East Lancashire Prostate Cancer Support Group Newsletter

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National prostate cancer campaign a first for NZ

Tony Ryall

27 November, 2013

Men and their families now have information resources to help them talk more confidently with their GP about prostate cancer.

"These resources are the first part of a $4.3 million programme to raise awareness of prostate cancer and ensure all men have access to quality information and care," says Health Minister Tony Ryall.

"This is the first time a New Zealand government has had such a focus on prostate cancer awareness and ensuring men can easily access the latest evidence based information. The resources include leaflets, detailed booklets and posters about the risks and benefits of prostate cancer tests and treatment.

"One of the resources is a leaflet which includes a checklist to help men decide if they need a prostate check. It asks nine simple yes or no questions, to get men thinking about their prostate health," said Mr Ryall.

Mr Ryall visited Capital Care Health Centre in Wellington today, and talked to doctors, including local GP Dr Samantha Murton, about the new prostate cancer resources.

The resources are based on the recommendations of the Prostate Cancer Taskforce, a group of clinical specialists and expert advisors chaired by Wellington urologist Professor John Nacey. They have been developed with input from consumers, GPs, specialist clinicians and other healthcare professionals.

"There has been a great deal of conflicting information about prostate cancer tests and treatments which has been confusing for men and their doctors," says Professor Nacey.

"These resources will provide clear and balanced information so men can talk to their GPs about all the available options and make decisions that are right for them.

"We also know that many GPs want more support and guidance around who to test for prostate cancer, who not to test, and who to refer to a specialist. A range of clinical resources are being developed for health professionals to help achieve greater consistency in the advice men receive.

"Next year a group of clinicians and experts, including GPs and nurses, will oversee the development of guidelines and standards so men have

What's Inside

Sex After Surgery

A recent article in the Dominion Post reported that a woman, Anne Maynard, has sued Wellington Hospital, saying that after her husband had surgery there, he lost all interest in sex.

A hospital spokesman replied:

"Mr. Maynard was admitted for cataract surgery. All we did was correct his eyesight."

Stuart Marshall 24/02/2014

equal access to specialist services for assessing and treating prostate cancer. The standards will help enhance early detection while limiting the harms and complications that can be caused by unnecessary treatment.

“A quick reference chart will be developed to guide GPs, and a decision aid will help men and their doctors agree on what action to take. Electronic prompts in patient management systems will remind doctors to talk to their patients about prostate cancer.

“New Zealand is one of the first countries in the world to develop a comprehensive national prostate cancer programme. Over time, this work will lead to better survival rates for men,” said Professor Nacey.

Prostate cancer is the most common cancer in men in New Zealand - each year around 3000 men are diagnosed with prostate cancer and the disease kills around 600 men annually.

An electronic copy of the resources are available on the Ministry of Health website www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/cancer/prostate-cancer

Health Minister Tony Ryall looks at the new prostate cancer resources with patient Mike Knott, local GP Dr Samantha Murton and Wellington urologist Professor John Nacey

Proton therapy for prostate cancer results in long-term patient survival and excellent quality of life

Five years after having proton therapy for early- and intermediate-risk prostate cancer, 99 percent of men are living cancer-free and with excellent quality of life, according to a University of Florida Proton Therapy Institute study. Three-quarters of those with high-risk prostate cancer are also disease-free.

The study, published in the *International Journal of Radiation Oncology Biology Physics*, adds to the body of evidence pointing to a significant role for proton therapy in the effective and efficient treatment of prostate cancer, said Nancy P. Mendenhall, M.D., lead author and medical director of the UF Proton Therapy Institute.

"These proton therapy results compare very favorably with IMRT results, particularly for intermediate risk-disease, where disease control rates of 70 percent to 85 percent are typical," said Mendenhall, the associate chair of the UF College of Medicine department of radiation oncology. IMRT is intensity modulated radiation therapy, a form of radiation that uses photons, or X-rays, to deliver radiation. Proton therapy uses protons, particles of an atom, to deliver radiation.

The study tracked 211 patients who participated in prospective Institutional Review Board-approved trials. In each track, patients were given proton therapy over an eight-week period, a shorter interval than typical with IMRT, which may last nine to nine-and-a-half weeks. Researchers used standardized data-gathering methods for both physician-reported and patient-reported outcomes.

Physician-reported data show cancer-free survival rates at five years for low-, intermediate-, and high-risk patients are 99 percent, 99 percent and 76 percent, respectively, while overall survival rates are 93 percent, 88 percent and 90 percent.

Moreover, the rate of serious gastrointestinal and urologic complications is low, at 1.4 percent and 5.3 percent respectively for all patients. Patients also reported good outcomes with respect to both urologic and bowel functions.

