

East Lancashire Prostate Cancer Support Group Newsletter



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Next Zoom Meeting
Thursday 1st July
2021

“Back in the Groove” Our First Awareness Day at the Burnley Classic Vehicle Show Sunday 27th June 2021



On page 2 are a few images of our Guys at the Burnley Classic Vehicle Show





21 Jun 2021

Many of you should have now received the physical copies of the latest edition of Prostate Matters in forward to your members. Since we recognise that many groups are currently not meeting face to face, I thought it could be useful to send you a PDF copy of Prostate Matters so that you can send it to your members who are on email.

If you follow [this link](#), you will be able to download the latest Prostate Matters, and then share.

Thank you to those of you who have already completed the **PSA Testing Event survey**, so far we have only received a small number of responses. We really value your input as this information will be very useful for us to gauge how many groups have already done events, or are thinking about doing events in the future, and more importantly as your federation, how Tackle Prostate Cancer could support you.

If you haven't already completed the survey, then please do so by July 5th. It needs to be completed once by each group. [Here is the link to the survey](#)

Stop Press Some of you were successful in applying for some small community grants from the National Lottery. The next round of funding opens on June 28th. Grassroots charities and community groups lacking loneliness in England will be able to apply for a share of £2 million of National Lottery funding to support their work. This second round of funding will be used to fund hundreds of microgrants between £300 – £2,500. It will be available to community groups with an annual income of less than £50,000.

I shall say more about this in the July briefing, but in the meantime, you can learn more about the process by [clicking this link](#).

Please do get in touch with any questions, comments or just to say hello.

With best wishes

Sarah

National Support and Development Manager

Tel. 07725 083533

Email sarah.gray@tackleprostate.org

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‘Lets Talk About the Hard Things’

Prostate Cancer Research UK

Earlier in 2021 Prostate Cancer Research (PCR), in partnership with Tackle Prostate Cancer and the pharmaceutical company Ipsen, launched a national survey to better understand the experiences faced by prostate cancer patients, especially related to the challenges concerning side effects.

We surveyed over 350 people with prostate cancer as part of this work. We have launched a new campaign, **‘Let’s Talk About the Hard Things’**, spearheaded by Good Morning Britain’s Dr Hilary Jones, to break down the taboos surrounding the side effects of prostate cancer treatment and encourage people with prostate cancer to talk about their experiences with friends, family and healthcare professionals.

In our research we found that nearly **7 in 10** men feel that speaking to other men living with prostate cancer, or having their friends and family understand how they feel, would help them discuss some of the ‘hard’ topics more openly.

That is why we have launched a new series of powerful videos, featuring a diverse range of people affected by prostate cancer, each showcasing a different pairing discussing their experiences of prostate cancer and the side effects of their treatment. The videos, along with more detailed findings from our research, can be found at: www.pcr.org.uk/hard-things.

We hope these videos and this campaign helps members of your group and others open up with their healthcare professionals, their family, their friends and their peers.

Kind regards,

David James

Head of Patient Projects

Prostate Cancer Research

www.pcr.org.uk | Suite 2, 23-24 Great James Street, London WC1N 3ES

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NEWSLETTER



Transforming research. Transforming lives. 0000

Hunting out prostate cancer

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Thank you to all our supporters

Welcome



It has continued to be a challenging time for people with prostate cancer and as I write this we are seeing more and more information about how COVID has led to late diagnosis. This will inevitably lead to an increase in late-stage cancer.

At the same time, fundraising has been particularly challenging as we haven't been allowed to undertake tried and tested ways of raising money such as the London Marathon or our big gala dinner.

We have worked incredibly hard to ensure that we are responding to the needs of the prostate cancer community during these trying times and I'm delighted at the response from our researchers, volunteers and staff. It's because of all your efforts that we were able to step up to the plate, and we are on the verge of awarding a number of new grants. For us to open a grant call right in the middle of a pandemic was a brave decision by the board, and I'm proud to work for an organisation that has supported research during this challenging period.

We've also turned two of our pilot projects that focus on particularly high-risk, high-reward research into full projects on the back of some strong data. One of these projects, being delivered by Bart Cornelissen and his team at Oxford, is working to improve targeted radiotherapy and was featured on the BBC this April. The other project was created by a young scientist, Jorge de La Rosa in Cambridge. He met all of the milestones we set him to prove that his idea could be implemented to investigate the genetics behind the spread of prostate cancer. These projects have proven our hypothesis that some great ideas in research just need a chance and a little time to show how good they are.

As COVID subsides and people go back to their doctors, we will need new treatments and better understanding of prostate cancer more than ever. As an organisation we are determined to do our bit to ensure that we reduce the damage that prostate cancer can cause. I hope you enjoy reading our newsletter and I hope to be able to see more of you in the next year than I did in the last.

Oliver Kemp
CEO


Prostate cancer accounts for 26% of male cancer diagnoses and is now **the most commonly diagnosed cancer in the UK.**

We have been able to navigate the pandemic without diminishing our impact or compromising our activities. None of our research budget or projects were cut due to COVID-19.

We are committed to funding innovative research that fills gaps in current understanding.

