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## EVENTS 2019:

### **What to expect at our meetings:**

A chance to meet those who have been touched by Prostate Cancer - many have gone through treatment, many are in the midst of their treatment and some have yet to embark on their cancer treatment journey. There are partners/wives and friends, all there to chat and share their experiences, to support and to learn in a casual, informal gathering.

We are delighted to have wives, partners, friends and family members join us.

**No need to book in - just show up - 6.30pm for 7.00pm at Oxford Golf Club Hill Top Road, Oxford OX4 1PF - (there's plenty of parking)**

**15 April** - Proton Beam Therapy - a radical new treatment for Prostate Cancer?

**10 June** Wives and partners' forum led by Committee member Caroline Prance, psychiatric nurse. Baroness Jan Royall, Principal, Somerville College, Oxford, Sue Boyes, Peer Support Manager from Prostate Cancer UK and Terri Gilleece, Researcher, will be amongst the attendees. All are welcome to this event, however the men (PC survivors) will be able to go to the bar for their own conversations.

For further information please contact: [CarolineOPCSG@gmail.com](mailto:CarolineOPCSG@gmail.com)

**9 September** – Mr William French, retired butler to HM The Queen, on his working life as butler to the Royal Family and other distinguished people

**14 October** - Simon Lord, OPCSG member who has qualified as a personal trainer worked with PCUK on development of materials and ideas, will speak on exercise for mild to moderate health conditions and cancer rehabilitation. Atif Kaudri, benefits adviser from Maggie's Centre Oxford, will also attend.



Chairman Steve Tuck

## A few words of introduction from our chairman

I just wanted to say hello as the new Chair of OPCS. I've been a member of OPCS since 2016 and vice-chair for the last 2 years, following diagnosis and a radical prostatectomy in 2014. Those that come to the skittles evening may know me best for my as the scorer with the flashing Christmas jumper, but I have been actively involved in OPCS events and have also volunteered with other cancer charities (both Movember and Cancer Research UK have featured my story as a patient to help raise awareness).

As a group, we owe an enormous debt of gratitude to John Grundy, who worked tirelessly to keep the group going and recruit new committee members and has left us in a very healthy position with solid finances and a reinvigorated committee. I'm delighted that John remains on the committee and grateful for his support and encouragement and I look forward to building on his work.

The key word in our name is the 'support' and continuing to offer support to Oxfordshire men diagnosed with prostate cancer and their families is our priority. I remember well the shock I had upon receiving my diagnosis and how difficult it was to come to terms with and decide on a course of treatment; I didn't know where to turn and I was inundated by conflicting advice. We are not a group of experts and we cannot offer medical advice, but we can do something that is really helpful to those who are newly diagnosed - we can listen and relate to their concerns, share our personal stories and we can point them to other sources of expert advice and support, such as Prostate Cancer UK, Maggie's and Macmillan. One of my priorities for the group is to increase our reach to newly diagnosed men and their families (online as well as through printed material) to offer them support.

I would also like to strengthen our efforts in raising awareness of prostate cancer. My level of knowledge about what a prostate does and what could go wrong was shockingly low at the time, and with my PSA and DRE results both normal, I consider myself extremely fortunate to have had symptoms severe enough to get me a referral to a urologist. Raising awareness of potential symptoms and explaining why every man should consider a prostate health check, is something I am passionate about and sharing our personal stories is one of the most powerful ways we can do that. I will be looking for new opportunities for us to raise awareness including speaking to clubs and employers.

If you have ideas about how we can raise awareness and better reach men that are newly diagnosed, I would love to hear them - please drop me an email at [steve.tuck@mail.com](mailto:steve.tuck@mail.com) or call me on 01865 880306.

Steve



Committee member Caroline Prance with our new chairman Steve Tuck (Right) thanking the outgoing chair John Grundy (centre)

## From our immediate past chairman...

In the last seven years I've had many wonderful but unexpected experiences that were not part of my retirement plan: judging a dog show at Uffington White Horse fair; addressing the audience at an Oxford Welsh Male Voice Choir concert; being interviewed on television news bulletins and in the local press; supporting new friends at difficult times in hospital; marvelling at 10,000 motor bikes in Cassington; jazz and cream tea on the Thames; meeting golfers, Masons and other generous sponsors; walking from Oxford to Somerset; going to a beer festival in Kidlington where the germ of an idea was sown from which grew the OPCSG bus; learning about life in a lighthouse; and working with some inspirational committee members and volunteers. How did all that come about?

