

tackle
prostate cancer

Prostate Matters

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To find out more go to our website or social media channels

website: www.tackleprostate.org twitter: [tackleprostate](https://twitter.com/tackleprostate) instagram: [tackleprostatecancer](https://www.instagram.com/tackleprostatecancer)

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Welcome

Welcome to the Spring Edition of Prostate Matters and I am delighted to be writing to you as newly appointed Co-Chair for Tackle. I hope you enjoy reading this edition, which celebrates partnership and collaboration – it showcases a range of exciting work going on to support prostate cancer care including the Boys Needs Bin campaign, awareness around the north/south divide, and launch of the Prostate Cancer Research (PCR) infopool.

In March, we held our first national conference in person since the start of the pandemic and it was a wonderful opportunity to meet with our local peer support group leaders and other national voices such as the Errol Mckellar Foundation, Men's Shed, and individuals from Prostate Cancer Research.

We were delighted to welcome Chiara De Biase from Prostate Cancer UK as our key note speaker, sharing with us their strategic direction and launching their alliance with Tackle leading on peer support.

As you read about these initiatives and events you can see how people up and down the country are working to address the needs that are so important for people living with and affected by prostate cancer. This is only possible through your active involvement in sharing your stories, highlighting the successes and the challenges that we need to address, and coming together as a community to tackle prostate cancer.

- Roshani Perera
June 2023

Editorial team



Roshani Perera,
Co-chair

Roshani is an established healthcare management consultant with over 20 years' experience providing strategic consultancy, patient advocacy, health policy and healthcare communications to a variety of healthcare organisations.



Aidan Adkins,
Co-chair

Aidan was diagnosed with aggressive, high-risk prostate cancer in 2015 through a routine work medical. Having joined a local support group soon after, he now leads 3 groups across the West Midlands and champions the value of peer support and the need to improve access to this vital service across the country.



Sarah Gray,
National Support and
Development Manager

Working across health and social care for most of her career, Sarah has previously worked for Macmillan Cancer Support, Prostate Cancer UK and British Lung Foundation. Sarah brings news from across the country, including local forums and campaigns.



Molly Jewitt,
Marketing and
Communications Manager

Molly is a freelance communications consultant, with experience in the third and public sectors. She is passionate about using people's stories to increase further awareness of important topics and using the power of communications to make positive change.



PCaSO 20 Years Anniversary!

The Prostate Cancer Support Organisation (PCaSO) in Eastbourne, recently celebrated their 20th anniversary! The PCaSO groups are true assets and although they have now grown to eight branches across Sussex, Hants and Dorset, they have still managed to maintain the intimacy of the meetings and ensure it's still a personalised approach.

Like the majority of the support groups, PCaSO are run by prostate cancer patients and their families and have used their expertise to help so many individuals and families over the years. So if you're in the area or know anyone who could benefit from reaching out to the PCaSO sphere, do get in touch www.pcaso.org

Around the country

Fundraising Champ!

This time around, we're showcasing the brilliant achievement of Jo, from Bristol, who recently completed the Kew Gardens Half Marathon while surpassing her fundraising target for Tackle! This race was quite a personal one for Jo, as her father co-runs the Prospect Prostate Cancer Support Group in Bristol, a fantastic group that has been running for several years.

If you want to donate to Jo's Just Giving page, there's still time to do so. Follow www.justgiving.com/fundraising/joanne-casley

We're always so grateful for any donation we receive, whether it be big or small. So, if you're wanting to raise some money for Tackle or would like to find out more information on how to donate then do email, Andrew, our Fundraising Manager andrew.moffatt@tackleprostate.org





Clinical news

Celebrating the STAMPEDE clinical trial

Recently, prostate cancer researchers celebrated a huge milestone: the STAMPEDE clinical trial has finished recruiting new participants after 18 years.

You might have come across STAMPEDE before, or may even have taken part. Since the trial began in 2005, almost 12,000 men who were starting long-term hormone therapy for prostate cancer have joined. STAMPEDE's goal is to find the best treatments for advanced prostate cancer. Unlike a regular clinical trial, it tests multiple treatments at once, helping get results and make new treatments available to patients more quickly. For example, in 2015 the NHS started offering the chemotherapy drug docetaxel to men with cancer that has spread

beyond the prostate after STAMPEDE found that it helps these men live longer.

