

Registered Charity No. 1108384

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Patron: Martin Bell O.B.E., President: David Haines

*a Founder Member of the Federation of Prostate Patient Support Groups known as 'TACKLE'*

Newsletter No. 69 - March 2019



## *IT'S OUR 15TH ANNIVERSARY*



Recently, the leading Cancer Charity in Norfolk, Big C, celebrated its 35th anniversary, and we extend our warm congratulations to this very successful local charity.

**In April 2019, our own Norfolk & Waveney Prostate Cancer Support Group will celebrate completion of its 15th year,** and I have been invited, as its President and first Chairman, to mark the occasion with some memories of the growth of the Group from its modest beginnings to where we are today.

In early 2004, Sally Jermy, Clare Fullalove, and Wendy Baxter, the Urology Department Specialist Nurses, with the support of the Urology consultants, Krishna Sethia Robert Mills, Edwin Ho and others, took the initiative and invited current Prostate Cancer Patients and their families to an exploratory meeting to establish just what their needs and concerns were.

45 patients subsequently attended a meeting in the Benjamin Gooch Theatre on 5th. April, 2004, and following a "brainstorming" session, it emerged that a prime need was for greater support on a patient-to-patient basis, along the lines of those voluntary groups existing to support Breast Cancer patients and other cancers, but none existed locally for Prostate Cancer. An appeal for volunteers to establish such a patients group resulted in the founding of a steering-committee to work with the nurses, and as a result we were fortunate in having a wealth of experience and talent to get the "show on the road".

That first Committee, all prostate cancer patients, had really dedicated members, and their efforts deserve mention. There was Chuck Lyons, international businessman and musician, (our first vice-chairman and later Newsletter editor); Martin Wolton, former Project Engineer with Cable & Wireless, our Treasurer, whose passions were for Suffolk Horses, (his family having bred them in Suffolk), pigmy goats, and his interest in candle snuffers; Stan Thompson our Secretary, (with much local charity experience); Steph Ganther, experienced Publicity Officer and first Newsletter editor; Ken Jones, a former Prison Officer and amateur horologist, (who left his hospital bed and made the tea at our Open meetings); Dave Cole our IT expert and who set up our web page, Ray Allen, who became our leading fundraiser,

and myself, a humble Chartered Aircraft Engineer, who found myself appointed acting Chairman, (after admitting previous experience in such a voluntary role).

The enthusiasm and common friendship that all displayed gave an impetus to "get things done", and a team ethos quickly emerged. We all agreed that the perception of Prostate Cancer among men and the general population was that of a poor relation in comparison with other cancers. We decided to do all we could to improve awareness of the disease in Norfolk & Waveney. Secondly, most patients had little contact with other patients outside the hospital, either individually or socially, where frank discussions on experiences of how others dealt with emotions and problems; giving support in these areas was badly needed. Finally, there was so much misinformed publicity in the media and on the internet, which gave rise, in

many cases, to false hopes or added to concerns. So, factual and reliable sources of information would be sought and made available, both in our Newsletter and by inviting presentations from leading clinicians and research bodies from across the country to our programme of Open Meetings. On no account would we give specific medical advice; this is the duty of clinicians and nurses. We also decided to become a registered charity, to establish credibility, aid funding, and benefit from taxation relief. Our first hectic year, with little funds, but much help from our volunteer supporters, established these core activities.



DAVID HAINES — LIFE PRESIDENT

Inevitably, as an active support group we attracted criticism and opposition, including from some quarters of the medical establishment and Government, in our campaigning for better diagnostic procedures, screening programmes and state-of-the-art treatment; . The key driver for us, as experienced patients, was for a concerted campaign leading to earlier diagnosis and treatment, a principle that was shared with the majority of our doctors, consultants, and nurses. The controversial Prostate Specific Antigen (PSA) test, which was and still is, the chief indicator of prostate gland problems, (not always cancer), needed to be readily available to all men at risk and our activities in lobbying M.Ps, Health Ministers, and

*Continued on page 2*

membership of leading National Urology Cancer Committees, contributed to the PSA test being available on demand, and not being refused by some G.P.s who doubted its efficacy.

