Prostate Cancer Support Group NEWSLETTER

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Group's £10,000 pledge to brachytherapy appeal

A £600,000 project that will mean that some Norfolk prostate cancer patients can be treated locally instead of having to make expensive and time-consuming trips to London has been launched by the Norfolk and Norwich University Hospital – and our group is pledging £10,000.

The pledge is dependent on the Targeted Radiotherapy Appeal (TRA) team raising sufficient funds to get the project started, and we have stipulated that our donation would be used to buy equipment, rather than bricks and mortar.

The treatment is high dose brachytherapy – targeted radiotherapy in which radioactive pellets are inserted in or near the tumour for a few minutes at a time. Standard radiotherapy uses radiation directed at the tumour from outside the body. The radiation travels through normal tissue to get to the tumour which means that some healthy tissue is damaged, although modern techniques aim to keep this to a minimum.

With the new treatment, the daily dose patients can receive is significantly higher, meaning that fewer treatments are necessary and there are fewer long-term side-effects.

The NNUH would be one of only ten hospitals in the country able to offer the new treatment for prostate cancer. It is not suitable for all patients but the aim is to treat about 90 a year in Norwich. The therapy is tailored to the individual but patients usually receive between one and four treatments and can return to normal activities within a few days.

The new facility will be established in the Colney Centre which provides services for oncology, haematology and palliative care. Existing rooms will be altered or extended and equipment such as an ultrasound scanner and anaesthetic equipment will be installed at an estimated total cost of more than £130,000.

A donation to the group of £1,045 in memory of Mr Peter Michael Rowland, of Gunton St Peters Avenue, Lowestoft, who died on October 6th, has been handed over to the TRA at the request of his wife Elizabeth.

Minister to speak on support for PCa patients

Norman Lamb, MP for North Norfolk and a Government minister, will be the speaker at our next open meeting at the Benjamin Gooch Theatre at the NNUH on Monday, April 8th (7.00pm). He will be speaking about social care and support for prostate cancer patients.

Mr Lamb, who is the son of one of UEA's most distinguished professors, the climatologist, Hubert Lamb, went to Wymondham College before taking a law degree at Leicester University. He practised as a solicitor, specialising in employment law with the Norwich-based firm, Steeles Law.

At the June 2001 General Election, he became MP for North Norfolk, ironically unseating David Prior who then became chairman of the NNUH Trust until a few months ago and is now chairman of the Care Quality Commission.

Following the 2010 General Election, Mr Lamb was chief parliamentary and political adviser to the Deputy Prime Minister and Liberal Democrat leader Nick Clegg and is now Minister of State for Care and Support.



Please note that this meeting is also our annual general meeting at which your officers and committee members will be elected and you will learn how they are spending the money!

There's no need for you to fight alone

You are given the shattering news that you have prostate cancer. Do you slump into deep despair and feel that you are "Facing the fight alone" – the title of a new report by Macmillan Cancer Support on "Isolation among cancer patients"?

Macmillan have found that a quarter of people diagnosed with cancer in the UK will lack support during their treatment and recovery, often because family or friends are too busy or live too far away. Health care professionals report that many patients skip treatment because they have no support. Patients say that the feeling of isolation causes them stress, anxiety or depression.

But it needn't be like that. Big C now provides every person newly diagnosed with cancer at the NNUH with information about the support services available and plans to extend this to patients at other hospitals in Norfolk and Waveney in the coming year.

As well as its wonderful centre at the NNUH, from which many of us have benefited, Big C now has a drop-in service at the Forum in Norwich, a community-based centre in Regent Street, Great Yarmouth, and support and information services in the new Louise Hamilton Centre at JPH, Gorleston. Further centres are to be opened in Norfolk Street, King's Lynn, and Church Street, Cromer.

And, of course, specifically for prostate cancer patients, there's us! As our founder chairman, now president, David Haines, pointed out in a letter to the Eastern Daily Press, for the past nine years we have been offering a wide range of support to patients and their families across the county, working closely with Big C, NNUH, JPH, Macmillan, Anglia Cancer Network and others. Our welfare and support network – led by our welfare officers, David and Adrienne Capp – is available seven days a week to fill the gaps not covered by other agencies, offering home and hospital visits to those living alone.

