September 2024 Edition 9 Vol. 9

Newsletter of the North Hampshire Prostate Cancer Support Group



## **Chairman's Chat**



Keith Jones

elcome as always to this month's Buzz.
We have now started to feel a chill in the weather and for most of us our holidays are behind us. However, this also means that we need to start planning for events later in this year and into next year. Nowhere is this more

true than at NHPCSG. We have the Malls Awareness and Christmas Lunch events to organise as well as speakers for next year.

### **Mayor's Charity Events**

On the Saturday 5<sup>th</sup> October there is the Mayor's Variety Show at the Anvil where we will be assisting with distributing programs, drinks and collecting donations as well as having our publicity banners and materials.

One week later, we have our own big awareness event at The Malls on Saturday 12<sup>th</sup> October. We are waiting to hear if the Mayor will be making an appearance at this event. We rely on the members and committee to man (or woman) our stall and still have some gaps during the day, so if you can give up an hour or two for any of these events, it would be greatly appreciated, just let Richard White or Allan Roper know through the email <a href="mailto:info@nhpcsg.org.uk">info@nhpcsg.org.uk</a>.

Finally, as we get to the end of the year, there is the Mayor's Christmas Carol Service at All Saints Church in Basingstoke on Saturday 7<sup>th</sup> December at 6pm. Last year this event was free but as space is limited, tickets needed to be booked in advance and I expect the same will apply this year. More information will be provided when I have it.

#### **DIARY DATES**

Saturday 5th October
Mayor's Variety Show at the
Anvil

Saturday 12th October
PC Awareness Basingstoke
Malls

Thursday 31st October
Group meeting
Professor Langley, Royal
Surrey Hospital, Guildford.
Mayor Putty will also be
attending

Thursday 7th November Red Lion Hotel, Basingstoke Pub Pint and Chat

Thursday 28th November
Group meeting
Health and Wellbeing - Steph
from our Exercise Class and
Alex from 5K My Way

Thursday 5th December Christmas Lunch

Thursday 5th December Red Lion Hotel, Basingstoke Pub Pint and Chat

We now have speakers arranged for January-April 2025



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#### **Partners Group**

The partners group under the leadership of Pat Twigg, has now got into a rhythm of monthly meetings. These meetings are currently taking place on the second Tuesday of the month. The next coffee morning is planned for Tuesday 8<sup>th</sup> October at 11am, once again at the Gaberdine Bar in Basingstoke.

As I have said before, if you are a partner and have not attended before, just turn up on the day and you will be made most welcome.

Pat has also made me aware of a request via the National Prostate Cancer Partners Group from Prostate Cancer Research asking for volunteers to join a partners focus group which will take place on Tuesday 22<sup>nd</sup> October from 3:30pm to 5:00pm on Zoom. The link to the sign-up page at PCR is included in the poster or as an alternative, the QR code on the poster will take you there. There will be a reimbursement for your time.

Speaking of partners, the National Prostate Cancer Partners Support Group meet on Zoom on alternate months. The meetings start at 6:30 and are open to all partners. The next dates are:

Tuesday 26<sup>th</sup> October

Monday 16<sup>th</sup> December

For Zoom details, contact either <u>carolineOPCSG@gmail.com</u> or <u>janetldaykin@gmail.com</u>.

### **Group Visit**

We now have a date for the visit to the operational headquarters of the Hampshire and Isle of Wight Air Ambulance at Thruxton airfield. This will take place on Tuesday 22<sup>nd</sup> October at 2pm. Numbers are limited but there are still a small number of spaces remaining so if you want to attend, please email info@nhpcsg.org.uk.





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#### **Tackle Prostate Cancer**

You will have heard me previously mention the £42m TRANSFORM research programme that was launched in November 2023. Tackle have managed to arrange for one of the chief investigators to participate in a webinar later this month. This is open to all, so if you are interested, you can sign up through the link below.

## Save the Date

Monday 21st October 7.00pm-8.00pm

Webinar with Professor Hashim Ahmed, Chief Investigator of the TRANSFORM study

We are very excited to announce a bit of a coup for Tackle. Knowing that lots of people have questions about the **TRANSFORM** trial, Tackle's Vice Chair Tony Collier, reached out to **Professor Hashim Ahmed** the Chief Investigator of the TRANSFORM study, to ask if he would come and deliver a webinar and Prof. Ahmed graciously agreed.

