## Norfolk & Waveney

# **Prostate Cancer Support Group**

Issue No 60

# **NEWSLETTER**

Summer 2016

## New drugs for aggressive prostate cancer 'promising'

A new type of drug could benefit men with aggressive prostate cancer that is no longer responding to treatment, researchers from the Institute of Cancer Research have said.

In a study on mice, Hsp90 inhibitors were found to strip cancer cells of defences against hormone treatments. This makes the drugs particularly promising for treating drug-resistant cancers, the research team said.

The cancer can sometimes be treated successfully with hormone treatments, which target androgen receptors linked to the growth of male hormones called androgens.

But some prostate cancers don't work that way. Instead they create an abnormal form of androgen receptor which is not linked to the growth of hormones and therefore does not respond to standard hormone treatment.

This is the most common form of resistance in prostate cancer which leads to aggressive, difficult-to-treat cancers.

#### 'Network drugs'

They have found that a new class of drugs reduced production of both receptors. Professor Paul Workman, study author and chief executive of the Institute of Cancer Research, said it was an exciting discovery. "We call Hsp90 inhibitors 'network drugs' because they tackle several of the signals that are hijacked in cancer all at once, across a network rather than just a single signalling pathway. These drugs can hit cancer harder than those targeting only one protein, and look promising for preventing or overcoming drug resistance. The next step is to test the Hsp90 inhibitors in clinical trials on patients with aggressive, drug-resistant prostate cancer."

Prof Johann de Bono, a professor of experimental cancer medicine at the Institute, said: "These drugs are already in clinical trials for several types of cancer, and I am excited that our work suggests they could also benefit men with prostate cancer who have otherwise run out of treatment options."

## Grateful patient to hold Open Garden weekends

Philip Greenacre, a member of our group, and his wife, Chris, will hold two Open Garden weekends to raise funds for the Radiotherapy Department at the NNUH. (See Philip's "journey" on Page 2).

They were farmers until their retirement in 2008. Because of Philip's love of gardening, and Chris's love of Philip, it seemed natural that their retirement project should be a garden. They bought Furze House in Rushall with its two acres of land. Initially, the garden was no more than lawn, trees and four herbaceous beds. But they had a vision and set out to achieve it.

The garden has evolved over the last eight years and now boasts over 50 beds full of shrubs, perennials and rare plants sourced from around the United Kingdom and Europe. They entered the National Garden Scheme yellow book in 2010 and received their five year certificate in 2015. But that was their last year of the NGS, because in 2015 Philip was diagnosed with prostate cancer.

They felt they needed to give something back to the NNUH for the marvellous treatment he had received, and they could see no better way than to reopen the garden to raise funds for the NNUH radiotherapy department. So they are holding two open weekends this year, plus all the 'by appointment' group visits. They look forward to welcoming you so they can raise as many funds as possible.

The talk at our next open meeting will be by Consultant Urologist Robert Mills, MB, ChB, FRCS, FRCS Urol on

"Recent Development in Prostate Cancer Treatments"

Monday 6 June at the Benjamin Gooch Theatre, East Atrium, NNUH from 7pm to 9pm.



Furze House will be open (10am - 5pm) on the weekends of:

- Saturday 4th to Monday 6th June
- Saturday 20th to Monday 22nd August

Furze House, Harleston Road, Rushall, IP21 4RT

Entry £3.50, children free. Light refreshments available.
Dogs on leads welcome

#### **Donations**

Our group has recently received a number of very generous donations.

Because of our extended obituary notice of David Paull, there is not enough space left to give appropriate details of these donations, but we will cover them fully in the next issue of the newsletter.

