

Norfolk & Waveney Prostate Cancer Support Group

NEWSLETTER

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Big names sign up to the TRA pledge



Left to right in the picture, taken by Denise Bradley and reproduced by permission of the editor of the EDP and Evening News, are: Anna Dugdale, Simon Bailey, John Rushmer, Bishop Graham James, Martin Bell, Noel Warner, Philip Blanchflower, Daniel Williams, Wendy Adams, Dr Tom Roques and Dr Jenny Nobes.

With our chairman Noel Warner leading the way, the NNUH's £600,000 Targeted Radiotherapy Appeal received a major boost in October when a galaxy of Norfolk's leading personalities pledged their support for the campaign in a ceremony at Bishop's House.

Signing the pledge with Noel were the Bishop of Norwich, the Rt Rev Graham James; our patron, Martin Bell; Philip Blanchflower, chairman of Big C; Daniel Williams, chief executive of Big C; Simon Bailey, the county's new chief constable; the Masons' Provincial Grand Master, John Rushmer; and Wendy Adams, vice-chairman of the Norfolk Federation of Women's Institutes.

Also present were Anna Dugdale, the NNUH chief executive, and oncology consultants Dr Tom Roques and Dr Jenny Nobes who came up with the idea of building and equipping a special centre for brachytherapy treatment for which cancer patients at present have to travel to London or Cambridge.

Others who have pledged support but could not be at the ceremony are Richard Jewson, Lord Lieutenant of Norfolk, the Rt Rev Alan Hopes, the new Bishop of East Anglia, Norman Lamb, health minister and MP for North Norfolk, and Nigel Pickover, editor of the Eastern Daily Press and Norwich Evening News.

"The publicity the pledge-signing received led to a quickening public response so that the fund currently stands at £250,000," says Noel. We have already pledged £10,000 for equipment to which has been added the £10,000 raised at Brundall's Cancer Community Chest (reported in our last newsletter) and other generous donations.

With the backing of the pledge, Noel is now writing to Norfolk companies and organisations inviting them to make donations to the appeal.

Our patron Martin Bell is presenting "A long way from Look East" on behalf of the TRA appeal at Norwich's OPEN centre in Bank Plain on November 21. Tickets are available from Louise Cook, 01603 287107.

Come and join us

Another year has flown by and it's Christmas lunch time again. This year we shall again be at Jerningham's Banqueting Suite at Costessey Park Golf Club on Friday, December 6. You can get your tickets – £16.50 for a two-course lunch – from vice-chairman Ray Cossey. For details, see back page.



A splendid head of broccoli grown by chairman Noel's wife Ann, one of our trustees, from plugs supplied by the Institute of Food Research following the talk at our June meeting by Professor Richard Mithen and his colleagues.

The claims for the superfood broccoli, Beneforté, are being tested by the IFR on volunteers at low or intermediate risk of prostate cancer who have opted for "waiting and watching" rather than immediate treatment.

What goes around ...

Newsletter editor David Paull writes:

It could be called serendipity but perhaps the events don't quite fit the dictionary definition of happy discoveries by accident.

Some years ago I was at a meeting of the Norfolk and Norwich Naturalists' Society when the speaker was the brilliant urologist Christopher Gaches, talking not about prostate cancer but about the flowers of the Himalayas, especially the dazzlingly blue *meconopsis* poppies. His photographs were superb and pin-sharp. Did you, a member asked, use a tripod? No, said Mr Gaches, but you must remember what my profession is. I proposed the vote of thanks and said that one or two members might at some time be grateful for that assurance.

Not long afterwards, I was! After two failed TURPS, I was summoned by Mr Gaches and told I had prostate cancer - and I reminded him of my vote of thanks. The prognosis was pretty good and a few months later I was elected to the first of two three-year terms as chairman of the Naturalists' Society.

That was 17 years ago. More recently I have been putting my journalistic experience to work as a patient-reviewer of publications for Prostate Cancer UK which, ironically, was founded in 1996, the year I was diagnosed. Among papers I have cast an eye over is the booklet, *Living with hormone therapy*, from which a number of our members have benefited.

Last year I was asked to review a fact sheet on bisphosphonates, the pain-relief and bone-rebuilding treatment used when prostate cancer has "gone walk-about" - metastasis. I contacted the information officer who was writing the fact sheet and said that, if I were to be told that my cancer had metastasised, the first thing I would do would be to reach for the whisky bottle. But would that affect the medication? She consulted PCUK's medics and the fact sheet now contains the advice that alcohol is not known to affect the treatment - just stay within the recommended national guidelines. My small service to the comfort of my fellow patients!

