

East Lancashire Prostate Cancer Support Group Newsletter



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EXCITING PROSTATE HOME TESTING KIT OPTION! NOW FULLY OPERATIONAL

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There can't have been many "silver linings" to the storm clouds created by Covid 19 but a small chink of light for us is the time it's given us to finalise and launch a home testing kit option.

For a long time we've been aware of the fairly major weakness in our armoury whereby men have been denied easy access to a test, often because for sound logistical reasons we can only visit certain venues once a year and sadly this often means men missing it through various unavoidable reasons.

We were on the verge of launching a home testing kit option two years ago but couldn't implement it at the time because of certain administrative constraints. The latter were removed with the introduction of the new fantastic online booking system launched this January and the break from running testing events since March has given us the chance to bring it all together.

We carried out a very successful pilot with around 100 men in early June and the new system is now fully operational.

The huge advantage it has over traditional testing events is that men can order a test online literally 24/7, 365 days a year from the comfort and safety of their own home.

We use the same laboratory as before....The Doctors Laboratory (TDL) who are very experienced in this type of service carrying out around 50,000 tests of this nature a month.

The clinical overview of results and the detailed follow up letters are in exactly the same format as before, so the only difference in the whole process is that rather than have a



nurse take a blood sample the men take a small finger prick sample themselves. The system is safe, robust and well tested. Having said this if any man registering for a test struggles to take the sample, he can have either a free replacement testing kit or a two thirds refund of the original cost, one third being needed to cover the costs of sending the kit to them when they registered.

This test is simple to do, it is a finger prick test.

TO ORDER FOLLOW THESE INSTRUCTIONS

Visit www.mypsatests.org.uk and register on our website, by inputting your email address and a personal password - which you can easily remember. You will then be sent a verification email to check you are a real person! Once you have clicked on the verification email, you can log back onto our website and request your kit by clicking on the button to order a Home Testing Kit. Once you have completed your contact details and answered a few questions, the kit will be winging it's way to you by post.

When you receive the kit, read the instructions, perhaps getting someone to help you carry out the test.

Then put the filled vial of blood in the plastic case provided along with the blood form in the return paid envelope. Put it in the post, and you will receive the results within a few days.

The quicker you return the sample the quicker you'll get your result.

If you'd like more information please contact Susan at the office on 01926 419959 or email to info@psatests.org.uk .

GFCT – PSA Testing

T > 01926 419959

Website Booking Platform > mypsatests.org.uk

W> psatests.org.uk



MASSIVELY IMPORTANT QUESTION?

The Bay, Lancaster Group

Hi Every one Greetings from The Lancaster group I hope you are all keeping well. The monthly meetings have been held over contacts via the phone to keep folks in touch I also belong to an online PC support group . one of the members wrote the attached message's following the publication of Nice's adjudication over Abiraterone for England.

Scotland has approved the drug So Anthony collier has hopes of trying to get the ban lifted, It has been available on the stampede trial But some like Anthony were able to take advantage through work connected Bupa . He has had to give up work and managed to fund the premiums until now .. The actual cost of the drug Is eye watering .So He is asking for feed back from anyone who has been on Abiraterone under what conditions
If you can help send me you contact details & I will forward them

Just heard that NICE have again refused Abiraterone as 1st line treatment for men newly diagnosed with metastatic prostate cancer. This is the drug that's kept my PSA not recordable for well over 2 years. I'm having it funded by insurers and next March I won't be able to afford the renewal premiums, it's already £750pm. I'm now extremely worried as I think everybody expected it to be approved. My Onco thought it was a certainty. Devastated! Maybe they expect me just to be left to die! each years premium goes up based on claims experience. If I was paying for Abiraterone at full price it would be costing me £30,500 for the half dose that I'm on but by the end of this year I'll have paid £20k over 3 years

I urgently need commentary about men who were diagnosed with advanced stage prostate cancer and had chemo. I need to put together evidence about the detrimental impact chemo had on quality of life.

Also, any men on Abiraterone who've done well on it who wish to share experiences.

I'm working on trying to gather as much evidence as possible to support PCUK's appeal against NICE's refusal to approve Abiraterone thus forcing men to have chemo.

PLEASE E Mail Me denbray@hotmail.com your Contact details if you can help

Interview with An Expert: African Ancestry and Prostate Cancer

If you are a man of African ancestry, prostate cancer needs to be on your radar. This is because, of all the men in the world, you are in the group that prostate cancer hits the hardest. Prostate cancer is different in you than it is in other men. It can be more serious.

