
Norfolk & Waveney Prostate Cancer Support Group

Registered Charity No. 1108384

Newsletter no 29 October 2009

Patron: Martin Bell OBE

Joint Funding of new equipment for N&NUH Urologists

This Support Group and local cancer charity, Big C, are jointly funding the purchase of state-of-the-art equipment which will give urologists at the Norfolk and Norwich University Hospital valuable information to establish whether prostate cancer patients need further treatment.

The Hitachi 7000Hv is an all-in-one system, which carries out both a transrectal ultrasound and prostatic biopsy at the same time.

It will allow direct examination of prostatic tissue under the microscope.

It will be used exclusively for prostate cancer patients.

Our Group is donating £5,000 towards the £43,000 cost of this equipment.

The committee unanimously supported our chairman's proposal that we should make the £5,000 contribution, to enable the Big C cancer charity to opt for the very best unit currently available.

Chairman, Ray Cossey said, "We have to be mindful of the fact that by our active promotion of PSA testing for all men over 50, we have brought about a 27% local increase in prostate cancer referrals over the past 12 months.

It is as a direct result of this increase in referrals that the N&NUH approached the Big C to finance the purchase of an additional ultrasound and biopsy unit."

Whilst I and the majority of the committee are staunchly in favour of this Group promoting the case for PSA testing, for all men over 50 years of age, we have to accept that not everyone shares our views. This includes many of our medical advisors.

In the last edition of this Newsletter David Kirkham questioned the true worth of such testing. This has prompted urology-consultant, David Baxter-Smith, to give you his contrary opinion, which appears in this edition.

Debate is a very healthy thing and is, in my opinion, to be encouraged. We need to hear both sides of the argument if we are to arrive at an educated opinion on this very thorny subject.

In March this year this Group organised a mass PSA testing session where 219 men were tested, many of them having previously been declined a PSA test by their GP.

We now know of at least five men who are receiving treatment for prostate cancer as a direct result of attending this session, .

Some of these men have been moved to write to David Baxter-Smith, the Kidderminster-based consultant-urologist, who supervised the March event, in association with the Graham Fulford Foundation. David has forwarded me extracts from a couple of letters;

having first removed all means of identification of the writers.

One man (65), who was found to have a PSA reading of 19.9, wrote-

"I am so glad I read the EDP that Saturday in February and attended your March 5 session at the John Innes Centre. I took your advice to consult with my GP and had another PSA test, which showed a reading of 18.5.

The view from the Chair

My GP referred me to specialist at the N&N University Hospital and a biopsy showed cancer cells on one side of my prostate. I had a radical prostatectomy on the 10th of July.

Thank you so much for pointing me in the right direction as I had no symptoms whatsoever!"

Another, aged 54 wrote:-

"I had a PSA reading of only 4.9, at the March session you organised, but a subsequent biopsy revealed I had a T1 prostate cancer, with a Gleason scale of 7. I subsequently underwent a radical-prostatectomy at the Spire, Norwich hospital."

And I have received a letter from a lady whose uncle, at her prompting, attended our March 5 event. She writes:-

"My uncle, who attended your PSA event at the John Innes Centre, had a strong family history of prostate cancer. His father and two brothers died from it and another brother is currently being treated for it; even so, he had been refused a PSA test by his own GP. He is now currently receiving treatment for prostate cancer because of your support group's work. I thank you and the group for this."

On 20th October, at the Imperial Hotel in Great Yarmouth, our Group is organising a second mass PSA testing session and I have little doubt there will other unsuspecting men who will, subsequently, be found to have prostate cancer.

I concede that the PSA test can, sometimes, be unreliable and may, on occasion, give rise to, misleading results.

Even so, I am convinced, like David Baxter-Smith, that PSA testing plays an important part in the early detection of prostate cancer.

Ray Cossey - Chairman

The Case for PSA Testing

by David Baxter Smith Consultant Urological Surgeon at the Droitwich Spa and Kidderminster Hospitals

I would like to take the opportunity of responding to Dave Kirkham's comments in the August edition of this Newsletter, about Prostate Cancer, as prompted by the 2008 Annual Report on the State of Public Health, by the Chief Medical officer, Sir Liam Donaldson.

I am of the impression that both are rather confused about the place of a PSA test in the management of men with suspected Prostate Cancer. It seems very much as though the "cart is being put before the horse".