Then, lo and behold, a few weeks later, what I thought was a sprained ankle was shown by Xrays and bone scan to be metastasis and, following a course of radiotherapy, I now have a monthly infusion of a bisphosphonate, Pamidronate, at the N&N's Weybourne unit.

And the irony doesn't end there. Since I became editor, almost every issue of this newsletter has included news on the wonder drug Abiraterone. With my PSA steadily rising, it became obvious that one of my cancer drugs was no longer working, so I am now - you've guessed it - on Abiraterone (trade name Zygita) and just hoping that it's as good as it's cracked up to be.

Footnote: The cluster of pills I am now taking reminded me that a friend told me he visited his mother in a care home and noticed that she had all her pills lined up on the arm of her armchair. Why, he asked. Well, she said, that lady over there hasn't got any tablets, so I give her some of mine!

The case for MRI scanning

Half the men who develop prostate cancer may have been told they did not have the disease because of flaws in diagnosis procedures. A study by the London School of Hygiene and Tropical Medicine and University College London appears to confirm what has long been the widely held belief that current biopsy procedures are missing significant levels of cancer in up to half the men tested while many more are being wrongly told they have cancer that needs to be treated.

The study suggests that diagnosis is far more accurate if patients undergo an MRI scan first, with the findings mapped via ultrasound, so that the biopsy can take tissue from precisely where a tumour is suspected. The MRI technique halved the number of men wrongly diagnosed with the disease.

The need for wider introduction of MRI mapping as a more effective diagnostic tool was one of the concerns we put to health minister Norman Lamb when he spoke to the group in April and which he undertook to refer to his ministerial colleagues.

Dr Kate Holmes, head of research at Prostate Cancer UK, said current methods meant that too many men underwent unnecessary biopsies which also increased their risk of infection. "This early data

suggests that giving men an MRI scan before a biopsy may put clinicians in a better position to tailor investigations and treatments further down the line. However, further research is necessary before we will know the true value of this method."

Shortly after reports of the study appeared, a consultant surgeon wrote to the Daily Telegraph pointing out that the study's findings had not been confirmed by clinical research. Should current trials confirm the usefulness of MRI in identifying prostate cancer, the process would need to be standardised by protocols endorsed by the Royal College of Radiologists and training would need to be undertaken by radiologists nationally. Because MRI scans cost £400, there were significant cost implications which would need to be funded by primary care commissioners and such funding was not currently confirmed.

Mr Witold Lukianski, Consultant Urologist at QEH Kings Lynn, will talk to us about "Advances in MRI Scanning for the Initial Diagnosis of Prostate Cancer" on Monday 2 December, 7pm, Benjamin Gooch Theatre, NNUH.

Retire at 80? Not a chance, says Terry

Sheringham-based entertainer Terry Chappelle raised £1,165 for our group with his spectacular variety show in September.

The money will be added to the £10,000 we have already pledged to the NNUH's Targeted Radiotherapy Appeal to provide a specialist brachytherapy unit for the treatment of prostate cancer and other urinary-related cancers. At the moment patients have to travel to Cambridge or London to receive this treatment.

In his "Deja Revue" show, which played to a full house at St Andrew's Church Hall, Sheringham, Terry enthralled his audience with tribute-impersonations of female entertainers of yesteryear, including Edith Piaf, Marlene Dietrich and Hilda Baker, a memorable performance, which involved no fewer than eight costume changes. The veteran performer was ably supported by fellow artistes and musicians.



Terry describes himself as a "prostate cancer survivor" and even though he was 80 in November has no intention of taking things easy. Prominent on the local entertainment scene for more years than he cares to remember, Terry and his friends are already planning to stage another show next year. Provisionally entitled "Sing As you Go", it will take a nostalgic look

back to variety in the 1940s and has been pencilled in for Saturday 13 September, at the same venue. It is planned to coincide with the annual wartime nostalgia weekend held each year in Sheringham. Make a note of the date and when the tickets go on sale you are advised to get yours early to avoid being disappointed. If this year's show is anything to go by it will be another cracker!

Before you pack those cases ...

In our last issue, we promised to pass on useful tips from Wendy Marchant, Big C information lead nurse, for men with prostate cancer who are off on their travels.