# Our journeys

#### David Haines - President & Founder Chairman

My journey begins in 1987, when I had a colo-rectal tumour removed successfully, and all was well (as I thought) until my wife and I moved house nearer to Norwich after my retirement. This meant registering with a new medical practice, and having a thorough checkup. I was now 75 years old, and experiencing a few problems which I attributed to growing older, and did not worry too much. My new doctor thought my nightly visits to the bathroom were too many, and sent me for a PSA test (which I had never heard of). After a PSA reading of 17, within a month and further tests and scans, I was diagnosed with a T2 prostate tumour and put on Xoladex implants to shrink the tumour prior to Radiotherapy. I then had a month on daily RT, followed with a resumption of Xoladex, which on follow-ups indicated success, with a new PSA reading of 0.01. With regular PSA tests showing small variations within accepted limits, I have recently passed my ten year survival point. I urged my three sons to have their PSA tested, all were in their 40s, and the youngest at 45 was diagnosed with a T2 Prostate Cancer, although he had no symptoms. This was removed by da Vinci robotic surgery, and he is now fit and back at work.

Having developed cardiac problems five years ago, I was subjected to regular medical reviews after a heart attack two years ago. A routine scan last Autumn to investigate chest pain, requested by my cardiologist and gastrologist, revealed that I had a large colon tumour, and once again, after 28 years, I was referred to the colorectal department. Major radical surgery followed within three weeks, and now 12 weeks later, I feel fitter than for many years, am driving, walking, exercising, and have an improved appetite. I am now on a regular check regime for both cancers, and have nothing but praise for our NHS.

Thanks to early diagnosis in all three visitations from the Big C, the support of informed GPs, and the skill of the clinical staff at NNUH, I am now able to enjoy a better quality of life, indeed being still here to enjoy life itself. I cannot stress enough my belief in Awareness and Early Diagnosis, and maintaining a positive attitude even when the prognosis is bleak.





David (left), with friend and fellow ex-RAF engineer, Phil Rigby, recently on board G-TIDY. Phil built this aircraft at his farm in Norfolk. They flew it from Norfolk to Duxford last summer. They are both Prostate Cancer survivors. Phil completed his Radiotherapy earlier this year, then visited a friend in Vietnam for a few weeks to recuperate, and is again fit enough to fly. G-TIDY is once more airborne, and is a testament to life after Prostate Cancer.

My plumbing systems, both fore and aft, are now in good working condition. However, I could give Le Pétomane some competition (but not in polite company). It could have been a very different story.

## Philip Greenacre (See Front Page for details of their Open Weekends)



Philip and his wife, Chris

'Get checked out dad', my daughters kept telling me. I had never thought about it and then, despite the repeated plea, I never had time. And then I did. I got checked, and everything changed.

I had no symptoms, so going to the doctors was not a priority. I felt fine, but gradually I was worn down by the determined nagging of my two daughters (no idea where they get that part of their nature from). The first PSA test came back slightly higher than normal so a retest was booked for three months. The second test showed an increase, so I was referred to a Urology consultant for a biopsy. The results from the biopsy stated 50% of the samples were cancerous. This was when the NHS, and especially the wonderful staff at the Norfolk and Norwich University Hospital, really got going. The first step was a course of hormone tablets followed by hormone injections. I then became a member of the "37" club as I endured 37 days of radiotherapy. It was hard – there is no getting away from that – but my treatment by the staff at the NNUH was nothing short of exceptional. Everyone always had a smile and was always positive.

And if you are wondering, in February this year I had my latest PSA test, it came back at 0.1%. I was clear of cancerous cells. Together we had beaten it. So my advice to all those gentlemen out there of a certain age, if you have a nagging daughter, or son, take a moment to listen and get checked.

## David Paull – A Gentle Man and a Gentleman

So our former chairman, Ray Cossey, perfectly summed up our editor, David Paull, who died aged 83 on 31st March.

Ray went on: "I first met David when our support group arranged the first of our mass PSA testing sessions. As the then chairman I sought volunteers to help at these sessions and David was among the first to step forward. His designated job was to marshal the seating arrangements for those attending and this he did with a quiet efficiency. His always polite but firm approach towards the attendees ensured that the events went off like clock-work.

"Over the dozen years the group has existed there have been a

number of editors of our Newsletters, but for me no one did the job better that David, who brought to the job his many years of expertise as a journalist, latterly with our local daily newspapers.