Five-Year Outcomes from 3 Prospective Trials of Image-Guided Proton Therapy for Prostate Cancer, Authors: Nancy P. Mendenhall, MD, Bradford S. Hoppe, MD, Romaine C. Nichols, MD, William M. Mendenhall, MD, Christopher G. Morris, MS, Zuofeng Li, DSc, Zhong Su, PhD, Christopher R. Williams, MD, Joseph Costa, DO, Randal H. Henderson, MD, MBA, International Journal of Radiation Oncology*Biology*Physics - doi.org/10.1016/j.ijrobp.2013.11.007

University of Florida Health Science Center Thursday 13th Feb 2014

From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

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We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.

Men United Vs Prostate Cancer

Prostate Cancer UK

Prostate cancer kills one man every hour. Men United v Prostate Cancer aims to challenge this strike rate.

It is time for men to come together, as Men United, against the common enemy of prostate cancer, one of the UK's biggest man killers.

We are building Men United, a growing team across the UK, to get the message out there about one of the UK's biggest man killers, support men affected by it, and raise funds to find more reliable tests and treatments for the future. Joining Men United is about men standing together, from the terraces to the pub and beyond, to say, quite simply, that men deserve better.

Men United v Prostate Cancer. We can win this.

Prostate development discovery could lead to new treatments

Scientists at the University of York have discovered how the prostate gland develops for the first time, according to research published in *Cell Press*.

The team behind the investigation, which was funded by the charity Yorkshire Cancer Research with further support from the EU FP7 Marie Curie ITN PRO-NEST project, says the findings could open the door to the development of new therapies for the treatment of prostate cancer.

Professor Norman Maitland, Director of the YCR Cancer Research Unit at the University's Department of Biology, and colleagues have successfully outlined the underlying mechanism behind the development of the gland after studying human prostate tissue.

During the study, Dr Jayant Rane and Dr Alastair Droop discovered a 'signalling pathway' - a set of signals which tell proteins inside stem cells how to evolve into prostate tissue cells called basal cells and luminal cells. They found that there are 80 genes involved in this process, and the main signals responsible for the activation and regulation of this system are retinoic acid - a chemical made from vitamin A which is supplied in our diet by carrots, green vegetables and liver - and male sex hormones.

The balance of retinoic acid and male sex hormones involved in the process is highly regulated in a normal prostate gland. This balance is disrupted in prostate cancer, where the level of male sex hormones is increased. This can lead to a tumour that consists mostly of luminal-like cells, with less than one stem cell in every thousand luminal cells.

Professor Maitland said: "The prostate gland is lined with specialised cells which make up the epithelium. Diseases that affect this lining are common in the prostate, but until now, very little has been known about the mechanisms which regulate prostate tissue.

"The 80 genes and the signalling mechanisms described by the team all provide potential targets for new therapies, which could be used to combat common prostate diseases, including prostate cancer. Further, comparative analysis across more than 20,000 patient samples has also shown that similar mechanisms may be used in a wide variety of human tissues."

Professor Maitland and his team are the first to identify the role of retinoic acid in the development of prostate cells. Last year, they discovered that treatments affecting the chemical's responses also have the potential to stop the spread of cancer.

The team at the YCR Cancer Research Unit achieved international recognition in 2005 when they became the first to identify prostate cancer stem cells, which are believed to be the 'root cause' of prostate cancer. Now supported by a £2.15m award from Yorkshire Cancer Research, they have since been exploring the exact molecular properties that allow these cells to spread, survive and resist aggressive treatments such as radiation and chemotherapy.

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Please visit elpcsg website under Links and Research for full details and articles.

Advanced prostate cancer risk could be identified by genetic screening

New research from the Institute of Cancer Research in the UK suggests that screening men with a family history of prostate cancer for certain gene mutations could identify those who are at increased risk of aggressive forms of the disease and need lifelong monitoring.

To reach their findings, recently published in The British Journal of Cancer, the investigators analyzed blood samples from 191 men with prostate cancer.
Using "second-generation" DNA sequencing technologies, the researchers assessed 22 different known cancer genes at the same time.
The team says this opens the doors for potential "rapid genetic screening" for prostate cancer that may identify a variety of genetic mutations.

All men had a history of three or more prostate cancer cases among close family. The researchers say they assessed men with this kind of family history in order to mimic existing gene testing methods that are used for breast cancer.

Mutations in eight genes 'increased risk of aggressive prostate cancer'

The research team discovered 13 "loss of function" mutations in eight DNA repair genes. The genes were BRAC1 and BRAC2 - genes already tested in women with a history of breast and ovarian cancer - ATM, CHEK2, BRIP1, MUTYH, PALB2 and PMS2.

The investigators found that men who had any of the 13 mutations were at much higher risk of developing an advanced and invasive form of prostate cancer and were more likely to die from the disease.

Commenting on the findings, Dr. Iain Frame, director of Prostate Cancer UK, which provided the majority of funding for the study, says:

"We urgently need to understand more about which men are at risk of developing prostate cancer and in particular aggressive forms of the disease.

[These results are exciting as they add to the growing weight of evidence that men with a family history of prostate cancer who possess certain genes may be at higher risk, providing us with another crucial piece of the jigsaw."