Know Your Genes “Genetic inheritance – your genes – actually discriminate against a man biologically, biochemically, and genetically,” says oncologist Jonathan W. Simons, M.D., President and CEO of the Prostate Cancer Foundation. “You may be white, but you may have an identical bad gene pattern to someone who identifies as African-American.” Simons hopes to be able to fund research to “really intensify our study of men of African descent, because the genetic differences in prostate cancer in these men are under-funded, under-appreciated, and under-communicated. “This is independent of poverty – poor medical care -- or whatever carcinogens a man might have been exposed to. This is genes, not environment. It’s what you got from your parents and your grandparents that you can’t help. If we can understand this more aggressive form of prostate cancer, it is going to help all men.”

This is not fear-mongering; it’s the stark truth: You are not only more likely to be diagnosed with prostate cancer, but also to have a more aggressive form that needs to be treated. You are twice as likely to die of prostate cancer as a man of a different heritage. So if you are a man of African ancestry and you are diagnosed with prostate cancer, you will more likely need to go after it with curative treatment – surgery or radiation. [Active surveillance](#) may not be the best option for you. And you need to get a baseline [PSA](#) and prostate exam starting at age 40.

“African-American men have a one-third higher chance of having more aggressive cancer than the [biopsy](#) suggests,” says Edward Schaeffer, M.D., Ph.D., Chairman of Urology at Northwestern University. This means that if you are diagnosed with cancer and have surgery to remove it, when the [pathologist](#) looks at the cancer under the microscope, it very well might turn out to be of a higher [grade](#), or there may be more of it than expected. More worrisome: “when these men need surgery, they are more likely to need additional adjuvant treatment, or to experience a recurrence of cancer, compared to Caucasian men. Biologically, their cancers are different.” Schaeffer is a pioneer in this area and what he has learned, and is actively continuing to study, may save your life.

One of the reasons why Schaeffer’s work is so groundbreaking: He noticed differences in the cancers of his patients who were African-American or Caucasian; then he began to look specifically at prostate cancer in black men to figure out why this might be. “Almost everything that we understand about prostate cancer is based on data from Caucasians,” he says.

“Our understanding of the presentation, natural history and biology of prostate cancer is based predominantly on research done on the cancer of Caucasian men.”

Many of the assumptions that scientists made about prostate cancer – and even some of the

markers developed to test for prostate cancer – don't hold up in black men.

To begin to unravel this important problem, Schaeffer teamed up with PCF young investigator Kosj Yammoah. “We both knew there are a lot of unknowns about prostate cancer biomarkers in men of African ancestry,” says Schaeffer. “We decided to look to see how 20 different established molecular markers for prostate cancer “performed in African-American men compared to Caucasian men. Surprisingly, we found that only about one-third of them were the same between whites and blacks.”

But in a striking development, “we also found that about one-third of these markers behaved in inverse fashion in black men compared to Caucasians.” This means that a marker that goes up in white men to signal cancer actually goes down in men of African ancestry when cancer or aggressive cancer is present. “In men of African ancestry, a lot of established biomarkers are not the same as the established markers in Caucasians.”

“The clinical implications for the behaviors of biomarkers and how they differ are unknown. We can certainly extrapolate that how we follow cancer in white patients may not be the best way to do it in men of African ancestry.”

One important thing you can do: Take Vitamin D. “African-Americans are very often Vitamin D deficient,” says Schaeffer. “Their body does not absorb that UVB radiation.” And this is important, because “Vitamin D is like a fire retardant,” explains [oncologist](#) Jonathan Simons, M.D., President and CEO of the Prostate Cancer Foundation. “It has an optimum protect effect against cancer, and it's really important in men between their 20s and 40s – because in the absence of fire retardant, more embers can get lit. Cancer can start more easily.”

Vitamin D “is a [hormone](#) but we call it a vitamin,” Simons adds. It has a powerful antitumor effect. In laboratory studies, vitamin D has been shown to slow down the growth of cancer cells; it also makes them less aggressive. In people, most vitamin D – 90 percent of it – comes from exposure to the sun. When the sun's rays hit our skin, vitamin D converts into an active form (called 1,25 dihydroxyvitamin D) that helps keep cells healthy and protects against cancer.

