

Tackle achieves great Lottery win!

We are delighted to announce that we have been awarded funding by the National Lottery for our project Tackling Prostate Cancer – peer-to-peer support for men with prostate cancer. The grant is for just under £238,000 over three years.

Here are the three main aims for this project:

- to increase the number of patient-led cancer support groups, particularly in areas where there is currently a lack of provision
- to support and encourage existing groups and increase membership by at least 10%
- to ensure that we are reaching out to all members of the community whatever their background.

A key element of the funding is for a National Support and Development Manager to help us to achieve these aims. We will let you know more details about this position in due course.



We don't need to tell you the benefits of an effective support group and we want to tap into that vital experience. Many groups contributed to our online survey back in May, the answers to which provided much of the background to our application and helped towards its success. We will be conducting more surveys during the project and trust that you will continue to help us. We need your support!

This is a really excellent start to 2020! It's a great opportunity to help more men – and their families – feel less isolated, better supported and more empowered to navigate their cancer journey.

Our thanks to the following who provided so much towards our successful application:

- All the support groups and members who contributed to our online survey.
- Ferha Farooqui who prepared the application and whose experience with Lottery applications was vital.
- Roger Wotton who instigated the project, oversaw it and, in two very long conference calls with the Lottery, conveyed real passion and enthusiasm for it. This will be a lasting legacy to him.

There is a full tribute to Roger Wotton on page 2.

Tribute to Roger Wotton, Tackle Chairman 2015–2019



We were all extremely sorry to learn of the death at the end of November of Roger Wotton – Tackle Chairman for the last five years.



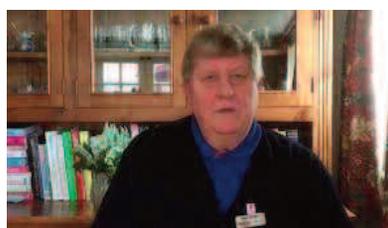
Roger at Tackle AGM, June 2019

One of his most important contributions to the success of Tackle was his determination to visit as many prostate cancer support groups that form part of 'the Federation' as possible – wherever they might be. We know that groups all over the country really appreciated him making the effort to come and listen to them, and tell them personally what Tackle was doing to help them.

When Roger first took over, Tackle had a Chief Executive but she left after 18 months. Roger was already doing an enormous amount but, in order to save money, he decided to take on that role as well, effectively becoming Executive Chairman. It became almost a full-time job for him: criss-crossing the country talking to groups, meeting representatives of the pharmaceutical industry to secure vital funding, attending meetings with all sorts of pressure groups to campaign for improvements for prostate cancer patients, and appearing on TV and radio to spread

awareness. He knew that he was doing too much and was extremely grateful to his wife, Susan, for tolerating his extended absences! She knew just how important this work was to him.

All of Roger's efforts have meant that Tackle is now in a far stronger position than ever before. Tackle is now very well-known across the prostate cancer community and has extended its reach dramatically, not least through his fundraising and awareness initiative Cycle to the Moon. Equally importantly, it has become financially sound and we now know that one of Roger's lasting legacies will be the success of our application to the National Lottery, which he initiated.



Roger on YouTube explaining his favourite image: 'Why the walnut?'

We've already talked about Roger's boundless energy in achieving these things for Tackle. But we should also remember his enthusiasm and his altruism. Roger was passionate about making people aware of the importance of early diagnosis in prostate cancer – best illustrated by the walnut he always carried with him

to whip out at every opportunity to explain the vital importance of that walnut-sized organ, the prostate gland.

And it was never handier than during the recent 'Save a Dad' campaign to illustrate brilliantly to children what the prostate is and why they need to be aware of it.



Image for interview with Sarah Lowther on Mixcloud

Roger in his 'Save a Dad' T-shirt — and walnut!

And he did all of this because he desperately wanted to make other people's lives better, an ambition he pursued tirelessly.



Roger presenting tirelessly, as usual

The members and Trustees of Tackle sincerely appreciate the fantastic work that Roger did. We shall sorely miss his passion, humour and drive. We have all lost a dear friend and shall certainly be keeping up the fight against this terrible disease in his memory.

tackle
prostate cancer

Prostate Cancer Research Centre works with Tackle on Patient Voice

The Prostate Cancer Research Centre (PCRC) funds research into advanced prostate cancer. Tackle is helping them with their research on ways to improve the development of treatments that the PCRC funds, via a project called Patient Voice.