There are essentially three processes in managing a patient with Prostate Cancer:-

1. Suspicion
2. Diagnosis
3. Treatment

Let's look at these with the "cart before the horse".

3. Treatment. I believe it is unhelpful, misleading and probably untrue to suggest that "twenty men need radical treatment to save one life". I do not believe there are any surgeons in this country who have a 5% life-saving rate following surgery and it has been my experience that this figure should be much higher.

It is mentioned that "five men are left incontinent and another four impotent as a consequence of their treatment".

It is true that incontinence can follow surgery and impotence can also be a problem.

But treatment may be by radiotherapy, brachytherapy, or

H.I.F.U., where these possible complications are very much less, or by active surveillance, which has no physical side effects.

I believe too much is made of the possibility of impotence. In my experience most men in the age group which Prostate Cancer affects are prepared to take the risk of forfeiting an active sex life if treatment will save their life.

It might be better to stay alive and be impotent rather than die from advanced hormone resistant Prostate Cancer; dead men are also impotent!

Quoting such misleading figures only serves to dissuade men from looking after their general health as well as their prostate glands. Treatment will only be initiated after:-

2. Diagnosis A diagnosis is always made prior to a treatment decision and this usually involves a series of prostate biopsies.

These may establish the presence of benign disease, such as benign prostatic hyperplasia or prostatitis, either of which may need treatment, but could also reveal Prostate Cancer.

A Gleason score will then be made to establish whether the tumour is a "pussycat" or a "tiger" and further staging of a tumour would likely need an M.R.I. scan and a bone scan. Diagnosis will only be made after:-

1. Suspicion. Prostate Cancer is now the commonest tumour to affect men over fifty and so any man in this age group may have a suspicion of this disease.

If there is a family history of the disease it would be appropriate to lower the age limit to 45. The P.S.A. test rarely diagnoses Prostate Cancer but can be an indicator of a prostate problem.

So let's turn things round the right way and put the "horse" and "cart" in the correct order.

Start with a suspicion of the disease; proceed to a diagnosis, if there is reason to be suspicious and then consider treatment if appropriate.

Suspicion will come from an abnormal P.S.A.

I also believe the figures given in Sir Liam's report are out-of-date. The figures generally accepted in 2009 are 35,000 new cases diagnosed each year and there are 10,000+ deaths per year.

I understand these figures do not include Scotland, Wales and Northern Ireland and, as the statistics are gathered from death-certificates, they are likely to be an underestimate.

In summary, Sir Liam's report focuses almost solely on treatment and quotes misleading and frightening figures for radical surgery.

This will only serve to put men off an awareness of health issues and dissuade them from looking for any suspicious changes within their prostate glands.

This will not in any way help to reduce the appalling figures of deaths from Prostate Cancer.

Christmas Lunch - only a few places left!

There are just a few places left for the Group's Christmas lunch. It will be held at Glen Lodge on Friday 11th December - 12.00 for 12.30.

The price remains as last year at £16.50 per head. To book your place (or places) contact David Haines:- - tel 01603 881213 or email - david.haines2@btinternet.com

Take part in a Patient Survey

PatientView - an independent researcher and publisher which works with patient organisations - has invited members of our Group to take part in patient survey focusing on cancer therapy and infection.

PatientView says its aim is to identify awareness of an infection called febrile neutropenia (FN), the impact FN has on chemotherapy regimens, and other factors that interfere with optimal chemotherapy regimens.

About the Survey

This survey of the opinions of people with cancer (and their carers) is sponsored by Amgen and is part of ongoing efforts to assess better ways to prevent and treat infections in people with cancer.

The aim of the survey is to gain a patient/carer perspective (rather than a clinical perspective) on issues that are important to people with cancer, in particular their experience of the following areas:

- Understanding frequency and content of healthcare professional-to-patient dialogue regarding risk of infection
- Determine level of understanding about risk of infection, particularly FN, during chemotherapy and strategies for prevention

· How FN and infection impacts patient treatment regimes and quality of life

It is also hoped the survey will identify gaps in perception and/or understanding between the patients and healthcare professional responsible for their cancer care.

Individual responses of all contributors will remain completely anonymous (no IP addresses or email details will be visible).

