage men to at least find out their PSA and have it on record for the future.

The Colchester Hospital Outreach Project, the Guildford Prostate Cancer Support Group and the Kidderminster/Leamington Group have all been running similar schemes.

Roger Kirby also said that the results of this approach in the USA had seen a marked increase in early diagnosis, and a consequent fall in the death rate. This is a point whose implications NHS Norfolk (formerly Norfolk PCT) do not seem to have grasped. Now that the NNUH is a Foundation Trust, it may be possible for them to give support to this initiative.

We think nothing of having our eyes and teeth checked regularly. Is there any valid reason for the opposition to an annual PSA test?

David Haines, Outgoing Chairman

# More Food for Thought

The Department of Health's eighteenth annual report includes:

"One of the DoH's 2007/08 objectives is to reduce, by 2010, mortality rates from cancer by at least 20 per cent in people under 75."

If the target is to reduce cancer mortality by 20% within two years, relating to Prostate Cancer this would mean a reduction in PCa deaths from 11,000 to 8,800 – at the same time as diagnosed cases are rising from 30,000 to 35,000 per annum. How this will happen without a more active Awareness and Screening plan to achieve earlier diagnosis for treatable cancers is a tremendous challenge, and will require an urgent U-turn in DoH and NICE thinking.

## A Big Thank You

We continue to receive donations, and thank all those concerned for their support. Acknowledgements are extended to:

| Ray & Vera Allen's April Car Boot Sale               | 1,064.05 |
|--|----------|
| Mrs Mary Yates, collections in memory of Frank Yates | 328.00   |
| Mr & Mrs Malt  | 100.00   |
| Mr & Mrs Allum                                       |          |
| Donations at April Open Meeting                      | 28.28    |

# RAY & VERA ALLEN ... HERE THEY GO AGAIN! CAR BOOT SALE

Date: Saturday 5th July

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

Time: 8am - 2pm

(Set up from 7am, and please take all rubbish away).

Pitch Fee: £5 per pitch

If you have any unwanted items and would like to donate to the

cause, we would be very grateful.

Please phone 01953 850863 for any information.

#### REFRESHMENTS STALL ... RAFFLE

So far we have raised OVEr £6,000

Proceeds to the N&W Prostate Cancer Support Group.

### **Dates for your Diary**

Saturday 7 June 10.30am - 5.30pm Social Outing to Dunwich

Sunday 29 June Big C Walk of Thoughts

Saturday 5 July
Car Boot Sale

£

Wednesday 4 June & 2 July 6.00-7.00pm
Radiotherapy Department
Open Evenings
Colney Centre, NNUH
Please ring 01603 288779
beforehand if possible

Monday 7 July & 4 August 7-9pm

Committee Meetings, NNUH

Monday 4 August 7-9pm
Open Meeting, East Atrium,
NNUH Lizzie Frampton,
Macmillan Information and
Support Superintendent, Colney
Centre, NNUH will speak on
"Radiotherapy for Prostate
Cancer"

#### TREK TO SNOWON500 - A Thank You Note from Kevin Betts

"Dear Members, The trek to the summit of Snowdon on 17 May was very successful. About 420 people took part from across the country, and approximately £150,000 was raised for the Prostate Cancer Research Centre. I would like to thank you for your support at the last meeting at which you kindly donated £90 – in all I managed to raise £340. I would like to offer a special thank you to Sallie for all her help at the meeting. Yours, Kevin Betts"

#### 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: Claire, Sallie 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:

01603 713463, 01603 881213 or 01328 862927

■ E-mail us:

David Haines <u>david.haines2@btopenworld.com</u>

- Letters to the Editor: Chuck Lyons, 71 Norwich Road, Fakenham, NR21 8HH charleswlyons@aol.com
- Visit our website: www.prostatesupport.org.uk