But the work doesn't end yet. Existing participants in the final treatment groups will keep taking their medication and attending check-ups for a few more years. At that time, the researchers will be busy analysing the data. This important research will continue beyond STAMPEDE, as a second clinical trial, STAMPEDE2, is currently in the planning stage.

STAMPEDE has been a huge collaborative effort, with 165 researchers and over 5,000 NHS staff working across 126 hospitals in the UK and Switzerland.

None of it would be possible without the men who volunteered to take part in STAMPEDE, including the patient representatives who brought patients' voices to the forefront. The STAMPEDE team would like to thank them for their invaluable contributions. For more information, visit <http://www.stampedetrial.org/>

General news

New groups have joined Tackle!

We've recently welcomed a few new support groups to the Tackle network. The Green Prostate Support Group (Bradford), the Huddersfield Prostate Cancer Support Group, plus, the North Dorset Prostate Cancer Support Group are the latest additions to our fold and we couldn't be more pleased.

We spoke with Chris, who co-runs the Huddersfield group about his prostate cancer experience, how the group became established and how they are finding things so far. To read the whole story, head to our blog at

tackleprostate.org/new-tackle-support-groups/

Let's share with you some industry news that's happened over the last few months.

Industry news

Lynparza (olaparib) approved for metastatic prostate patients in England

Tackle is delighted that NICE (National Institute for Health and Care Excellence) has recommended the use of Lynparza for certain metastatic prostate cancer (and breast cancer) patients in England.

The decision came after NHS England negotiated a commercial deal from its manufacturer, AstraZeneca. In the past, NICE had not recommended Lynparza as a treatment for certain types of prostate cancer, due to concerns about its cost-effectiveness.

The drug will be made available through the NHS for more patients with inherited mutations in DNA

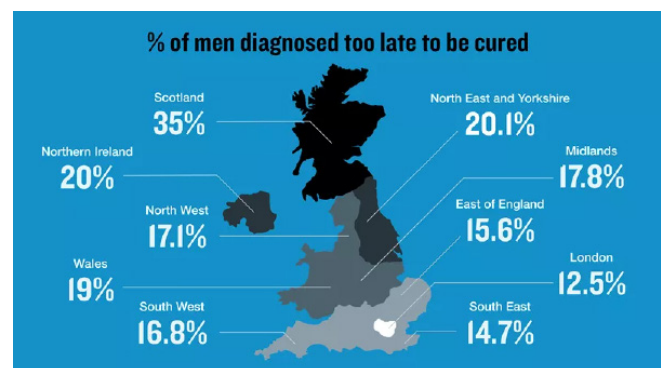
repair genes called BRCA genes. These faults raise the risk of certain cancers, but they can also be targeted with Lynparza. For adults with advanced prostate cancer it can also mean delaying chemotherapy and its associated side effects and allowing them to have more time with their families and loved ones.

NICE has estimated that around 500 individuals with advanced prostate cancer will be eligible for the treatment, which is brilliant news. For more information, please visit www.nice.org.uk UK's website.

Postcode Lottery with Prostate Cancer Diagnosis

Our friends over at Prostate Cancer UK have recently done a fantastic job of reaching one million people checking their risk as part of their campaign to find 14,000 men living with undiagnosed prostate cancer. However, the stats that came back revealed that there is a huge divide in the UK and that certain regions are being left behind in a 'postcode lottery'.

There's huge variation in the likelihood of men being diagnosed when it's too late for a cure. In London just 1 in 8 men (12.5%) with prostate cancer are diagnosed, rising to more than 1 in 3 (35%) in Scotland. See the infographic below for a breakdown of what the stats show.



Credit: Prostate Cancer UK

The research shows that those who live in more deprived areas are more likely to be diagnosed later. The pandemic also had an impact people being diagnosed late, with a 29% fall in the total number of men diagnosed in the first year of the pandemic.

To tackle these health inequalities, Prostate Cancer UK has launched a refreshed 30 second online risk checker to help men understand their risk and what they can do about it.

