

Norfolk & Waveney Prostate Cancer Support Group

NEWSLETTER

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The View from the Retiring Chair

At the end of a four-year stint in which his principal aim has been to raise the profile of prostate cancer in the region, Ray Cossey retired from the chairmanship of the group at the AGM on April 2 and handed over to Noel Warner who had been "shadowing" him as vice-chairman for the past year.

The major feature of Ray's leadership of the group has been the programme of mass PSA testing sessions in Norwich, Great Yarmouth and Fakenham. Looking ahead to the fourth and possibly final session at Thetford on May 24, Ray forecast that, if the pattern of the previous sessions continued, they would find up to ten men who had prostate cancer but were unaware of it.

Mass PSA testing for all men over 50 had been rejected by the government, at least for the foreseeable future. "All I will say is that at least 20 men, living in Norfolk and Waveney, have had their prostate cancer detected as a direct result of our group's testing initiative," Ray said.

There was still a great deal more to do to bring about a greater awareness of prostate cancer and to ensure that it had the same high-profile and resources as does breast cancer. The group no longer believed that a national programme of mass testing was the best way forward. They were now convinced that targeted testing was the preferred route, whereby men most likely to be at risk were tested – men with a family history of prostate and/or breast cancer.

"We are also greatly concerned about the number of men who are being refused a PSA test by their GP, despite Department of Health guidelines stating that every man over 50 shall, if he requests it, be given a test. We now know of local instances where this guideline is being ignored by a few GPs. Any government will, I hope, take it more seriously in the future and devote more resources to reduce the needless high loss of life caused by this most prevalent of male-only cancers," Ray said.

Thanking the group and his fellow officers and committee members for their support over the past four years, Ray paid tribute to the specialist nurses at the two hospitals for their invaluable help and support for all who needed it. He paid particular tribute to Ray Allen, a group founder and former committee member, who had fought a truly brave fight and had left his hospital bed in his pyjamas and dressing gown to attend the February meeting. He and Vera had raised well over £10,000 for the group. [Obituary page 3]



A trio of leaders: David Haines, founder chairman and now president; Noel Warner, our newly installed chairman; Ray Cossey, retiring chairman but continuing in office as vice-chairman.

The need for vigilance

Thanking members for electing him as chairman, Noel Warner said that Ray Cossey along with David Haines and the entire committee had set very high standards in raising money, buying equipment, finding first-class speakers and spreading the word about the importance of PSA testing.

The reorganisation of the NHS meant that they had to be ever vigilant that the disruption that came with restructuring did not allow the authorities to put prostate cancer patients to the back of their minds.

Our funds

Treasurer Dave Kirkham has confirmed that over the past year the group has raised nearly £9,500 and has spent just over £7,000. There is a "fighting fund" of £15,000 available to be spent on charitable activities in the coming year.

A special message for the ladies

Some of you who are members of women's organisations such as the WI may know how difficult it is to find speakers for your meetings – especially free ones! You will certainly know how reluctant men are to see their GPs if they might have a problem.

Why not suggest to your organisation's speaker finder that they might like to invite us to give a talk so that we can get the message across that men might need to be persuaded or even bullied into making that appointment to see their doctor?

Big C funds pioneering research project

By Kim Briscoe, *Eastern Daily Press* health correspondent

A two-year research project into prostate cancer will be based in Norfolk and Waveney thanks to local funding and the "unique facilities" at Norwich Research Park.

The Big C will be funding the work of Colin Cooper, a leading professor of cancer genetics, to work with patients to develop a biomarker for the diagnosis and treatment of early stage prostate cancer.

Prof. Cooper, who was born and bred in Norfolk, said he was attracted to the prospect of working in the county because of Norwich Research Park. He said: "It has a number of unique facilities that are relevant to cancer research that nowhere else in the world has, let alone the UK."

Prof. Cooper said this included the John Innes Centre and its work on plants, which provides an excellent opportunity to look at developing new natural products to treat cancer, while the Institute of Food Research can further understanding of how diet is linked to cancer.

The Genome Analysis Centre is one of only two in the country and it is a stone's throw from the Norfolk and Norwich University Hospital, a large and thriving hospital which offers the chance to further clinical work and research with patients.

Prostate cancer is the most common cancer in men in the UK. Nearly 40,000 men are diagnosed with prostate cancer every year with 250,000 men currently living with the disease. Many men in the UK are living with prostate cancer unaware they have the disease. This is because early stages of prostate cancer are difficult to diagnose and there are often no symptoms, which is why prostate cancer is one of the largest causes of death in men in the world.

