

East Lancashire Prostate Cancer Support Group Newsletter



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Breakthrough: world's first precision prostate cancer treatment

This week's results offer a brand-new precision treatment option for a group of men with particularly aggressive forms of advanced prostate cancer. PC UK 2 Oct 2019

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Next Meeting is Indeterminate Due to The Corvid19 Pandemic we will keep you informed when the all clear is given, Please keep safe and Well.

The Crew @ ELPCSG

Precision medicine is an exciting and effective approach to cancer care that uses information about the genetics of a man's tumour to work out the best treatment for him.

New research presented at the ESMO conference this week is the final piece of the puzzle to show the drug olaparib (Lynparza) could be the first-ever precision medicine treatment for prostate cancer.

The drug is part of a class of drugs called PARP inhibi-

tors, which target defects in cancer cells' ability to repair damage to their DNA. Recent results from a new study have shown that Olaparib could delay the progression of advanced prostate cancer for over four months. Crucially, the men who responded all had mutations in one of 15 genes in their prostate cancer, including BRCA.

It marks a landmark achievement in treating advanced prostate cancer. But this breakthrough

didn't happen overnight. It's the result of two decades worth of research, funded by you, to unpick the genetics behind prostate cancer to create new precision treatments.

Here's a deep dive into how we got to this incredible milestone.

Lab studies to lives saved: how you've helped create the first precision medicine for prostate cancer

1990s: Researchers discover BRCA genes increase cancer risk

The cells in our body undergo a daily cycle of DNA damage and repair. In a normal day, the DNA in each cell can be damaged between 1,000 and 1,000,000 times. Luckily, we've evolved ways to either repair the DNA or destroy the 'broken' cells.

In the mid-90s, researchers identified the genes BRCA1 and BRCA2, which are an important part of this repair process. Faults, or mutations, in these genes reduce cells' ability to repair the daily onslaught of DNA damage. This means that mistakes can start to build up in the DNA, which increases the chances of the cell becoming cancerous.

Scientists knew that mutations in the BRCA genes were associated with increased risk of breast or ovarian cancers, but their influence in other cancers was unknown.

In 1999, an international group of researchers discovered that BRCA gene mutations also increased the risk of getting other cancers, including prostate cancer. Nobody knew how common these mutations were in men with prostate cancer, or how to find the men affected.

2002: Investigating the scale of the problem

With your donations, we part-funded research carried out by Professor Ros Eeles and her team at the Institute of Cancer Research (ICR) in London, which gave us the first insight into the importance of BRCA mutations in prostate cancer. This revealed that two percent of men diagnosed with prostate cancer before the age of 55 had a BRCA gene mutation.

2009: Understanding the link between prostate cancer and BRCA

With your support, we funded Professor Thomas Helleday at the University of Sheffield and Professor Freddy Hamdy at the University of Oxford to explore what effect BRCA mutations might have on prostate cancer cells. They found that a BRCA mutation disabled one method prostate cancer cells' use to repair damage to their DNA, meaning they resorted to another method using the PARP protein. This led scientists to realise that the drug Olaparib, which inhibits the PARP protein, could be an effective treatment for men with prostate cancer and a BRCA mutation.

2012-2015: Shifting focus to advanced prostate cancer

In 2012, Professor Ros Eeles' group at ICR, again part funded by Prostate Cancer UK, showed that only 0.5 - 1 percent of all men newly diagnosed with prostate cancer at any age had an inherited BRCA gene mutation.

Then in 2015, an international team of researchers, led in the UK by Professor Johann de Bono at the ICR, discovered that if we looked for these mutations in men with advanced prostate cancer only, rather than any prostate cancer - BRCA, and other DNA damage repair mutations were far more common. In fact, over 19 percent of men with hormone-resistant prostate cancer that has spread around the body had a mutation in either a BRCA gene, or another DNA damage repair gene called ATM.

More importantly, by comparing the DNA in a man's cancer with that in his blood, they were able to tell that not all of these mutations had been inherited. Many of them had developed spontaneously in the cancer. Together, these results meant that far more men than previously suspected were likely to benefit from treatment with a drug like Olaparib.

2014 - 2019: Finding the men who respond to Olaparib

A new trial called TOPARP was cleverly designed to test Olaparib in men with prostate cancer. The first stage tested Olaparib in all men with advanced disease to see if enough responded to make it worth taking further. The result of that first stage was that around 30%

of men seemed to get benefit from taking olaparib and so, together with The Movember Foundation, and the Medical Research Council we funded Dr Joaquin Mateo, a Clinical Training Fellow in Professor de Bono's lab to do the crucial next stage of work.