You can access it at bit.ly/3NSkjPI

They are also supporting GPs in areas of high deprivation to send targeted messages to men at the highest risk, to share the risk checker and help them make an informed choice about testing.

United we stand, divided we fall

On 22 March 2023, around 80 representatives from dozens of different cancer charities and a selection of MPs gathered outside Parliament with a unified message for the Prime Minister: it's time to address

the cancer emergency in England and take action to improve outcomes for people affected by cancer. Over a year ago we were promised a strategy to address this crisis. Yet, here we are, a year later, and there is no plan. The UK Government also recently announced in January that they will be instead publishing a five-year general 'Major Conditions Strategy' – a short-term, catch-all plan rather than the targeted cancer response we need.

In response to this, more than 60 cancer charities, including Tackle, have united as the coalition One Cancer Voice to petition the Prime Minister for fully funded, ambitious, long-term action on cancer in England.

The content of the new Major Conditions Strategy needs to be bold and inclusive of the evidence from the cancer community, and the UK Government needs to strive towards a longer-term, more comprehensive and sustainable strategy.

Although we're still waiting on the plan to address the cancer emergency, this was truly a collaborative effort and couldn't have been done without the support from the thousands of people nation-wide.



Photo Credit: Cancer Research UK



Campaign update

Boys NEED bins

Incontinence is a common consequence of prostate cancer treatment and can sometimes have a huge impact on the men it affects. In the last edition of Prostate Matters we told you about the Boys Need Bins campaign. Tackle Prostate Cancer are campaigning alongside a number of other charities including Prostate Cancer UK, and Bladder Health UK, under the campaign name Boys NEED Bins.

Working collectively, we are determined to build a world where men are not restricted by incontinence. This campaign is the starting point towards achieving this goal. Our aim is to have incontinence bins available in all male public toilet cubicles and establishments across the country, enabling men to dispose of their incontinence pads and stoma products, and other hygiene waste items in a convenient and secure manner.

Over the past few months, we have organised a letter writing campaign, asking men with experience of incontinence to write to their MPs. So far almost 1700 people have written to their MP and 82% of all MPs have been contacted. Questions have been raised in the House of

Commons, and our partner PCUK has had several meetings with MPs from across the house who has expressed interest in the campaign. If you have already written to your MP, then please accept our HUGE THANKS. If you haven't, then please join us by using the template letter at <https://prostatecanceruk.org/get-involved/campaigning/incontinence>.

Alongside the letter writing and engaging with MPs we have also written a survey to ensure more of your voices are heard. The survey was produced following an insight session with several men living with prostate cancer, who spoke honestly and openly about the impact of incontinence following their treatment for prostate cancer.

Please complete our 5 minute survey which can be found at bit.ly/3pqjpPT and help us understand the need for the specific provision of male sanitary bins within the cubicles of men's toilets. Let us know what your experience is of disposing of your products, how it has impacted you and what improvements can be made for men affected by incontinence.

We will keep you informed on what happens next. In the meantime, if you had an experience with any aspect of incontinence that you would like to share then please do get in touch: editor@tackleprostate.org



Henry Andrews from METRO Walnut

Infopool. An online hub for all your prostate cancer information

The Infopool, is powered by Prostate Cancer Research and aims to guide and provide individuals at all points through their prostate cancer journey. We hear from Henry Andrews, one of the users of The Infopool. Henry is coincidentally part of X support group, which is part of Tackle's cohort and led our AGM key speaker panel back in March.

"A diagnosis of cancer is a frightening experience, filled with uncertainty. When it happened to me, I had a strong need to talk with others who had prostate cancer (PC). I found that I wanted to be able to air my concerns with people who I

expected to understand, and where I did not need to worry about others' negative reactions. As a gay man this meant the Metro Walnut support group for LGBTQ+ people affected by PC was ideal for me. There was a whole lot we could take as read, allowing us to get on with addressing the nitty gritty!

Facilitators who are seen as advocates for equality, diversity and inclusion could get the PC peer support groups a reputation for being safe and welcoming for all. Prostate Cancer Research has collaborated with multiple partners to create the infopool (www.theinfopool.co.uk). This uses the experiences reported by individuals affected by PC to create anonymised data that can be used by patients, partners, friends, family and carers, researchers, charities, and educators and learners in healthcare professions.