Patient Voice is evolving in collaboration with men affected by prostate cancer. It is designed to help make medical research accessible to non-experts, and to highlight how important it is to take lived experiences into account when developing treatments.

Patient Voice aims to devise and deliver innovative activities that provide men with a platform and help them feel comfortable giving their opinions on medical research projects and become more involved in decisions that affect prostate cancer-related health research.

In one example, opinions are being sought via workshops at support group meetings, asking questions such as:

What are the biggest challenges men face when being treated for prostate cancer?

What sort of information would be most useful to men during treatment? And could this information be improved?

Tackle trustee John Coleman said,

“We are pleased a couple of our support groups could get involved with this pilot project.”



PCRC poster for Patient Voice

New Manversation leaflet

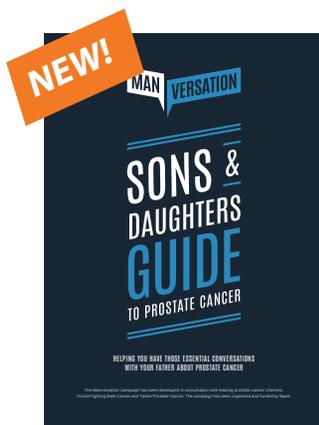
Manversation is a campaign to encourage men to speak about prostate cancer, particularly advanced prostate cancer. ‘How to’ booklets on how to broach their concerns and issues have already been produced for cancer patients themselves, for women, for family and friends and for experts. The campaign has been generously funded by Bayer.

A Manversation survey revealed that over half of sons and daughters avoided talking about prostate cancer with their fathers for fear of upsetting them, although they had questions they would like to ask. Many agreed that they would like to feel more confident about having such conversations.

In response to these findings, a new booklet, **Sons and Daughters**, has just been published. Simon Greenstreet, Head of Communications at Bayer, said:

“We hope that by providing real-world, insight-based support and practical advice, we can help motivate and equip men and their families with the tools to have these difficult conversations.”

This booklet and all the others in the Manversation range are available online and in printed form from **Tackle**.



New Manversation Sons and Daughters leaflet

Tackle trustee Alphonso Archer and his son, Josh, were interviewed on ITV along with Ali Orhan from Orchid, the male cancer charity, about the importance of the Manversation series.

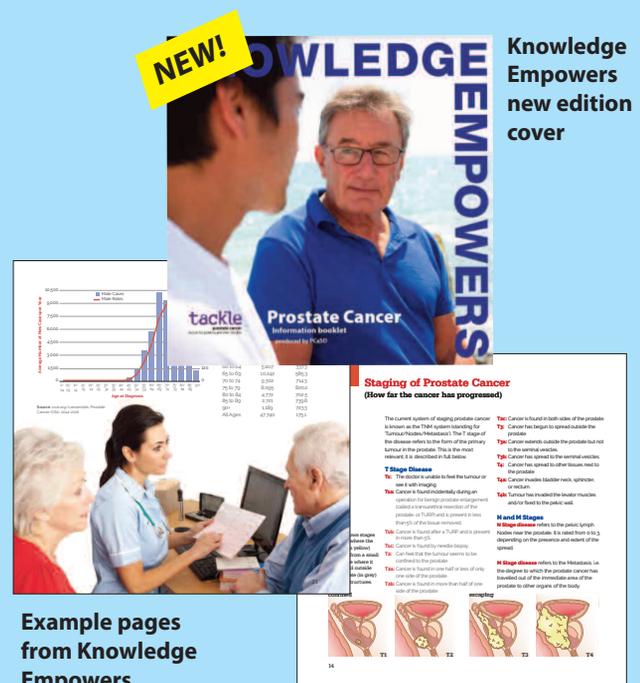
Knowledge Empowers – new edition

The acclaimed booklet, **Knowledge Empowers**, has been extensively revised by PCaSO Prostate Cancer Support Organisation.

It is an information booklet which provides a comprehensive guide, from a patient’s perspective, to most aspects of prostate cancer. It aims to help men diagnosed with the disease (and their partners, friends and family) to understand about prostate cancer and its effects in order to have sufficient knowledge to give them confidence when talking to health professionals, such as GPs, hospital consultants and specialist nurses.

Tackle are pleased to announce that a new edition is now available, containing all the most recent advances and information. It is available online and in printed form from Tackle at www.tackleprostate.org/infosheets.php.

