Norfolk & Waveney Prostate Cancer Support Group NEWSLETTER

Issue No 41

February 2013

We're bottom of the research league

A table compiled by Prostate Cancer UK shows that prostate cancer is bottom of the league for research spending. Breast cancer receives twice as much funding, even though the two diseases kill similar numbers of people.

Despite being the most common cancer in men and the fourth most common cancer overall, prostate cancer is 20th in the "league table" of annual spending per case diagnosed – £417 for each of the 41,000 men diagnosed in 2011, compared with £853 for breast cancer. The highest spend per patient is for leukaemia – £3,903.

The figures have been published by the charity to mark the start of a fund-raising campaign, The Sledgehammer Fund, fronted by the actor Bill Bailey whose father-in-law was successfully treated for prostate cancer.



Bill Bailey with his Sledgehammer

Owen Sharp, chief executive of Prostate Cancer UK, said: "Men in the UK have a problem and don't want to talk about it. Neither do the wives and partners who will end up supporting them, the doctors who will treat them, or the politicians who count on their vote.

"Prostate cancer is simply not on the radar in the UK. We need to follow the lead of the successful female movement against breast cancer and create a real change for men. We are going to need a very big sledgehammer to crack prostate cancer. This is more than a campaign. It is a call to arms."

The campaign is based on a series of TV and print advertisements featuring Bill Bailey, who said: "I read an article about the number of men with prostate cancer. I was shocked. I had no idea it was so common but, if caught early enough, can be successfully treated.

"My father-in-law was diagnosed with prostate cancer, treated, and now leads a fulfilling life, so it can be done – but more than 10,000 men every year in the UK are not so lucky."

See also "From where I sit" – page 3.

They're there to help!



Wearing their distinctive gold sashes, our new welfare officers, David and Adrienne Capp, were on parade at our Christmas meeting, circulating among members and offering help and information.

The Capps maintain the list of members who comprise our "telephone helpline" – volunteers who have had various forms of treatment and are willing to talk to – and especially listen to – new patients.

One form of treatment that is at present missing from the list is brachytherapy, so we are looking for a volunteer, a member who has had that treatment and is willing to take the occasional call from someone who has had or is about to have that form of therapy. Please contact either the Capps (see page 4 for details) or our membership officer, Stan Thompson (01603 713463).

Rosamund Wiseman

It was with great sadness that we heard that Ros Wiseman – whose husband David, our welfare officer, died on July 16th – died suddenly while spending Christmas with her family. A tribute to her contribution to the work of the group will appear in the next issue.

Patron: Martin Bell OBE

One-stop clinic: the speedy route to diagnosis

One-stop clinics are a highly efficient way of providing rapid diagnosis and sparing new patients the anxiety and bother of repeated visits to hospital – but only if all the equipment is readily available and in one place rather than having to be assembled for each clinic. And that is where our group is helping.

The prostate cancer team at the Norfolk & Norwich have been operating a one-stop clinic for some time but, now that the service has been expanded to the rest of the urology department, storage and instant availability of equipment became a problem.

So, following a request to our committee by uro-oncology specialist nurse Sallie Jermy, we have met the £475 cost of a multi-purpose trolley because NHS funding was not forthcoming. The money was raised for the group by The Norfolk Ploughing Society.

Sallie and her team are able to use the trolley – 890mm x 600mm and 810mm high – to house all the equipment for tests, including ultrasound, flexible cystoscopy, flow-rate and prostate biopsies (but note that because of the detailed microscopic analysis required biopsy results take a week to come through).

It is all part of today's cross-discipline approach where the urology teams work with other specialisms such as radiology to provide patients with rapid – and often instantly reassuring – results, so that by comparison with the drawn-out processes of the past, they can learn within the day whether they have anything to worry about.

One-stop clinics are just one of many significant changes that Sallie has seen since she trained as a specialist nurse back in 1997. There has been a big increase in the number of prostate cancer patients in that time, both because men are living longer and because, thanks to greater awareness and more PSA testing, they are being diagnosed sooner. Across the board in urology, they are now treating 800 new cancer patients a year.

