This year’s AGM and Conference has as its theme “Healthy Mind, Healthy Body”

We chose this theme after listening to support groups and noticing the topics of lifestyle, diet, psychological and emotional issues regularly come up in discussion.

We have assembled a really interesting array of speakers for you, based on the feedback from Trustees and support groups who have heard them speak.

The date is Tuesday 12th June 2018. The venue is Horton Grange, 53 Edgbaston Road, Edgbaston, Birmingham B15 2RS. This is just across the road from last year’s venue.

The event starts at 10.30am and finishes at 4.30pm. One difference this year is that we will have the AGM in the middle of the conference as one of our speakers can only attend for the morning. Rather than lose out on Professor Robert Thomas we decided to modify the programme. After the first speaker we will have our AGM and Open Forum, then lunch and then continue with the conference. The provisional agenda for the day is as follows:

10.00-10.30 Arrival and registration
10.30 : Lifestyle and Prostate Cancer: Professor Robert Thomas, Consultant Oncologist, Bedford and Addenbrooke’s Cambridge University Hospitals
11.30 : AGM & Forum followed by Lunch
13.30 : A Holistic view of managing health : Dr. Stéphanie McArdle, Senior Researcher in Tumour Immunology, Nottingham Trent University
I make no apologies for mentioning this initiative again. It is a gentle reminder of our most important event for the this year. Each support group will shortly be receiving a pack containing all the information they require to plan, organise and run a successful Cycle to the Moon event. All the information in the briefing pack is already available online at www.tackleprostate.org

It is really important to have support groups involved in this initiative. We do hope each support group is able to run some sort of event. We have also been in contact with cycling groups and gyms across the country. The Federation Board of Trustees met recently and agreed to make it more attractive for local groups to raise funds during a cycling event by allowing them (if they so wish) to retain 25% of any monies raised. This will benefit your group as well as our national campaign.

We had Stephen Fry tweet about our initiative to his 13.1 million followers and we are pleased to report David Grant, the TV personality and voice coach has agreed to be our ambassador.

I hope that, at your next group meeting or committee/council meeting, you have a discussion about how you could participate in Cycle to the Moon. In the meantime, please feel free to call our freephone number: 0300 365 4080 or email me personally at: roger.wotton@tackleprostate.org

I do hope you are able to participate in Cycle to the Moon and help us Save a Dad.

Kayleigh Davies,
Raising Funds for Tackle Prostate Cancer
Kayleigh is raising funds for us this year by doing a number of swims including the Channel in June. Her fundraising page is https://www.justgiving.com/fundraising/kayleigh-davies6
A new test, developed by a multidisciplinary team as part of a study involving Nottingham Trent University and University Hospitals Leicester NHS Trust, has the promise of improving the accuracy of diagnosing whether an individual with a raised level of PSA in their blood has prostate cancer.

“This test has the potential to spare men with noncancerous disease or low-risk cancer from unnecessary invasive diagnostic procedures and tests,” said Professor Masood Khan, Consultant Urologist at University Hospitals Leicester NHS Trust and Visiting Professor at Nottingham Trent University.

The research involved analysing blood samples of 72 men with raised PSA levels (but lower than 20 ng/ml) who underwent biopsies (TRUS-guided biopsy and then a TPTPB) to determine the presence of disease and the severity of their condition. As a result of the biopsies, a total of 41 patients were diagnosed with prostate cancer. The remaining 31 patients were classed as having benign disease.

The blood samples were analysed using flow cytometry, a system where cells are fluorescently labelled and then illuminated by a laser as they pass through a detector. The resulting fluorescence ‘fingerprint’ is measured to assess the profile and status of white blood (immune) cells in the sample. This approach identified 20 features of the immune system in the samples. Analysis of these 20 features resulted in a subset of five which could potentially discriminate between the presence of a benign condition and prostate cancer. A computational prostate cancer prediction model was then developed by the research team using the five selected features, this outperformed the predictive model which takes PSA values alone as input.