We are extremely grateful to the trustees and officers of PCaSO for permitting us to use this booklet.



Example pages from Knowledge Empowers

Evaluating psychological support services available for men living with prostate cancer and their carers and families across England

Tackle are very pleased to announce that the results of our Freedom of Information request to all NHS Trusts regarding the availability of psychological support for men with prostate cancer and their families in England and Wales have been published in *BJU International*.

This study was initiated by Roger Wotton who believed strongly that the emotional and psychological aspects of prostate cancer can be more debilitating than the physical manifestations of the disease. He wanted to find out what support the NHS offered in this area.

The report states, "It is concerning that NHS-commissioned services, where they exist, seem to be under pressure and 28% of hospital Trusts have no NHS-commissioned psychological support services ... and therefore rely on psychological services offered by national and local charitable organisations." This underlines how important prostate cancer support groups are in providing the emotional and psychological support required.

Read the full report in [BJU International](#) online. Or see the print version of the BJUI.

Summary of responses

The response rate to the FOI request was 87% (18 Trusts did not respond). Here are some of the findings:

- Only 28% of Trusts had a record of the number of men being offered and referred to psychological support services.
- 36% of Trusts offered psychological support services to the majority (90% or more) of men with prostate cancer.
- 74% of Trusts offered families and carers a psychological support service.
- 93% of men living with prostate cancer beyond active treatment had access to psychological support services.
- Only three Trusts said all men living with prostate cancer were referred to a psychological support service when offered.
- Seven Trusts did not routinely offer or have access to psychological support services.

The services offered varied enormously, from specialist support to providing a Macmillan booklet on the subject. It seems likely that psychological distress for men living with prostate cancer is ongoing, with peaks and troughs during the cancer journey, and that therefore many levels of support should be available in each Trust.

- 76% of existing psychological support services are delivered by charitable organisations.
- 67% are delivered by NHS-commissioned services.

The findings show the NHS seems to be over-reliant on charities, some of which are starting to raise concerns about the sustainability of this model. Most services offered by charities are volunteer-led or supported through fundraising. The report concludes: 'For these services to be sustainable and fit for purpose there needs to be a national framework in line with clinical guidelines and underpinned with Government funding, so that there is a more consistent and equitable approach to providing psychological support for men with prostate cancer across England.'

Tackle is very grateful to trustee Frank Chinegwundoh and Roshani Perera of Wicked Minds who prepared the paper.

The National Prostate Cancer Audit – can you help?

Steve Allen writes:

Following on from my recent article in *Prostate Matters* (November 2019), I am now actively looking for some members who would be interested in joining a group of patients to become involved with the National Prostate Cancer Audit.

The NPCA produce some of the most accurate and up-to-date figures concerning PCa and its treatment in England and Wales. Data is very carefully collected from many sources and scrutinised by a team of statisticians and renowned clinicians.

In order to ensure they are producing what the public needs, the NPCA would like to increase the input from the public and patients.

Fuller details can be found in the

[NPCA website FAQ sheet](#)

Please do give some serious thought to whether you would like to become involved. It's an initiative that is very important in promoting the views of the people that matter – the patients.

Meetings are normally held twice a year in London, but we are anxious not to be centred just on London and the south. We realise access to treatments varies across the country and it's important to have as wide a spread of opinion as possible. Travel expenses will be reimbursed. If you'd like to discuss any of this, please email me: drstephenallen@btinternet.com.

Thank you.
Steve Allen, Patient Representative,
Tackle Prostate Cancer

Have your say

Give patients a voice

Reaching the parts other messages can't reach...



Available free from **Tackle**, these beer mats promote the Save a Dad campaign and explain the 'Why the walnut?' image to spread the message about prostate cancer and the importance of getting tested, as well as encouraging people to fundraise.

And all this in the informal, friendly atmosphere of the pub, a place where men are known to gather and chat...!

Why not ask your local landlord/lady if they would accept some Tackle beer mats? Or print your own mats like the Beds PCSG did (see oppostie).

Support Groups and diversity

Leighton PCSG and the LGBT+ community; a report by David Laundon, Chairman Leighton Hospital PCSG

While at a Health & Wellbeing Fair promoting PCa awareness recently, we talked with another stallholder there called BodyPositive. They are a local group based in Crewe representing the LGBT+ community, promoting healthy sex and relationships. One of our members was talking to them about prostate cancer awareness and the private PSA blood testing that we carry out around Cheshire.