We invite you, and your group members to join us for an exciting online event with Professor Hashim Ahmed. This will be a great chance for you to hear more about what the study is hoping to achieve and how soon it might make a difference to prostate cancer screening in the UK.

### Topics covered will include

- Why TRANSFORM is needed
- What TRANSFORM is hoping to achieve?
- What are the timescales for the trial and how soon could it make a difference to prostate cancer screening in the UK?
- · What are the different arms of the trial?
- How can Tackle's support group members help spread the word about the trial.

### Sign up here



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#### **Prostate Cancer Research (PCR) News**

#### **Proactive For Your Prostate**

This is a campaign sponsored by PCR where they are encouraging as many people as possible to write to their local MP to get prostate cancer screening on the political agenda.

This is from the *Proactive For Your Prostate* website

Our campaign recognises that the current framework of 'informed choice' is ineffective. It is inefficient at detecting clinically significant prostate cancer as well as being widely inequitable.

We aim to change this framework by highlighting the need for change to national screening policy before the National Screening Committee (NSC) decision later this year.

PCR believe that developing a screening programme to diagnose prostate cancer early should be a priority for the NHS. We understand that the current evidence shows that a PSA test by itself is inadequate. However, changes to clinical practice over the last decade mean that as a minimum a targeted screening programme for those at higher risk of prostate cancer should be introduced as soon as possible. Alongside this, greater investments must be made in improving diagnostic technologies so we can develop a universal screening programme that effectively saves lives as soon as possible. This must be a priority for this government.

The link below provides more information on the campaign.

<u>Proactive for your Prostate - Prostate Cancer Research (prostate-cancer-research.org.uk)</u>

You can include some of the text above in your communication to your MP or contact us through our email address if you want assistance at <a href="mailto:info@nhpcsg.org.uk">info@nhpcsg.org.uk</a>.

#### **Prostate Progress**

Another reminder about the initiative from Prostate Cancer Research creating a patient data platform which can then be used by those involved in research projects related to prostate cancer. Data will be gathered through online surveys at various times from men diagnosed with prostate cancer who have signed up and will cover a wide range of subjects. Some of the data requests may be repeated, for example a prostate cancer health survey will be repeated to gain information on how respondents health may have changed over time.

If you have not signed up, I encourage you to do so.

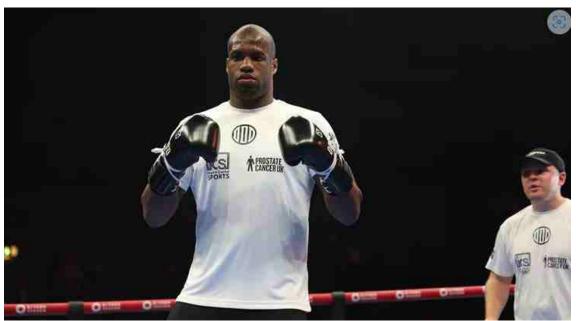
Prostate Progress - Prostate Cancer Research (prostate-cancer-research.org.uk)



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#### **Prostate Cancer UK (PCUK) News**

And the sports news. Putting aside any negative views we may have on boxing as a sport, something worth bringing to your attention is that two weekends ago, the IBF heavyweight



boxing crown changed hands in a bout between Anthony Joshua v Daniel Dubois. This was watched by 92,000 packed into Wembley Stadium along with many more live on SKY Sports. What is the

relevance to prostate cancer you may be

asking? Well, the eventual winner, Daniel Dubois, was promoting prostate cancer awareness with the PCUK logo prominent on his T-shirt and shorts and that of his team. In interviews he spoke of PC and encouraged men to take the PCUK risk checker as well as posting content on is Instagram page.

Heavyweight champion Daniel Dubois boxing clever to boost prostate cancer awareness | Prostate Cancer UK

### **Other Support Groups**

### **Reading PCSG**

Our near neighbours hold their meetings on the first Friday of the month from 6:30pm both in person and over Zoom. The venue is the meeting hall in St. Andrews church, which is next to the Royal Berkshire Hospital and is located at the junction of London Road and Craven Road. All are welcome. There is no speaker for the October meeting but I will endeavour to include details in future editions of Buzz.