To sum up, Professor Khan said, “What we have found in our study is that alteration in the profile and appearance of the white cells in our blood can more accurately predict prostate cancer in men with an elevated PSA. Hence this is more accurate than PSA alone. As such, we may be able to avoid unnecessary prostate biopsies in men unlikely to harbour prostate cancer. However, it is a relatively small study. Consequently, we are about to embark on a much larger study, for which we are currently seeking funding. We also want to determine whether the same approach can differentiate low risk from higher risk cancer. If that is the case, then we will hopefully avoid biopsies in men with low risk cancer. The study is promising, but we need to be cautious, as the larger study is needed.”

The study is published in the international journal Frontiers in Immunology, from where the report may be accessed.
The STAMPEDE prostate cancer study has opened a new treatment arm, Arm L, testing transdermal oestradiol. We are looking at whether giving oestradiol through the skin using a hormone patch is as effective as standard hormone therapy in controlling prostate cancer, but with fewer side effects. Arm L opened in June 2017.

**STAMPEDE and PATCH**

The STAMPEDE (Systemic Therapy in Advancing or Metastatic Prostate Cancer: Evaluation of Drug Efficacy) study looks at the effect of adding new or different treatments to the standard way in which prostate cancer is managed. The study has been running since 2005 and has compared 9 different treatment approaches so far.

Transdermal oestradiol is currently being tested in another large clinical trial called PATCH which already has over 1,400 men participating. Approximately another 500 men are needed to take part, to be enrolled from STAMPEDE and PATCH.

**Why is this important?**

Over half of men diagnosed with prostate cancer are treated with hormone therapy at some point. This is usually done by giving hormone injections for a long time, for a decade or longer in many cases.

Unfortunately these injections can cause a range of side effects which may become serious. For example, they can cause bones to thin which might lead to them becoming fragile (osteoporosis) and more likely to break. They might also increase the chance of developing diabetes or heart disease. For some patients the side effects of hormone injections can have a big impact on their quality of life.

Transdermal oestradiol is an alternative form of hormone therapy which might be able to treat the cancer in a similar way to standard hormone injections without causing some of these side effects. There have been some encouraging results from the PATCH trial so far, with patients on transdermal oestradiol having better bone health and quality of life than those on hormone injections.

The trial is funded by Cancer Research UK and Prostate Cancer UK, Sanofi-Aventis, Pfizer, Novartis, Jansen, Astellas, Clovis, and the Medical Research Council.

**How do I take part?**

Many hospitals across the UK are taking part in the STAMPEDE and PATCH studies. If you are interested in participating, it is best to talk to your doctor. You can also find further information through the links below.

- **STAMPEDE website**: [http://www.stampedetrial.org/](http://www.stampedetrial.org/)
- **PATCH website**: [http://www.ctu.mrc.ac.uk/our_research/research_areas/cancer/studies/patch_pr09/](http://www.ctu.mrc.ac.uk/our_research/research_areas/cancer/studies/patch_pr09/)

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**STAMPEDE Trial recruits its 10,000th participant.**  

Annabelle South

The STAMPEDE trial has now recruited its 10,000th patient. We would like to thank everyone involved, particularly participants and their families. It would not be possible to help improve care for men with advanced prostate cancer without the dedication and continued involvement of all of these people.

STAMPEDE is the largest ever prostate cancer treatment trial. The study has already found that adding docetaxel or abiraterone to long-term hormone therapy helps men live longer. The clinical results from STAMPEDE on docetaxel were published in early 2016 and have changed the treatment for men with prostate cancer worldwide.

Docetaxel is now available on the NHS to men with cancer that has spread to distant parts of their body. However, it is not currently widely available to men with locally-advanced disease who are starting long-term hormone therapy. A more recent analysis of the STAMPEDE data supports use in these men and the researchers are urging clinicians to consider whether these men should be offered docetaxel. The extension of use of docetaxel in these men is currently under consideration by NICE.

The data showing the survival benefits of the drug abiraterone were published last summer, and NICE are in the process of reviewing whether men with metastases starting long-term hormone therapy should have routine access to this drug in the NHS.

