

Norfolk & Waveney Prostate Cancer Support Group

Registered Charity No. 1108384

Newsletter no 28 August 2009

Patron: Martin Bell OBE

The view from the Chair



I would like to take this opportunity of saying a big 'thank you' to all those good folk who give so generously of their time and energies in their fundraising for our Support Group.

All sorts of people assist us, raising money in a variety of ways.

In June I went along to the Imperial Hotel, Great Yarmouth to receive £1,000; £500 of which was raised by the Norfolk Stag Owners' Club, at a special exhibition event earlier in the year.

The management of the Imperial Hotel then generously matched this amount. Other clubs and organisations have also been supportive of us, through their donations and all of these are deserving of our thanks. Individuals also make donations, invariably motivated by their close experience of prostate cancer, through a family member, friend or work colleague.

Then there is that wonderful trio of fundraisers, Vera Allen, husband Ray and friend Ken Eaglen, who together have raised just over £10,000, over the past four years – a truly magnificent effort.

Quite deservedly, they have decided that four years of intense fundraising is enough and are now taking a well-earned rest from it. We all owe them a debt of gratitude for their endeavours and fortitude over these past four years. On behalf of all our members, I thank you, Vera, Ray and Ken.

Ray Cossey - Chairman

Another PSA testing session in the pipeline - this time its Yarmouth's turn

Arrangements are being made for a second free PSA testing session – this time at Great Yarmouth on October 20th.

The owner of the Imperial Hotel at Yarmouth, Nick Mobbs, has kindly offered us the free use of the hotel facilities, for the event.

Because of size constraints there will be two sessions, at probably 6.30pm and 8.00pm, allowing us to take test blood samples from up to 100 men at each session.

Consultant urologist, David Baxter-Smith has told us that is able to join us again.

We hope that the local media will help us to promote this event, and to invite men to apply by sending us a SAE and for us to reply with the usual pre-registration form.

We are hoping to attract those men who are over 50; have no previous history of prostate cancer; or who have been refused a PSA test by their GP. Also those with a family history of prostate or breast cancer.

This is another opportunity for us to raise the profile of PSA testing in this area. Over the past year we have made our presence felt and, as a result, we now know that there has been a 27% increase in referrals, for biopsies, over the past year.

Target achieved!



When our Group was formed in April 2004, Ray and Vera Allen (above) took on the role of fund-raisers – and set themselves the target of raising £10,000.

Their chosen method was house clearances and car boot sales, and now, with the help of fellow prostate cancer sufferer Ken Eaglen, who gave the use of his farm premises at Hingham for storage and sales, and a team of 10 volunteers, they have reached their target.

Ray, who handed over the final cheque to chairman Ray Cossey at an open meeting at the James Paget Hospital, said "We've enjoyed it tremendously, but it feels good to step back and take a rest."

Accepting the cheque at an open meeting at the James Paget Hospital, chairman Ray Cossey said "This was tremendous achievement - Ray and Vera have my greatest admiration.

PSA Testing - the other side of the coin

Member Dave Kirkham shares some thoughts prompted by the 2008 Annual Report on the State of Public Health by the Chief Medical Officer Sir Liam Donaldson

I think it is fair to say that as a group we are pretty much committed to advocating PSA testing for all, perhaps even mass screening of PSA.

This is understandable for we are all 'survivors of prostate cancer'. Most of us are thankful that we had our own PSA tested when we did.

Those of us with low grade cancers are thankful that we nipped it in the bud. Those of us with higher grades are thankful we caught it just in time, and there will be some of us who wished we had it tested earlier. But are we right?

Well not according to Sir Liam Donaldson. The review is a hard hitting document with sections on the usual suspects, obesity, alcohol and tobacco, but he devotes five whole pages to the question 'Prostate cancer: what to do with the pussycats?'

It is a well made argument highlighting that while some prostate cancers are potentially terminal high grade 'tigers', most men diagnosed with prostate cancers have the more benign low grade 'pussycats'.

He pulls no punches, highlighting that '...prostate cancer is second only to lung cancer as England's biggest cancer killer in males.' He also identifies the other side of the coin, that '...localised slow-growing tumours of-

ten produce no symptoms and do not shorten life, while full-blown treatment can cause incontinence and impotence'.

The facts speak for themselves, the current toll is around 35,000 men diagnosed with prostate cancer each year, while only 10,500 die of it. So do the maths, what happens to the other 24,500?

Men diagnosed with prostate cancer are three times more likely to die of something else!

The big issue for the newly diagnosed is therefore, have I got a tiger or a pussycat? Sir Liam's point is that for most men the answer is pussycat and left well alone most won't become tigers, leastwise not in the ordinary lifespan.