Your funding was critical to build a platform that allowed testing of prostate cancer patients from across the UK. That was huge. This allowed us to start selecting patients who would benefit from treatment. It also allowed us to test different scenarios (for example tumour metastases, tumour biopsies, diagnostic biopsies, and plasma) to work out the best ways to test and select men in future.

- Dr Mateo

From that work Joaquin and Johann worked out that the men who responded were those who had certain mutations in DNA damage repair genes, including BRCA, as Professor Helleday's work had suggested. They then developed a test to find the men who had those mutations, the men most likely to respond to Olaparib.

2019: Making it global

The test developed by Joaquin and Johann, and funded by you, enabled a trial called TOPARP-B to trial Olaparib on a selection of men with advanced hormone-resistant prostate cancer, who also had a mutation in a DNA damage repair gene. This was the first precision medicine trial for men with prostate cancer in the world.

This trial revealed that Olaparib works better for men with certain DNA damage repair mutations. The results were positive enough to suggest that AstraZeneca, the pharmaceutical company that owns Olaparib, should test Olaparib in a Phase III trial. This type of large scale international clinical trial is big enough to provide the evidence that health regulators need to recommend a drug for widespread use. They're also extremely expensive, so can normally only be run by pharmaceutical companies.

In this new international trial, called PROfound, doctors took biopsies from men with advanced prostate cancer across the world and tested the tumour for DNA damage repair gene mutations. The results, published last week, showed Olaparib to be effective in men with advanced prostate cancer who had one of 15 genetic mutations in their prostate cancer.

Thank you, for helping to make breakthroughs in treating prostate cancer possible

These results represent a giant leap forward for men with prostate cancer. A leap we've been building towards since 2014, with your support, through research funding and behind-the-scenes work.

With your help we're moving from a one-size-fits-all approach to treating advanced prostate cancer to a much more effective approach where drugs target the genetic drivers of an individual's cancer. Thanks to you Olaparib is ready to blaze a trail for future precision medicines of this kind.

This is by no means the end of the story. There's still plenty of work to do to ensure that all the men who can benefit from drugs like Olaparib can get access. We will continue to champion the use of Olaparib, through working with the relevant pharmaceutical company, healthcare regulators, researchers and men to make sure this happens.

Help develop our precision treatment programme by donating today.

New evidence for world's first ever precision medicine for prostate cancer

Today, results released at the ESMO 2019 conference in Barcelona showed targeted breast

and ovarian cancer drug olaparib could slow the progression of advanced prostate cancer. Find out how these advances are set to transform men's lives.

Read more

Understanding BRCA1 and BRCA2

You've probably heard about the genes, BRCA 1 and 2 - most likely when Angelina Jolie's double mastectomy hit the headlines – or maybe more generally, in relation to risk of breast or ovarian cancer in women. Perhaps you've also heard about BRCA 1 and 2 in relation to prostate cancer, and the world's first preventative prostatectomy that wasn't? But what are the BRCA genes? Why is it such a problem when they change or 'mutate'? And, what does a BRCA gene mutation mean for men?



5 Mar 2020

Dear Stuart

I trust that you are keeping well during these extraordinary times.

We know that many of you may well have some concerns about how the coronavirus (COVID-19) might affect you and we recommend you view the [Prostate Cancer UK website](#) which has some excellent information.

I am sure that many of you will be wanting to keep in touch with each other. We held our recent Board meeting virtually using [Skype](#) but many people are using [Zoom](#). It's a great way to keep connected.

Here at Tackle, like many other organisations, we are putting things on hold:

AGM & Conference. We had scheduled this in for June at the same venue in Birmingham as last year. We are reviewing the date with the venue at the moment with a view to holding it in September. We will keep you posted.

Prostate Matters. The next issue of our quarterly newsletter will now not be on 1 May but will be postponed until the summer.

I am very pleased to report that we have appointed two new Trustees: Julian Burgess and Roshani Perera. You can [read about them here](#).

Finally, please keep safe and well.

Best regards
Ken Mastris
Chairman



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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.

Coronavirus (COVID-19) and prostate cancer

Prostate Cancer UK 26th March 2020

Questions Answered

- I 'm having treatment for prostate cancer – am I at increased risk if I get coronavirus?
- I 'm worried that I may have coronavirus – what should I do?
- Someone I live with has symptoms – what should we do?

- Will I have my prostate cancer treatment as planned?

- I 've had prostate surgery – am I at increased risk of coronavirus?

- I 've had – or am having – radiotherapy. Am I at increased risk of coronavirus?

- Does being on hormone therapy increase my risk of coronavirus?

- Does taking steroids as part of my prostate cancer treatment increase my risk of coronavirus?

- I usually have a PSA test every 3 months. Will this still happen and, if so, where?