Connect with us to stay up-to-date with our latest news and tell us your stories:

-  [@prostatecancerresearch](https://twitter.com/prostatecancerresearch)
-  [PCR_News](https://www.facebook.com/PCR_News)
-  [/prostatecancerresearchnews](https://www.youtube.com/prostatecancerresearchnews)
-  [/prostate-cancer-research](https://www.linkedin.com/company/prostate-cancer-research)

 **Featured on cover:** Professor Bart Cornelissen's initial success leads to pilot project being extended by PCR. Read more on page 4.

Steve Eales' story

Say it with flowers

My prostate cancer was detected in January 2020, a few months before my 50th birthday.

My father was diagnosed with prostate cancer over 15 years ago and is currently having chemotherapy, having completed radiotherapy and several drug trials. Because of this, I have had regular PSA checks since I was 40 but had no concerns. In 2018, I started passing water much more frequently. I would have to pull up by the side of the road or in city centres while driving. As a result, my wife pushed me to go to the doctors, who referred me to my local urology department.

After numerous urology tests, some medication, a body scan and a biopsy, prostate cancer was diagnosed on 27th January 2020. Following diagnosis, I had a full robotic prostatectomy on 11th March 2020 – a five-hour operation.

The recovery following the operation is quite slow in regards of no exercise apart from walking, no heavy lifting and generally taking things easy. My recovery has been very good and eventually in September 2020 my consultant said I could start light running again – not long distances, but a few miles a couple of times a week.

In October I came across PCR looking for applicants to run the 2021 London Marathon – a big challenge, but one that I thought I needed. Not only to help my recovery, but also to give something back.

The topic of prostate cancer and men's health is often a taboo subject and if by sharing my story one person reading this visits their doctor, I will feel I have achieved my goal.

I hope to raise as much as I can through my 2021 marathon challenge. I'm aiming for £100 per mile to help motivate me through each mile or maybe even more!

At the beginning of April 2021, I had my annual follow-up. My PSA is undetectable and my prognosis is good. I'm hopeful that it stays this way and that I'm fortunate enough to get the opportunity to see my teenage children grow up and live their lives.

My business is my late mother's flower shop in Godalming, Surrey. My mother, Rosemary, died of a very aggressive cancer in July 2007 and her shop, to me, is her legacy. We are supplying a new range of charity bouquets, which include a matched PCR donation by our family company Flowers by Rosemary. Each bouquet includes a message stating that a donation has been made to PCR, and these bouquets can be sent anywhere throughout the UK.

Please visit flowersbyrosemary.co.uk if you would like to send any flowers and help support this cause.

If you'd like to sponsor my marathon challenge, I would be very grateful. Please visit justgiving.com/fundraising/steve-eales



Science news

REGENERATING DAMAGED NERVES FOLLOWING PROSTATECTOMY

Radical prostatectomy is one of the main treatments for localised prostate cancer but it can damage the nerves surrounding the prostate. Researchers in New York hope their new treatment could improve erectile function after prostatectomy. They developed a drug that switches off the FL2 gene known to become overactive and to slow healing when nerve cells are damaged. The drug was applied directly to nerves in rats with similar nerve damage to that seen after prostatectomy. Three weeks later these rats had significantly better erectile function compared to those who didn't receive the drug. The drug was even able to regenerate severed nerves. Rats treated with the drug also had higher levels of the enzyme, which produces nitric oxide.

'This is important because drugs like Viagra don't work if there's no nitric oxide to kick things off,' explained Dr David Sharp, the study co-leader. 'But if we can restore even some of the nitric oxide in these nerves, Viagra and other ED drugs may then be able to exert their effects.' While this research is still in the very early stages, it could lead to improved treatment options for erectile dysfunction in the future.

HEALTHY LIFESTYLE MAY LOWER RISK OF LETHAL PROSTATE CANCER

If you have a high genetic risk of prostate cancer, then maintaining a healthy lifestyle lowers the chance that you will develop metastatic disease or die from prostate cancer. This is according to a large US study in which scientists wanted to test whether increased genetic risk of prostate cancer could be offset by a healthy lifestyle. The different factors looked at included healthy weight, vigorous physical activity, not smoking, reduced intake of processed meat, and high consumption of tomatoes and fatty fish. They found that in men with the highest genetic risk, those with the healthiest lifestyles had about half the risk of developing lethal prostate cancer. However, having a healthy lifestyle did not reduce the overall chance of developing prostate cancer in these higher-genetic-risk groups.

This study contributes to a wider body of research that indicates the benefit of a healthy lifestyle in cancer prevention.

IMMUNOTHERAPY VACCINE FOR PROSTATE CANCER

A company called ImmunityBio Inc. recently published results from a Phase 1 clinical trial. The trial was investigating the safety and efficacy of an immunotherapy vaccine that is being developed. The vaccine is designed to boost your immune response to prostate cancer cells, so that your body gets better at targeting and killing them. The vaccine works by delivering proteins into the body that are found on the surface of prostate cancer cells. It trains the immune system to detect these proteins, so that it can better find and destroy cancer cells in the body.

The trial showed that the vaccine succeeded in increasing the immune response to prostate cancer in all of the patients. Importantly, the trial also found that the vaccine was safe to give to patients, with no adverse effects reported at the dose given in the trial. The trial was in patients with prostate cancer that had spread and become resistant to hormone therapy. These are early results, but they are encouraging for patients with highly resistant advanced metastatic disease.