This will mean access to information about treatments and side-effects, and their management, and more. It will provide data about personal characteristics of those affected by PC, like age, ethnicity, sexual orientation, and more, as well as disease characteristics.

The website will offer information and educational resources about PC, including symptoms, treatment options, side effects and clinical trials. This gives support group members access to accurate, up-to-date information, which can help them make informed decisions about their health.

The website provides a platform for people to share their experiences and knowledge and offer support to one another. This will allow people connection with others who share similar characteristics, diagnoses and treatments, in a safe and supportive environment. Knowing that you are not alone is so incredibly important.

The website will serve as a hub for resources, such as websites, books and articles, and contacts for local support services. This would make it easier for group members to access the information and resources they need to manage their condition and improve their quality of life. "

Please see the next page for more information on The Infopool.

*Want to know more
about prostate cancer?*

The infopool

A website all about testing,
treatments, side effects,
clinical trials and more



Prostate
Cancer
Research
pccr.org.uk



Scan the QR code to visit
www.theinfopool.co.uk



Advice for people who support family, friends and loved ones

A cancer diagnosis is never easy to digest for a patient, nor their family. The dynamics of the family shift in ways unimaginable. Each person relies on another for different things, whether it be emotional, physical, mental, or financial support. Each person serves the family in a new capacity.

A caregiver position is the one job you don't apply for but are hired on the spot. So, although, you learn through on-the-job training there a few things that could be implemented to consider when taking on this 'new role'.

- Embrace the differing emotions you feel along the way. Each emotion you feel is justified, simply because it is your natural instinct. Society is not allowed to put a cap on your emotions. Emotions that are swept under the rug can cause bigger recurring issues later.
- Document and modify everything. Maintain a journal for doctors' appointments. List medications, dosage, and schedules. Keep positive mantras close to hand for those darker days.
- Keep communication consistent and transparent. After doctors present the information, it is important that you and your loved one are on the same page as to moving forward with care. A large part of communicating is understanding what is being communicated.

- Join a support group. As we know, support groups are a fantastic way of encouraging you to talk and find other people who are experiencing similar things. At Tackle, there's a National Prostate Partner Support Group that's specifically for partners of those living with prostate cancer. Janet and Caroline, lead on these sessions and have helped many over the years. Please find more information about their support groups in the orange box. If you're looking for your local support group, head to our website: tackleprostate.org/supportgroups

Online workshops

Prostate Brachytherapy UK Support Group.

Support group for those who have had, or who are considering Prostate Brachytherapy. If you are interested in joining this group, please email support@prostate-brachytherapy.uk

National Prostate Partner Support Group

Supporting partners, families and those close to people diagnosed with prostate cancer. Please note this is a support group for partners only, not patients.

If partners wish to attend, please email Janet Daykin at janetdaykin@gmail.com and Caroline at carolinepcsg@gmail.com



More from us

Seeing things in a different light.

Earlier this year, one of our trustees, Aidan Adkins, visited London's Science Museum and came across Prostate Cancer Research's 'Cancer Revolution: Science, Innovation and Hope' exhibition which explored the treatment and understanding of cancer. Aidan shares his experience:

'Cancer, a topic that since my diagnosis in 2015, I had continued to try and ensure that I was an informed patient. I had read pamphlets, books, watched videos, attended talks, workshops, webinars so why not add an exhibition to this exploration?

The exhibition was created by the Science Museum Group with expert help from Cancer Research UK and had previously exhibited in Manchester, before coming to London. It demystified cancer while acknowledging that there is still a lot to learn before cancer, like smallpox, itself is a topic that is confined to history and museums.

Amongst other things, I learnt that evidence has been discovered that dinosaurs had cancer, cactuses get cancer, the earliest written description of cancer is in an Egyptian document from 3000 BC - it gets its name from the Greek word for crab - as the tumour growths seen by the famous ancient Greek doctor Hippocrates looked to him like crab legs.