The collective findings of the survey will be made public to help raise awareness of the issues surrounding infection risk among people with cancer.

If you would like to take part in the survey go to our Group website at www.prostatesupport.org.uk

The deadline for taking part is Monday October 19th 2009.

If you have any questions about the survey, please contact the survey administrator,

Louise Oatham

PatientView,
on

01547 520965,

or

info@patient-view.com.

PSA Test Session October 20th - Tell your friends

There are still some places available for people wanting a PSA test at our next screening session, at Great Yarmouth on the evening of October 20th.

So if you have friends or relatives aged around 50 who you think would benefit from a test, encourage them to write to us to book a place.

We are happy to give tests to anyone aged 50, or thereabouts, but we would particularly encourage anyone from a family with any history of prostate cancer to have a test.

Men who would like to book a place should send a large (A4 size) envelope stamped and addressed to themselves, to:

**N&WPCSG/Big C
10A Castle Meadow
Norwich NR1 3DE**

They will then receive paperwork to be completed to book their place. The session is taking place at the Imperial Hotel.

CANCER RESEARCH UK scientists have discovered a molecular 'flag' which could be used to distinguish men with aggressive forms of cancer that need immediate treatment from men with slow-growing forms which they can live with for many years.

At the moment, there are no reliable tests to make this distinction.

Research led by pathologists based at the University of Liverpool measured the levels of a protein called Hsp-27 in prostate tissue samples taken from 553 men at the time they were diagnosed with prostate cancer.

During a 15-year follow-up, the research showed that those men who tested positive for the protein at

diagnosis were almost twice as likely to die from prostate cancer than men who did not have the protein.

Lead author, Professor Chris Foster, a Cancer Research UK-funded scientist at the University of

**Discovery may provide
test to distinguish
aggressive from slow
growing cancers**

Liverpool's School of Cancer Studies, said:

" Our study shows that this protein marker -currently found in tissue samples - can give us a reliable and accurate indication of whether

individual cancers will become aggressive.

We are working on developing this finding into a blood test to monitor men with prostate cancer in order to determine when their individual disease needs treatment."

The protein is a key component of signalling pathways that control the movement of cells around the body. The study suggests that new drugs could be developed to block these signals and halt the spread of prostate cancer cells.

Professor Foster added: "If further research shows that blocking these cell message systems is successful, it could provide a new treatment for aggressive forms of prostate cancer."

Dates for your Diary

Tuesday October 20th

PSA Screening session, Imperial Hotel Great Yarmouth

December 7th - Open Meeting

Norfolk and Norwich University Hospital 7 p/m
Dr Tom Stuttaford

Dr Stuttaford retired as the Medical Correspondent of The Times at the end of 2008, but still writes "Dr Stuttaford's Surgery" for The Oldie. He has had a radical prostatectomy, radiotherapy and hormone therapy, which he is still on 12 years since he was first diagnosed. He is now 78.

Monday 1st. February - Open meeting

Norfolk & Norwich University Hospital 7 p.m
Dave Rea and John Pike will give a talk on something we need to be aware of

'TYPE 2 DIABETES'

What it is — What the symptoms are— How it is treated

The Big C Centre

The Big C Family Cancer Information Centre at the Norfolk & Norwich University Hospital is an amazing facility, for all cancer patients, their families and/or friends.

In a non-medical environment you can relax in the comfortable, lounge, use an extensive reference library, use the internet, or just have a cup of tea or coffee.

You can chat with fellow cancer patients and qualified nursing staff, all of whom will listen to your concerns and, if asked, give advice.

The Big C Centre is the cream and blue coloured circular-shaped building overlooking the first roundabout as you enter the hospital grounds.

The Newsletter

We are now producing the newsletter at four-monthly intervals – in October February and June.

You can get the newsletter via the internet, where it can be read or downloaded from our website; www.prostatesupport.org.uk.

If you would like to to this please email Harvey Meadows at rvmcolt@hotmail.com

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NORFOLK AND NORWICH PROSTATE CANCER SUPPORT GROUP

Registered Charity No. 1108384

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Trustees 2008/9 David Haines, Stan Thompson

Do you need help or advice?

Perhaps a friendly chat or a visit would be welcome. We have 29 Group members available at the end of a telephone ready to help. There is probably one near you.

For details please ring David Wiseman, our Welfare Officer, on 01603 260539.