He acknowledges that the individual is confronted with a 'hellish decision', do you opt for watchful waiting, and run the risk, no matter how slight, of letting your pussycat become a tiger, or do you opt for the safe if somewhat radical solution?

Seen from the doctor's perspective, '...Twenty men need radical treatment to save one life. In saving one man's life, five men may be left incontinent and another four impotent as a consequence of their treatment'.

Sir Liam does advocate that men who request a PSA test should get one, but that this should follow a discussion about the pro's and con's of PSA testing so that the man can make an informed choice.

Does that strike a cord with any of us? How long do we get at the doctors, five minutes, ten minute's tops, and I guess most of us are a little anxious, I know I was, it was rather unsettling to hear the 'C' word being spoken about me! So how informed are our decisions?

It is certainly a worthwhile read, there is clearly another side to the coin, and perhaps we need to reflect upon whether we are right to advocate PSA testing for all?

It made me reassess my views about Doctors who question their patients need for PSA testing, as a group we might not agree with them, but perhaps we should acknowledge that they hold genuine views based upon honest scientific facts.

You can get the report on line, at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports

Contributions from members are very welcome. This one is about 500 words - Email them to: bernardfarrant@norwich.clara.co.uk

The Group continues to benefit from the generosity of individuals, societies and clubs - such as the Norfolk Area Stag Owners' Club.

The picture shows our Chairman, Ray Cossey (right) at the presentation of cheque for £500 from the club at the Imperial Hotel, Gt Yarmouth - whose directors promptly matched it to bring the benefit to the Group to £1000. In the picture are SOC's Norfolk Coordinator, Chris Liles, and the Imperial Hotel's owner, Nick Mobbs.

Other recent donations include:-

Mr & Mrs J McIver - £10; VG & FM Allum £5; Ray and Vera Allen £1,920; Mrs HYJ Downes £20; Dr J Efstratiou £1,500; D S Smith £15; Waveney Motor Cycle Club £175; Mr DL & Mrs I J Paull £60; Anonymous £100; Coin box collections £72.48



Pain-free day surgery to remove prostate

A 'nerve-blocker' drug that acts as long-lasting anaesthetic has enabled a patient to have pain-free day surgery to remove his prostate gland in a UK first.

Michael Sinclair, 68, was able to return home within hours of having his prostate gland removed by radical prostatectomy surgery at Imperial College Healthcare NHS Trust. His speedy discharge was made possible by a new technique using ultrasound technology to insert 'nerve-blocker' drugs into a precise area of the abdominal wall, to stop the surrounding nerves transmitting pain signals back to the brain for up to 18 hours after surgery.

Future Newsletters...a word from the chairman

Like all similar groups we have to keep a watchful eye on our expenditure, having only limited funds available to us.

The cost of printing and posting the Newsletter is very high so, bearing this in mind, your committee has decided that after this edition there will be only three publications a year; at four-monthly intervals – in February, June and October.

Having just three editions each year will ease the burden on our voluntary editor, Bernard Farrant.

I know that he has sometimes found sufficient readable material hard to

come by. I am always for quality rather than quantity

Many members, to help reduce printing and postage costs, have elected to have their Newsletters 'delivered' via the internet.

When a new edition is published they each receive an e-mail telling them the latest Newsletter is available and they can then read or download it from our website; www.prostatesupport.org.uk.

If you would like to join our 'silver surfers' please call Harvey Meadows on 01603 737588.

Group member Colin Mortimer believes that overcoming fear is an important part of healing all physical illnesses - including cancer. He has written about his beliefs, and is inviting anyone would a copy of what he has written, or would like to talk to him about it to ring him on Norwich 740202

Cancer researchers probe unexpected success of experimental treatment

Researchers are probing an unexpected success in a study of an experimental treatment for prostate cancer.

In three men with advanced disease, use of an immune drug called ipilimumab, shrank their tumours to such an extent surgeons were able to operate.

In men with advanced prostate cancer, which has spread outside the prostate, surgery cannot usually be done.

The Mayo Clinic team in the US said the "startling" results in the study of 108 men had prompted them to set up a second trial using higher doses. Hormone therapy is usually given to try to

shrink the tumour to some degree and buy some time.

The trial was set up to see if a drug called MDX-010, would improve on hormone treatment. Half the men had normal therapy and half also received MDX-010.

In three cases, where the experimental drug was given, the tumours shrank dramatically, enabling surgeons to remove the tumour.

Dr Eugene Kwon, a surgeon at the Mayo Clinic in Rochester, said the results in those men were well beyond their expectations. "Our surgeons had never seen this happen before and we were really taken by surprise."