**Trial Chief Investigator Nick James said:** "It has been an honour and a privilege to be involved in the practice changing STAMPEDE trial. The impact of the study has been on men with the disease worldwide and is a tribute to the UK clinical trials research community."

Since opening to recruitment in 2005, STAMPEDE has already tested and published data on whether adding docetaxel chemotherapy, abiraterone, zoledronic acid, or celecoxib, is beneficial in controlling prostate cancer growth and improving life expectancy. Further results on prostate radiotherapy, the combination of abiraterone and enzalutamide, metformin and oestrogen patches are due in the next few years.

**Further information**

- **STAMPEDE website** [http://www.stampedetrial.org/](http://www.stampedetrial.org/)
We were contacted by the Regional Loss Prevention team at TK Maxx, who had a senior member diagnosed with prostate cancer. As a result of a collection locally they raised £2400 for Tackle Prostate Cancer. Here is a picture of Heather Walker, the team manager, making the presentation to our Chairman, Roger Wotton, with Jerry, the recently diagnosed staff member next to Roger.

After a brief talk on what Tackle is doing to help raise awareness and get a better deal for men Heather said “Thank you for coming to see us, we really did appreciate it and loved your stories. Your positivity was a breath of fresh air and I know Jerry found your attitude uplifting and encouraging. You must write a book with your interesting ditties!”

This donation will certainly help the cause. Thankyou TK Maxx!
PCaSO Prostate Cancer Support Organisation is pleased to be able to provide extra investment into NHS facilities in our area.

Latest figures show that more men die from prostate cancer than women die from breast cancer and we want the facilities for these killer diseases to be brought to similar standards.

PCaSO works along the south coast counties of East and West Sussex, Hampshire and Dorset supporting men diagnosed with prostate cancer and their families with information and advice and combatting ignorance in those at risk. With nearly a thousand members we run support groups in various towns and villages where men can find out about the treatments and talk to others who have experienced the various treatment options.

We have no offices, no highly-paid executives and, indeed, no paid staff at all. We are all volunteers working from our homes and all have a connection with prostate cancer, mostly as patients.

We raise money from donations by our members, from gifts by groups such as the proceeds of a village carol concert or a concert by a music group.

We are especially keen to have men at risk checked early so the cancer is found while it is still curable. We run free testing events and in 2017 we tested 2665 men and found 231 with a raised result that needed investigation. In these events we work with local Lions, Rotary and Masons and often they will make a substantial donation to cover costs.

David Hurst, Pulborough group leader said, “We look for ways to help make treatments easier for prostate cancer patients. A year ago Suzie Venn and Debbie Greenfield came to my support group in Pulborough to talk about incontinence and in conversation mentioned that their bladder scanner was old. We asked them to find out what a new one would cost and then we agreed to pay for it. We are pleased to see it finally arrive.”

Roger Bacon, chairman of Sussex Branch said, “We are proud of the work that our friends in the Urology Department at St Richards and Worthing do to help men undergoing treatment for prostate cancer and are keen to help make their job as easy as possible. Anything that saves time while giving fast and useful information to the clinicians is worth supporting.

Our PSA testing programme to get men diagnosed early already has nine events planned for Sussex this year so we are pushing men into the system to be checked. We can at least make a small contribution to making that checking and treatment easier.”

PCaSO recently gave £25,000 to help buy template biopsy equipment for St Richards to make diagnosis faster and more accurate.
There are benefits in exercise for people faced with cancer.

Some two or so years ago, the North Hampshire Prostate Cancer Support Group approached Basingstoke Sports Centre to see if they would run a weekly exercise class just for our members. The Sports Centre was very receptive to the idea. So, every Monday morning, a group of us get together to do a circuit class. The session is mix of cardio-vascular and strength exercises.

The session encourages a sense of togetherness as we all face the challenges that prostate cancer brings. The matching polo shirts, with the Group’s logo, also add to the sense of team spirit.

Some members were a bit apprehensive at first about joining in. The session is designed to be fun with people exercising at their own pace. Some partners were also a bit worried! Those interested in joining are encouraged to come along with their partners and observe a session in action before committing themselves.