David Haines is one of our welfare team who has carried out such visits and writes:

On the question of loneliness, some of us have found when visiting patients at home or in hospital that it is best to let the patient lead the conversation, as per Macmillan visitor training. If they want to talk about concerns with cancer then we can talk about that with some knowledge. My own experience has included such chats, but more often we have both (the patient and I) been able to enjoy a man-to-man chat about a great variety of subjects, which have included hobbies, favourite authors, model-making, sports, services experience etc., and have found that this approach has gone some way to reviving an interest in life beyond cancer.

One of the saddest experiences I had was visiting a chap in a nursing home each weekend (he had previously lived alone with no family nearby). He spent all day in his room and had virtually no conversation as most of the other residents had nothing in common with him to talk about. Although wheelchair-bound, he found the visit the highlight of his week, and came alive when we talked about his life spent working overseas, and talking about places we both knew, and occasionally we had a game of chess.

Another had a passion for model railways, and took much pleasure in us climbing up to his attic where he had built a magnificent layout, which few other people ever saw. Quite often the visitor can gain as much as the patient from these exchanges, and as few of the more formal agencies are equipped to offer this sort of companionship (most work 9 to 5 Monday-Friday) this is where we can fill the gap.

In most cases our approach on this to date has been reactive, i.e. responding to requests, rather than pro-active, where members of the support network take the initiative and inquire if the patient would like such contact. I know David Wiseman and I had thought about how best to approach this, but sadly he was unable to develop it. Perhaps this is the way forward. What do members think?

If you would like a home or hospital visit, do let our welfare officers David and Adrienne know (01603 712601).

Barclays matches Rotarians

As reported earlier, Rotary Club of Broadlands raised £706 for us via collections, raffles etc. This was doubled to £1412 by Barclays Bank, encouraged by one of the Rotarians who is an ex employee of the bank.

Here is Mrs Judith Jermy, President of Rotary Club of Broadlands, handing over the cheque to our chairman, Noel Warner.

Many thanks to both.



Not chips with everything

Killiov scientists have discovered that eating chips can increase the risk of prostate cancer! According to research results published in the journal The Prostate, experts at a cancer research centre in Seattle have found that eating deep-fried food such as chips, fried chicken, battered fish and doughnuts can promote aggressive, life-threatening tumours. Another of life's little pleasures in the firing line!

Rosamund "Ros" Wiseman - An Appreciation

We were all shocked and saddened to learn that Ros passed away suddenly, but peacefully, on December 29th, having just spent Christmas with her family. It was doubly tragic that Ros had suffered a stroke so soon after the loss of her beloved husband David, our Welfare Officer, who had died just a few months earlier.

At our December meeting, only a few weeks before she died, she told several of us that she was planning to train as a Macmillan bereavement counsellor.

Rosamund was a popular member of the Group and – as well as giving David her full support – she was always ready to give a helping hand in more mundane tasks such as providing the teas at our meetings, helping with Christmas Raffles, and



working on the registration team at our mass PSA Test sessions.

She also attended many of our fundraising events held with other clubs etc who have supported us. At the memorial service held, as

for David, at St Peter Mancroft church in Norwich, a large congregation of family, friends, and colleagues had gathered on January 18th, in spite of the wintry conditions, as evidence of the wide love and respect in which she was held.

She was a committed Christian and, as with David, this showed through in her everyday life. Her son, Charles, gave a moving address, and revealed that she had always been prepared to help others, and had a lively sense of humour and a welcome for each new member of her local church community.

We extend our sincere sympathy to the family, and will always remember Ros and David's friendship and kindness.

She will be sadly missed.

David Haines

From where I sit – the chairman's view

West Norfolk Support Group preliminary meeting

There has been a move afoot to test the feasibility of setting up a Support Group in West Norfolk, and a preliminary meeting was held on February 26th at the Queen Elizabeth Hospital in King's Lynn.

The prime organiser was Fiona Cutts, the patient & public involvement lead at QEHKL. The urology unit are getting around 5-7 prostate cancer referrals per week, which means that there are easily enough to establish and make use of a support group such as ours.