A simple blood test can help here, says Schaeffer. “If you check the levels of vitamin D in the blood, having a lower vitamin D level is a predictor of having a positive or negative biopsy. If a man of African ancestry has a lower vitamin D level, the chances of having a cancer detected on biopsy are even higher.” Schaeffer recommends having your vitamin D levels checked by your primary care doctor. “Your vitamin D levels have a big impact on a lot of things, including bone health, risk of heart disease and stroke — and being diagnosed with prostate cancer.” How much should you take? About 2,000 IU (International Units) daily is probably enough, but if your levels are low, your doctor may recommend a higher dose.

[AFRICAN DESCENT](#)

<https://www.pcf.org/c/interview-with-an-expert-african-ancestry-and-prostate-cancer/>

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

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.

Urine Test (The Taking Of)

My urologist's office called the other day and explained that my scheduled appointment would now be done over the phone due to the coronavirus.

One hour before the scheduled teleconference, I was instructed (via email) to administer my own urine test. This was to avoid those lab tests because they're shutdown too.

Simply go outside and pee in the garden.

If ants gather: **DIABETES.**

If you pee on your feet: **PROSTATE**

If it smells like a barbecue: **CHOLESTEROL**

If your wrist hurts when you shake it: **OSTEOARTHRITIS**

If you return to your house with your willy outside your pants: **ALZHEIMER'S**

Sponsors



HPV could cause prostate cancer: Scientists find firm link between the disease and sexually transmitted virus for the first time

Findings suggest the HPV vaccine might help lower the risk of prostate cancer
Researchers based in Australia compiled all the results from 26 previous studies
HPV already causes certain cancers in men, including tumours of the genitals
By [BEN SPENCER MEDICAL CORRESPONDENT FOR THE DAILY MAIL](#)
PUBLISHED: 01:00, 14 July 2020 | UPDATED: 07:40, 14 July 2020

Prostate cancer has been convincingly linked to the sexually transmitted human papillomavirus (HPV) for the first time.

Experts have found evidence that a significant number of prostate cancer cases are 'highly likely' to have been caused by the same virus that causes cervical cancer in women. And they say it may be transmitted to the gland through sex.

The researchers say their findings suggest the HPV vaccine might help lower the risk of prostate cancer.

Research has found evidence that suggests the HPV vaccine may help lower the risk of prostate cancer

The vaccine, which has been given to teenage girls since 2008, was last year made available to schoolboys at the age of 12 and 13 for the first time.

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HPV was already known to cause certain rare cancers in men, including tumours of the mouth, throat and genitals, accounting for around 2,500 cases a year.

But its implication in prostate cancer – which affects more than 57,000 men a year in the UK – significantly increases the consequences of contracting the virus.

It also highlights the importance of the vaccination programme.

The research team, from the University of New South Wales in Australia, compiled the results from 26 previous studies to create the biggest evidence base yet linking HPV to prostate cancer.

Writing in the *Infectious Agents and Cancer* journal, they concluded: 'A causal role for HPVs in prostate cancer is highly likely.'

Prostate cancer, which kills 12,000 men in Britain each year, has previously been linked to genetics, environmental pollutants and lifestyle factors.

But the researchers said: 'Although HPVs are only one of many pathogens identified in prostate cancer, they are the only infectious pathogen which can be prevented by vaccination.'

The team found 22 per cent of prostate cancerous tissue contained traces of HPV, compared with only 7 per cent of benign prostates.

The vaccine, which has been given to teenage girls since 2008, was last year made available to schoolboys at the age of 12 and 13 for the first time

They also found countries with high cervical cancer death rates also had high prostate cancer mortality. The reverse was true for countries with low death rates from cervical cancer.

This suggests HPV as a common factor, they said.

HPV is a common infection spread through skin-to-skin contact, usually during sex. Around eight in 10 people will be infected with HPV at some point in their lives and there are hundreds of different types of the virus.

Around 13 HPV types are known to cause cancer, including cervical cancer, penile cancer and some types of mouth and throat cancer.

But the researchers found HPV types 16 and 18, which cause most cases of cervical cancer, were also linked to prostate cases.

Professor James Lawson, one of the researchers, said: 'Many people assume HPV infections mainly lead to cancers in women. This is not the case.

'The data may indicate that HPV infection may be transmitted during sexual activity and play a causal role in prostate cancer as well as cervical cancer.'

The scientists said more studies needed to look at how HPV infection may lead to prostate cancer.

