

# prostate matters

The Newsletter of The National Federation Of Prostate Cancer Support Groups

Free Help Line - 0800 035 5302

# tackle

prostate cancer

Action for patients

Registered Charity No. 1163152

May 2018 issue 40



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Bluebell Woods Swithland, Leicestershire

## Tackle AGM, Tuesday 12th June 2018. "Healthy Mind, Healthy Body"

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 Hornton 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



tackle Has now produced a Lapel Pin Badge. Each group has been sent a complimentary ten. If you need more, we would suggest a donation of 50p each plus P.P. Please contact [rob.banner@tackleprostate.org](mailto:rob.banner@tackleprostate.org).

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Integrating the Art of Living with the Science of Health : Sue Cooper, Integrative Health and Well-being Advisor and Ambassador to Nottinghamshire Hospice

A personal battle with Terminal Cancer : Connell McNelis

15.00 : Tea

15.30 : Panel Discussion/Q&A with speakers

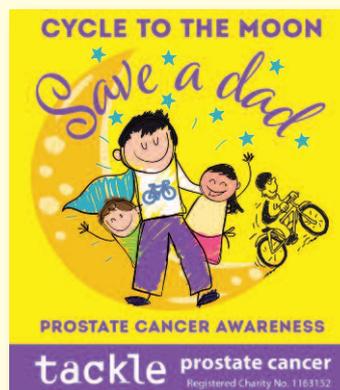
16.30 : Close

We would encourage as many support groups as possible to attend the day's events, and we will be reimbursing normal travel costs for up to two representatives per group.

Wives or partners of members are most welcome to attend. More details will be sent out in May including the formal AGM agenda and proxy voting forms.

We do hope you are able to join us at this year's conference, which promises to be of interest to all those wishing to understand issues facing men and their families, particularly some of the topics less often discussed.

If you wish to reserve places at this stage please confirm your requirements by emailing [simon.lanyon@tackleprostate.org](mailto:simon.lanyon@tackleprostate.org)



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](http://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](mailto: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 screenshot of a fundraising page for Kayleigh Davies. It shows a photo of a group of people on a beach holding a blue banner with a white circular logo. To the right, there is a progress bar showing '10%' raised of a '£160.00' target by '3 supporters'. Below the photo, it says 'kayleigh's 2018 swimming for Tackle' and 'Fundraising for Tackle Prostate Cancer'. There are buttons for 'Donate' and 'Share on Facebook'. At the bottom, there is a 'tackle' logo and 'Tackle Prostate Cancer' text.

**Professor Graham Pockley, Director of Nottingham Trent University’s John van Geest Cancer Research Centre says “Although the PSA (Prostate-Specific Antigen) blood test is commonly used to test for the presence of prostate cancer, it can be relatively non-specific. Elevated levels are not necessarily related to the presence of disease, and normal levels might not exclude the presence of disease. A particular challenge to the clinician is diagnosing the presence of prostate cancer in individuals who do not have symptoms of the disease, but do have a mildly elevated level of PSA in the blood.”**

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.

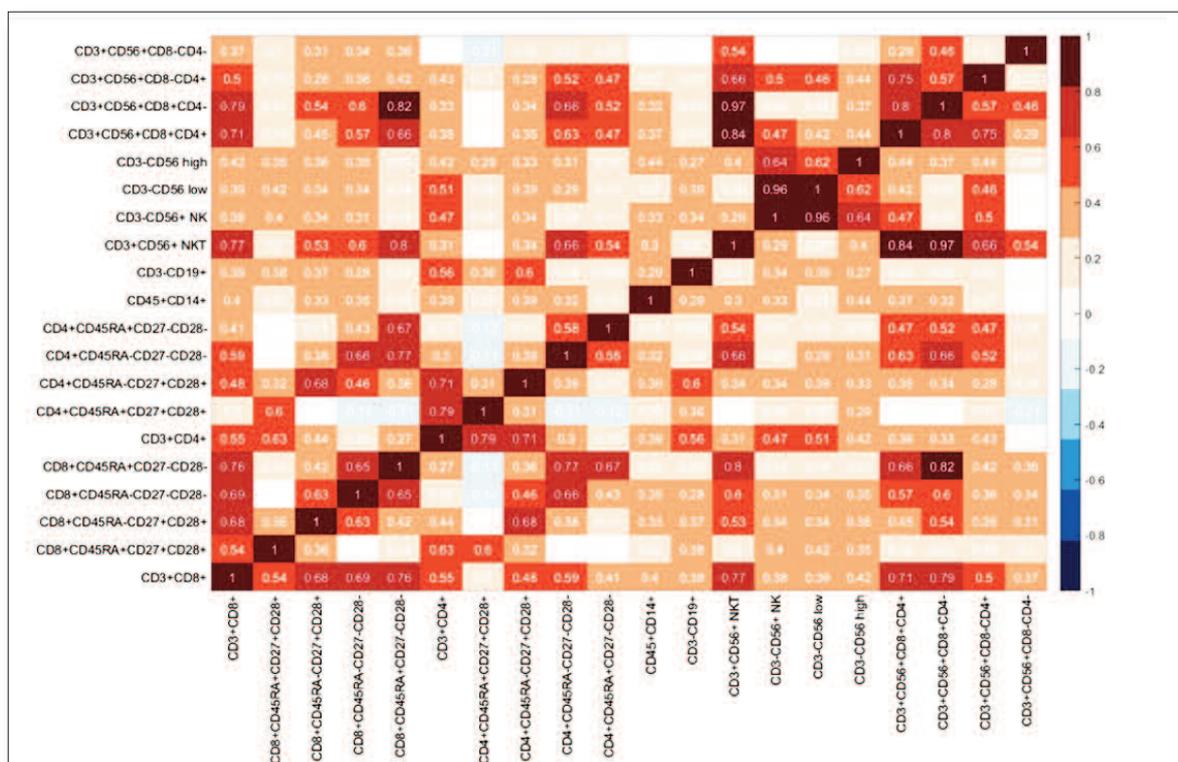
The research involved analysing blood samples of 72 men with raised PSA levels (but lower than 20 ng/ml) who underwent biopsies (TRUS-guided biopsy and then a TPTPB) to determine the presence of disease and the severity of their condition. As a result of the biopsies, a total of 41 patients were diagnosed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