- Time your holiday so it doesn't coincide with your hormone injection. You cannot have your injection early because this is potentially an overdose. You cannot have your injection late because it could mean your treatment has effectively lapsed.
- Incontinence pads can take up a lot of luggage space. Pack them in hand luggage in case checked-in luggage goes astray and bear in mind possible delays when thinking how much to take with you. Also it is helpful to carry baby wipes to freshen up, plastic bags for soiled clothing and some clean clothes in case of emergencies. Ask the airline to seat you near the toilet if you are likely to need urgent access.
- Men who need to take drugs abroad must keep them in hand luggage in case checked suitcases go astray. It is worth having a few more than you need in case of a delayed return. If taking strong painkillers such as morphine-based medicines, check with the embassy of the country you are visiting what is allowed, take a doctor's letter or prescription with you, and you may need a licence from the Home Office. Do check well in advance because some paperwork takes a while to come through. Translated paperwork for non-English speaking countries can be helpful. Failure to do this can lead to drug trafficking charges.
- Radiotherapy and the sun don't mix well. Do cover up in the sun and use the normal precautions.
- Chemotherapy and the sun – some drugs also react in sunlight. Check with your medical team.
- Brachytherapy seed implants are radioactive for some time after insertion. If you walk through an airport security scanner you may well set it off. Don't be alarmed but carry information about this from your doctor for airport staff to check.
- If your immune system is compromised by treatment you are at greater risk of infection. Be careful of what you eat and drink abroad. If you need to boil tap water check the altitude of your location. The boiling point of water is lower at altitude. If you try to boil water you will see it bubbling but it won't be hot enough to kill any bugs. In this case use sterilising tablets. If you are at risk of infection some doctors will give you antibiotics "just in case". Also be aware from an insurance perspective. Companies can refuse to pay up for a claim for ill health due to an infection because of lowered immunity from cancer treatment. Do also bear in mind risk of infection from insect bites, so use a sun cream with an insect repellent. In addition bites from larger animals abroad can be a problem. Make sure any vaccinations are up-to-date as required for the country you are travelling to. Make sure this is completed well in advance of your departure date.
- For more information and a helpful checklist pick up a copy of the Macmillan booklet Travel and Cancer.



**Two Course
Traditional
Christmas
Lunch**
with coffee
£16.50 per head

We invite you to join us at
**NORFOLK & WAVENEY
PROSTATE CANCER
SUPPORT GROUP'S**

Christmas Lunch

FRIDAY 6th. DECEMBER

(12.30 for 1.00 pm)



To obtain your tickets complete
& mail the Order Form below

Dates for your Diary

Thu 21 Nov. 7.30pm

OPEN centre, Bank Plain,
Norwich

*Martin Bell OBE – TRA appeal
'A long way from Look East'*

Mon 2 Dec. 7-9pm

**Open Meeting at Benjamin
Gooch Theatre, NNUH**

*Mr Witold Lukianski, Consultant
Urologist, QEH King's Lynn
'Advances in MRI Scanning
for Initial Diagnosis of
Prostate Cancer'*

Wed 4 Dec & 8 Jan.. 5.30-7pm

Radiotherapy Department

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

To: R. Cossey, 73 Blofield Corner Road, Little Plumstead, Norwich, NR13 5HU

Please send me.....tickets for the Christmas Lunch, on Fri. 6th December,

at Costessey Park Golf Club. I enclose my cheque for £.....

(Make cheque payable to 'Norfolk & Waveney Prostate Cancer Support Group')

Please include a stamped & addressed envelope

Name

Address

Post Code

Telephone No.



Recent visitors to the NNUH Urology Department may have spotted a noticeboard with information about the support group on it, and a large banner. Noel Warner discussed the idea with Liz Rooney at Urology (to whom we are hugely indebted) and an existing noticeboard has been made available for our use pending putting up a new board which will be "ours" on a permanent basis. Ray Cossey and Tim Farnham collaborated with Noel to produce the information sheets for the board and the text for the banner.

How to Contact Us

■ **Specialist Nurses: Sallie, Wendy, Helen & Rachel**
NNUH

01603 289845

Angie, Wendy & Simon

James Paget

01493 453510

Sally, Clare & Anne-Marie

QEH, 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

■ **Letters to the Editor:**

David Paull, Editor

DavidLPaull@aol.com

■ **Visit our website:**

www.prostatesupport.org.uk