- I 'm on hormone therapy – will this continue as normal?

- I 'm worried about self-isolating and being on my own. What can I do to keep busy?

- How do I get food, other groceries and medicines while I self-isolate?

- I 'm worried about paying bills while I self-isolate – where can I get information and support?

- Will coronavirus affect my holiday plans?

Below is some information about coronavirus (COVID-19) for people who have, or have had, prostate cancer.

This information aims to answer some of the questions you may have at this time. We will update this page in line with any official advice changes and to make sure it answers common questions. You can also contact our Specialist Nurses for further information and support.

As always, it 's important to follow the advice of your doctor, nurse or other people in your medical team.

We have also worked with other UK cancer charities as part of ' One Cancer Voice ' and with NHS England to develop information on coronavirus for people who have, or have had, cancer and their loved ones, and for people who are worried they may have cancer. Both the ' One Cancer Voice ' information and the information on this page will be kept up to date if official advice changes.

For the latest information about coronavirus for the general public, including symptoms to look out for, what to do if you think you have coronavirus, and ways to reduce your risk of catching or spreading coronavirus, visit the NHS website.

Help us to support you at this time

We want to know from you how we can best support people affected by prostate cancer during the coronavirus outbreak. Please complete our short survey to let us know what support and information would help.

I 'm having treatment for prostate cancer – am I at increased risk if I get coronavirus?

The effects of coronavirus infection could be particularly severe for certain people with prostate cancer. These include:

men having chemotherapy

men having clinical trial drugs that affect the immune system, such as olaparib (Lynparza®) or pembrolizumab (Keytruda®).

If you're having one of these treatments, it's very important to follow the government's guidance and stay at home for the next 12 weeks. You may hear this called 'shielding'. It aims to protect those people who are at greatest risk of becoming very ill if they catch coronavirus.

It's very likely that your doctor or nurse will limit the amount of time you need to spend at the hospital or GP surgery. For example, you will probably have phone appointments, wherever possible, instead of visiting the hospital or GP surgery. It might also be possible to have blood tests done

at home. Speak to your doctor or nurse if you're concerned about your appointments.

If you've had one of the treatments listed above in the last three months, but are no longer having it, speak to your hospital doctor about your level of risk from coronavirus. They can help you decide whether or not to follow the government's guidance on shielding.

For other men with prostate cancer

Even if you aren't having one of the treatments listed above, it's very important to follow the expert advice on social distancing. This means avoiding contact with other people, including friends and family, to reduce your risk of catching coronavirus.

If the advice for people having cancer treatment changes at any time, health professionals and charities will take steps to make sure patients have the latest information.

I'm worried that I may have coronavirus – what should I do?

If you've been in contact with someone with coronavirus, or if you have a new and continuous cough or a high temperature (fever), stay at home and contact your medical team at the hospital straight away.

If you're having chemotherapy, you should already have the number of someone to call at the hospital if you have any signs of an infection. Call this number if you're worried you may have coronavirus.

If you can't get hold of your medical team, contact the following:

In England, Wales or Northern Ireland, call 111 for advice

In Scotland, call your GP surgery (or 111 if your GP surgery is closed).

Make sure you tell them about your prostate cancer diagnosis and any cancer treatments you are having.

Someone I live with has symptoms – what should we do?

If you're having one of the treatments mentioned above or you're over 70, and someone you live with has a new and continuous cough or a high temperature (fever), it may be sensible to stay somewhere else for 14 days, if possible. If this isn't an option and you have to stay at home together, try to keep away from them as much as possible.

Will I have my prostate cancer treatment as planned?

The NHS is continuing to provide cancer treatments and has taken steps to make sure necessary

drugs are still available. But some men and their doctors will have to decide whether to delay or change their prostate cancer treatment. This could be for the following reasons.

Some prostate cancer treatments increase your risk of getting infections, which could put you at risk of catching coronavirus. In this case, other treatments may be safer for you at this time.

Some prostate cancer treatments involve regular hospital appointments or time on a hospital ward, which could put you at risk of catching coronavirus. In this case, other treatments that don't involve spending time at the hospital may be safer for you until the risk has reduced.

Prostate cancer often grows slowly, so for many men a delay or change to their treatment shouldn't affect how well their treatment works in the long term. If tests show your cancer is more likely to grow quickly or spread, your doctor should make your treatment a priority so that you get the treatment you need without unnecessary delays.

If your doctor does need to delay or change your treatment at all, they will talk to you first to make sure you understand your options and why this is happening. Speak to your doctor if you have any concerns.

Your appointments and check-ups may happen over the phone so that you don't have to go into the hospital or GP surgery. If you're not sure whether to go to any planned appointments, contact your doctor or nurse to check.

