Firstly, we hope you and your family are staying safe. The pandemic has caused huge disruption, including inevitably to prostate cancer patients.

We are aware that many support groups have been working really hard to carry on supporting their members with tremendous virtual meetings (see article on page 2).

Meanwhile, the strain on the NHS has meant millions of delayed cancer treatments, causing much suffering. Read what Tackle has done to lobby the NHS and government on page 6.

We can ALL help. Many organisations need prostate cancer patients for research and studies. Steve Allen (Tackle’s tireless Patient Representative) shares one opportunity below.

Sharing your story... Sharing your experience

Pharma says: “We seek patient and carer insights at every stage... ensuring that we are working towards outcomes that matter most to patients.”

Would you be happy to share your story with others?

Pharma says: “We wish to engage in activities that help the public better understand the impact of living with prostate cancer...”

The treatment of prostate cancer is determined by definitive treatment guidelines. Research into new drugs, clinical trials etc. require close monitoring of patients and meticulous recording of ‘hard’ data – often including how quality of life is affected. However, this does not always capture the intricacies of how patients (and equally importantly their carers) really feel about themselves and their treatment; their concerns for their future and their disease.

Those involved in the pharma industry – the marketing people, information managers, research scientists, statisticians etc. – rarely have personal experience of the drugs they produce and the diseases they are dealing with. The industry recognises this and companies are keen to ensure they have a full understanding of patients’ needs. Sometimes they do this through formal ‘Public and Patient Involvement’ groups but possibly more valuable is the opportunity to talk with patients and carers on a one-to-one basis.

Since companies are not allowed to contact patients directly, organisations such as Tackle are often asked for their help in finding people willing to talk to them about their journey with prostate cancer. Understandably, the areas of particular interest can sometimes be those that were traumatic for the patient: being told you have cancer, treatment of advancing disease, the spread of the disease. This may not be easy, but speakers are always treated with the utmost sensitivity and respect. It is really important that all people involved in the management of prostate cancer know what it is really like.

Could you do it? Want to know more?

Please contact me:

Steve Allen
Tackle Patient Representative
Email: steve.allen@tackleprostate.org
Mobile: 07809 563879

PCa speaker says: “It wasn’t easy re-living the whole process... but I felt I was doing something worthwhile...”

PCa speaker says: “They were surprised at the information topics I found important – ones they had not rated as such.”

Pharma says: “We seek patient and carer insights at every stage... ensuring that we are working towards outcomes that matter most to patients.”

PCa speaker says: “It wasn’t easy re-living the whole process... but I felt I was doing something worthwhile...”

“Sharing your story... Sharing your experience”

CAN YOU HELP?
Throughout this issue you will see this logo introducing various ways you could join in and help fight for better treatment for prostate cancer patients.
Update from Sarah Gray, Tackle’s National Support and Development Manager

These strange times of restrictions and lockdown have meant that I still have yet to meet any of you in person. Despite this I have been fortunate to meet many people from all over the country, from Cornwall to Tyneside, from the comfort of my office chair via Zoom.

I have heard about the great work that is being done by countless volunteers across the country, all determined to support people living with and beyond a diagnosis of prostate cancer and raise awareness in the wider population.

I have attended many groups as both an observer and a speaker, to talk to members about our work at Tackle and outline my project. Groups may have fewer than ten members, or more than 40, but they all display a strong sense of community and fellowship.

I continue to learn valuable information on how we can support the groups to reach more people living with prostate cancer and we are working to plan some Listening Events which will bring groups and members together to explore ways to grow their membership. I am also working with some trustees and our fantastic PR support, Siobhán, to find ways to improve communication with groups.

I am looking forward to getting to meet more of you over the coming months and working with you and your Group Leads and Committees to reach more men, carers and families who could benefit from the support given by your groups. By working together we can make sure that people living with prostate cancer do not feel alone and can draw strength and support from those with similar experiences.

Please do get in touch with me, invite me to your group, or drop me an email at sarah.gray@tackleprostate.org

Support through Zoom

Reading Prostate Cancer Support Group is one of the many groups who have successfully moved to offer their monthly meetings over Zoom.