Feedback has been good. Just one example: “My partner really enjoys these sessions and gets a lot out of them. Apart from the exercise bit, it’s like a mini-Group meeting when there is a pre-circuit get together in the Sports Centre café. He’s really glad that he took the plunge and signed up.”

The photo is of course with everyone standing still. The camera wasn’t up to getting the real action shot once things were in full swing!

For those keen to develop their arm muscles even more, the Group runs a monthly skittles afternoon at a local “olde worlde” Hampshire pub. The event has been running for well over a year and has proved very popular.

At least 20 or so members regularly attend, some arriving early to have lunch together. It’s a great credit to our social events secretary, Brian Rolfe, that the event is so popular and continuing to attract members.

There is fierce competition between the “Kittens” (wives and partners) and “Tigers” (their men folk) on the skittles alley. The “Tigers” may have won most games but the “Kittens” can claim the highest individual match score. Fortunately, it’s honours even.

But the afternoons are not just beer and skittles. One afternoon the teams were entertained by two talented violinists who are Group members. There has also been a wide variety of other events including a picnic, Easter egg day, lucky dips, guess what it is, best hat competition (won by the wearer of an impressive fez (rumour has it that it once belonged to Tommy Cooper) and general knowledge quizzes. Arm wrestling between the teams may be on the agenda soon!

All in all, the skittles afternoon helps build a sense of camaraderie. With its emphasis on fun and getting together in a relaxed and social atmosphere, it nicely complements the main Group meetings.

Calling all Quizzers

Roger Wotton

Many of our members are interested in quizzing and I run a couple a year for my local group, Aylesbury Vale. Here’s an offer if anyone is interested.

If you would like to run a quiz and use some of my quizzes with categories as Trivia, The World around Us, Stage, Screen and the Written Word, Picture quizzes, Food and Drink, Sport & Pastimes, etc please get in touch (roger.wotton@tackleprostate.org). I’d be happy to email or post a set of questions. I might even include the answers!

For those of you not sure here are three questions to whet your appetite.

1. Which English county has the shortest coastline
2. In which year did more people cross the Atlantic by Air than by Ship?
3. How many English born actors have played James Bond in authorised films?
PROSPECT Bristol & District prostate cancer support group

About 40 of us enjoyed a lively talk given at our January meeting by Sally Crocker, of LinkAge Macmillan.

Sally is the Macmillan Prevention and re-enablement Project Manager. She told how the organisation can help patients get back into exercise with interesting activities. It also helps to improve social activities that enrich lives, reduce isolation and encourage active participation. These have been proved to promote wellbeing and positive ageing.

LinkAge partnered with Macmillan to support people over 55 affected by cancer to access more than 40 fun, social, creative or physical activities across Bristol. But people from surrounding areas are welcomed. Sally also made it clear she would help people who might be slightly younger.

She pointed out that becoming more active can help you feel great and improve your outcomes, reduce symptoms and side effects, and improve your wellbeing. It can also improve sleep and appetite and prevent or control constipation.

Sally asked us to name activities that might be considered exercise and members mentioned things like gardening, golf and walking, all things that Sally approved of.

Sally stayed around afterwards to talk to members and thanked us for our warm welcome saying “It was great meeting everyone and it was a pleasure to come and speak to you all about the Macmillan project and opportunities available.”

She also offered to do a write-up and share on the LinkAge social media that directs people to the Prospect website.

One South Gloucestershire member who approached Sally for help was given loads of information, with ideas to join local classes in things such as Pilates, aerobics and walking football – plus a few SportsPounds vouchers to start some activities free.

John Dwyer

It is with great regret that we have to announce the passing of John Dwyer. John was a founder member of PCS and later became one of the first Trustees of the Prostate Cancer Support Federation when it was first formed in 2008. His contribution and wisdom to both organisations were invaluable, especially at the very beginning when we were all on a very steep learning curve. John was also an early researcher on the STAMPEDE trial when that first started some ten years ago. A record to be truly proud of. A more complete obituary about John will be in the next edition.