I then received an email approach from Dr Christopher Thomas Tomkinson, their Health Promotion Specialist. I spoke to him and said that we would welcome the opportunity to offer them PSA testing. He made it clear to me that even their gay members would shy away from our public testing events, even though I assured him that sexual orientation was not an issue for us at all.

It seems their reluctance stems from many years of misunderstanding and mistrust.

We suggested that our Support Group go into their community to talk about prostate cancer and the risks to both their gay and transgender members. We are very keen to demonstrate that our Support Group is inclusive. Once we have gained their trust, we have proposed arranging an exclusive PSA testing event at their community hall, with members of our Group that have done the initial talks, plus one or two of our trained phlebotomists. We have assured them of privacy at every stage. We now wait to see how this will progress.

We reported these developments to our Group members and distributed the minutes of that meeting to all

members, including colleagues in Macmillan and Urology.

This was the response from a Consultant Urologists at Leighton hospital:

I've just been reading the Group meeting minutes and wanted to say how impressive it is for the Group to be embracing the particular challenges around PSA testing in LGBT+ communities. I have had a few transgender people in my clinics and know how challenging getting PSA testing and a biochemist who can correctly interpret the result can be. Particularly important as research suggests transgender people are at higher risk of some cancers than cis people.

Leicester and the African/African-Caribbean community

Robert Banner, Tackle trustee and member of PROSTaid, Leicester, sent us these photos from events with their PROSTaid African/African-Caribbean Support Group in Leicester. The group was set up in 2018 and has been very successful, with an average attendance of around 67 men and their families at each gathering. The group has fulfilled a need of the local African/African-Caribbean community, as it is known that black men are often reluctant to talk about illness.

PROSTaid is at the moment planning to set up a similar Asian group. It is considered that, if there is greater success in getting men from ethnic minorities to talk about prostate cancer with others from the same community, then groups such as these are a worthwhile and important service to provide.



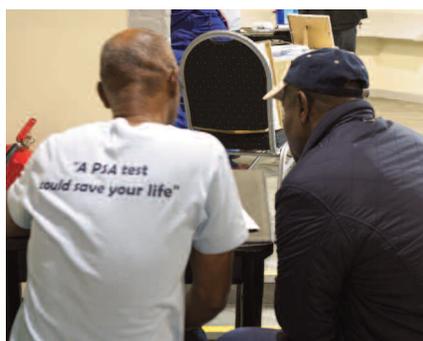
Rob with attendees at a meeting of the Leicester African/African-Caribbean support group

Beds PCSG, PSA testing and BME groups: a report by Brian Webb, Chairman Beds PCSG

The Beds PCSG pride themselves on holding as many PSA testing events as they can.

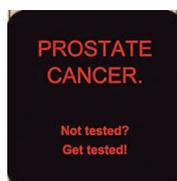
In 2019 they put on three events with a total of 738 men being tested. From the results, 37 Red, 21 Amber and 681 Green letters indicating whether further testing should be requested were sent out.

As they have found it difficult to get BME men to attend PSA events, they held one in Bedford specifically for African/African-Caribbean men and 61 attended it.



Men talking at the Bedford BME PSA testing event

Photo with thanks to Cultural Aspects Photography



Personalised beer mats

In other news about the Beds group's efforts to reach as many men as possible, they have started distributing their own personalised beer mats to local pubs which have their collecting tins in. The pub landlords/ladies readily accepted the mats. There's a punchy reminder on the front of the need to get tested. The back has details of why and how to do it.

The group is hopeful that just seeing the beer mats might prompt some men to get tested. They bought 10,000 beer mats for £289 (excl. VAT). If distributing them saves just one man's life that's a very small outlay.

Save a Dad/Uncle/Grandad in Manchester: a report by Phil Ormesher

This initiative began with a request via Prostate Cancer UK to deliver a series of four assembly talks at Burnage Academy (boys of 11–16). I decided that the theme of 'Save a Dad', established by the late Gary Steele MBE (one of Tackle's stalwarts) would be very appropriate.

After the talks, the organiser sent a letter to the Manchester Healthy Schools Programme, saying: 'I wanted to let you know about a charity organisation we had in school last term. They delivered 4 assemblies over 2 weeks (which were) well thought out, age appropriate and well delivered. Our students and staff said they were by far the best assemblies given by a visiting speaker.'