Our Group's organisation and activities were assessed in 2006 by the Prostate Cancer Charity, (now Prostate UK), and identified as the largest, most efficient Prostate Cancer Support Group in East Anglia. With other Groups, in the Midlands and West, the seeds were sown for the formation of a National Federation of Prostate Cancer Support Groups, giving a stronger voice in both the diagnostic and treatment of the disease.

When Ray Cossey took over from me in 2008 as the Group's second Chairman, he brought his enthusiasm to extend a more practical approach to both Awareness and Information. With the invaluable help of consultant, Mr. David Baxter-Smith, our eight volunteer phlebotomy nurses, our team of willing helpers, and the co-operation of the N.N.U.H. Pathology department, we embarked on a series of large public meetings across the county, aimed at men with no knowledge of Prostate Cancer, or who had met with a refusal, by their G.P., for a test. We offered free PSA tests to those who wanted it, after being advised by Mr. Baxter-Smith as to the pros and cons. Some 1,000 men took advantage of this at our mass meetings, and several cases were uncovered, where men were unaware they had the disease, in some instances of an advanced nature. Attendant publicity from this activity, and our presentations to the medical establishment did much to change attitudes, both locally and nationally.

Other highlights were our campaigns in support of the trial of Cryotherapy treatment at the N.N.U.H., which we sponsored and raised a total of £50,000 over 18 months. More recently we helped to fund the new Brachytherapy treatment at the N.N.U.H Radiology Department and we have also provided essential equipment to meet needs in diagnostics, pathology, and radiology.

We have expanded over the years as new blood has joined our Committee with new ideas. We were very fortunate to have had the strong support of Noel Warner, our third and longest serving Chairman. I must also acknowledge the service of the late David Paull, an experienced newspaper editor and editor of our own Newsletter. Also the dedicated work of the late David Capp, who with his wife Adrienne brought a new emphasis to our welfare support role, Today, our current management team is one of the strongest to date and is now under the chairmanship of the indefatigable Nigel Gardiner, who with the support of the other members of the Committee, will ensure the Group will continue to meet those needs of patients, which other agencies do not cover, and to give a voice to Norfolk & Waveney Prostate Cancer patients and their families. A key part of our Support mandate has been our regular 'Meet and Chat' events, held at the Big C Centre at the N.N.U.H, and at the Louise Hamilton Centre at the James Paget Hospital. The feedback has been most encouraging regarding the positive help given to new and existing patients and their families.

Finally, a big thank you to all our Committee members, past and present, our helpers and fundraisers. There is still much to be done, and the constant renewal of people and ideas will ensure we are there to help and inform. The good news is that since our formation, new technologies, treatments, and an increasing national awareness have made great strides in increasing survival rates from this disease, even though annual diagnosed cases now exceed those for Breast Cancer. Prostate Cancer remains a scourge, but there is now hope that in the near future, with current advances, it will be relegated to a controlled condition comparable, for example, to diabetes.

**DAVID HAINES**

*We all owe David a debt of gratitude for all he has done, not only in being the prime-mover in the setting-up of our patient support group, but also for his undiminished endeavours in bringing about a greater awareness of prostate cancer, both locally and nationally.*

*Despite having his own health problems, in recent years, his commitment, in promoting our Group's aims and objectives of **Awareness, Support and Information**, has remained undiminished.*

**Ray Cossey - Chairman of Trustees**

Our thanks, for sponsoring this edition, go to

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## NOTICE of the ANNUAL GENERAL MEETING