In the spring of 2011, six months after my radical prostatectomy, I returned from working abroad to find that my wife had kept an article from the Oxford Mail entitled 'Prostate Cancer – providing invaluable support'. <https://www.oxfordmail.co.uk/news/9179395.prostate-cancer-providing-invaluable-support/?ref=erec>. It told the story of a new group formed by prostate cancer patients. There would soon be a meeting at Oxford Golf Club. I got in touch and went along, little thinking that it would lead to three years as Vice Chairman and four as Chairman. It has been the most exhilarating journey, building on the work of Dave Beesley, George and John Goldsmith, Simon Brewster, Rose Southby and many others. When I had been diagnosed, I had asked if it was possible to speak to other men who had had the two treatments I was offered. That possibility did not exist. Once OPCSG had been formed, putting men in touch with others who had been that way became a central part of the group's work, and the one that I am most proud of. Putting enquirers in touch with men who've been through it has been immensely rewarding when we hear how much it has helped and reassured the men facing choice. There has been a lot of work to do, particularly in the last two years when we had no Secretary in post, but OPCSG is now moving forward into good new times, exploring what we can offer for wives and partners as well as continuing to broaden the work with men. Thank you to so many people – the men who took referral calls, the volunteers at events, and the committee members who have put in so many hours to keep the show on the road. Long may OPCSG flourish!



## **News from Tackle - the federation of prostate cancer support groups**

### **The National Lottery**

I am pleased to report our application for National Lottery funding has cleared the first hurdle. We made an application for bringing on a full-time resource to help us grow our support organisation with a three-year programme to try and make sure every man diagnosed with prostate cancer is signposted to a support group. This means looking at all the urology and oncology centres across the country and working with Clinical Nurse Specialists to set up additional patient-led support groups. Having a full-time resource will also give us better coverage instead of relying on the goodwill of Trustees.

### **Pushing the Screening Debate Forward**

You will be aware there is increasing media coverage about screening for prostate cancer, why we do not have a screening programme and the need to have more widespread, earlier and better testing. This is nothing new. We have been pushing for earlier diagnosis for some time, and through our efforts with Chris Booth, one of our Clinical Advisers and head of the CHAPS charity, together with the ORCHID male cancer charity, we have embarked upon a number of initiatives to raise awareness in the political arena. We recently held an event at the House of Commons, with invited speakers from UK and Europe, to share the latest thinking on prostate cancer screening. I have to say the passion with which some of our speakers talked about the need to do more on Q2 2018 Q1 2019 Tackle Prostate Cancer is the campaign name of The National Federation of Prostate Cancer Support Groups Charity Registration N° 1163152 Registered Office: Kemp House, 152 City Road, London, EC1V 2NX. A Company limited by Guarantee. Registered in England N° 9672970 2 earlier diagnosis certainly made an impact with the politicians present at the event. We are also participating in a new All-Party Parliamentary Group on Male Cancer to try and push the debate further.

### **#Save A Dad**

You will have heard me mention previously about our wish to try and influence the next generation to get their Dad to be more aware of prostate issues, what to look out for and the importance of getting tested. This is a challenge, but we are in discussion with secondary schools in the North West, building on some earlier work undertaken by Phil Ormesher, one of our stalwarts in that region. This looks promising, as we would like to get prostate cancer on the National Curriculum, just as breast cancer is today. To this end we have reviewed and updated our merchandise and we now have a wider range of material available. We have Tackle beer mats (for the dads!), Tackle origami paper aeroplanes, wrist bands, larger badges, and a new credit card sized leaflet to get the message across. My plan is to send a selection to each support group to kick-start the awareness message. At the same time, I'm working with ORCHID Male Cancer to produce a leaflet specifically aimed at encouraging conversations between teenagers and their dads about prostate cancer. Watch this space for more information.



## Partners in Prostate Cancer Study

A study is currently underway exploring the effects of prostate cancer on the wives/female partners of men living with or beyond the condition.

### **Purpose:**

Treatment for prostate cancer can be very successful, but it can also result in long-term side effects that can have an impact on others besides the person diagnosed with the condition. It has been documented that partners provide the greatest source of emotional and physical care for these men. The purpose of this research is to find out how partners/spouses of men with prostate cancer feel about the diagnosis and treatment of prostate cancer and understand the impact it has had on them as individuals. We recognise that some changes are good and some are less positive. We would like to hear about the impact that your partner having prostate cancer has had on you. We would also like to find out what support has been or would be helpful in dealing with the cancer journey.

### **What is required of participants?**

You will be invited to speak to Terri, a female researcher, with just the two of you present at a location and time that is convenient for you. She will record the conversation but confidentiality is assured throughout the process. Most conversations take between 30 and 60 minutes but she will be guided by how much you wish to tell her about your journey with your partner's/husband's cancer.

The study has undergone peer review within the School of Health Sciences at Ulster University and the University Research Ethics Committee (Approval No. REC/16/0099).