This led to a meeting with the Manchester Healthy Schools Programme in which they asked me to present the 'Save a Dad' theme at their 'Voicebox' meeting.



Voicebox is a pupil participation network for secondary schools which encourages Manchester pupils to use their voices in meaningful and effective

ways. The idea is to increase participation and engagement so that young people in Manchester schools are linked to, and represented at, strategic and decision-making levels in the city.

I attended the Voicebox meeting in October 2019 and delivered my 'sales pitch' inviting them to take the initiative into their schools. The talk went well, evoking huge interest and some excellent questions from the audience of 40 boys and girls, mainly aged 11 to 16, plus some teachers.

I have since received two requests to become involved in schools in South Manchester; one arrived immediately after the talk before I even got back to my car! I am hopeful there will be more.

A workshop after the talk threw up some excellent initial ideas. This one from a pupil could prove a winner:

'Schools have lots of IT screens. If we had a 'Save a Dad' week at a school we could do a screensaver with the logo etc. which would be on every PC in the school – highly visible and in your face.'

One of the highlights was meeting a teacher and one of his pupils at the Pupil Referral Unit (PRU) in Manchester. The PRU is mainly for Year 7 and 8 boys who are excluded from mainstream school. Apparently this pupil normally says little but, for some reason, at the event he was totally involved. On his return to the PRU he presented his version of the session at Voicebox to his fellow pupils. Brilliant!

Comment

We are extremely grateful to Phil for getting involved and doing these talks. Tackle is committed to early diagnosis and the Save a Dad campaign is a key part of that. We are actively trying to get prostate cancer awareness onto the PSHE part of the school curriculum in the same way that breast cancer is. We have written to the Chief Medical Officer and have received a holding reply. We will keep you posted!

Surveys and studies

Caterina Gentili, a PhD student who reported on her body image survey findings in the last issue of Prostate Matters, is conducting an online survey aiming to shed more light on the daily experience of men with prostate cancer who are currently undergoing hormonal therapy (ADT). Find out more at:

https://uwe.eu.qualtrics.com/jfe/form/SV_0cSA4Z8sXU2eB3n

Imperial College, London, has approved a study about how to better support patients in the consenting process for surgical clinical studies. They want to talk to survivors of prostate cancer, their families and friends to see how these conversations can be improved. If you are interested in taking part, contact Francesca Oldfield at:

fro18@ic.ac.uk

New hope for men in Scotland with advanced PCa

The Scottish Medicines Commission has approved the use of Abiraterone as additional therapy to standard hormone therapy (ADT) for newly diagnosed men with high risk, metastatic, hormone-sensitive prostate cancer.

Combination therapy has been shown to give significant benefits to these men compared with standard ADT alone. Chemotherapy (Docetaxel) is already used in this context. This approval gives men a choice for therapy, and those unsuitable for chemotherapy additional hope. A similar appraisal is being assessed by NICE for the rest of the UK. For further details see the [Tackle](#) website.

Report: Steve Allen, Patient Representative, Tackle Prostate Cancer

ManVan update



We hoped to be able to report to you in this issue that the ManVan is available for use by your group, but there are still some issues to clarify.

We don't yet know how far it can be taken and for how long, nor if the price increases the further it has to go. We also want clarity on insurance.

If your group is interested in hiring the van for awareness, please email Simon Lanyon at:

simon.lanyon@tackleprostate.org

We will report progress again soon.

Letter to the Editor

In the November issue of Prostate Matters we published a heartfelt article by Timon Colegrove about his positive experiences with Proton Beam Therapy (PBT). It prompted this response from reader Ian Ferris.

Dear Editor,

I'm a very new member of Prospect, the Bristol PCSG, and yesterday received my first (November) issue of Prostate Matters in which I read the inspiring article from Timon Colegrove about his successful treatment by Proton Beam Therapy.

I was glad to read his good news story, but I did feel that his article gave a very negative and even alarming message regarding the surgery option. My own, very recent, experience of diagnosis, consideration of treatments (including PBT), and eventual choice of a radical prostatectomy through the NHS were extraordinarily different from Timon's expectations.

My robot-assisted keyhole operation was undertaken just five weeks ago today. I received the very best advice, care and experience and have been told I may return to the gym next week. I had no incontinence problems or pain, plenty of 'sensation' and a hugely relieved smile on my face. I realise that not everyone is this lucky, but I felt that other newly-diagnosed patients might be put off surgery by Timon's article and was surprised that there was no footnote about the availability and success of other treatments.