We caught up with Chris Addison their current Chair to ask him for his top tips for a successful Zoom meeting.

Chris told us that the most important point about the Reading PCSG meetings is that they have continued to be on the first Friday of the month, just as the meetings in person had been. They follow the same format, but now it is all online.

6.15pm Meet and Greet, (time to get comfy, sort out technical issues and to welcome any new members)
6.40pm Introduction and notices
6.45pm Start talk/presentation including Q&A session
7.30pm Open forum for members and guests to discuss subjects of their choice, mainly related to prostate issues
8.30pm Close – but this is often later!

Before the pandemic they held walks and coffee mornings at a local pub. Between full lockdowns, they enjoyed some walks and pub/garden centre meet-ups with smaller numbers.

Chris says, “pleasingly, our meetings have been attended by members from other groups around the country, which have enriched discussions”; and “our members seem to have benefited by remaining in contact and discussions and questions, even over Zoom, have become quite detailed and challenging, showing an engaged audience ready to support one another”.

However, concerns remain especially around how groups promote themselves to new members. Chris reports, “our biggest concern is that awareness-raising activities have ceased and gaining new members from newly diagnosed people has dropped off considerably”.

Compass Prostate Cancer Support Group used to meet in Slough, and now meet monthly on Zoom as well as running an informal drop-in Zoom on a Friday morning. David Manthorpe, their Chair, told us that they started the Friday drop-ins during the first lockdown, when he was on furlough. Concerned that many members would miss the support they received during physical meetings and become isolated, the Friday morning chats have become a lifeline for many. Knowing that problems could be discussed and shared on a Friday, before the weekend loomed, has galvanised the support given by the group.

One member who lives alone described the group as a huge help with feelings of isolation during lockdown and described it as feeling they had become “like a band of brothers”. This was echoed by another member, who said the group gives him “a sense of belonging to a group that cares and has experience in dealing with my concerns, also we have experts coming to the Zoom meetings and giving their advice which is invaluable. I cannot emphasize enough the valuable support this group gives me”.

If your group hasn’t managed to make the move to virtual meetings and support, or if you want some help in promoting your group, please contact Sarah:
Email: sarah.gray@tackleprostate.org
Mobile: 07725 083533

Free Help Line - 0800 035 5302
For many men diagnosed with cancer, the period of post treatment can be as difficult as the treatment itself. Patients often struggle to adapt to life after cancer and anxiety and depression are common emotions which can be surprising and difficult to manage.

‘Cancer Coach’ is a six-week online and telephone support group, developed in partnership with The Mental Health Foundation. ‘Cancer Coach’ is a unique service that focuses solely on providing post treatment support for men living beyond their cancer diagnosis, where they can access support from the comfort and privacy of their own home. Another benefit is that it brings men with a shared experience together, where comfort and reassurance is given through peer support.

Our men’s group is facilitated by a male facilitator and gives men who have completed treatment the chance to speak about how they are feeling, how they are managing the physical and emotional side effects of treatment and how they can move forward past their diagnosis and navigate the future.

The service is free of charge and is available to anyone aged 18 years or over, living anywhere in the UK. Participants can choose whether they would like to join an online (Zoom) group or a phone group and they can also choose between a daytime or an evening group.

These are a few quotes from previous participants in ‘Cancer Coach’:

“It was designed to enable proactive living with cancer rather than to give sympathy... it made me realise I was allowed to feel this way.”

“Thank you for saving me from isolation. It has been extremely hard to have cancer during the pandemic. Thank you for caring.”

“Just to have my feelings validated... it has made my year to know I’m not alone.”

Self-referrals are quick and easy either by filling in the form on our website www.cancersupportuk.org or emailing cancercoach@cancersupportuk.org

Anna James, Head of Services, Cancer Support UK

We have been aware of the importance a review and analysis of our data might have for research purposes for some time, particularly given it now covers more than 153,000 results from over 103,000 men in more than 77,000 different postcodes in the UK.

This project will cover not only an analysis of our results but also men’s attitudes to genetic testing and other factors which could help improve the diagnostic pathway for prostate health conditions for future generations.