NATIONAL SCREENING PROGRAMME FOR PROSTATE CANCER

A study from University College London and the University of Cambridge claims that a national screening programme 'could prevent one in six prostate cancer deaths'. Researchers developed a computer model to simulate different screening programmes for prostate cancer and explored the possibility of either an age-based or risk-tailored programme. In the age-based screening programme, all men between 55 and 69 would receive a PSA every four years. A high PSA would result in an MRI and biopsy. The risk-tailored programme would instead offer men a PSA test once their risk, based on factors such as age and genetics, reaches a certain threshold.

Researchers found that screening those with a 3.5% risk of developing prostate cancer in the next 10 years could prevent up to 16% of prostate cancer deaths and reduce over-diagnosis by 27%. This suggests a national screening programme for prostate cancer could be possible.



You can read more about our research goals on our website pcr.org.uk/our-research

Research update

PTEN: finding the off switch



Dr Jorge de la Rosa
UNIVERSITY OF CAMBRIDGE

In 2019, Dr Jorge de la Rosa, based at the Sanger Institute at the University of Cambridge, applied to PCR for funding to delve into the biology of PTEN. The nature of cancer is that important genes or proteins rarely act alone. What was exciting about Jorge's research was that he was going to make changes to hundreds of genes at once, to identify what else needs to happen inside a cell for PTEN to stop working. This would not only give us more information about what needs to happen to cause prostate cancers to grow and spread, but could also lead to more treatments in future.

There was, however, one great unknown – to carry out his research, Jorge would first have to develop a brand-new technology. We wanted to give this research a chance, because we saw that it could have huge potential for patients. We also have to be responsible with our funds, though, and were reluctant to commit several years of funding to a project that might, after a year, prove unfeasible.

So, we granted Jorge a pilot award, giving him the resources to spend a year developing his bespoke technology, which is based on the Nobel-prize winning CRISPR method.

Making this technology for the first time ever proved to be challenging, and Jorge had to go back to the drawing board a few times. He also had to contend with COVID-19, which led to his lab being closed. As he couldn't do his PCR work from home, we supported his temporary secondment to the research effort against the pandemic. Despite these challenges, he persevered and managed

to develop and prove his technology can successfully change different genes at once – both in dishes in the lab and in mice. This major breakthrough not only shows the rest of his plan is feasible and likely to lead to very important insights for patients, but also indicates that it has the potential to benefit other scientists working on cancer who can also use this technology.

We are delighted to award Jorge an additional grant so that he can continue this work, and we look forward to sharing his achievements with you in the future!

“I'd like to extend my gratitude to all PCR staff, supporters and the Board of Trustees for giving me the opportunity to continue working on this project. I truly believe our work is very promising and innovative, and in due course it will provide new clues about how prostate tumours spread and new approaches to tackle them.
Dr Jorge de la Rosa

“We're really excited about the progress that an early-career researcher has been able to make on this grant over the last year despite all of the COVID disruption, and glad to be able to fund for another three years.

Matt Ellis, Chairman, PCR



RESEARCH NEWS

Dr Christina Galustian, Dr Efthymia Papaevangelou and their colleagues at King's College London published an article in the renowned journal *ImmunoTargets and Therapy*, showing that injecting the immunotherapy they are developing into mice delays the growth of prostate cancer.

Congratulations to Dr Harveer Dey at the University of Cambridge on the successful start of his project and to Dr Tanmay Gupta, who joined the team at the start of the year. They will uncover why certain tumours are vulnerable to DNA-damaging agents (DDAs), such as radiotherapy and PARP inhibitors, so that we know more about who should receive these treatments and who should be offered an alternative.

Big congratulations to Dr Emily Griest, who received a distinguished Merit Award from the Conquer Cancer Foundation for her research with Professor Gert Averbodt and his team. This will be presented at the ASCO Annual Meeting, one of the largest cancer conferences in the world. Emily will share the latest results from their work on samples from STAMPEDE, the largest trial ever in prostate cancer to identify any genetic patterns, which will help us make treatments more effective.

Dr Megall Williamson and Dr Ritub Gang at King's College London, in collaboration with Professor Matthew J. Smalley and Dr Boris Shorning at Cardiff University, are continuing to improve our understanding of how PloidyB1 could help cancer spread, with the ultimate hope of eventually being able to use this knowledge to stop cancer spreading.

Dr Luke Gaughan, Dr Dominic Jones and Ryan Nelson at the University of Newcastle have refined the technique they themselves developed so that it can now more accurately identify the essential ingredients needed to make AR-Vs, proteins that can stop hormone therapy from working.

Research update

Lu-PSMA update



Professor Bart Cornelissen
UNIVERSITY OF OXFORD

Featured on cover



Dr Tiffany Chan
UNIVERSITY OF OXFORD

In 2019, we awarded a pilot grant to Professor Bart Cornelissen and Dr Tiffany Chan at the University of Oxford to investigate if they could make a targeted radionuclide therapy called ^{177}Lu -PSMA work for more people with prostate cancer. Based on their achievements and the potential of their approach, we've made a further £400,000 award so that they can continue their work.

