

Norfolk & Waveney Prostate Cancer Support Group

NEWSLETTER

Issue No 39

October 2012

A chance to meet our patron

Our meeting at the NNUH on Monday, December 3rd, will be a special occasion because the speaker will be our patron, Martin Bell OBE. Martin, who was born in Beccles and began his career as a journalist with the *Eastern Daily Press*, became known as "The man in the white suit" during his time as a distinguished BBC war correspondent. Members may recall the graphic television pictures when he was badly wounded while reporting the war in Bosnia.

Martin, who is the son of the legendary *EDP* columnist and *Times* crossword compiler, Adrian Bell, achieved further fame in a different sphere when he unseated Neil Hamilton to become the Independent MP for Tatton – but kept his promise that he would serve only one term.

Although he is still very busy as a freelance television programme maker, lecturer, author, and UNICEF Ambassador for Humanitarian Relief, he readily agreed to become our patron soon after the group was launched in 2004.



Our Patron, Martin Bell OBE

And it's a small world. Our president, David Haines, who approached Martin because he was already patron of a Norfolk ex-servicemen's charity and David was on an RAF ex-servicemen's committee, discovered that he was in the six-day war in the Middle East when Martin was covering it for the BBC – and Chuck Lyons, founder vice-chairman, now newsletter production editor, discovered that he had been in the US Army in Vietnam when Martin was, once again, on the spot for the BBC.

Farewell David – Welcome David and Adrienne

The Church of St Peter Mancroft in Norwich was packed on Friday, July 27th, for the funeral of our welfare officer and committee member, David Wiseman, who died on July 16th. David was best known for his initiative in recruiting volunteers from among the group's members who are willing to be a local "telephone helpline", offering not medical advice but comfort, reassurance and helpful information, especially to new patients, based on what they themselves have experienced. Our president, David Haines, pays tribute to David on page 3.

We are very pleased to announce that David's welfare role has been taken over by two newcomers to the committee, David and Adrienne Capp, who will be reviewing and updating the list of volunteers and seeking to fill any gaps in our geographical coverage. See "From where I sit" (page 2) and "How to Contact Us".

Caught in time

One of the eight men who received "red" letters from consultant David Baxter-Smith following the Thetford PSA testing session in May has been diagnosed with prostate cancer but has been told that the disease is still contained within the sac. Len Moore, who lives in Thetford, is now receiving hormone and radiation therapy. He has generously sent the group a £100 donation and writes: "I feel that without your PSA test this problem may have gone unnoticed and the outcome could have been considerably worse. Please accept my sincere gratitude for your help".

Thanking Len for the donation, our treasurer,

Dave Kirkham, has told him that he was in a similar situation five years ago but, as a result of the treatment Len is now undergoing, he is – fingers crossed – cured.

"So you do have plenty of grounds for optimism. However, I have no doubt that you will have lots of concerns during your treatment. Therefore, please do not hesitate to contact our group as and when you need any help or support".

Our president, David Haines, adds: "Len's letter makes all we do worthwhile, and hopefully another life will be saved".

Speaking with one voice

The Prostate Cancer Charity – newly renamed as Prostate Cancer UK – is to become an affiliated partner of the Prostate Cancer Support Federation, the charity's new chief executive, Owen Sharp, announced at the federation's annual conference.

He said he had been impressed by the passion and energy shown by the federation and its member groups, including our Norfolk & Waveney Group, notably in the Abiraterone campaign. Much could be achieved to raise the agenda UK-wide by speaking with one voice.

He said that prostate cancer had been neglected for far too long with too much variation across the UK, both geographical and economic. There was growing public demand for more Government action.

The charity did not support a national screening programme but had come closer to agreement on targeted screening as proposed by the federation – and now the policy of our group.

For far too long the mantra of politicians of all parties had been to "change nothing". Although there were still areas of disagreement, there was an overriding agenda with which PCUK could work with the PCSF and Prostate Action. Subsequently, it was announced that Prostate Action is merging with Prostate Cancer UK "to form one, unified force in the fight against prostate cancer and prostate disease".