Until large scale studies are carried out it is unclear whether this response can be repeated in other patients or is an anomaly.

John Neate, chief executive of The Prostate Cancer Charity said they would wait for further results with anticipation. "If a cancerous tumour has spread beyond the prostate gland, it would currently be regarded as inoperable and alternative types of treatment, typically hormone therapy are necessary.

"If these early and small scale results are replicated in larger trials, this represents a potentially very exciting development.

"Living with Hormone Therapy".....You don't have to suffer in soggy silence!

At the August Open meeting member David Paull gave a plug for a new Prostate Cancer Charity booklet on hormone treatment – and was almost bowled over by the rush of people wanting details.

So to give it a bit more exposure, David writes :-

Are you on hormone treatment? Are you sitting uncomfortably, drenched in perspiration? Help is at hand. An excellent new booklet, *Living with hor-*

none therapy, has been published by the Prostate Cancer Charity (to which our group is affiliated).

It details the forms of hormone therapy, with their advantages and disadvantages, but its main message is how to manage the side effects, such as those embarrassing and infuriating hot flushes.

They can be treated!

You don't have to suffer in soggy silence.

Get the book, see your GP and discuss possible drug treatments (listed on page 22) that could make life so much more comfortable.

You can either phone the charity on 020 8222 7622 and ask for a copy, or download the book from the charity's web site: www.prostate-cancer.org.uk

(Having just started hormone therapy I have taken David's advice and downloaded the booklet– well worth having – Ed)

Dates for your Diary

Monday 7 September 2009

Committee Meeting
7-9 pm at NNUH.

Monday October 5th - Open Meeting
Norfolk and Norwich University Hospital 7 p.m
Christine Adams

will give an illustrated talk entitled "A Lifetime in the Building" - the story of May Savidge, engineer, who devoted 25 years of her life to moving her house from Hertfordshire to Norfolk and rebuilding it brick by brick at Wells-next-Sea

Tuesday October 20th

PSA Screening session, Imperial Hotel Great Yarmouth

December 7th - Open Meeting
Norfolk and Norwich University Hospital 7 p/m
Dr Tom Stuttaford

Dr Stuttaford retired as the Medical Correspondent of The Times at the end of 2008, but still writes "Dr Stuttaford's Surgery" for The Oldie. He has had a radical prostatectomy, radiotherapy and hormone therapy, which he is still on 12 years since he was first diagnosed. He is now 78.

The Big C Centre

Not everybody knows of the existence of the Big C Family Cancer Information Centre, at the Norfolk & Norwich University Hospital.

It is an amazing facility, for all cancer patients, their families and/or friends. In a totally non-medical environment you can relax in the comfortable, home-like lounge; make use of an extensive reference library; use the internet, or just pop-in for a cup of tea, or coffee.

Here you can chat with fellow cancer patients and qualified nursing staff, all of whom will listen to your concerns and, if asked, give advice.

You'll find the Big C Centre very easily - it's the cream and blue coloured, circular-shaped building overlooking the first roundabout, as you enter the hospital grounds.

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:

Sally Wendy or Helen 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

NORFOLK AND NORWICH PROSTATE CANCER SUPPORT GROUP

Registered Charity No. 1108384

Committee members 2008/9

Medical Advice/Help (Specialist Uro-Oncology Nurses)
Norfolk and Norwich University Hospital 01603 289845

Sally Jermy - jermy@nnuh.nhs.uk

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

Helen Abigail - helen.abigail@nnuh.nhs.uk

James Paget University Hospital 01483 453510

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

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

President - David Haines 01603 881213

david.haines2@btinternet.com The Corner House 2

Peacock Close Easton NR9 5JD

Chairman - Ray Cossey 01603 720980

ray@thecosseys.co.uk 73 Blofield Corner Road Little

Plumstead Norwich NR13 5HU

Vice-Chairman - Edward Hare 01603 400424 Mobile:

07787124143 edwardhare@btinternet.com

84 The Warren Old Catton Norwich NR6 7NN

Secretary - Brian Smith 01603 860954

smiths.online@virgin.net 81 Nightingale Drive

Taverham Norwich NR8 6TR

Treasurer - Dave Kirkham 01953 456858 Mobile: 07799

074372 dsdavekirkham@yahoo.com

Membership Sec - David Winter 01603 868967 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 737588

rvmcolt@hotmail.com 31 College Close Coltishall Norwich NR12 7DT

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

1603 437291

Trevor Watson 01603 437291

trevor.watson@mypostoffice.co.uk 59 Vincent Road Norwich NR1 4HQ

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.