"During the time of his editorship I was privileged to work closely with David and I always admired his professionalism and quiet efficiency. When, as I did on occasion, I struggled to find the right word or phrase for an article I was composing, David knew exactly how to resolve my difficulty. Furthermore, David always ensured that both sides of the argument, especially with regard to PSA testing, were aired in the columns of our group's Newsletter.

"I last met with David, at his Eaton home, just before last Christmas at the time he had told us that he had to retire from his editor's position, owing to his deteriorating health. He was totally reconciled to his condition and never once complained about the situation he found himself in.

"To my mind David Paull was both a gentle man and a gentleman. I shall miss him very much."

I would also like to quote from the moving eulogy of David's daughter, Gill: "I'd like to say a few words about David that have been written together with my mother, Iris and my brother, Alan.

"David was born in Enfield in 1933, the only child of Ida and Leonard. Leonard was the receptionist at the Press Association on Fleet Street, which began a lifelong connection to journalism for David. David attended Enfield Grammar school and excelled academically. He was also, apparently, something of a sportsman, cutting a dashing figure in green as the goalie on games afternoon – according, that is, to a young lady called Iris who would gaze out across the school fields from the adjoining girls' school rather than concentrating on her school work. And it was the local youth club and playing table tennis which brought David and Iris together.

"David left school at 16 to begin his career in journalism at the Press Association in London. He held reporting roles at local newspapers before becoming editor at the Enfield Gazette. Those early years were a tough apprenticeship in a demanding trade – anti-social hours, meeting deadlines, cold hours on the touchline at football matches and, perhaps most challenging of all, long evenings at the dinners of local political parties. Yet journalism was not so much a career choice for David as a vocation: he had a natural interest in people and the world and a desire to fairly report what he learnt – to help, in some small way, to make the world a better place.



David and Iris on their 60th Wedding Anniversary

"David and Iris were married in 1955 and children subsequently arrived first Alan and then me. Dad was a very involved father - perhaps somewhat ahead of his time. Always willing to join in, Dad once played Father Christmas at our playgroup without Alan or myself recognizing him. He was someone who would always try things - be it sometimes with mixed success: for example, although he produced some very drinkable wine in his home-brewing, an exploding demijohn of fermenting beer in the garage meant that the remaining jars had to be removed to the safety of the garden.

"Perhaps the most important message David gave as a father was

to have faith in ourselves. When I was advised that university was not really an option for a girl from a family where no-one had attended before, it was Dad who said I was good enough to apply to Oxford and pursued it with the school, leading to life-changing success for me in the entrance exams. That same spirit of determination doubtless had its influence when Alan returned to study as a mature student, achieved a well-earned degree and developed the skills to become an indispensable part of an innovative IT business.

"In 1981, we moved to Norwich for David to start a journalist training scheme for Eastern Counties Newspapers. He greatly enjoyed teaching and helped to produce future journalists with the same love of and respect for the profession as he had. Several of his trainees won national prizes and David was described as an "outstanding journalism trainer with a deserved nationwide reputation". In so-called "retirement", he continued to learn and to train others, becoming an expert in media law. Perhaps crucial to his career success was David's enthusiasm and respect for those he worked with. As a former colleague said "David was always a pleasure to work with — a true gentleman with a great sense of humour, always willing to share what he knew."

"It was about the time of his 40<sup>th</sup> wedding anniversary in 1995 that a shadow fell across David's life. He was diagnosed with prostate cancer and the initial prognosis was bleak. David often said that he feared he would not live long enough to his grandchildren start school. But he saw all three, Thomas, Seb and Oliver, grow into young men and the eldest two start university. Moreover, he and Iris shared not only a golden wedding anniversary, but also celebrated their diamond anniversary last year. Against the odds, David enjoyed more than twenty years after that initial bleak prognosis.

"And what valuable years they have been! David played an active in role in many groups – wildlife, bowling, Probus and cancer support – often a keen committee member and using his journalistic skills where needed, although it was the social side of these groups that he enjoyed the most. Those additional years allowed David and Iris to travel, to see friends, spend time with family and just enjoy their retirement. Most precious, Dad was able to see Alan settle in his new home in Manchester in a loving family with Amy and Seb and to enjoy the arrival of a beautiful granddaughter, Alice. There is no better tribute to a man as a father than when his own son becomes a good father in his turn.

