# Norfolk & Waveney

# **Prostate Cancer Support Group**

Issue No 59

# **NEWSLETTER**

Spring 2016

# Electronic nose – is this the future?

It's certainly not the present – where initial diagnosis of prostate cancer relies on a combination of a PSA blood test, a digital rectal examination and the GP's experience of analysing patients' symptoms. A prostate biopsy can then follow.

But a new prostate cancer test that "smells" the disease in urine is now one step further to becoming a reality. Essentially, the test uses a special tool to "smell" the cancer in a man's urine. The discovery, published in the Journal of Breath Research, raises hope of tests which can give an accurate diagnosis from the outset.

Mr Raj Prasad, Consultant Urologist at Southmead Hospital, Bristol, said: "If this test succeeds in a full medical trial it will revolutionise diagnostics. Even with detailed biopsies there is a risk we may fail to detect prostate cancer in some cases. An accurate urine test would mean many men who currently undergo prostate biopsy may not need to do so."

Called a gas chromatography (GC)-sensor system, the device, called Odoreader, can successfully identify patterns of volatile compounds from urine samples – and detect which indicate cancer.

In a trial, run in collaboration with a team at the University of the West of England, Southmead Hospital and Bristol Royal Infirmary, 155 men who attended a urology clinic were assessed. Of this group, 58 were diagnosed with prostate cancer, 24 with bladder cancer and 73 with poor stream/urine flow without cancer. The trial involved inserting urine samples into the Odoreader which were then measured using algorithms developed by the research team at the University of Liverpool and UWE Bristol.

Professor Chris Probert, from the University of Liverpool, said: "There is an urgent need to identify these cancers at an earlier stage when they are more treatable – as the earlier a person is diagnosed the better. After further sample testing the next step is to take this technology and put it into a user friendly format. With help from industry partners we will be able to further develop the Odoreader, which will enable it to be used where it is needed most: at a patient's bedside, in a doctor's surgery, in a clinic or Walk In Centre, providing fast, inexpensive, accurate results."

Professor Norman Ratcliffe, of the University of the West of England, added: "There is currently no accurate test for prostate cancer, the vagaries of the PSA test indicators can sometimes result in unnecessary biopsies, resulting in psychological toll, risk of infection and even sometimes missing cancer cases.

"Our aim is to create a test that avoids this procedure at initial diagnosis by detecting cancer in a non-invasive way by smelling the disease in men's urine. A few years ago we did similar work to detect bladder cancer following a discovery that dogs could sniff out cancer. [See our recent article on complementary trials using sniffer dogs]. We have been using the Odoreader, which is like an electronic nose to sense the cancer.

"The Odoreader has a 30 metre column that enables the compounds in the urine to travel through at different rates, thus breaking the sample into a readable format, which is then translated into an algorithm enabling detection of cancer by reading the patterns presented. The positioning of the prostate gland – very close to the bladder – gives the urine profile a different algorithm if the man has cancer."

Dr lain Frame, director of research at Prostste Cancer UK, added: "A non-invasive test for prostate cancer would be game-changing. Although this research is interesting, we are a long way from this being used to benefit men, We look forward to further results from larger clinical trials".

# Major donation by The Freemasons' Grand Charity



Since 2006, The Freemasons' Grand Charity has donated over £249,000 towards research into the detection and treatment of prostate cancer.

In 2015, it awarded a grant of £100,000 to the Cancer Genetics team at the UEA, led by Professor Colin Cooper, to help fund research that will focus on distinguishing between aggressive ("Tigers") and non-agressive ("Pussycats") forms of the disease.

Professor Cooper, pictured with some of his team (centre, behind nurse) will give a talk on "Prostate Cancer – Tigers and Pussycats" at our open meeting on Monday 7 March at 7.30pm in the Benjamin Gooch Theatre, East Atrium, NNUH.