Some Lu-PSMA treatments are already used in the UK, but on a private basis only and at the moment primarily for pain relief. Bart and Tiffany's new award comes at a very exciting time for radionuclide therapies. Recent results from pharmaceutical company Novartis' phase 3 VISION trial suggest that ^{177}Lu -PSMA significantly improves overall survival in patients eligible for the treatment compared to current standard treatment. As Bart described it: 'Rather than just being pain relief, we can now start to think of these as cures as well.'

To celebrate their new award, we spoke to Tiffany, who told us all about her journey into cancer research, why working with those affected by prostate cancer is so important and much more!

How did you get into cancer research?

I first became interested in the idea of a career in medical research after doing some work experience in a hospital when I was in high school. This led me to study an undergraduate degree in chemistry, and then a PhD in chemistry and biomedical engineering.

What's your favourite thing about working in cancer research?

I'm still very new to cancer research. However, I have always been drawn to projects in which there's a clear application, as well as those that have a high level of interdisciplinarity. Medical research tends to involve not only biologists, but also chemists, physicists, engineers, clinicians, etc, and I really enjoy getting to work with and learn from all these people.

Your project is looking at ^{177}Lu -PSMA. How is this different from standard radiotherapy?

Standard radiotherapy is typically what we call 'external beam', meaning that it involves an external beam of radiation focused onto the tumour. ^{177}Lu -PSMA is an example of a radiopharmaceutical – in other words, a radioactive drug. It has two parts, a radioactive part (in this case, ^{177}Lu , which is a radioactive isotope of the element Lutetium) and a non-radioactive targeting part (in this case, a small protein, PSMA, designed to specifically target a protein called prostate-specific membrane antigen). Prostate-specific membrane antigen (also abbreviated as PSMA) is a protein that's found at high levels on the surface of prostate cancer cells, but rarely at the surface of healthy cells, allowing us to use it as a marker to differentiate between the

two. ^{177}Lu -PSMA is injected directly into the bloodstream. It then travels throughout the body, seeking PSMA-expressing prostate cancer cells and showering them with radiation.

Could you give us a brief overview of your project?

While ^{177}Lu -PSMA therapy has shown really promising results in patients with advanced metastatic prostate cancer, with positive responses observed in about 56% of patients, there's still room for improvement. In an effort to improve how well it works, we're trying to combine ^{177}Lu -PSMA with another drug in an attempt to find combinations that work better than either drug alone. So far, we've screened around 2,000 ^{177}Lu -PSMA + drug combinations in prostate cancer cells, and we've identified some promising combinations that have never been reported before. The next steps are now to validate these hits in other models, both in cells and in mice, and to begin exploring the biology behind how they work.

What will this project mean for those living with prostate cancer?

Because ^{177}Lu -PSMA is a systemic treatment, we're likely to have better treatment of metastatic cancer than with standard radiotherapy, as we don't necessarily need to know where the cancer cells are in order to target them. Also, because healthy cells rarely express PSMA, we should be able to reduce side effects as they should remain unharmed.

Why is it important for researchers to communicate and work with prostate cancer patients?

There's no point doing any research if no one gets to know about it. I've always tried to do as much public engagement as possible alongside my research – both on social media and with in-person events – as I find it really useful to hear from different people (not just scientists!) and get their perspectives.

You can follow the work and get in touch with the team:
@TiffanyChan
@Cornelissen_Lab

Prostate cancer treatments

5 key facts about radiotherapy

- 1 Radiotherapy is one of the main treatments for prostate cancer. Its aim is to destroy cancer cells and stop them from growing, while minimising damage to healthy cells.
- 2 Radiotherapy can be offered in combination with other treatments including surgery and hormone therapy.
- 3 There are different forms of radiotherapy. The two main types are external beam therapy, in which high-energy X-rays are aimed at the prostate from outside the body, and brachytherapy, in which radioactive seeds are placed directly inside the prostate. Brachytherapy is not suitable for those with urinary problems and can be given as high-dose rate (HDR) temporary brachytherapy (for locally advanced or high-risk prostate cancer) or low-dose rate (LDR) permanent seed brachytherapy (early prostate cancer).
- 4 Short-term side effects can include sore skin, bowel and bladder changes, and feeling tired or sick. Long-term side effects include bowel, bladder and sexual changes. Most side effects improve after treatment has finished, and your healthcare team should be able to offer advice and help you manage any problems.
- 5 It can take many months after treatment for your PSA to fall and you will still have a measurable PSA level because normal prostate cells will produce a small amount of PSA. You will continue to have follow-up appointments for many years after radiotherapy.



We provide comprehensive information on radiotherapy treatment for prostate cancer in our free information booklet available at pcr.org.uk/patient-info

Our booklet is also available via Vinhealth, an award-winning free health app that helps those living with cancer track, manage and understand their cancer treatment, at vinhealth.ai

Yes, I'd like to support prostate cancer research

Title and name _____

Address _____

Postcode _____

Gift Aid Declaration

You can boost your gift by 25p for every £1 donated

I am a UK taxpayer. I understand that if I pay less income tax and/or capital gains tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I want to Gift Aid my donation today and any donations I make in the future or have made in the past 4 years.

Signature _____ Date _____

I am not eligible for Gift Aid.

I wish to make a donation to PCR:

£20 £40 £50 Other £ _____

Cheques payable to Prostate Cancer Research

I wish to donate by credit/debit card:

Mastercard / Visa / Visa Debit / CAF card

(Please delete as appropriate or specify other)

Cardholder's name _____

Card number _____

Expiry date _____ Security code _____
(last 3 numbers on back of card)

We will take payment online through our website

Staying in touch with PCR

We keep our supporters updated about our research and send our newsletter and appeals by post.