To this end, ALL men who have received an ‘abnormal’ letter (Red or Amber) between 2010 and 2020 will be contacted over the next few months to ask whether, having previously indicated they would be happy to help with research, they are willing to take part.

We appeal therefore to any man who has received either of these colour letters over this period to participate in this very important work. Even if you have already kindly supplied information about your diagnosis, involvement in this project will be a huge help to us. The questionnaire, while only taking ten to fifteen minutes to complete, has several key questions in areas such as genetics which will enable the researchers to write a much more meaningful report at the end of the project.

Moreover, even if your letter was a Green one, involvement in the research will be invaluable to us, particularly if your score was at the upper end of the range for your age.

Please feel free to share this project with any of your friends who may have had a test result either directly from us or from one of the many Prostate Cancer Support Groups, Masonic Lodges, Lions Clubs, Rotary or other groups for whom we send out the results. The more responses we can get the better, and the more chance we have of making a real difference.

If you would like to participate in the research, please go to the following website and answer the questions.

www.mypstatests.org.uk/Research

If you have an account on our website, please log in with your username and password.

GFCT in conjunction with MANCHESTER UNIVERSITY have just launched this 2-year project. 50,000 men are needed to participate

CAN YOU HELP? ... with an exciting new research project?

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CAN YOU HELP?
Could you get involved in shaping the future of prostate cancer treatments?

Tackle are looking for someone who would like to become involved in the development of new pathways for the approval of new treatments – including for prostate cancer.

With Brexit, the system of regulation for new drugs is changing (see ‘Brexit and drug authorisation’ opposite).

The MHRA (the Medicines and Healthcare products Regulatory Agency) are planning a new ‘Innovative Licensing and Access Pathway’ to cope with the change in legislation that Brexit will demand.

This will be an extension of the existing EAM (‘Early Access to Medicines’) scheme. This scheme already enables very early access to new treatments where it is established that the treatment confers such great benefits that it is deemed inappropriate to withhold the drug until the more lengthy and complex process of formal marketing authorisation has been completed.

A very recent example of this is the new anti-viral drug Remdesivir. This has broad activity against many viruses but has yet to get full authorisation. However, because of its recently proven successful activity against Covid it has now got limited approval for use under the EAM scheme.

The MHRA are aiming to get significant involvement with patients/patient support charities in the development of this new licensing and access pathway and will be urging pharma companies to involve patients at a very early stage in drug development – for instance giving patients a voice when drug trials are being set up.

This is a unique pathway – no other country is currently planning such patient involvement.

It is a great opportunity for Tackle to show its commitment to its members and to influence the development of new treatments. It will not require a huge amount of your time and promises to be a very interesting and informative project.

If you are interested in finding out more, please get in touch with Steve Allen, Tackle Patient Representative (contact details on front cover).
MHRA – the Medicines and Healthcare products Regulatory Agency – has begun intensive work in re-structuring its processes.

MHRA was closely allied to its EU counterpart EMA (the European Medicines Agency), but as a result of Brexit this relationship will change. Previously, decisions made by EMA were automatically ratified for the UK by MHRA. The UK is now free to take fully independent regulatory decisions on authorising new drugs, which will then need separate authorisation for use in the EU (and vice versa). However, this process will be gradual and no significant change is envisaged for two years.

It has also been recognised by the DHSC (Department of Health and Social Care) that supplies of medicines etc. from abroad could be impacted and they are working hard to ensure the minimum of disruption and consequent shortage of medicines, both prescription-only and more widely available products.
Tackle in action

During the unprecedented Covid-19 pandemic and the extreme pressure it has placed on NHS services, it has become increasingly clear that other hospital services, including cancer diagnosis and treatments, have been suffering. Urgent cancer services have mostly been continuing, but with the rising Covid cases due to the new variant, cancer charities are concerned that cancer services should not deteriorate.

Declaration and letter to The Times

A joint declaration urging the Government to revisit the investment decisions announced at the CSR (Comprehensive Spending Review) was endorsed by many cancer care stakeholders and sent with a letter to The Times newspaper, who published them.