Genetic testing 'a potential part of the prostate cancer care pathway'

According to the American Cancer Society, approximately 233,000 new cases of prostate cancer will be diagnosed this year.

Prof. Ros Eeles, professor of oncogenics at the the Institute for Cancer Research (ICR) and co-leader of the study, says the team's findings put genetic testing of prostate cancer on par with genetic testing for breast cancer.

"We already have the technical capabilities to assess men for multiple mutations at once," she adds, "so all that remains is for us to do further work to prove that picking up dangerous mutations early can save lives. If so then in the future, genetic testing may be needed as part of the prostate cancer care pathway."

Dr. Zsofia Kote-Jarai, senior staff scientist at the ICR and co-leader of the study, says it is important to note that the study findings show at least eight gene mutations may significantly increase the risk of aggressive prostate cancer.

But she says there are likely to be many more genes with mutations that increase the risk of prostate cancer aggression.

"Any future screening program would need to assess as many of these genes as possible - more than we currently look for in women at risk of breast cancer, for example," she adds.

Last year, Medical News Today reported on a study suggesting that following a low-fat diet and taking fish oil supplements may reduce disease aggression for men with prostate cancer.

Written by Honor Whiteman

Friday 21 February 2014

Article from Medical News Today **MNT News Desk:**
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Minutes

Minutes of meeting Thursday 6th Feb 2014, 2-4pm

Venue: Burnley Gen Hospital, Mackenzie centre/Library

29 People were in attendance including our regular Specialist nurse Debbie. Apologies were received from Colin S., Deborah Dobson & Glenn S.

4 new members were in attendance. (David J., William S., John K., John Miller.

Secretary Stuart opened the meeting in the absence of the Chairman Dave, introducing 3 new members. He went on to tell the members of the amazing response that the scanner appeal had had in Marks & Spencer (for the bag packing) members of the support group were talking to so many people who had relatives or friends with Prostate problems, it more than justifies having the display stand and our members at these events. From this awareness it is hoped that new members will come to the Support Group for advice or help (as one did today).

Terry who lives in Canada intended being here today but couldn't make it and sent his apologies – he is having tremendous trouble with incontinence and wanted to speak to one of the specialist nurses. He hopes he will make the next meeting in March.

Stuart went through the minutes of the previous meeting and said we are well supported with people who have been coming since the Support Group was first started and he felt that it should be the object of existing Support Group members to encourage new members to come to meetings and once at the meetings we should sit them with other members who know something about their concerns or problems and this should be of help to them.

Debbie Hesketh, one of Specialist Urology nurses was introduced to be available for anyone who needs to speak to her.

Stuart spoke about the Scanner Appeal organised by Gordon Birtwistle, by giving a resume of the proceeds of the Burnley Football match where Burnley played Sheffield Wednesday on 18th January. The full total raised on that day including the auction of a bottle of whiskey in the 1882 lounge which raised £500 & proceeds of a bucket collection – of which members of our support group were taking part was £4,341.00. The bag collection at Marks & Spencer- again supported by members of our own support group - made £1,800 of which £900 was donated to the scanner appeal and £900 to Marks & Spencer's own charity (Air Ambulance). The scanner appeal now stands at £32,000 – the target is £50,000 and another £25,000 needs to be raised for the mobile scanner which is to be used throughout the East Lancashire area.

Our own member Shaun T raised a fantastic £200 by growing a moustache for the Movember campaign. He donated this to the scanner appeal. He arrived at the meeting just as this information was being given out and he rightly received a good round of applause on his entrance!

Stuart informed the meeting that he had received a circular about a decision by NICE not to allow an extremely successful drug Enzalutamide to be available to patients who have already been prescribed Arbiraterone. Patients have been recommended by the Prostate Cancer Federation to write to NICE expressing their disapproval as Enzalutamide has been proven to extend the life of men with aggressive P.C.

Glenn South, one our members who royally entertained us at our Christmas Jacob's join is holding an event at the Nelson Ace Centre with 3 or 4 other entertainers for people who find it difficult to get out together socially or maybe cannot always get out to functions. Tickets are only £2.50 for anyone interested. This will go ahead on Thursday, 13th March, 2pm. Stuart sent a list around for people who are interested.

BREAK FOR BREW

The second half of the meeting was taken up with a talk by Steve Jeffries of Collective Legal Solutions — his talk was entitled 'Tax, Care & Toyboys' and was basically about putting ones legal affairs in order and the implications of such as we and our families grow older. This was followed by an extremely interesting question and answer session and a few members made contact with Steve Jeffries at the end of the meeting.

The meeting concluded, 'sadly' without one of Dave's Prostate jokes as he was having a tough time sunning himself and roughing it in Los Angeles!

A Donation of £5 was received yet again from Jimmy C.

The raffle made £45.

At our next meeting there will be a short talk by our own member Colin O. who lives in France and a presentation by Deborah Dobson, one of our regular Specialist Urology nurses from the Royal Blackburn Hospital.

Next meeting: Thursday 6th March 2014, same venue, 2 – 4pm