For us to contact you digitally or by phone/9465, please opt in below:

Email _____ Telephone _____ 0845 Opt-out of all further PCR communications

Visit our website to read our privacy policy pcr.org.uk

New patient platform

The Infopool

In March 2021, Prostate Cancer Research launched the first phase of our new patient information and education platform, [TheInfopool.com](https://www.theinfopool.com)

On The Infopool, patients and their family members have the chance to find out about – and share their views on – developments in prostate cancer diagnosis and treatment in our ‘Scanning the Horizon’ section. We are also using this platform to raise awareness of having inherited certain genetic variants or mutations from family members that could increase the risk of developing certain cancers.

The Infopool was also the site of one of our most recent patient-involvement projects. Over the last six months, PCR has been working with the biotechnology company CellCentric to investigate prostate cancer patients’ knowledge, experiences, perceptions and expectations of clinical trials. The project has been looking to understand the experiences of people with prostate cancer who had been in clinical trials. It also sought to gain a better grasp of the level of understanding of clinical trials from people who hadn’t been part of one, and to explore potential barriers to involvement.

The aim of the project has been to ensure that future clinical trials are informed by the insights of real patients, with greater focus on ensuring better patient-quality-of-life outcomes and experiences in these trials, and also to help PCR identify gaps in information provision and support around clinical trials for prostate cancer patients.

We used a survey (hosted in the first two weeks of March) and two patient panels (conducted via Zoom) to gather our findings. We’re extremely grateful to the 173 survey participants and the 22 patients who took part. Additionally, we’re pleased to have had such a representative mix of participants from across the UK, displaying diversity in terms of their self-identified ethnicity and sexuality, their age, the stage of their prostate cancer at first diagnosis and their participation in previous clinical trials.

The project’s findings, and associated recommendations, are currently under development by our team. We will be holding conversations with CellCentric and other partners in industry to create tangible recommendations that we will encourage organisations to follow when designing future clinical trials. We look forward to sharing these with you later on in 2021, both in our newsletter and a future webinar.



Join the Patient Voice group and help us to know what matters to you
www.pcr.org.uk



Prostate
Cancer
Research

[pcr.org.uk](https://www.pcr.org.uk)

IN PARTNERSHIP WITH

CellCentric



THE PROSTATE POD

Last year, we launched our very own charity podcast – the Prostate Pod! In each episode, our host Ben Munro-Davies chats to the people at the heart of PCR; from scientists to patients, fundraisers and medics on the front line fighting this disease.

If you’ve ever wanted to know the answer to questions such as: ‘What’s it like to navigate prostate cancer as a couple?’, ‘What exactly is epigenetics?’, or perhaps even ‘What classic car is the perfect on-the-road representation of this disease?’, then this is the podcast for you.

Sit back, relax and tune in to the Prostate Pod, available at [pcr.org.uk/prostate-pod](https://www.pcr.org.uk/prostate-pod)

LET'S TALK ABOUT THE HARD THINGS

Troubles and taboos

In early 2021, Prostate Cancer Research, in partnership with Tackle Prostate Cancer and pharmaceutical company Ipsen, launched a nationwide survey to better understand the experiences faced by people living with prostate cancer, particularly in relation to the challenges patients face with treatment side effects.

The findings from this survey informed a new campaign, spearheaded by Good Morning Britain's Dr Hilary Jones, which we launched in May – **Let's Talk About the Hard Things** – to help break down taboos around the side effects of treatment and encourage those with prostate cancer to talk about their experiences with family, friends or their healthcare professional.

As part of this campaign we launched a series of powerful videos, each showcasing a different pairing discussing their experiences of prostate cancer and the side effects of their treatment. We hope these will help raise awareness among not only the prostate cancer community but also a much wider audience, ensuring that more informed and supportive conversations can take place across the country.

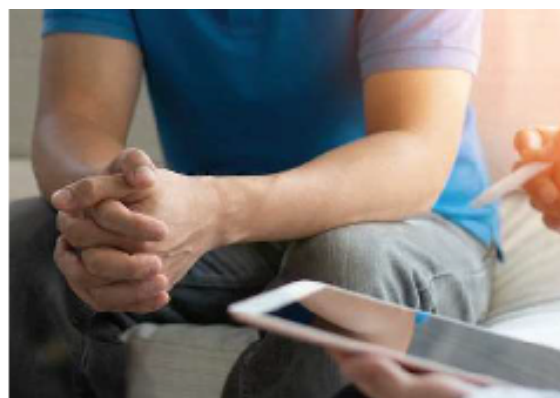
To find out more and watch these videos, please visit pcr.org.uk/lets-talk



More answers to common questions can be found on our website pcr.org.uk/patient-life



For more information about prostate cancer, please request a free copy of our patient booklet pcr.org.uk



In our research we found that:

- One of the most common side effects was revealed to be erectile dysfunction, which affects 86% of participants.
- This was followed by loss of libido (79%). Of those who experienced a loss of libido, almost half (42%) said their sex drive has 'completely diminished'.
- Nearly two thirds (60%) experienced incontinence, of which nearly three quarters (73%) said it affected their quality of life.
- Over a third (39%) were affected by the growth of breast tissue, which can lead to a loss of confidence and feeling emasculated.
- Over a quarter of participants said that changes associated with their physicality have directly affected their mental health. Worryingly, four out of five were not offered mental health or psychological support from a healthcare professional.
- Participants also feel uncomfortable talking about their side effects and mental health with the people they are closest to. Only 2% feel most comfortable discussing the topic with family, and even fewer (1%) with friends. Some of the key reasons expressed for this discomfort were the feelings that others would have a lack of understanding, peer pressure to appear to have a healthy sex life and/or health in general, and feeling as though the problem is 'left for you to sort out yourself'. This reluctance to talk about both the physical and mental impacts of prostate cancer treatment was felt across all ages, ethnicities and sexualities of the prostate cancer community.
- We found that over two thirds (69%) said speaking to other patients or having their family and friends understand how they felt, would help them discuss these 'hard' topics.
- 62% felt more resources are needed to help improve awareness and understanding – not just among the patient community but also for partners, family and friends, and over half want more mental-health support.

Meet the team

Amy Russell

PCR's Events and Community Manager brings a creative and supporter-first approach to the Fundraising team.

I joined Prostate Cancer Research in 2019, fresh out of studying Philosophy at the University of Edinburgh. I knew that I definitely wanted to work in the charity sector, so the role of Community Fundraising Officer was perfect! I had fundraised for a prostate cancer charity before by taking on the Edinburgh Half Marathon for my grandad, and was immediately drawn to working for PCR because of their focus on patient need and funding impact-driven research.

I held the position for just over a year in the Events Team and primarily focused on stewarding our incredible fundraisers as they took on all sorts of challenges to raise money for our research. Essentially, I ensured that they had the best experience possible with PCR – from signing up to being thanked, and beyond. I particularly loved getting to know our supporters and being inspired by their fundraising ideas, especially when they linked their activity to the cause. Some favourites include the Maestro Madness Team, who are organising a classic car road trip to different towns beginning with the letters 'P.R.O.S.T.A.T.E.', and superstar fundraiser Robin, who cycled 130 miles to represent the 130 men diagnosed with prostate cancer every day.

I only had a few months in the role before the Coronavirus pandemic hit and entirely changed the fundraising landscape. It was a challenging year, but it also gave time for reflection and re-shaping how we approach fundraising. Going virtual was the new big thing! I organised Legend in the Balding, a virtual balding challenge in which people dedicated their beaks to someone affected by prostate cancer. I also had the opportunity to work on other organisational projects, including recruitment for our online research community, to better understand different people's experiences of prostate cancer. I was so proud to be involved in such an important research project.

A few months ago, I was promoted to Events and Community Manager and my main focus is organising and delivering all of our internally organised fundraising events (such as Snowdonia for Science, set to take place over Father's Day weekend), external fundraising events such as the London Marathon, and managing community fundraising campaigns. I am having a blast working in such a varied role and taking on more responsibility, and as we are hopefully coming out of the other side of the pandemic I am so excited to kick-start in-person fundraising events as soon as possible!

23

65m

23

By 2023 we will scale up the amount of our research grants to £50m and projects to at least 23 per year



If you would like to fundraise for us, drop us a line on 0205 735 6446 or email us at events@pcr.org.uk

Thank you to all our supporters



New charity partner: the Lotus Seven Club

We are absolutely delighted to announce that Prostate Cancer Research has been selected as the new charity partner for the Lotus Seven Club. Over the next three years, the club will be fundraising for different projects and activities to support our research and patient outreach – initially raising £1,000 to help fund the drug tests used in Bart and Tiffany's project to help improve radiotherapy.

Established over 30 years ago, the Lotus Seven Club started off as a group of friends meeting up with one big passion in common – the Seven. And at its heart, not a lot has changed! Area meetings are organised all over the world for the club's 3,000 members, and getting together to enjoy their cars is still what the club is all about. It has a long-standing tradition of supporting different charities that resonate with its members, and we are so proud to join the list of amazing charities they have supported.

We'd like to say a huge thank you to the membership for voting for us and choosing to support our research. We are grateful for this opportunity and cannot wait to support the club with its fundraising, and to offer as many engagement opportunities as we can with our work. We would also like to thank the incredible Leadership and Management Team for their enthusiasm and dedication to getting our partnership started. We are so excited to work with you on making the next three years a great success.

You can find out more about the Lotus Seven Club by visiting lotus7.club

The last year has been extremely challenging for everyone. We are incredibly grateful to our supporters, for the spirit and resilience of our amazing fundraisers, and for their energy and enthusiasm in coming up with innovative ways of fundraising. Because of amazing people like you, we have not only been able to continue funding our current research projects but have also run a successful grant call to fund even more research.

Virtual reality creates real cash

Thank you to Anna and her fellow students at Sheffield Hallam for organising a virtual games night and raising £341. We commend your creativity in using Zoom to bring people together for an evening of fun!

Swimming in memory of dad

A huge shout-out to Stacey, who is challenging herself to swim 1km to 12km from January to December, increasing the distance every month! Stacey says that her dad, JB, who sadly died of prostate cancer in 2020, will be behind her, spurring her on. So far, Stacey has raised an incredible £1,645 – what an amazing achievement already. We are so excited to continue supporting Stacey throughout the year.