Please note that calls from your GP surgery or hospital may come up on your phone as a withheld number, or you may not recognise the number that appears. It may be worth answering any calls from withheld numbers, or from numbers you don't recognise, at this time in case your doctor or nurse is trying to contact you.

I've had prostate surgery – am I at increased risk of coronavirus?

If you've had prostate surgery in the last 6 weeks and are still recovering from the operation, follow the expert advice on social distancing. This means avoiding contact with other people as much as possible, to reduce your risk of catching coronavirus.

If you've had surgery to treat prostate cancer in the past and have recovered from the operation, this won't increase your risk of catching coronavirus. It also won't increase your risk of more severe symptoms if you do catch coronavirus.

Your risk should be the same as other people in general. All people need to be careful, and particularly if:

you are 70 or over

you have a long-term health problem, for example with your lungs or heart, or a weak immune system

you 're having a treatment that puts you at increased risk of infections.

Some men have lymph nodes near the prostate removed during surgery – this is known as a pelvic lymph node dissection. Lymph nodes are part of your immune system. However, as coronavirus affects your respiratory system, having the lymph nodes near your prostate removed shouldn't affect your risk of getting coronavirus.

I've had – or am having – radiotherapy. Am I at increased risk of coronavirus?

External beam radiotherapy to the prostate shouldn't affect your immune system. So if you've had – or are currently having – radiotherapy to treat cancer inside your prostate, this won't affect your risk of catching coronavirus. It also won't increase your risk of more severe symptoms if you do catch coronavirus.

However, if you're going into hospital to have radiotherapy at the moment, there's a chance you might catch coronavirus from other people there. Hospitals are taking extra measures to lower the risk of staff or patients catching coronavirus, but talk to your doctor, radiographer or nurse if you're worried.

Some men have radiotherapy to a wider area, including the nearby lymph nodes. Lymph nodes are part of your immune system. However, as coronavirus affects your respiratory system, having radiotherapy to the lymph nodes near your prostate shouldn't affect your risk of getting coronavirus.

Some men with advanced prostate cancer have radiotherapy to relieve bone pain in parts of the body where the cancer has spread. Depending on the bone that is being treated and the dose of radiotherapy, this might affect the bone marrow, which can cause a temporary drop in the number of blood cells that help fight infection. If this happens, it might mean you're more likely to get infections. Speak to your doctor, radiographer or nurse if you're having radiotherapy to treat symptoms of advanced prostate cancer and are worried that you might be at increased risk.

If you're having radium-223 (Xofigo®) to treat bone pain caused by advanced prostate cancer, this can occasionally affect the bone marrow and increase your risk of getting infections. Speak to your doctor or nurse if you're worried.

Does being on hormone therapy increase my risk of coronavirus?

LHRH agonists, GnRH antagonists and anti-androgens

Standard hormone therapy treatments, including LHRH agonists, GnRH antagonists and anti-androgen tablets, don't affect your immune system. This means that being on standard hormone therapy won't increase your risk of catching coronavirus, or of having more severe symptoms if you do catch coronavirus. However, remember to think about any other treatments you might be taking, and whether those might increase your risk.

Abiraterone

If you're taking abiraterone (Zytiga®) tablets, you will also be taking a steroid called prednisolone or prednisone. Steroids cause some people to have a slightly higher risk of getting infections, but this will depend on the amount you are taking.

If you're taking a steroid with abiraterone, you'll only be having a low-dose steroid. This means the effect on your risk of getting infections should be small. We don't yet know the effect that taking a low-dose steroid for a long time could have on your body's ability to fight infections. Read more about steroids and coronavirus risk.

Enzalutamide

If you're taking enzalutamide (Xtandi®), this could affect the number of white blood cells in your blood. If this happens, you may be more likely to get infections, including coronavirus. Speak to your doctor or nurse if you're concerned, and always contact your medical team at the hospital straight away if you have signs of an infection.

Does taking steroids as part of my prostate cancer treatment increase my risk of coronavirus?

Steroids can affect the cells that help your body fight infections. This means they cause some people to have a slightly higher risk of getting infections, and can also lower the body's response to existing infections. Whether or not this happens will depend on the dose of steroids you are taking.

Most men who take steroids as part of their prostate cancer treatment will be having a low-dose steroid. This means the effect on your risk of getting infections should be small. Check with your doctor or nurse if you're not sure about your dose.

We don't yet know the effect that taking a low-dose steroid for a long time could have on your body's ability to fight infections. It's possible that the effect on your immune system might increase over time, and you might become more likely to get infections. But we don't know this for certain. If you've been taking a low-dose steroid for a long time and are worried about your risk of catching coronavirus, speak to your doctor or nurse.