They also have a Walk and Talk, and Coffee/Lunch at Dinton Pastures Country Park on Tuesday 15<sup>th</sup> October at 10:30 with Coffee/Lunch at The Coffee House at around 12:30pm if anyone is interested.

Reading Prostate Cancer Support (rpcsg.org.uk)



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#### **Living Well with Advanced Prostate Cancer**

This is a supportive group of people living with advanced prostate cancer. It meets monthly online starting at 6:00pm. The next meetings are

Monday 28<sup>th</sup> October

Monday 25<sup>th</sup> November

If you wish to attend the Zoom meetings, please get in touch with Aidan Adkins for more information.

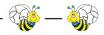
#### aidan.adkins@tackleprostate.org

#### **Christmas Notice**

Finally, a date for your diary, we will be returning to BCoT for our Christmas lunch on Thursday 5<sup>th</sup> December. Final prices will be confirmed but we are hoping to hold the price to the same as last year. Registration was opened at the September meeting but if you were unable to attend that meeting and want to join us for the Christmas lunch, let Allan know at <a href="mailto:info@nhpcsg.org.uk">info@nhpcsg.org.uk</a>. There will be a separate communication regarding menus to follow.

Well, that is all for me this month, I hope to see you all at the October meeting.

Keith Jones
Chair



## **Meeting Notes from 26 Sept 2024**

liot Stackhouse National Sales Manager for Imedicare a company specialising in continence aids and pelvic health for men and women.

Their website is <a href="https://www.myPelvicHealth.co.uk">www.myPelvicHealth.co.uk</a>. Todays presentation was obviously orientated towards equipment and aids for men recovering from PC and the effects of the treatments on penile health and bladder control.

There was considerable discussion and demonstration of penis pumps and the valid reasons for needing one to encourage normal penile health after nerve sparing surgery and other treatments for prostate cancer. It has to be said that everybody is different hence the variety of aids available.

To summarise the vacuum pump was likened to physio for the penis to help restore normal function. Ten minutes a day vacuum therapy was recommended for the first 4 weeks with a follow up once a fortnight. It is less invasive than injections or creams applied to the penis.

Continence aids ranging from washable underwear with a variety of integral pads absorbing from 150 to 650ml, which were claimed to be more comfortable than simple pads and possibly



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### Meeting Notes .... continued

more cost effective over time. PaciCuff a clamp for the shaft to avoid leaks and allow the bladder to stretch back to its normal size. Mens Liberty and Mens Liberty Acute sheath-like devices to divert the urine away from the body and into a bag or similar receptacle.

I would recommend a visit to their web site for further, more complete information.

All devices can be prescribed by your continence clinic or privately, with a referral from your GP to direct you to the Bladder and Bowel team as an appropriate first step.

#### Some dates for your diaries.

Pint and Chat, Red Lion Basingstoke, First Thursday of every month. Next one is on 7 November 19:00 - 21:00. Then 15/12.

Next meeting October 24 - Professor Langley of Guildford - Brachytherapy and other treatments, and the Mayor will be present.

28 November - The Benefits of Exercise, Steph from the Monday exercise class and Alex from 5K Your Way. Plus, we hope to have the presence of a Clinical Nurse Specialist or two from Winchester and Basingstoke hospitals.

#### Awareness stands at the follow events.

All volunteers welcome, please contact Richard White (07768 904231) or any committee member if you want to help out.

12 October - The Malls, Basingstoke - 09:00 - 17:00

#### Social events

Visit to Hampshire Air Ambulance October 22 pm and/or October 25 am.

December 5 Christmas Lunch at BCOT.

Richard White whiri02@gmail.com

07768 904231

## **Group Meetings**

Brighton Hill Community
Association Hall
Gershwin Court
Basingstoke.
RG22 4NN

Meetings are held on the last Thursday of every month except December





## Contact

For more information

call or text: email : info

07377 430242 info@nhpcsg.org.uk www.nhpcsg.org.uk

website:

www.nhpcsg.org.uk North Hampshire Prostate Cancer Support Group