A goodly number of prostate cancer patients, along with their partners, attended. The meeting was opened by Fiona and our president, David Haines. Two consultant surgeons, Mr W Lukianski and Mr P Maheshkumar, gave talks on prostate cancer - the contents of which will be well known to our readers. However, two pieces of information that caught our attention was that the USA seems to be coming to the conclusion that PSA screen testing can reduce cancer deaths by 29%. If this has some solid evidence behind it then it must be put to our NHS decision-makers. The other interesting fact was the change in procedure following a PSA test which showed a raised level. At the QEHKL, instead of going straight to the biopsy stage they are "sector mapping" using an MRI scan. This gives them valuable clues as to where the cancer cells are.

It remains to be seen if a support group can get off the ground in this part of Norfolk, but all the signs from that gathering were pointing in the right direction – ie **West!**



King's Lynn consultant surgeons Mr P Maheshkumar (left) and Mr W Lukianski (centre) with our vice-chairman Ray Cossey.

Information & Support

As far as I know all of our registered members – over 200 and growing – got to hear about us through information available via the Urology Department at NNUH. There is a suspicion that "private patients" who have been treated at the Spire Hospital have no knowledge of us. In the strictest confidence, if there is a member reading this who was treated there, would you please contact me. Just because Spire patients can afford to "go private" doesn't mean they are in any less need of support so it's a gap that we want to fill.

Research grant to tackle resistant cancers

A £250,000 grant to support Professor Colin Cooper's prostate cancer research at UEA and NNUH has been made by Prostate Cancer UK. It is one of 11 project grants and five pilot awards totalling £2.7 million this year.

The grant to Professor Cooper is for a three-year project to create new targeted combination therapies for patients with prostate cancer that has spread outside the prostate (metastasis). The research is aimed at creating a new treatment that uses tiny nanoparticles to deliver both a drug that weakens prostate cancer cells and the standard chemotherapy drug docetaxel at the same time.

Currently, docetaxel is one of the last treatment options available for men with metastatic prostate cancer but many develop resistance to the drug. The results of the research could lead to better results and longer survival for men with advanced prostate cancer.

Professor Cooper's application for the grant stated that it was their hope that nanoparticles combining new inhibitors and standard chemotherapy would offer survival benefit for patients with difficult-to-manage cancer resistant to chemotherapy and would lead to a trial within the remit of the Norfolk and Norwich NHS Trust.

Professor Cooper said: "We hope that, with this generous grant from Prostate Cancer UK, we can develop a new way to target the chemotherapy to the cancer cells and deliver a more effective treatment."

The project grants and pilot awards, also known as feasibility studies, are the first under Prostate Cancer UK's 2012-2020 research strategy.

PCUK has already spent more than £12 million on research since it was founded in 1996 and thanks to generous supporters, including the Movember Foundation, is committed to spending up to £25 million over the next three years.

"We are very lucky to have such a community of motivated and talented professionals all champing at the bit to help us beat prostate cancer through our programme of research," said Dr Iain Frame, the charity's director of research.

"Finding new methods and ways of attacking prostate cancer can be very much like entering a maze. Pilot grants are designed to see whether taking a particular route has the potential to be an exciting new path to explore in greater detail. Project grants fund research projects that are looking at a very specific topic. They go into greater depth than pilot awards and as such attract a larger amount of funding.

"Taking into account our other commitments to research, including our training and fellowship awards, the Movember Centre of Excellence, and other strategic awards, we will be spending a colossal £11million this year. When it comes to cracking prostate cancer, there is no better tool for the job than a dedicated programme of research".

Dates for your Diary

Wed 3 Apr & 1 May.. 5.30-7pm Radiotherapy Department Open Evenings, Big C & Colney

Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C. Call 01603 288779 to book.

Norman Lamb MP, Minister for Care and Support (see page 1)



This is the cover of the first issue of Prostate Cancer UK's excellent and very readable new magazine.

To sign up for your free subscription (print or email), go to:

http://prostatecanceruk.org/aboutus/progress/subscribe

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

Sally & Clare

Queen Elizabeth Hospital, King's Lynn 01553 613075

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
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