Prof. Cooper has already made considerable advances through DNA studies at the Royal Marsden Hospital in London. Working in partnership with the Big C's



Professor Colin Cooper (left) with Daniel Williams, chief executive of Big C

prostate cancer research team at the University of East Anglia, the N&N will provide access to large numbers of patients within Norfolk and Waveney living with prostate cancer, so a programme of trials can be developed. The first is to identify biomarkers in the hope that in future men may be able to have a simple urine test to diagnose aggressive prostate cancer.

Prof. Cooper said: "Since 1947 we've known that prostate cancer cells can be found in urine, but because of the different toxic layers in urine it's been difficult, until now, to identify which cancer cells are aggressive and which are non-aggressive." He added: "We're nearly at that point of successfully identifying these cells correctly which is a massive breakthrough."

He will also use genome technology, to look at the sequence of DNA (genes) in the body of a cancer patient and decode it to establish which genes have broken down to cause the cancer. Once this is established it

is possible to re-sequence the broken genes, so that the body responds to cancer treatment more effectively. The treatment would then consist of personalised medicine for cancer patients.

Daniel Williams, chief executive of Big C, said: "We are really excited at Big C. Norfolk is unique because we have the Norfolk and Norwich University Hospital, the UEA and the Norwich Research Park which incorporates the Genome Analysis Centre all in such close proximity. Norfolk could one day be the world-leading hub of genome technology in the fight against cancer."

Prof. Krishna Sethia, medical director and consultant urologist at the N&N, said: "We are delighted that such an internationally distinguished scientist as Professor Cooper has joined us in Norwich. We are all looking forward to working with him to improve our understanding of and ability to treat cancers."

Ray Cossey, chairman of the Norfolk and Waveney Prostate Cancer Support Group, said: "As prostate cancer patients, the members of our patient support group very much applaud the Big C's initiative in enabling Professor Cooper to bring his expertise to this area. We are keen to assist him in whatever way we can to progress his research into identifying a bio-marker, which will remove the uncertainties that presently exist when it comes to accurately diagnosing the precise nature of prostatic cancer. There has always been difficulty in differentiating between 'pussycat' and 'tiger' prostate cancers and Professor Cooper's research will assist greatly in overcoming this problem."

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Come and hear Professor Cooper talk about **"Hot Topics in Prostate Cancer Research"** at our next Open Meeting in the Benjamin Gooch Theatre at the NNUH on Monday, 11 June, 7-9pm.

Raymond Edward Allen – A Tribute

Founder Member and N&W PCSG Leading Fundraiser

Ray died peacefully after a long and courageous battle on March 20th at Priscilla Bacon Lodge in Norwich, surrounded by his wife and family.

Ray was one of our 17 founder members, and took a keen and active part in our activities. He had served both as a Committee Member and a member of our Support Network for many years.

Ray was born in 1943 in Little Ellingham, Norfolk, and lived most of his life in Hingham, with Vera, his devoted wife.

From an early age he had an interest in tractors and lorries, and after working on a local farm, spent over 40 years as a long-distance HGV driver, including a period with his own haulage business, delivering Norfolk farm produce across the country. After he retired, due to increasing ill-health, in 2006, Ray devoted his energies, in spite of his declining health, to organising regular charity barn sales at Kenny Eaglen's farm in Hingham, which attracted people from across the county. He will be remembered where he, together with his wife Vera, and many willing helpers, raised well over £10,000 for our funds from these events. He had a dry sense of humour and a wide range of interests and hobbies, from



visiting and entertaining his many friends across the UK, to his beloved allotment, his enjoyment of Country & Western music, his large collection of commercial vehicle models and his vast model railway network, which he took much pleasure in showing us and which filled the attic of his attractive cottage.

He was a very sociable man who would help anyone, and was much loved by his family and friends, as was evidenced by the packed St Andrews Church in Hingham for the thanksgiving and celebration of his life. He was also

a supporter of the Quidenham Children's Hospice and when he had to give up the barn sales, he donated the remaining stock to them for their shops, amounting to two truckloads of saleable items.

Ray will be greatly missed by all who knew him, and Yvonne and I were privileged to count him as a friend, and who, with others, enjoyed many evenings in his and Vera's company. Our sympathy goes out to Vera, Vikki and Stuart and his wider family. He was an example to us all, and never gave up.