Continued overleaf

#### David Paull – continued

"For me, Dad's support when I returned to a full-time career after raising my family meant so much: he would read my reports with interest and send relevant newspaper cuttings and I know he was proud of what he helped me to achieve.

"But what allowed David – and us – to enjoy this extra time? David would want to give credit to the medical researchers who have helped fight cancer and to the health professionals who treated him. He often praised the medical staff and, even in his final few days, was saying how "absolutely marvellous" the support of the community services had been. But more than that, David would want me to say how wonderful Iris has been, particularly in the recent few years – how much she helped and cared with a tireless devotion, all the more effective because it was undertaken out of simple love and acceptance of the situation. Mum has a habit of saying that she "did her best", but I think Dad would want to say that, in caring for him, she did the best.

"Yet perhaps most important in David beating the medical odds was his sheer determination. He took on whatever medical treatment was required, researching the latest developments and being willing to try new options. This was not easy – there was considerable pain and huge frustration at times – not least for David in having to be helped rather than being the one who helped others. But he always kept fighting and, for that, we are truly grateful and value so much the extra time that was given to us.

"This is a day of great sadness as we say goodbye to David. But it is also one of gratitude that we did get that "little bit more time" that people so often wish for. Moreover, we can look back with happiness that we were so fortunate to share our lives with David as a wonderful husband, a loving father and grandfather, and a good friend or colleague: David was a man who was always interested in and supportive of the people around him and who enjoyed life to the full."

I recruited David to be our newsletter editor. The deal was that he would do the words and I would do the computer equivalent of typesetting. It is hard to describe how much fun I had working with him, not to mention with our Proofreader-in-Chief, "Eagle Eyes" Iris.

He was a hard taskmaster – everything had to be perfect, with no "white space", etc. But I learnt a great deal from him and it is always challenging and fulfilling to work with someone who knows his chosen profession so well.

My last quote is – fittingly – from David himself. He wrote to me just a week before he died, attaching seven key articles he had spotted.

"Dear Chuck, It must have been prescience on my part when I felt that I couldn't continue with the newsletter! I've really done it this time. Leg gave way – flat on floor – sequel, an emergency operation. They obviously thought it was pretty serious because I had a private room on Edgefield Ward for a week.

"Back home now and making very good progress but using wheelchair and a variety of walking aids. The community nurse service has been absolutely superb, providing all sorts of useful kit and coming in daily without fail to change my dressings. I'm obviously not allowed to drive yet but I hope I might be able to in another month.

"But you can't keep an old sweat of a journalist down. I keep scouring the papers for any reference to prostate cancer and attached are a variety of cuttings which may or may not be of use. I'll keep looking. Best wishes, David"

What a man! Chuck Lyons

#### **Dates for your Diary**

Wed 1 Jun, 6 Jul & 3 Aug. . . . 5.30-7pm Radiotherapy Department Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C. Call 01603 288779 to book. Mon 6 June..... 7-9pm Open Meeting at Benjamin Gooch Theatre, NNUH Robert Mills, Consultant Urologist "Recent Developments in Prostate Cancer Treatments" Tue 21 June. . . . . . . 10.30am - 4.30pm Tackle Annual Conference "Trouble Down Below!" Galleon Suite A, Royal National Hotel, 38 Bedford Way, London, WC1H 0DG For more information and to reserve places, please email: simon.lanyon@tackleprostate.org Mon 1 Aug. . . . . . . . . . . . . . . 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.

### Yes, it's him again!

Terry Chappelle, aged 82¾, once again wowed a full house of 135 with his revue 'Table For Two' in aid of our group and raised just under £1,300.

This energetic, fellow prostate cancer patient is already planning his next show, to aid



our fundraising, which is planned to take place in September 2017.

Watch this space!

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Help or Advice – We have over 30 members available to help.
There is probably one near you.

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