# Our journeys

With the help of our members, we hope – on a regular basis – to highlight the individual "journeys" we have made from being diagnosed with prostate cancer to the treatments we have had and how we are coping post-treatment.

Each journey is unique, and yours can help and reassure others – we are not a "support" group for nothing!

Please send your story to Chuck Lyons, charleswlyons@aol.com, or by post to 71 Norwich Road, Fakenham NR21 8HH. Handwritten is fine – I have a digital program to handle that (brain to digits to computer file).

The series kicks off with a "double bill" in the best BBC4 Scandi Noir tradition.

### Roger Bassham

On February 3rd last year, I was told the news that no man wants to hear – I had Prostate Cancer.

It had all started two years previously when my wife nagged me to have a blood test (PSA) as I was getting up two or three times each night. Sure enough my PSA rose from 3.4 to 5.4 over that two year period. After a rectal examination it was found I had a lump on my prostate.

Subsequent biopsies confirmed I had cancer. I had keyhole surgery in April and after two days in hospital I was sent home with a catheter inserted which I had to keep in for two weeks. As I had gone in as a private patient and not put onto the oncology ward, I was sent home with no knowledge of the Norfolk & Waveney Prostate Cancer Support Group. This would have helped me in the ensuing weeks regarding problems I would encounter such as controlling my bladder, where to obtain pads, pelvic floor exercises, etc. It was a

friend of mine who put me onto the group when he knew of my problems.

Five years later I am still totally clear of the cancer, I didn't need any followup treatments and can do all the activities, walking, golf, bowls etc that I did before. However I have turned the experience I had to become a serving member of the NWPCSG and do talks to groups on their behalf and Prostate Cancer UK.

I am one of the lucky ones – diagnosed early and dealt with promptly. It's clear to me and my advice is to push – to get a PSA test – insist on it. My two boys will have a blood test soon as although 1 in 8 men will get the cancer, they are  $2\frac{1}{2}$  times more likely to get it as I have had it.

DO YOU KNOW SOMEONE WHO MAY HAVE SYMPTOMS? PUSH THEM TO HAVE A SIMPLE BLOOD TEST (PSA) – IT COULD BE LIFE OR DEATH.

### **Graham Manning**

#### PROSTATE AWARENESS!

Having received the devastating news back in March that I had Prostate Cancer, I was immediately swamped by a huge flood of emotions and questions, but my one defining thought that came through all of this was that no matter what lied ahead or what I had to do I had to 'buy time' to be here with my wife, my three sons and the rest of the family in whatever form that took!

Although no man wants to have to consider the dreaded 'C' word, more men than we ever imagine find themselves in this situation and having to deal with the same thoughts and the emotional roller coaster that as yet, they have no idea where it will take them, let alone the much changed life that lies ahead!

For me, thankfully as it turned out, the cancer was diagnosed early and was contained within the prostate so the choice was simple – surgery!

Buying time for me was surgery as Plan 'A'. Plan 'B' would be radiotherapy, chemotherapy or anything else that may be suitable!

I am extremely lucky for several reasons, not just the fact that the cancer was contained but also from a large circle of shocked but supportive friends, but most importantly from a loving family, who not only had to deal themselves with the fact that their Dad, Husband, Brother or Uncle had cancer but also the mental anguish they were going through themselves!

Many men don't have a choice of treatment simply through lack of knowledge or because of age or cancer stage or unfortunately it is too late. The sad reality is that in many cases they could've had a choice if only they'd known about, asked for, or been offered a PSA test at the doctors.

This simple, but still largely unknown blood test, as we know is not a definitive cancer diagnosis in itself, but it does highlight that something may not be 100% normal and therefore should perhaps be subject to further investigation! This makes Prostate Cancer Awareness all the more important!

I had surgery on 31st May. The surgeon, Mr Kumar at the N&N, was happy he had got what he wanted and had taken some good 'all important' marginal tissue. During

my follow up appointment on 30th July he advised that my PSA was 0.01 and that the marginal tissue he'd taken had proved negative for cancerous cells!! The relief was immense and the emotional release was beyond words.