If you would like to take part in this important study please contact contact Terri via email: [tm.gilleece@ulster.ac.uk](mailto:tm.gilleece@ulster.ac.uk) or by telephone: direct dial office no. 02890 366 043 or Caroline Prance, [carolineOPCSG@gmail.com](mailto:carolineOPCSG@gmail.com) Terri will also be attending the Wives and Partner's forum in June.

## A note from members Jill and Ed Burrell

Hi,

This is just a short note to let you know that my wife and I,(regular members of OPCG for the last 5/6 years), are moving house and leaving the area.

We have both found the Group so helpful and supportive since my diagnosis and through treatment, my PSA has been about zero for some time now, and so we decided to move on to a retirement village, our present house is too big for us to manage now.

We would like to say thank you to all the Committee members, (past and present), as well as all the other members that we have met over the years, for making the meetings, and summer river outings, enjoyable and informative.

Best wishes,

Jill & Ed Burrell



## The TrueNTH Sexual Wellbeing project

The TrueNTH Sexual Wellbeing project has completed a number of resources one of which is a self-help guide for men and partners:

The online self-management resource (for men and partners) can be accessed at home.

The resource provides personalised information, support and strategies based on treatment, relationship status and sexual orientation, to help men cope with sexual challenges after treatment for prostate cancer.

It also includes specific information for single men, younger men, and black men who have been diagnosed and treated for Prostate Cancer.

The online self-management resource can be accessed at:

**<http://prostate.lifeguidewebsites.org>**

Kind regards,  
Susan

Susan Drew  
Peer Support Officer  
Prostate Cancer UK  
Counting House  
53 Tooley Street  
London SE1 2QN



## Speakers at our February AGM

Mr Simon Brewster and Dr Richard Bryant, Consultants from the Churchill Hospital, presented on “The use of MRI prior to diagnostic biopsy and during prostate cancer active surveillance.” They shared results of research that they have conducted at the Churchill looking at the effectiveness of using mpMRI (multi-parametric magnetic resonance imaging) before conducting a trans-rectal biopsy. Their conclusions were that the use of mpMRI allowed suspicious areas of the prostate to be targeted in the biopsy and yielded more cancerous cells, but they also found that random biopsy sampling was needed as some men with no suspicious areas found by mpMRI were still found to have significant cancers. We thanked Simon and Richard for sharing this interesting and valuable research and their continued support of OPCS.

**Steve Tuck**

## An Important Opportunity...

When you finally make it through, it is a humbling experience as one reflects on all that came to pass. The support you received from professionals and fellow patients; your family and your friends... It was at this point that I realised I needed to give something back, to try to help those who might be starting their own cancer journey, and to support the awareness campaign – so I joined the Oxfordshire Prostate Cancer Support Group committee. Under the chair of Steve Tuck we have a formidable team taking OPCS into the 2020s. Already a committee of eight, we have created two more places for those who want to make a difference, give something back and play their part in helping others. Have a word with either myself or our chairman Steve Tuck.

**Timon (Secretary)**

## And finally.....

Dear all,

When we got home last night, Diana immediately settled down with a hot drink and the first of the shortbread. I meanwhile unwrapped your lovely presents - and wondered who is the psychic among you: just the other day we had a bottle of red wine which said that it wanted to be decanted. Not having a decanter I made do with a glass jug, which wasn't at all the thing. So your choice of a gorgeous Dartington decanter was a bull's eye, as were the tumblers that you also included. Thank you all very much from both of us, and for the kind words you said. It's great to know that OPCS is in such good hands from here on, and now I'm looking forward to riding in the bus at the Wallingford parade!

Best wishes to all,  
John and Diana (Grundy)



# Social Events

## Sunday 23 June

### Our annual river cruise

Cruising down the Thames on a Salters Steamer listening to a Jazz Trio sipping tea or something stronger

This year we will be departing from Abingdon at 2pm, returning at 5pm. Only £15 each (including a cuppa)

To book your places, payment in advance please to David Hawes Email:- [davehawes@btinternet.com](mailto:davehawes@btinternet.com)

Mobile:- 07773 508 024

*Please make cheques payable to Oxfordshire Prostate Cancer Support Group*

*There is a large car-park just over the bridge at a cost of £3.10 for four hours/£3.80 for six hours*

## Saturday 14 December

### Skittles Evening

Another evening of competitive bowling with family and friends - details to follow.

# And where we're going in 2019...

Spare a couple of hours to be with us on our stand at any of the following events, where we chat to the public raising awareness of OPCS and the importance of getting checked.

Macmillan Wellness Day at Dorchester village hall Friday 12th April 11:00 – 16:00.

Wallingford Car Rally 12th May

Cassington Bike Night 24th June

West Oxon Steam Fair 20th July

Uffington White Horse Show 25th August

Henley Show 14th September

The Distinguished Gentlemen's Ride 29th September