David Haines

A (New) View From The Chair

Having now taken over the chair from Ray (or is it the hot seat?), I am glad to report that not only did the vast majority of the present serving committee members agree to stay on and work with me but our pleas for new members were also answered. We now have two ladies on the team – Margaret Smith and Adrienne Capp, who is joined by her husband David and by another new member, Ravi Sharma.

Another welcome addition is David Paull who has volunteered to edit this newsletter, aided by Chuck Lyons. They plan to return to bi-monthly publication.

I was interested to read in the *Eastern Daily Press*, back in March, that relatives of two prostate cancer patients who had died were embarking on major fund-raising projects on behalf of the Prostate Cancer Charity. I checked our membership list to see if the two gentlemen concerned had been members of our group. They were not ... which begs the question: why not?

I am not suggesting for one moment that as soon as you are discharged from hospital you have to sign up and join the N&WPCSG but it saddens me to think that they may have been unaware of us. When I see the turnout at our open meetings and the "meet and chat" events, it is clear to see that these gatherings are of benefit. Perhaps the men concerned were too ill to attend, or felt that they could cope alone, but there is still truth in the saying that a problem shared is a problem halved.

So, not only do we have to continue raising awareness and encouraging men to get a PSA test, but we must ensure that every PCa patient in our "patch" knows about us and is welcome to join should they wish to do so.

In the next issue of our newsletter we will be publishing details of a walk being planned by one of our committee members, Tim Farnham.

Noel Warner

A Big Thank You

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

	£
Norfolk Ploughing Society	1,600
Marks, Wolton, Jeffries & Others	1,111
Reepham Rotary Club	1,000
Wroxham Lions Club	800
Diss Bowls Club	575
Mr & Mrs FV Hopkins	550
Mr & Mrs S Mitchell	544
Mr TC & Mrs G Farnham	310
Mr R Harrison	300
Mr D Haines	278
Residents of Leyham Court	170
J & P Durrant Wedding Guests	125

£50-£100

Mr Johnson, S Thompson, J Murry (Sainsbury's Veterans Association), Marks, Calton, Clarke & Others, H Meadows, Mr AJ Mark, Mr Bailey, Mr D & Mrs V Parker, Mr RE and Mrs RET Emms, Mundesley Ladies Club

£20-£25

H Bye, Mr Coleman, Mr Hutchings, R Cossey, M & S Platten, Mr Gilmore, R Williams

Other Donations

Choppers - Caister Heliport, ES & AMH Mayhew, M Peake, Marks, Mr Allum, Mr Esherwood, Mr M Peake, Ms C C Tatton, Mr Vincent, HMCE Anon

Dates for your Diary

Wednesday 6 June & 4 July

Radiotherapy Department

Open Evenings, Big C & Colney Centre, NNUH

Meet at Big C Centre 5pm (optional). Tour 6-7pm

Monday 11 June 7-9pm

Open Meeting at Benjamin Gooch Theatre, NNUH

Professor Colin Cooper

Professor of Cancer Genetics at the University of East Anglia

"Hot Topics in Prostate Cancer Research"

Monday 14 May, 9 July & 3 September 7-9pm

Committee Meetings, Big C

Monday 6 August 7-9pm

Open Meeting at James Paget Hospital, Great Yarmouth

Dr Jenny Nobes

Consultant Oncologist

"Drug Treatment for Prostate Cancer: It's not just Hormones"

Monday 3 December 7-9pm

Open Meeting at Benjamin Gooch Theatre, NNUH

Martin Bell OBE

Our Patron, former MP and war correspondent

Former JPH Chaplain Dies

The Rev. Walter Currie, a long-serving chaplain and specialist counsellor at the James Paget Hospital, died in March at the age of 72. Among his many activities, he was chairman of the NNUH's Research Ethics Committee until he was diagnosed with advanced prostate cancer. While he was rector of All Saints' Church, Postwick, he was part-time chaplain at the former St Andrew's Hospital, the Yare Clinic at the West Norwich Hospital, Priscilla Bacon Lodge and Caroline House in Norwich.

Oregano 'kills prostate cancer'

According to scientists at Long Island University, New York, oregano could be used to treat prostate cancer. The herb could form the basis of a new kind of treatment without serious side effects, they found.

Carvacrol, a compound from oregano, can start a process called apoptosis – "cell suicide" – among prostate cancer cells. Food for thought?

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■ Help or Advice:

We have 29 members available at the end of a telephone ready to help.

There is probably one near you.

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■ Visit our website:

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