Walking and baking, but at least not at the same time!

A massive thank you to Chris, who took on the PCR Challenge in February in memory of her brother-in-law. Chris walked five miles every day throughout the month and raised an amazing £360 to support our research. Having also dedicated a beautiful bake for our Legend in the Baking campaign last year, she truly is a PCR Legend. Thank you, Chris, for your ongoing support!



**Prostate
Cancer
Research**

pccr.org.uk

**Transforming research.
Transforming lives.**



We offer a free
will-writing service
with Guardian Angel
(RFP 850)



Downloadable guide
to writing your will
available online

Leave a gift for the future

Together, we will develop and deliver breakthrough treatments

Families affected by prostate cancer need breakthrough treatments. Research is the only way we can turn this hope into reality. It's thanks to our supporters who leave us a gift in their will that we are able to progress towards our vision of a world where people are free from the impact of prostate cancer.

If you would like to leave us a gift in your will, please get in touch with our legacy team.

Prostate Cancer Research
Suite 2, 23-24 Great James Street
London WC1N 3ES
0203 735 5444
info@pccr.org.uk

pccr.org.uk/legacy-donations

Registered Charity No. 1186027

From: riley.d7
Sent: 09 June 2021 14:43
To: Leon Wright
Subject: Fwd: Tackle Prostate Monthly Briefing

Sent from my iPhone

Begin forwarded message:

From: Sarah Gray - Tackle Prostate Cancer <sarah.gray@tackleprostate.org>
Date: 9 June 2021 at 12:59:37 BST
To: Dave <riley.d7@sky.com>
Subject: Tackle Prostate Monthly Briefing
Reply-To: Sarah Gray - Tackle Prostate Cancer <sarah.gray@tackleprostate.org>

[View this email in your browser](#)



Tackle Monthly Briefing

June 2021

Welcome to our June briefing, the monthly briefing we send out to group leads and committee members. The purpose of this briefing is to give information that help committee members support their members and to ask for feedback, case studies and ideas from them to campaign ensuring your voice and that of your members is front and centre of all our communications. We recognise that some of you already provide monthly updates so we hope you find this informative and you'll be able to select from what you find relevant.

This briefing is shorter than usual as copies of Prostate Matters will be landing on your doorstep any moment now.

Helpful Info and tips for you and your members

Last month saw us launch a campaign in partnership with IPSEN and Prostate Cancer Research. Let's Talk About the Hard Things is a campaign that breaks down the taboos surrounding the side effects of prostate cancer treatment and encourages men to talk about their experiences with friends, family and healthcare professionals. Many of you responded to the survey earlier this year, with which we collaborated alongside Prostate Cancer Research & IPSEN. The results of this research revealed that men with prostate cancer do not feel supported with the psychological and emotional consequences of living with the disease and often feel unable to talk openly about 'taboo' issues such as sex and relationships.

The campaign highlighted the importance of the support people receive at groups, with the research reporting that two thirds (69%) of men feel speaking to other men living with prostate cancer, or having their friends and family understand how they feel, would help them discuss some of the 'hard' topics more openly.

The campaign launched three powerful videos which showed people talking about the side effects of their treatment, how they overcame the taboos and the benefit of having conversations with their friends, family and their partner. Watch the videos by clicking [here](#).

We've had a great response to the campaign securing regional press in both

Please help us..

PSA Testing Events. We know that many of you run your own PSA testing events, as we begin to open up after COVID restrictions, it would be useful for us to know if you are planning to start PSA testing, and if you haven't run an event before, what would be helpful to you. We have produced a very short survey, which we would ask that one committee member or Group Lead from each group complete by clicking on the survey button below



Thank you .

As the success of The Hard Things campaign has highlighted, hearing your stories and learning about real life experiences of what it is like living with and being affected by Prostate Cancer, helps us to promote the work you all do and drives awareness of Prostate Cancer. If you have a story to tell or an experience you would like to share, [please get in touch](#)

print and broadcast media. The films have been viewed over 30,000 times
Huge thanks must go to all of our campaign spokespeople who were open and honest, offering us their stories and experiences to highlight these important campaign messages.
Support groups that were mentioned included Solihull, Metro Walnut, Prostate Pedlars and FOPS

Upcoming Events

Due to continuing restrictions we have decided to postpone our AGM until later in the year, watch this space for further details

Our friends at Orchid Male Cancer have recently been awarded money from the National Lottery for a new project, the focus of which will be to support individuals from identified communities to overcome barriers to engaging with prostate cancer, including those additional barriers resulting from the coronavirus pandemic by recruiting and training Volunteer Community Champions to help cascade prostate cancer messages to those at risk of this cancer. As part of their project Orchid are looking to develop a taskforce of individuals and organisations that reflect the various communities that face barriers in accessing prostate cancer awareness, information and support.

If you would like to be part of this taskforce, then please get in touch with [Sarah](#) who will pass on your

details to the project manager.

A Note From Ken Mastris

As I write, decisions are being made by Government as to whether we can open up further following the easing of some COVID restrictions last month. Having now had both of my vaccines, I certainly feel a little more easy, however, I still feel uncertain that we will fully be back to pre COVID times.