The exhibition covered the history of the treatments of surgery, radiotherapy and chemotherapy. Then onto the dramatic improvements that have come about in the last 40 years. The research into how cancers start, grow and spread, why some cancers are treatment resistant, and some cancers come back. The 'new horizons' of genetics, imaging, big data. The quest to diagnose early.

There was a mix of science and personal stories, of videos, interactive screens, photographs, personal objects, and soundscapes. Myths are busted and above all there is a strong message of hope for the future. The final exhibit is ACT: Ask for Advice, Care for yourself, Talk about it. Who can argue with that?

Although the exhibition has sadly now finished, it prompts us to think about educating ourselves about prostate cancer in different ways and sharing these experiences with others.



Errol McKellar Foundation

We speak with so many inspirational people every day, however sometimes, we come across certain individuals who have the passion and drive that really set our bellies on fire with excitement.

Meet, Errol McKellar MBE; the founder of the Errol McKellar Foundation, an organisation that aims to raise the awareness of prostate cancer through workshops, initiatives and networking.

Errol is a prostate cancer survivor and Prostate Cancer UK Ambassador who is passionate about doing all that he can to ensure the rate of late diagnosis for prostate cancer is reduced. Along with other inspirational key speakers, he co-runs

the Sit & Talk Prostate Cancer workshops across London where individuals meet and talk through different topics associated with prostate cancer. The foundation also recently organised a 5k Walk & Talk in Gladstone Park for people to join, to show their support of those living with or who are affected by prostate cancer. If you're in the London vicinity, do see what Errol and co are up to, their passion is really motivational.

www.theerrolmckellarfoundation.com

Together We Tackle

Back in March, we held our annual conference in Birmingham, where we were joined by some brilliant prostate cancer support group leads, to connect, collaborate and converse. The event's theme was partnership and collaboration and gave us a real chance to showcase everything within our 'Together We Tackle' rebrand. So for those who weren't there, here's a whistle stop tour on the takeaways from the day.

Firstly, we would like to say a big thank you to all of those individuals who were able to attend the event. Although not every group was able to attend the conference, those who did, brought such positive energy and were really engaged in the day's topics of conversation. What was so special, was that people were really committed to making changes to support people who are living with or affected by prostate cancer and network with others in order to achieve so.

Our keynote speaker was Chiara De Biase, Director of Support and Influencing at Prostate Cancer UK, who announced their three year partnership with Tackle. This means that Tackle will become the sole organisation providing direct support to prostate cancer support groups & offering membership to their leaders. The partnership will bring valuable funding to allow us to support groups who are currently not members of our federation. We shall also be able to work with groups in other areas of the UK, especially Scotland, where we currently

have no support groups. Nothing will change to our structure or how we do things, it just means we have more signposting coming our way and we have the support to continue our legacy!

The event concluded with an inspiring panel discussion hosted by Henry Andrews, a retired urologist and prostate cancer survivor. On the panel was Janet Daykin who runs a fantastic Prostate Cancer Partners Support Group, Errol Mckellar MBE from the Errol Mckellar Foundation, Simon Faulkner, our newly appointed Trustee and lead of METRO Walnut Prostate Cancer Support Group. The panel discussed the challenges and solutions to ensuring peer support is accessible to all communities regardless of gender, race, religion, sexual orientation and others.

Angela Jones, our Finance Director and Company Secretary and Andrew Moffatt, our Fundraising Lead are recent additions to the Tackle team. We're really excited for the ways that Angela and Andrew can support each other in their roles and enable Tackle to grow.

As for our new Board of Trustees, at a recent board meeting current Trustees Aidan Adkins and Roshani Perera, were appointed as our co-chairs. Tony Collier, was elected as a Trustee at the AGM and the board appointed him as Vice Chair to further strengthen the leadership at Tackle. Last but by no means least we warmly welcome newly elected Trustees Peter Corbishley, Simon Faulkner and Ken Mastris. Read more about each of their roles on our blog: Tackle Prostate Cancer - Changes to the Tackle Team!

If you want to find out how you could be a part of our next conference then please email info@tackleprostate.org





Very proud moment for Daniel and his team when they won the Bart's Hero Award for most engaging team.

