

## Minister to look at end-of-life care anomaly

Norman Lamb, MP for North Norfolk and minister for care and support, spoke at our April meeting about his concern over the cost to families of end-of-life care. He said that if this took place in hospital, it was all available at no cost, but if the patient wanted to die at home, as most do, then substantial costs were met by the family. This was an unfair anomaly that he was looking into.

Mr Lamb, who has given the group his support since 2008 when he was a shadow health minister, spoke of the issues he is dealing with since becoming a member of the Department of Health team last September.

Key points of interest to the group included his view that the burden of costs placed upon the elderly, who after working hard as taxpayers all their lives, were now in many cases having to face the loss of their savings and home to meet care needs. He thought this was grossly unfair, and had commissioned an inquiry to see whether it would be possible to reduce the cap on costs still further from the planned £75,000.

On the question of the Liverpool Care Pathway being



*Norman Lamb taking notes on our questions*

applied to terminally ill patients without reference to family members, and in some cases with a much-reduced standard of care, he found this deplorable and was working to ensure this situation was rectified.

A lively question and answer

session followed his talk, and he asked for a record of the main questions to be sent to him for further consideration by himself or his ministerial colleagues.

These covered the following concerns raised from the floor:

- Discrimination in End of Life Care
- Increased government action on awareness and selective screening for prostate cancer
- The importance of early diagnosis
- Wider introduction of MRI mapping as a more effective prostate cancer diagnostic tool
- Action to deal with improper use of the Liverpool Care Pathway
- Future funding for Abiraterone treatment for prostate cancer, after the Drug Emergency Fund has been exhausted.

Mr Lamb was thanked by our chairman, Noel Warner, for giving us his time and in return he said he would follow up all the issues raised.

Voluntary support groups such as N&W PCSG were making a significant contribution to the country's health care, and he wished us continuing success.

## Situations Vacant

Our secretary Brian Smith and membership manager Stan Thompson have both expressed the wish to retire next April. Between them they have served your committee for over 16 years, and are both three score years and ten plus, so ready for a break!

**We are appealing for some members to think seriously about taking over these roles.**

You can find out more by talking directly to them (**Brian 01603 860954 and Stan 01603 713463**) and ideally, having chosen the role that suits you best, you will be able to work alongside them for the remainder of this term. This will allow you to learn "on the job" and therefore be more confident when you take office.

These are purely voluntary posts but probably give more job satisfaction than salaried roles!

**So how about stepping forward and offering your services to the group?**

# Genetic screening on the horizon

Genetic screening for prostate cancer is now a real possibility following results from the largest-ever study into inherited risk factors for the disease. A cheap and simple saliva or blood test could be available to GPs within five years. A clinical trial is likely to start this year as a result of the ground-breaking findings from an international group led by the Institute of Cancer Research (ICR) and Cambridge University, funded by Cancer Research UK, the Wellcome Trust and the European Commission.

The three-year study of 50,000 men – half with prostate cancer and half without – identified 23 new genetic variations associated with an increased risk of the disease. This raised the total discovered so far to 78. Significantly, 16 of the 23 newly discovered genetic changes are associated with the disease at its most aggressive and life-threatening.

None of the 23 genetic changes on its own raises a man's risk of prostate cancer by more than a slight amount. But when a man has a number of the changes these can combine to raise the risk considerably. With the changes discovered, scientists can for the first time identify men who have inherited just over a 50% lifetime risk of developing PCA.

Following these discoveries scientists now think they can identify the top 1% of men with the highest risk of developing prostate cancer who have 4.7 times the risk of the population average. It is these men who, it is hoped, will be identified by screening. They would then receive close monitoring so that, if they do develop the disease, it is caught early when it is

easier to treat.

Study leader Ros Eeles, professor of oncogenetics at the ICR, said: "These results are the biggest leap forward in finding the genetic causes of prostate cancer yet made. They allow us, for the first time, to identify men who have a very high risk of developing prostate cancer during their lifetime through inheritance of multiple risk genetic variants. If we can show from further studies that such men benefit from regular screening, we could have a big impact on the number of people dying from the disease, which is still far too high."