We have been listening to the uncertainty that many groups feel about physically restarting their groups. Questions from who is responsible for COVID compliance of venues, or how you can attract new members in a post pandemic environment to whether your members will feel safe sitting in a room with others seem to be occupying your thoughts at the moment. Many groups are considering keeping some elements of the last 15 months, and having a hybrid of Zoom and face to face meetings. Whilst many groups have found Zoom difficult for some of their members, other groups have recognised the value of being able to attend meetings from across the country. I know I have certainly welcomed being able to meet so many of you, and on a couple of occasions, I have attended two groups on the same day, over 200 miles apart, all from the comfort of my office.

It would be good to know what your group is intending to do. Some groups are looking at buying equipment to support hybrid meetings, and other groups are looking at how advertising and marketing materials might promote their groups as they restart in a post COVID world. Don't forget that as one of our members, your group is able to apply for a small grant of up to £500 for a variety of things which helps you to run your group.

In other news the work on our website and branding refresh is coming along well. We are very keen to engage our members in this work, so have been joined by some Group Leads to look at the branding concepts. We hope to have everything finished by the time we hold our AGM later in the year. Alongside the website and brand refresh we shall start bringing together Group Leads to look at what content would be useful for the Members Portal, which is the section that will host tools, case studies and other assets to help you run your group, and make sure that we aren't all reinventing the wheel! We shall be asking for your help on this next month, so please look out for the briefing.

As always, as your federation, we are here to support you to run your groups. You can contact me on ben.morris@tackl prostate.org or contact our National Support and Development Manager Sarah on 07726 083533, or email her at sarah.gray@tackl prostate.org.



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This email is being sent to all the member groups of Tackle Prostate Cancer and to you as our main contact for. Please would you distribute it to your committee and members as you think fit.

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Paul Parker

26 Jun 2021

"I want to help other black people, my two sons and grandson" after his dad's diagnosis, football star Paul Parker joins pioneering study to understand why black men are at higher risk.

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Tags: [Paul Parker](#)



1 in 4 black men in the UK will get prostate cancer. That's twice the risk for all men, and we don't know why. Former England and Manchester United footballer, Paul Parker is taking part in [a study to help us find out](#), and he wants other men to join him.

When Paul Parker heard about [PROFILM, a study trying to understand why black men are at higher risk of prostate cancer](#), he knew he had to get involved.

37-year-old Paul, who also played for Fulham, Queens Park Rangers and Manchester United, has supported our work for many years. He raised funds at the Football in Amsterdam gala night, joined GPs and has joined top football-themed walking events, including Jeff Brasing's 2016 March for Men. When Paul's Dad was diagnosed at 80 with prostate cancer last year, all of his walk became even more meaningful.

"It's become an even bigger cause for me because of my dad. During lockdown we found out he had prostate cancer, which was a big surprise. Through the bike rides and walks, my involvement was very much sport related. Once my dad was diagnosed, it earned the one of the few times I got something right, and I felt I was helping him in some way."



they were very, very insensitive.

They told me everything that was going to happen to my dad, and then told me what could happen depending on how his cancer developed. Everything they said was absolutely spot on and I suspected no less. My involvement with Prostate Cancer UK has been an essential, an positive and has made life easier for my dad. I still don't think he could understand the fact that his son knew so much about it, so I think I surprised him there?"

"We're alone in our own way, but I think this made us closer, because I was taking him to and from the hospital for his scans, then for his MRIs, and injections, I was able to be there for him. My dad is almost back to normal now. With the age here at and what he's been through, he isn't going to come out and say how he really is, he'll just grin and bear it, but naturally he's a lot better. He's back to what he was, rather than being in worry mode."

"Try black men out there who are BR and looking, aged between 40 and 69, please come and join PROFILE with us. Just do it. Do it for other black men out there. That's why I'm doing it. I don't know who I'm going to be helping, but I know that I'll help a lot of people."

Former England footballer Paul Parker joins phone...



*For the Video Follow the Link to;
<https://youtu.be/tuqdZ4wvKm0>*

What is PROFILE?

In 2020, in partnership with Eleuther, we started funding the PROFILE study, based at the Royal Marsden in London and led by Professor Rob Hales. It's the first of its kind in the UK, looking at the genes of men of African and Caribbean descent to try and predict prostate cancer risk and find better ways of diagnosing and treating the disease.

PROFILE has two branches - the first branch studies the genes of men with a family history of prostate cancer. This branch is full, and no longer accepting new participants. The second, which will study the genes of men of African or Caribbean descent, is still open for new recruits. It will continue to recruit men until March 2022.

If you are a man of African or Caribbean descent aged 40-69 and haven't had prostate cancer, you may be suitable to take part in PROFILE.

Paul told us: "Being involved in PROFILE is about helping other black people, but more importantly my two boys and my grandson. I feel quite proud that I've gone from jumping on the bandwagon to now getting involved in a study that is going to help black people in the future. I know I'm playing a really big part. I'm looking forward to see how far it goes and what I can give back."



SEARCH

Call Our Specialist Nurses
0800 071 070

more about the genetics of the disease, so we can save more people."

[Find more information about PROSTATE UK.](#)

[Join a regular gym](#) to help shed the excess that can drive, through ground-breaking projects like [PROFILE](#).



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Contact Information

Tel: 07548 033930
E Mail elpcsginfo@virginmedia.com

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.