**“Heatmap” of flow cytometry features used to help select the best subset of predictors.**

© 2017 Cosma, McArdle, Reeder, Foulds, Hood, Khan and Pockley; Front. Immunol., 18 December 2017 |

<https://doi.org/10.3389/fimmu.2017.01771>

## STAMPEDE trial opens arm testing hormone patches for men with prostate cancer Annabelle South

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/>
- **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/)

## 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/>
- Film about the STAMPEDE docetaxel results <http://bit.ly/STAMPEDEpatientfilm>
- Film about the STAMPEDE abiraterone results <http://bit.ly/STAMPEDEabiresults>

## Bury charity ride for the "Ride to the Moon" event



**Pictured are a representative group from Bury Cycle Speedway making an early start on their 26th annual Good Friday charity cycle ride, this year supporting the fight against prostate cancer, by taking part in the Bury charity ride for the "ride to the Moon" event.** Riders aged 8 to over 80, were joined later by further members of the club for the off road ride around the National Route 6 route. A great time was had by all, despite slightly chilly weather early on.

Third from the left is John Burston and fourth from the left at the back, is Colin Stott Bolton and District, PCSG Vice Chairman A BIG thank you to all who took part!!

## TK Maxx Tackles Prostate Cancer!

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 provides extra investment into NHS facilities

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.

Left to right are:

Suzie Venn – Consultant, Debbie Greenfield – Urology Nurse Practitioner, Amanda Tucker – Head of Charity, Love Your Hospital, David Hurst – PCaSO Secretary, Dan Magrill – Consultant, Viv Miles – PCaSO Treasurer, Paul Carter – Consultant, Roger Bacon – PCaSO Chairman, Katherine Hunt – Care Group Manager for General Surgery and Urology, Annette Martyn – Macmillan Uro-Oncology Clinical Nurse Specialist



## North Hants Prostate Cancer Support Group Fighting Prostate Cancer: Exercising Together



### **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 session is run by one of the Sports Centre's trainers. See photo.

*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](mailto:roger.wotton@tackleprostate.org)). I'd be happy to email or post a set of questions. I might even include the answers!

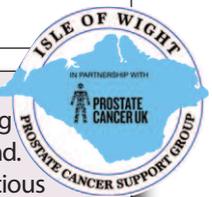
**For those of you not sure here are three questions to whet your appetite.**

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?

### **Isle of Wight Prostate & Urology Cancer Support Group**

is moving their AGM to Newport Football Ground.

The venue offers a relaxing, spacious environment and doubt the bar will help! The intention is to turn the event into an 'information' evening. Anyone who is concerned about Prostate Cancer, either on their own account or on behalf of a family member is invited. Key stake holders have been invited to have information stalls, such as the Local Cancer Centre, St. Mary's Hospital on 'Palliative Care', The Island 'Carers Association' and of course ourselves. Anyone interested in talking 1:1 about Prostate Cancer will be linked there and then with one of our members. The evening will include a 'free' buffet with a mini race-night to help raise funds. There will be a brief AGM, then move into the Information Giving section before concluding with the Race Night. We are optimistic in attracting about 100 people to the event.



# tackle

prostate cancer

[www.tackleprostate.org](http://www.tackleprostate.org)

The National Federation Of Prostate Cancer  
Support Groups

Tackle Prostate Cancer is the campaign name of  
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### Our support:

Group Liaison Simon Lanyon

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Fundraising

The Editor would like to thank  
everybody who has contributed to  
Prostate Matters.

Without you, we would not exist. Please  
keep the contributions coming.

## Prostate Matters Delivery IMPORTANT

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.  
Contact details can be found here  
<http://tinyurl.com/omp6y5e>



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Tackle @TackleProstate



Text Giving - Text:

TACK13 £

## Please Check Your Details

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

We are asking 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 there are any corrections required please

contact Simon Lanyon by email:

[simon.lanyon@tackleprostate.org](mailto:simon.lanyon@tackleprostate.org).

## 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](mailto:info@tackleprostate.org) with the date,  
time, town, post code, contact name and phone  
number.

Don't forget, the National Help Line  
is now Free of charge:

0800 035 5302

## 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