of the

### NORFOLK & WAVENEY PROSTATE CANCER SUPPORT GROUP

to be held on

**Monday 8th. April, 2019**

**at the Big C Centre,  
Norfolk & Norwich University Hospital**

*(Immediately following the Committee  
Meeting, which starts at 7.00pm)*

### AGENDA

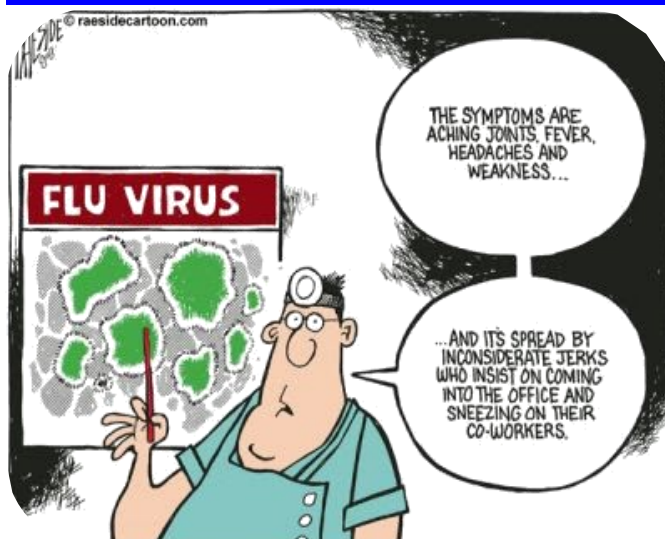
1. Apologies for absence
2. Minutes of AGM, held Monday 9/4/18
3. Matter Arising
4. Chairman's report
5. Secretary's report
6. Treasurer's report
7. Nominations and election of the Executive Committee Officers  
Chairman, Vice Chairman, Secretary & Treasurer
8. Nominations & election of Committee Members
9. Re-appointment of : -  
Bankers (Barclays plc) Auditors (M+A Partners)
10. Re-affirm re-appointment of Roger Bassham, Ray Cossey,  
David Haines & Edward Hare as Trustees
11. Any Other Business

### Nominations are invited to serve as Committee members

*Signed nominations, with the name of a member-seconded  
should be submitted in writing to :-*

**Noel Warner, Swan Meadow, Low Road,  
Fornsett St. Mary. Norwich, NR16 1JJ**

*to be received no later than 31st. March, 2019 Nominations  
will be accepted from the floor, with the nominees' consent.*



Our thanks to cartoonist, Adrian Raeside for allowing us to reproduce his cartoon

(This article is reproduced from the Eastern Daily Press of 22/10/18)

## World first for cancer treatment at the Norfolk & Norwich University Hospital



N&NUH chief executive, Mark Davies (left) and chief operating officer, Richard Parker (right) with the hospital's Bravos Team. (photos - N&NUH)

Patients at the Norfolk and Norwich University Hospital are the first in the world to benefit from a new cancer treatment machine. The state-of-the-art device, called the Varian Bravos after-loader system for brachytherapy treatments, is being used to treat some gynaecological and **prostate cancers** with a form of radiotherapy at the hospital's Colney Centre. The new system, made by Varian, can potentially reduce the amount of treatments patients need by directly targeting tumours with high dose rate (HDR) radiotherapy.

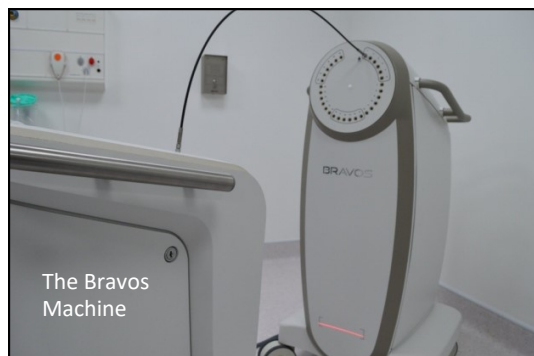
Bravos replaces a cancer treatment machine that had been used at NNUH since 2003. Vicki Currie, lead clinical scientist for brachytherapy at the hospital, said standard radiotherapy uses radiation directed at the tumour from outside the body. Brachytherapy places radioactive sources inside or near a tumour to reduce long-term side effects and reduces the risk of damaging healthy tissue. She added that brachytherapy can result in fewer visits to hospital for some patients.

Vicki said: "We hope it will make a difference to patients in Norfolk and the wider area as the only other centres that offer brachytherapy in the region are in Cambridge and Colchester. They can have this done as a day case and it gives us capacity for more patients to be treated," she said.

The new machine was launched on October 20 last year and is not used at other centres which offer brachytherapy. Katie Cooper, consultant radiographer added: "This gives a much higher dose with less side effects. It is safer, cuts down on treatment times and it frees up space in our theatres."

Sophie Wetherall, product manager for Varian, said: "The NNUH is the first in the world and the first clinical site to be using Bravos." An expansion of brachytherapy treatments, to include **prostate cancer**, was made possible thanks to the generosity of people, who supported the Targeted Radiotherapy Appeal – a £600,000 public appeal that funded the creation of a purpose built brachytherapy space within the department at the hospital to provide a multi-purpose room for anaesthesia and brachytherapy treatment with a dedicated recovery area as well as additional equipment needed for these treatments.