The declaration

We, the undersigned, urge the Government to acknowledge the scale of the Covid-induced cancer backlog. We further urge the Government to revisit cancer related aspects of the Comprehensive Spending Review and to provide the investment required to 'super boost' cancer services to clear the backlog.

The appeal by Chief Executive of Cancer Research UK, Michelle Mitchell, to Boris Johnson demanding a commitment that cancer diagnosis and clinical trials will not be delayed again, was supported by Tackle along with many other cancer charities, including Breast Cancer Now, Prostate Cancer UK, Macmillan Cancer Support, Brain Tumour Research, Ovarian Cancer Action and the Teenage Cancer Trust.

It was signed by CEOs of One Cancer Voice charities, including Ken Mastris from Tackle.

What a result!

Tackle trustee and Walking Football enthusiast, Alphonso Archer, has sent us this cheering story. Alphonso says:

We received a heartening story from one of our Walking Football players today who emailed us with this message:

"As a result of one of your guys from Wilts FC (Alphie Archer) at the England trials encouraging men to get a PSA cancer test early, I did just that. I showed I had Stage-2 prostate cancer but identified early enough for me to have a radical prostatectomy. I had this last month and am now well on the road to recovery!

If it wasn’t for the recent lockdown I’d be back on the pitch now, better than ever!

Anyway, please thank your man who helped me catch this early – it’s a lesson for others as well."  #tackleprostatecancer

It is wonderful to hear stories like this which I am sure you would agree is great news!

Free Help Line - 0800 035 5302

CAN YOU HELP?
Penis clamps – could they be better?

Many readers will be aware that incontinence can be a very unpleasant side-effect of treatment for prostate cancer - both urinary and bowel incontinence.

Those men who are suffering from urinary incontinence may be familiar with penis clamps. John Hughes from the Prospect Bristol group certainly is and he thinks that they could be better designed, cheaper and provided by a supplier in the UK. John would very much like to hear from anybody with experience of penis clamps with a view to trying to develop an improved device.

John can be contacted at jahughes1@btinternet.com

We really hope John is successful. In the meantime, if you would like to know more about urinary incontinence and some lifestyle modifications which can help, please see www.tackleprostate.org/urinary-function.php
CAN YOU HELP?
Covid and consultations

- How are your hospital appointments currently being arranged – face to face, by telephone, by video call?
- Were you told you had cancer by phone rather than in person?
- What is your experience of a video consultation?
- Are there any advantages to a video consultation?

These questions and more like it are being asked amongst support groups up and down the country during this current pandemic. To some people a video consultation is ‘like marmite’ – you either love it or hate it! For some, video calls mean no more long trips to the hospital and no more expensive parking... the opinions are endless.

What is currently happening with the pandemic may be with us all for a much longer time to come.

Welcome to Tackle

Tackle is delighted to welcome new Partner Member, Cancer Testing South. It was started by John Goodridge and Roy Sowersby who both volunteer on our Tackle Helpline. Their mission is to organise regular PSA blood testing events for men of 40 years and over at venues across Sussex and Surrey.

Luton and Dunstable Prostate Support Group has just been created covering Luton and Dunstable Hospital, Central Beds, and North Herts. Please get in touch if you have prostate cancer, or other prostate disease, to help this group get going. Email: support@dpsg.org.uk

Prostate Brachytherapy UK Support Group was founded last year, and just held its second meeting, a combination of peer-to-peer support about treatments, and questions about after-effects answered by Consultant Urologist Julian Shah. The next Zoom meeting is 11 March, and the group will continue on Zoom as it is UK-wide.

Email: support@prostate-brachytherapy.uk

Free Help Line - 0800 035 5302
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.

PSA testing events
Due to current Coronavirus restrictions, there are no PSA testing events taking place at the moment. We hope new events will be able to start up again soon. When they do, let us know the details of your event and we’ll add it to the list on the Tackle website. Email info@tackleprostate.org

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Helpline
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Our telephone helpline is manned by prostate cancer patients, for patients and their families
365 days per year
9:00am to 9:00pm

We are grateful for the support of Astellas Pharma Ltd in the production of Prostate Matters.

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

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