Day in the Life of a CNS

Ever wondered what a day in the life as a Urology-Oncology Nurse Specialist is like? Well, we hear from Daniel Richardson from St Bartholomew's Hospital, who gives a bit of an insight...

I work as a Urology-Oncology Clinical Nurse Specialist (CNS) at St Bartholomew's Hospital. On Thursday afternoons I attend the metastatic prostate cancer clinic alongside my CNS colleagues Shievon Smith, Michelle Greenwood and oncology consultant Dr Jonathan Shamash. My role in clinic is to support patients by providing information and advice about their diagnosis and treatment, as well as performing holistic need assessments reviewing any physical, practical, spiritual, psychological, or financial needs.

Our Macmillan Navigator, with support from the CNS team if needed, will then create a personalised care plan to help address these concerns.

We also run a busy nurse-led clinic reviewing patients on treatment assessing any toxicities, reviewing blood results, and ensuring patient are happy to continue treatment if safe and in the patients' best interest. On occasions a patient will present to clinic with a clinical concern, and the CNS team can undertake a comprehensive psychical assessment if required to try establish any causations and formulate a plan. We support patients during bad news and signpost to any support groups/charities such as Tackle Prostate Cancer and Prostate Cancer UK. Outside of clinic we are contactable via email or phone during office hours if patients need further support.

Community chat

This is the section where we share any resources, social accounts or websites that might be of use to you. If you have any you would like to share, we'd love to hear them: editor@prostatecancer.org.uk

Fancy a laugh?

One of the member's groups, the brilliant Cancer Don't Let it Win CIC, is hosting a night of laughter through comedy for prostate cancer awareness fundraising. The evening is to raise money and awareness for prostate cancer. Join them for a night full of laughter, busting the myths surrounding prostate cancer. Happening on June 1st 2023, at The Front Room in Croydon, London. Get your ticket at bit.ly/3pL9lkX

If you can't make it to the event, be sure to check out the support group to see what they're up to. They hold regular events and workshops throughout the year!

Get Involved

Have you heard of The Association of Service Drop-In Centres (ASDIC)? Well, earlier in the year we had two of their representatives talk to our Support Group Leads about their service. So, if you haven't heard of ASDIC before, it's an organisation that represents and links veterans' Drop-Ins across the country. Sometimes called Hubs or Centres, the ASDIC Drop-Ins offer a variety of welfare and mental health support, together with comradeship and a sense of well-being, to the ex-military community and their families.

With over 150 Drop-Ins across the country, ASDIC helps each hub to enhance the service they can provide and make them more accessible. If you're part of the ex-military community or a family member who is living with or affected by prostate

cancer, then definitely think about reaching out to ASDIC for their support. Find out more information: <https://www.asdic.org.uk/>



Have you phoned our helpline?

- 0800 035 5302

Thanks to our amazing Helpline Volunteers our Tackle Helpline is open 365 days a year 9.00 am to 9.00pm. It is always answered by someone with a lived experience of prostate cancer.

Callers are encouraged to talk about their current situation; which varies from a new diagnosis to stage 4 of the disease. With an understanding of being diagnosed, treated, and living with prostate cancer our volunteers can offer emotional support and advice based on their lived experience. You can also email us at helpline@tackleprostate.org

For regular updates on industry news, what we and our support groups are up to, why not follow us on social media!

 @tackleprostate
 @tackleprostate
 @tackleprostatecancer
 @tackleprostatecancer

Or, browse our website www.tackleprostate.org.uk. Here is where you'll find information about your nearest support group.



Together We Tackle

"Tackle Prostate is a brilliant charity. There are a lot of people who are diagnosed but aren't coming forward, especially those from the Black community. Maybe they don't know how, or they're scared. We encourage people to come forward & join the Tackle Prostate support groups."

- Warren | West Midlands Support Group member



Through our national network of support groups we unite, guide & hero those living with or affected by Prostate Cancer. Find a local support group today at tackleprostate.org/supportgroups

Tackle Prostate Cancer is the campaign name of The National Federation of Prostate Cancer Support Groups, Registered Charity No 1163152. A Company Limited by Guarantee. Registered in England No: 9672970. Contact us at info.tackleprostate.org