Constant advances in information technology have greatly aided diagnosis and treatment. Whereas X-ray results once involved carrying film from one department to another, they are now sent electronically. The results of a whole range of other tests are now produced and transmitted much more quickly.



Specialist Nurses Sallie Jermy (front) and Rachel Matthews with the fully-equipped new trolley.

Consultant urologist Mr Ralph Webb, who has treated many of our members, told the hospital magazine Pulse recently that the one-stop clinic had been a huge success. When he came to the hospital 19 years ago patients would have to wait up to four months to see him. "Now they get an appointment in about two weeks. If we need to discuss a particular case with our specialist colleagues we can do so there and then, without delay, and the medical students love it because they can move from room to room and learn from each member of the team. From a patient's perspective, it's a huge improvement because it takes away the uncertainty and they don't have to keep coming back for more tests."

The plaque on the trolley reads:

This equipment was provided by:
THE NORFOLK & WAVENEY
PROSTATE CANCER SUPPORT GROUP
And paid for with money raised by:
THE NORFOLK PLOUGHING SOCIETY
December 2012

Latest donations

The East Anglian Motor Trades Golfing Society has been wound up and Norman Thurtle of Acle has very kindly sent us the cash that was left in the kitty – the splendid sum of £1582.54.

We are also delighted to receive a donation of £100 from Swaffham and District Tangent Club. Tangent is an organisation for the ladies of members of 41 Club, the Round Table "old boys".

We are grateful to Ken Gee of New Buckenham who has sent us a donation of £10.

At our Christmas meeting, the raffle, with a host of prizes donated by members, raised £170, with a further £58 in the coin collection towards the cost of the refreshments.

Next job: Poet Laureate?

Our patron, Martin Bell, is now a published poet, he proudly told us at our December meeting. And he kindly gave us a signed copy of his new book of verse as a raffle prize.

By turns hilarious and moving, Martin regaled us with stories about his time in Parliament, his wide-ranging and often dangerous career as a BBC war reporter, and the heart-breaking scenes he witnesses as a Unicef ambassador visiting strife-ridden, poverty-stricken third world countries.

Wearing his trade-mark white suit, Martin leavened his stories of tragedy and atrocity with samples of his mostly irreverent verse, including a light-hearted but distinctly uncomplimentary Ode to Manningtree jotted down on his train journey to Norwich. The local civic leaders will not be including it in the town's guide book!

Our president, David Haines, says that since Martin became our patron in 2004, he has visited other PCSGs around the country, and also knows and admires David Baxter-Smith, who conducted our mass PSA tests. "Martin told me our group impresses him greatly – and he does not give plaudits lightly," says David.



From where I sit – the Chairman's view

On behalf of our President, Trustees and Committee may I wish you all a Happy and Healthy 2013.

MATERIAL FREE TO MEMBERS

Lifestyle & Cancer – book by Professor Robert Thomas

This publication was given to all members who were on our register up to the end of 2011. For those of you who joined us in 2012, and would like to obtain a free copy, see below.

■ Sitting Room Circuits – a DVD of exercises that can be carried out at home. This was issued at our December meeting, with some 40 members taking up the offer.

Those of you who were unable to get to the meeting, and would like a copy of the DVD, please contact Noel Warner on 01508 488088 or e-mail noel.windfall5@btinternet.com with your name and address. If you wish to make a donation toward postage or the cost of the product, please send it to our treasurer, Dave Kirkham, at 3 The Coppice, Attleborough, NR17 2PY

BEFORE & AFTER Research in PCa

I wonder how much longer we are going to have to rely on the PSA test as a means of finding prostate cancer in our male population. Critics say that the test is unreliable, but some of you reading this would not be here today were it not for the PSA test – and this fact is supported by a number of men who attended our four public test sessions who have written to us saying exactly that.

Genetics research is being conducted by Professor Colin Cooper in Norwich, and others, but will take some time to bear fruit, and even the much talked about urine test devised at Kingston University seems to have stalled.

Given that prostate cancer kills one man every hour, isn't it time that research funding, currently equal to £417 for each of the 40,000 plus cases diagnosed each year, is stepped up to the £853 that is available for each case of breast cancer diagnosed?