Professor Eeles added: "It is clear from our study that prostate cancers linked to the inheritance of the BRCA2 cancer gene are more deadly than other types. It must make sense to start offering affected men immediate surgery or radiotherapy, even for early-stage cases that would otherwise be classified as low-risk. We won't be able to tell for certain that earlier treatment can benefit men with inherited cancer genes until we have tested it in a clinical trial but the hope is that our study will ultimately save lives by directing treatment at those who most need it."

ICR chief executive Professor Alan Ashworth commented: "Up until now, our management of prostate cancer has been a fairly crude process involving the evaluation of just a handful of major risk genes. But our new research really changes the game for use of genetics in prostate cancer by identifying so many new variants that screening for different levels of risk now becomes a real possibility."

## Backing for PSA testing

A study by scientists in Sweden and the USA suggests that PSA testing can predict nearly half of all deaths from prostate cancer before the age of 50. A research paper published by [www.bmj.com](http://www.bmj.com) (the on-line British Medical Journal) argues that focusing testing on men at highest risk is likely to improve the ratio between benefits and harms.

There is, say the scientists, now evidence that PSA screening can reduce prostate cancer mortality in men who would not otherwise be screened. However, this can come at considerable harm.

The researchers focused their studies on men close to 40, mid-to-late forties and early-to-mid fifties. They considered when PSA testing should start and concluded that even for men with PSA in the top 10% at the age of 40 the risk of metastatic cancer was very low

after 15 years of follow-up checks. It would therefore be difficult to justify testing at 40 for men with no other significant risk factor.

By contrast the risk of developing cancer within 15 years is close to three times higher for men with high PSA readings at age 45-50 and close to 10 times higher at age 51-55. This, they argue, suggests that initiating PSA screening after 50 would leave a significant proportion of men at elevated risk of later being diagnosed with an incurable cancer.

They say that screening programmes can be designed so as to "reduce the risk of over-diagnosis whilst still enabling early cancer detection for men at highest risk of death from prostate cancer".

The best way to determine risk, they say, is a single PSA before the age of 50.

## Help us save money

We believe this newsletter is essential to maintain contact with members – but the ever increasing cost of printing and distribution makes it a major operating expenditure.

Significant savings could be made if more members – with Internet access – simply downloaded it from our website. If you can use this option please email Harvey Meadows at:-

[nwpcsg@hotmail.co.uk](mailto:nwpcsg@hotmail.co.uk)  
marking the subject of your email "On Line Newsletter".

## Is that roight?

Did you know that the word "prostate" was first used by Norwich's very own Sir Thomas Browne in 1646? It was one of more than a hundred "new" words that he introduced to the English language. He was actually writing about the effect of castrating horses and bulls!

# IFR to study protective effect of 'super broccoli'

A dietary intervention trial with men on active surveillance for prostate cancer will be launched this year by Norwich's Institute of Food Research (IFR) to study the protective effect of eating extra portions of the Beneforté "super broccoli" that was developed as a result of research at the IFR. It is part of the growing programme of prostate cancer research at the institute and its neighbours on the Norwich Research Park.

The trial will monitor how diet may affect changes in metabolism to make it less likely that more aggressive forms of prostate cancer will develop. This research has been funded at IFR by the Prostate Cancer Foundation and involves close collaboration between IFR, UEA and the NNUH.

Professor Richard Mithen, who is leading the studies to understand the health benefits of the Beneforté broccoli, said: "Currently, we are waiting to get approval for the study from NHS Ethics, which we will hopefully have by mid May. Once we have this, we will begin to recruit men into the study through the urology clinic at NNUH."

Men who eat diets rich in cruciferous vegetables, such as broccoli, have been shown to have a lower chance of developing prostate cancer or of progressing from localised cancer to more aggressive forms of the disease. Studies using model systems have suggested that sulforaphane, which is found at high levels in broccoli, may be behind the protective effects.

The new study will follow



*Professor Mithen with his Beneforté broccoli*

changes in the metabolism and gene expression in prostate tissue of men identified as being at risk of developing prostate cancer, and see how these changes are affected by eating a diet enriched with sulforaphane.