In a joint statement, the two organisations say: "Together we will be stronger. Speaking with a direct, singular voice we will be able to better achieve our aim of giving men's health the prominence it needs

and address the long-term challenges around prostate cancer and prostate disease and by joining forces we will be able to achieve more for men than we can on our own".

Prostate Action says that it has achieved a great deal over the past two years. As part of PCUK, more research into the prostate diseases can be funded and more healthcare professionals trained.

How can the merged charity help our members individually?

It has a dedicated prostate cancer telephone and email Helpline service, staffed by specialist nurses. They can provide confidential information and support to anyone affected by prostate problems. The confidential helpline number is 0800 074 8383; it is manned Monday-Friday 10am-4pm and on Wednesdays 7pm-9pm.

The charity publishes excellent booklets and fact sheets ranging from "Know your prostate" to "Recurrent prostate cancer". They are reviewed not just by experts by a panel of patients. [I have helped to review several of them. Ed] Some of these publications are available at our meetings or at the Big C centre.

The full list can be found on the charity's web site www.prostatecanceruk.org and they can be ordered by telephone or on line at literature@prostatecanceruk.org. They are free but the charity does rely on voluntary subscriptions and donations.

From where I sit – the chairman's view

What a dedicated group you are – not only did 50 (including five newcomers) and more of you turn up for the Open Meeting at the James Paget on August 6th, but you did so in the teeth of a storm and shunned the TV coverage of the Olympics.

Dr. Jenny Nobes gave a interesting talk, and went on Radio Norfolk a couple of days later to talk about prostate cancer with Nick Conrad. Not wanting to waste an opportunity, our committee member Tim Farnham called into the programme and managed to get a few minutes to talk about his walk around Norfolk during September and the need to maintain a healthy lifestyle. During the meeting, I asked about the nature of future talks – whether these should always be Prostate Cancer related or try some new subjects. The show of hands was overwhelmingly in favour of medical speakers. So be it.

Most of you will recall that, at the diagnosis stage, you were handed an envelope with various pieces of

information, partly in connection with the nursing care and your procedure, and some information about us and the Big C.

Our leaflet included a name and telephone number to contact. It was felt that nominating an individual was possibly not the best way forward, given availability etc. Our new leaflet now shows the Big C centre as the initial point of contact. Staff there will take the calls and pass them on to our Welfare Team, David and Adrienne Capp.

Any reader / member of the Support Group who would like to be included as a Volunteer networker willing to talk to new patients, please contact David or Adrienne on 01603 712601.

In the next edition of our newsletter I will be giving details of a "lending library" of various books and DVDs that will be available on loan to our members. Until then, wishing you all well.

Noel Warner

Further thanks

We have received a donation from Joan Leese of Oulton Broad whose husband Robert, a group member, died in April after suffering a range of problems, including prostate cancer for which he had successful radical surgery in 1999. Joan writes: "I am enclosing a cheque for £50 in memory of my husband and wish you success in keeping the fight for cancer treatment alive, in particular prostate cancer, and hopefully they will eventually find a treatment to prevent cancer".

David Wiseman, Our Welfare Officer – An Appreciation

We were all saddened to learn of the loss of David, who passed away peacefully at his home on July 16th, after a short but courageous battle with advanced recurring cancer.

David was born in Norwich in 1940, and spent most of his working life in the City, and until retirement was Premises Manager for the United Reform Church, Norwich.

David had served on the Committee for many years, firstly as our Membership Secretary, then as Displays and Information organiser, but most of all he will be remembered in his capacity over the past five years as our Welfare Officer, ably supported by Rosamund, his devoted wife. He also served as a Trustee of the Group, and as one of our panel of speakers.

David was a gentle man, a committed Christian, and these values shaped his life, and his understanding of, and sympathy with, his fellow patients and their families.