Ian Ferris



Thank you, Ian, for your letter. There is a lot of controversy at the moment regarding the effectiveness of PBT and its availability. Tackle supports the use of PBT and advocates that it should be available on the NHS, so we felt that Timon's article was timely and interesting.

However, we take your point about the possible alarm it might have caused newly-diagnosed patients and agree that a reassuring note about other treatment options would have been appropriate. We will bear this in mind in future.

Spreading the word at Santander

In November 2019, several Tackle talks were arranged at Santander sites around the country. Santander is keen to raise awareness of prostate cancer and the need for testing among their personnel.

Three groups took part in the initiative: Leeds PCSG, Reading PCSG and Milton Keynes PCS. They gave talks in, respectively, Bradford, London and Milton Keynes.

Tackle are extremely grateful to all the groups who helped to spread the word.

Tackle talk at Santander Head Office

Ian Yearwood, David Hedley and Graham Johnson, of Leeds PCSG presented to an audience of 20 people at Santander's Head Office in Bradford.

Ian sent us this report:

To make a contribution to International Men's day on 19 November 2019, Santander invited Tackle to give a presentation on prostate cancer.

David and Graham gave a brief synopsis of their prostate cancer journeys, and Ian talked about the awareness of prostate cancer in general and the need to get checked out as you get older, or experience any untoward symptoms of the urinary tract.

Everyone was very appreciative of the event, especially the reminder that all men have a prostate, an overview of the problems that could be encountered and the support available.

Gillian Finch who organised the events, said:

“Once again I would like to say thank you so much for helping me in achieving getting speakers to three of our sites ... The feedback I received was fantastic ... Following the talks in Milton Keynes, three attendees confirmed to me they had booked PSA tests.

What I found really good was all of the speakers are either living with or have been through prostate cancer which ... made it real and easier to understand and take in.

(Everyone) felt at ease asking questions, either in a forum or one-to-one afterwards.”

Good news follow-up

Following an article in our last issue about a charity ball held by Peter and Sharon Constable to raise money to fund a PSA testing session, here's a photo of Peter handing over a cheque for £5000 to Martin and Gillian Conlon of Shirley Lions, who will be organising the testing event at the Methodist Church, Shirley, on Saturday 18 April.

A cheque was also given to the Solihull PCSG in appreciation of the advice and support Peter received from them when he was diagnosed with prostate cancer in 2018.



tackle

prostate cancer

www.tackleprostate.org

The National Federation of Prostate Cancer Support Groups

Tackle Prostate Cancer is the campaign name of The National Federation of Prostate Cancer Support Groups. Charity Registration N° 1163152.

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Information officer: Alan Ashmole

NICE coordinator: Steve Allen

Regional coordinators:

John Coleman	North West
John Burton	London
Brian Jones	Wales
Robin Millman	North East
Sandy Tyndale-Biscoe	Western Counties
Allan Higgin	South East

Our support

Group Liaison	Simon Lanyon
PR & Marketing	Siobhan Connor

Prostate Matters delivery

Your individual copy of Prostate Matters is delivered to you from your local prostate cancer support group. If you have a change of address or any other notifications, please would you contact your local support group.

Check your details

Unless otherwise requested, your details will appear on the list of groups on our website.

We ask all affiliated groups to check their details on the Tackle website. The information has been updated to include meeting times and places.

See the map at: <http://tinyurl.com/omp6y5e>

If you require any corrections, please contact
Simon Lanyon: simon.lanyon@tackleprostate.org.

Helpline

0800 035 5302

Our telephone helpline
is manned
by prostate cancer patients,
for patients and their
families

365 days per year

9:00am to 9:00pm



PSA testing events

If your group is holding a PSA testing event, we'll add it to the list on the Tackle website. Email info@tackleprostate.org with the date, time, town, postcode, contact name and phone number.

Editor's note

Many of our articles contain links to information on the internet.

The best way to access these is to go to our website: www.tackleprostate.org where you will find the web edition of this and past issues of Prostate Matters with live links.

Contribute to Prostate Matters

Without you, we would not exist! Please keep contributions coming to: editor@tackleprostate.org (send photos separately at high resolution).

Edited by Cheryl Lanyon
Printed by Zipp Design

Thank you to everyone who contributed to this edition.



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