My wife, Trudy, was on this rollercoaster with me every twist and turn, the highs and particularly through the low dark moments that I experienced – as with any wife or partner I can only imagine how she must have felt – yet she stayed strong and that helped me immensely and for that I will be eternally grateful.

Along with the massive sense of relief, knowing the importance of early diagnosis and feeling that there is a lack of public knowledge for men to get themselves checked, Trudy decided that she wanted to do something that would hopefully raise awareness and some money for the cause! She decided to arrange a Prostate Awareness 'Coffee and Cake' event with funds going to Norfolk & Waveney Prostate Cancer Support Group. A date was set for Sunday 23rd August!



# 100 Club

The group is launching a 100 Club, a brand new fund raising initiative that might benefit you too! We'd love you to be involved!

We very much hope you will feel able to support our fundraising

event on Saturday 7 May, in Sheringham. We can assure you that

long-time local entertainer, Terry Chappelle and his friends are very

By your support of this event you will be assisting our support group

to raise the awareness of prostate cancer and informing our fellow

prostate cancer patients of the many and varied treatments available

If you feel able to bring along another couple, or two, we will soon be able to sell all the 120 seats available, which will help us raise well over £1,000! We do hope that you will feel able to support this event.

to them for this most prevalent of male-only cancers.

entertaining and good value for money.

#### This is how it works

You sign up to donate £5 a month to NWPCSG for each named person. Each will be allocated a unique 100 club membership number which will be entered into a prize draw held quarterly.

One third of the amount raised through the 100 club will be returned as prize money and the balance will boost our funds and help us in our work with prostate cancer sufferers.

We are grateful to our treasurer, Andrew Hadley, for this initiative. He has extensive experience of setting up and running 100 Clubs.

Entry forms and rules will shortly be available on our website, www.prostatesupport.org.uk

# NHS fast-tracks docetaxel

The NHS has fast-tracked a drug that can extend the lives of men with advanced prostate cancer by more than a year following clinical studies, and it can now be prescribed immediately.

The announcement scraps the previous guidelines that patients had to wait for the chemotherapy drug docetaxel until existing hormone-based treatments had stopped working. The drug could offer hope of extended life for about 4,560 men each year whose cases are already advanced, and incurable, when diagnosed.

Angela Culhane, the chief executive of Prostate Cancer UK, said the announcement was great news for men newly diagnosed with advanced prostate cancer.

"It is critical that specialists are made aware that this use of docetaxel treatment is available so that no man misses out. Earlier docetaxel must become the standard for men who can benefit from it and we will continue applying pressure until we are sure this is the case. This fast-track response to new evidence indicates what can be achieved when there is the will in the system. It must set a precedent for other treatments that demonstrate clear clinical benefit when used in different ways."

Jonathan Fielden, the director of specialised services at NHS England, said: "Rigorous new evidence shows that this drug brings significant benefits for patients with advanced prostate cancer.

"So working closely with patient groups and cancer specialists, NHS England is now pleased to be fast-tracking its wider availability."

Older men, men with a family history of prostate cancer, and black men are more at risk of the disease.

Docetaxel chemotherapy is already a routine treatment for men with advanced cancer, but until now has only been prescribed after men have become resistant to androgen deprivation therapy (ADT). Now both treatments can be started at the same time.

# Radiotherapy time halved?

At our recent "Meet & Chat", the talk was all about higher dose/shorter duration radiotherapy treatment. The time could be cut in half after a study has shown men can handle higher doses. The new procedure involves applying higher doses of accurately targeted radiation over a shorter period of 20 days compared with over 37 days with lower doses.

A five-year CHHiP trial, funded by Cancer Research UK, involved more than 3,200 men with prostate cancer and compared standard radiotherapy with two alternative higher dose/shorter duration regimes.