He was always cheerful, even in adversity, and had a lively sense of humour.

I remember an occasion when he and I, with our wives, attended



a fundraising for the Group at a riverside pub in Stokesby, organised by the Halesworth ACE Motorcycle Club.

We expected to be greeted by a local Hells Angels chapter, and were highly amused to be welcomed by a group of about forty, including many OAPs, (some older than us), attired in their black leathers and mounted on an impressive range of high powered Harley Davidsons, all in showroom condition.

A happy day, and full of fun, ending with a generous donation to our funds.

David took his role as our Welfare Officer very seriously, and was responsible for setting up our Support Network across the county, offering to all who needed it, a chance to talk to a fellow patient in their own locality. To equip himself for this task, he completed a six month training course with Macmillan Cancercare, obtaining the diploma in Cancer Support from the National Open College Network, a nationally recognised qualification.

He was held in great respect and affection by all who knew him, and his memorial service at

St.Peter Mancroft Church in Norwich, which he attended as a boy and as a young man, was filled with family, friends, and others whose lives he had touched, including many from our Group, Macmillan Cancercare, City Hall, Age UK and the BBC. At David's request it was a joyous occasion to celebrate his life, and one which will be long remembered.

He will be greatly missed, and our sympathy and condolences go out to Rosamund, and the wider family. His friendship was valued and he was an example to us all.

David Haines

Travel insurance

Cancer patients can sometimes find it difficult or even impossible to get insurance cover for their holidays. The following appeared in the Daily Telegraph travel supplement in July and we pass on the advice of consumer expert Nick Trend for information:

Q. I am nearing the end of a period of treatment for cancer and am in desperate need of a holiday. I had surgery some months ago, which was successful, and will be finishing chemotherapy at the end of July. Can you advise me on holiday-cancellation and health insurance?

A. One insurance company that specialises in covering people with cancer, or who have had cancer treatment, is insurecancer.com – you might want to try it first. Other insurers that specialise in travellers with existing medical conditions are PJ Hayman (free-spirit.com); Avanti Travel Insurance (avanti.co.uk); All Clear Insurance (allcleartravel.co.uk); Insurancewith (insurancewith.com); Freedom Insurance (freedominsure.co.uk); JD Travel Insurance (jdtravelinsurance.co.uk); and World First (world-first.co.uk).



**Two Course
Traditional
Christmas
Lunch
with coffee
£17.50 per head**

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

Christmas Lunch

FRIDAY 7th. DECEMBER

12.30 for 1.00 pm



To get your tickets complete
& mail the Order Form below

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

Please send me.....tickets for the Christmas Lunch, on

Friday 7th 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.



Dates for your Diary

*Wednesday 3 October &
7 November*

Radiotherapy Department
Open Evenings, Big C & Colney
Centre, NNUH. Meet at Big C
5pm (optional). Tour 6-7pm

Monday 1 October 7-9pm
"Meet & Chat" at Big C Centre,
NNUH

*An opportunity for newly
diagnosed patients to chat
with members who have
already been through the
same journey. Why not come
along and share experiences
with others who have
received your treatment and
might have some helpful tips
and advice?*

Monday 5 November 7-9pm
Committee Meeting, Big C

Monday 3 December 7-9pm
Open Meeting at Benjamin
Gooch Theatre, NNUH
Martin Bell OBE
*Our Patron, former MP and
war correspondent*

Situation Vacant

Wanted – A Trustee for N&WPCSG. The purpose of the role is to ensure that our charity is run in a proper manner. The role carries no legal or financial responsibility. We just need someone who has some knowledge of charity administration and can meet with other Trustees two or three times a year.

As a registered charity, the group has a legal responsibility to ensure that it is run in accordance with its Constitution and the rules of the Charity Commission. Trustees are indemnified against any financial loss incurred by our charity.

If you feel that you could offer to serve the group in this important role, please get in touch with our chairman, Noel Warner.

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