

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

Issue 109: January 2021

Website: www.rpcsg.org.uk

THE JANUARY MEETING.

Our January 2021 meeting was held by Zoom and was a very enjoyable social occasion. There was no speaker and members were able to chat among themselves. There was some discussion on medical matters such as the managing of Personal Protection Equipment and the use of Darolutamide.

NEXT RPCSG ZOOM MEETING - 5th February 2021

The February group meeting will be held by Zoom on the 5th February starting at 6:45 p.m. with sign-in from 6:15 p.m. The meeting will start with a very short EGM at which RPCSG members can vote on a resolution to make an addition to the RPCSG Constitution. The reasons for the resolution concern meetings held by Zoom and details were sent to members by email on the 14th January.

The EGM will be a very short occasion and will be followed by a talk by Jessica Finch, Senior Research Nurse at Mount Vernon who will talk about the promising treatment immunotherapy. The title of her talk is "A discussion about our experience with the immunotherapy drug Pembrolizumab and current clinical research trials using it".

Members' partners are welcome to the meeting.

RPCSG WALKS AND COFFEE MORNINGS

I am afraid that the coronavirus lockdown means that we cannot hold any further walks or coffee mornings until the restrictions are changed and allow us to gather in person again.

To remind us of happier times here is a selection of photographs of previous walks that we have carried out:



In the grounds of Reading Abbey

OTHER SUPPORT GROUPS

This is a reminder of some other support groups. The first two are treatment specific groups so will be of help to anyone undergoing or considering the treatments:

Active Surveillance Support Group.

This is a support group that is managed by Prostate Cancer UK and meets monthly by Zoom. This group can be contacted at this web site: [Active Surveillance Online Support Group](#)

Prostate Brachytherapy UK Support Group.

This is a new group for patients who have had brachytherapy, or who are considering brachytherapy. The group caters for both LDR/seed/permanent brachytherapy, and HDR/temporary brachytherapy. It meets periodically on Zoom, next meeting 11th March. Contact support@prostate-brachytherapy.uk if you would like to join the group.

Metro Walnut.

This is a support group for LGBTQ+ prostate cancer patients. The group currently meets twice a month on Zoom during COVID, but one of these sessions will revert to being in-person in London when COVID restrictions are no longer required. For more information click here: [Metro Walnut](#)

MACMILLAN SUPPORT

The Macmillan Trust does a very worthwhile job of supporting people with cancer. Macmillan has an office in the Royal Berkshire Hospital, near to the reception desk of the Berkshire Cancer Centre which is at the London Road end of the hospital. Their office remains open in spite of the coronavirus and face to face contact is possible. Their staff will wear appropriate Personal Protection Equipment.

If you would like some more information on Macmillan support and their office opening times please visit this web site:

<https://www.royalberkshire.nhs.uk/wards-and-services/macmillan-cancer-information-centre.htm>

If you would like to visit them it would be a good idea to contact them first to make arrangements.

The following message has been copied from a Macmillan email:

We are open for support and Sarah can see face to face by appointment and wearing appropriate Personal Protection Equipment. Both Sarah and I will support via telephone, email and virtual SO....

Please continue to call or email and advise patients and families to continue to contact us - we are here and will continue to support all patients, families and staff.

0118 322 8700 or macmillan.information@royalberkshire.nhs.uk

LOCKABLE PUBLIC TOILETS

There are thousands of locked disability toilets throughout the country that can be accessed if you have a key that is often called the 'Radar' key. Anyone with a need to have access to these toilets can buy a key. If you would like to have one you can search on-line for them and several companies sell them typically about £5 or less. You can also find the keys on-line in auction sites.

The keys have different shapes of heads and some have wider heads for easier turning in the lock. The image on the right is a standard length key with a wide head. The standard keys are quite long at about 90mm and on an auction site I found a shorter version, by adding 'Mini' to the search.



On-line you can find maps showing the location of public toilets nearby, some of which could be the 'Radar' locking toilets. There are several such maps, this is a link to one of them:

<https://www.toiletmap.org.uk/>

ONLINE SURVEY - REMOTE CONSULTATIONS

In these days of coronavirus many people are having remote online consultations rather than consultations in person. The organisation 'Tackle' would like to improve the quality of these remote consultations and would be pleased to receive input. They have produced an online survey and will be very grateful for anyone who has had remote consultations to complete. The following is part of an email from Tackle and if you would like to complete the survey just click on the link following this message from Tackle:

'We'd like to hear the views of men with prostate cancer about their experiences of having phone or video appointments – known as 'remote consultations' – with their hospital doctor or nurse. We're really keen to understand views – good or bad - to help us understand more about the remote consultations.

To share your views please complete this short 10 minute survey. Thank you for helping us ensure men with prostate cancer have the best possible experience of prostate cancer appointments in the future.'

Survey is: <https://project.tolunastart.com/s/k8MXx3>

PROSTATE MATTERS

The organisation 'Tackle' produces a regular newsletter, the most recent is issue 49 dated November 2020. This edition has a report on some recent talks that Tackle arranged, and also several articles of great interest concerning diagnosis and treatment of prostate cancer. You can find Prostate Matters in the Tackle website, or you can click on this link to read it directly:

https://tackleprostate.org/uploads/files/ProstateMatters_49.pdf

Steve Parkinson
Newsletter Editor.
NewsEditorRPCSG@yahoo.com

DISCLAIMER

This newsletter does not offer medical advice. Nothing contained in the newsletter is intended to constitute professional advice for medical diagnosis or treatment or to advocate or recommend the purchase of any product or use of any service or guarantee the credentials or appropriateness of any health care provider. Members are strongly advised to consult with an appropriate professional for specific advice tailored to their situation.

This newsletter may refer to named providers and their products or services, and such reference expresses no inference upon any aspect of any provider's business, services or products, and expresses no recommendation or preference for any such products or services.

DATES FOR YOUR DIARY.

Friday 5th February 2021 will be a meeting held using Zoom and will be a short EGM followed by a talk by Jessica Finch on immunology.

Friday 5th March 2021 will be an AGM followed by a talk by Sarah Gray of Tackle.