Prostate Cancer UK are determined to get PCa "on the radar" and are running a series of advertising campaigns. Good! Meanwhile we will continue with our own awareness programmes.

Treatment explanations

The Sunday Times & Raconteur produced a very useful description of the treatments available and have given their kind permission to make copies. The article covers hormone therapy, brachytherapy, HIFU, Da Vinci robotic surgery and Cyberknife. If you would like a copy of this article please contact me (see above).

BRACHYTHERAPY APPEAL

Closer to home?

Whilst on the subject of treatment, you may be aware that the N&N have launched a "targeted radiotherapy" appeal to help fund a "high dose rate brachytherapy" suite. The anticipated cost is around £600,000, and fund-raising has begun. This project means that treatment previously carried out at Addenbrookes would become available in Norwich.

Noel Warner

Not just about money but...

Tim Farnham, committee member and publicity officer, announced at our Christmas meeting that his round-Norfolk walk raised the magnificent sum of £10,000. But it was not all about money. Tim's equally important theme was "Exercise", as he explains below:

"In September I did a three-week, 240-mile walk around Norfolk, partly to raise funds and partly to raise awareness of the importance of exercise for people who have had a cancer diagnosis. The relevance of lifestyle factors — diet, exercise, smoking, alcohol consumption, obesity and so on — is well documented, and the specialist nurses at NNUH are keen to encourage prostate cancer patients to exercise.

"Having had weeks of radiotherapy or a prostatectomy, exercise may be the last thing on people's minds but it is an important component of recovery and maintaining good health. The essential point is that on average, cancer sufferers who continue to take moderate exercise live longer and with a better of quality of life than those who don't. It's as simple as that.

"I'm not talking about running half-marathons or even walking around Norfolk, just trying to achieve, within one's own limits, the recommended 30 minutes a day five days a week of aerobic exercise.

"This is a way that we can tilt the scales in our favour, independently of what the staff in the hospital can do for us via medical intervention. That's the message we have been trying to promote over the last few months"

Exercise – but don't overdo it!

To complement Tim's talk, Dan Goodwin came to the meeting to show us – on screen and in person – how we can exercise at a level that suits our ability and fitness. The picture is from the "Sitting Room Circuits" DVD that is available free to all members. If you haven't got a copy, you can collect one at future meetings (see "From where I sit" – page 3).

The DVD has been developed with a team of qualified experts and health professionals and is intended, as it says on the label, to be "fun, adaptable, flexible and safe". It is produced by the NHS Norfolk health trainer service which can, if you wish, assess you at a brief meeting to ensure that the programme of exercise is suitable for you.

What matters is that you take it gently and don't try to overdo it and do more harm than good. The exercises are designed to be done at home, using the furniture or the stairs for support, and although Dan Goodwin is dressed for the part you do not need special clothing or equipment. You can wear what you like as long as it is comfortable.

 A fact sheet on "Diet, exercise and prostate cancer" is available free from Prostate Cancer UK (tel: 020 8222 7622).

Dates for your Diary

An opportunity for newly diagnosed patients to chat with members who have already been through the same journey.

Wed 6 Feb & 6 Mar.... 5-7pm Radiotherapy Department Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C.

Tue 26 Feb. 6.30-8pm Public Meeting at QEH Kings Lynn Lecture Theatre

Proposed West Norfolk Prostate Cancer Support Group

Mon 8 Apr. 7-9pm

Open Meeting at Benjamin

Gooch Theatre, NNUH



How to Contact Us

■ Telephone the Specialist Nurses: Sallie, Wendy, Helen & Rachel Norfolk and Norwich University Hospital 01603 289845

Angie & Wendy

James Paget Hospital 01493 453510

Sallie & Clare

Queen Elizabeth Hospital, Kings Lynn 01553 613613 Ext 3075

Lizzie – Macmillan Info & Support Radiographer 01603 289705

Help or Advice – Our Welfare Team: We have over 30 members available to help. There is probably one near you.

For more information please call our Welfare Team, David and Adrienne Capp, on 01603 712601

- E-mail us: Noel Warner, Chairman noel.windfall5@btinternet.com
- Letters to the Editor: David Paull DavidLPaull@aol.com
- Visit our website: www.prostatesupport.org.uk