Mark Davies, chief executive, said: "I am delighted that NNUH is the first in the world to use this new machine, which reinforces our reputation as a major centre for cancer treatment at the forefront of modern technology. "I'd like to pay tribute to everyone at the hospital, our supporters and Varian who have made this project a reality."



The Bravos Machine

**Our support Group made a substantial contribution to help the Targeted Radiotherapy Appeal reach its target of £600,000.**

### FANTASTIC SUPPORT FOR OUR GROUP BY THE 'DOCK TAVERN' AT GORLESTON



Adam and Amanda Colburn are flanked by George & Jill Siely (left), Harvey Meadows and Graham Manning (right), committee members of N&WPCSG

Landlords of the **Dock Tavern, Gorleston**, Adam and Amanda Colburn, have presented us with a cheque for £3,224.08, on behalf of their customers, who have so energetically backed their fundraising efforts, during 2018, in support of our Group.

**Since March 2016 the customers of the Dock Tavern have raised a magnificent £7,653 to help us in our work, supporting prostate cancer patients and their families.**

Our chairman, Nigel Gardiner has applauded their fundraising, saying "Adam and Amanda, and their amazing customers, have been truly wonderful in their support of us over these past years and we are very appreciative of all they have done. We rely on the help of folk like them to enable us to continue to support those affected by prostate cancer."

## THE FORUM'S CHARITY CHRISTMAS TREE COLLECTION IN AID OF OUR SUPPORT GROUP



Photos - Zoe Ford

**Vice-chairman, Roger Bassham speaks about our support group's work**

Our vice-chairman, Roger Bassham spoke of the Group's work in supporting prostate cancer patients. The collection, leading up to Christmas, raised just over £ 800 for our support group.

**Thanks to Taverham Garden Centre for their support**

On the 29th. November the lights on the Charity Christmas Tree at The Forum were turned-on to aid two charities - The Royal National Institute of the Blind and our own **Norfolk and Waveney Prostate Cancer Support Group**. The choir from Bignold Middle School, standing in front of the very tall tree, entertained appreciative shoppers, who enjoyed a medley of Christmas songs and carols.

The tree was kindly donated by the **Taverham Garden Centre**, the management of which selected us as one of the two charities to benefit from donations collected in the run-up to the festive day, because some of their own members-of-staff are prostate cancer patients.



## Diary Dates

### Open Meetings with Speaker

**Monday 4th March**  
(7.00pm)  
Benjamin Gooch Theatre  
Norfolk & Norwich Hospital

**Monday 3rd June**  
(7.00pm)  
Benjamin Gooch Theatre  
Norfolk & Norwich Hospital

### Meet & Chat' Meetings

**Saturday 27th April**  
(11.45 am)  
Louise Hamilton Centre  
James Paget Hospital  
Gorleston

**Monday 13th May**  
(7 pm)  
the Big C Centre,  
Norfolk & Norwich  
University Hospital

### Committee Meetings

**Monday 8th April**  
**(AGM)**  
(7pm)  
the Big C Centre  
Norfolk & Norwich Hospital

## OUR WELFARE TEAM ARE GEORGE & JILL SIELY

who live in Happisburgh and are always available to give help and support to any member, and/or their family, who requests it. They have a contact list of fellow members of our support group and are able to put you in contact with someone who has been on the same prostate cancer treatment journey as you.

**Call 01692 650617 if you would like to have a chat with either of them.**

## How To Contact Us

### Specialist Nurses:

Sallie, Wendy, Rachel & Elaine  
Norfolk & Norwich University Hospital - 01603 289845

Angie, Wendy & Simon  
James Paget Hospital, Gorleston - 01493 453510

Sally, Clare & Anne-Marie  
Queen Elizabeth Hospital, King's Lynn - 01553 613075

### E-mail us at

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### Visit our website:

[www.prostatesupport.org.uk](http://www.prostatesupport.org.uk)

### Letters to the Editor:

Email : [geoffreyowalker@googlemail.com](mailto:geoffreyowalker@googlemail.com)