Dr Emma Hall, deputy director of the Clinical Trials and Statistics Unit at the Institute of Cancer Research, said "Our trial shows that modern radiotherapy allows men to undergo fewer, higher doses for the same result. Delivering 20 treatment sessions at a radiation dose of three Grays a day was found to be as effective as 37 sessions at two Grays, while halving the rate of side effects." [Editor's italics].

Professor David Dearnaley, from the Institute of Cancer Research in London, said: "Overall our results make a compelling case to change practice within the NHS and move from a 37-day regime to one that lasts 20 days. As well as saving men from repeated hospital visits, this could save tens of millions of pounds per year."

Dr Hall added: "Historically we've seen radiotherapy given in smaller doses over quite extended periods of time – and in prostate cancer treatment, the standard is still more than five weeks of daily treatment. But radiotherapy technology has developed over recent years, meaning we can target doses to tumours more accurately and reduce the dose to surrounding tissue.

"Our trial shows that modern radiotherapy allows men to undergo fewer, higher doses for the same result, both in terms of treatment effectiveness and quality of life."

### David Paull hangs up his editorial hat



David Paull (pictured at our recent Open Day flanked by chairman Noel Warner, left, and Big C chief executive Dr Chris Bushby) has retired as editor of our newsletter.

His career in journalism started rather a long time ago – in 1949 when he left school at 16 and headed for Fleet Street to become a trainee at the Press Association news agency.

After a year learning the trade from some of the finest reporters in the Street, he moved to newspapers in Hertfordshire, later returning to his home town of Enfield to become assistant editor, then editor of the principal local newspaper.

From there he became deputy director of the National Council for the Training of Journalists and in 1981 – having advised the Eastern Counties Newspapers Group (now Archant) how to set up a journalism training centre – he was invited to come to Norwich to run it.

After 12 years he took early retirement but for the next 10 years he was a freelance tutor, running media law and journalism courses for television and newspaper companies across the country. He then had a five-year stint as editor of Norfolk Wildlife Trust's magazine, Tern.

He then thought he had finally retired – only to find himself some years later back in harness as editor of our newsletter.

Over more than three years and 22 issues, David has revitalised our newsletter into the outstanding publication it has now become.

Heading rapidly for 83 and currently going through yet another round of tiring treatment, he has finally, finally decided to call it a day.

The Sorcerer's Apprentice, Chuck Lyons, gingerly takes over, buoyed by the knowledge that our new "Editor-in-Chief" is always available for help and advice. Chuck will miss the regular challenge of helping David with the latest edition – but he has learnt a great deal from observing how it should be done.

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

Wed 2 Mar, 6 Apr & 4 May. . . . 5.30-7pm Radiotherapy Department Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C. Call 01603 288779 to book. Mon 7 Mar. . . . . . . . . . . . . . 7-9pm Open Meeting at Benjamin Gooch Theatre, NNUH Professor Colin Cooper Director, Cancer Genetics team at the UEA on "Prostate Cancer -Tigers and Pussycats" AGM at Big C Centre, NNUH (See our website for the Agenda) Sat 23 Apr..... 11.30am-1.30pm "Meet & Chat" at Louise Hamilton Centre, James Paget, Gorleston Mon 9 May. . . . . . . . . . . . . . 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.

### A big thank you

The group gratefully acknowledges recent donations of over £2,500, including from:

Mr D Burlingham £325.00
Catfield Village Hall £98.50
Norwich Accordion Band £146.80
Reepham Rotary Club £1,500.00
Mr Searle £100.00
Mr Shipman £10.00
Somerleyton CC £300.00
Wymondham Rotary Club £1,000

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

For more information please call or email Noel Warner on 01508 488088 / noel.windfall5@btinternet.com

■ E-mail us:

Noel Warner, Chairman, noel.windfall5@btinternet.com

- Letters to the Editor:
  - Chuck Lyons, CharlesWLyons@aol.com
- Visit our website:

www.prostatesupport.org.uk