"The results of this study could help men by providing evidence that diets rich in cruciferous vegetables or sulforaphane can reduce the likelihood of metastatic cancer, leading to the provision of higher quality dietary advice. It will also result in a greater understanding of metabolic and gene expression changes in prostate tissue that may lead to

better drug development," said Professor Mithen.

Research published in the journal *New Phytologist* shows that Beneforté takes up an increased amount of sulphur from the soil and channels more of it into glucoraphanin, a compound believed to aid cardiovascular health and reduce the risk of some cancers.

Field trials were conducted at 50 sites across Europe and North America. "What this research shows is that the levels produced are reliable and not particularly influenced by factors like where it is grown or the season, so the retailer and the consumer can have confidence in what they are buying," said Professor Mithen.

The specific properties of Beneforté were developed by crossing standard cultivated broccoli with a wild relative from Sicily by conventional breeding rather than genetic modification.

- Research on sulforaphane at the Norwich Research Park led by Professor Mithen has been undertaken at both the IFR and the John Innes Centre which are strategically funded by the Biotechnology and Biological Sciences Research Council.

Professor Mithen will speak at our 3 June Open Meeting on **'Diet and prostate cancer research at the Institute of Food Research'**. He will be joined by Dr Antonietta Melchini and Dr Omar Alkadhi.

## Spreading the word

The Norwich Race for Life event takes place over the weekend of 18-19 May at the Norfolk County Showground. Our group is starting a drive to raise awareness of prostate cancer among women, who in turn can be encouraged to talk to their partners or close male relatives in an informed way about the disease.

As the Race for Life is specifically aimed at women, and most women there will have been touched by cancer in some way, this is a good venue for us to start our campaign.

We will have a stand at the event for both days and are looking for volunteers (of both sexes!) to help. It doesn't need to be for the whole of the two days, and having a good number of helpers will spread the load.

If you think you can help, please contact Tim Farnham on 07831 106246 or [tim@farnhamfarms.co.uk](mailto:tim@farnhamfarms.co.uk) as soon as possible.



**The Church Hall  
St. Andrew's Church  
Cromer Road, Sheringham**

(FREE PARKING - Interval refreshments available)

**Saturday 7th September**

(Curtain-up 7.30pm)

**DÉJÀ REVUE**

*An Entertaining Evening with*

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Light-hearted family show of music & laughter

In support of

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**All Tickets - £6.00**

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Please enclose a stamped & addressed envelope and make cheques payable to "N&WPCSG"  
Also on sale at the door on the night - subject to availability.

*Terry Chappelle is a fellow prostate cancer survivor and long-standing friend of our group. The entertainers will be appearing for free, with all proceeds benefiting the group. There is free parking on site.*

*Terry and his friends are putting a lot of time and enthusiasm into staging this show, which is guaranteed to be great fun.*

*Please keep the date free and help make this one-off event a big success.*

### Dates for your Diary

Sat 11 May. . . . . 11am-4pm  
**Information Open Day, Big C  
Centre, NNUH**

Mon 3 Jun. . . . . 7-9pm  
**Open Meeting at Benjamin  
Gooch Theatre, NNUH**

*Professor Richard Mithen and  
colleagues*

**'Diet and prostate cancer  
research at the Institute of  
Food Research'**

Wed 5 Jun & 3 Jul. . . 5.30-7pm  
**Radiotherapy Department  
Open Evenings, Big C & Colney  
Centre, NNUH. Meet at Big C.  
Call 01603 288779 to book.**

Mon 5 Aug. . . . . 7-9pm  
**Open Meeting at James Paget  
Hospital, Great Yarmouth  
Speaker to be confirmed**

### Big C Information Open Day

This is for people living with and beyond cancer. It will be held at the Big C Centre, NNUH, from 11am to 4pm on Saturday 11 May.

Charities such as Age UK and Crossroads along with various NHS specialists will be present to offer support and advice on a range of subjects which affect people living with cancer.

There will also be tasters to try from recipes taken from cancer recipe books.

A stand with information on every cancer support group in Norfolk and north Suffolk will also be there.

### 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 & Anne-Marie**  
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  
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