

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

Issue 101: April/May 2020

Website: www.rpcsg.org.uk

This newsletter covers both April and May 2020. There was no separate newsletter in April due to the devastating consequences of the coronavirus pandemic that caused the cancellation of all activities that involved proximity to other people. This disease seems to have appeared very suddenly and we had to cancel our group meetings and the speakers that we had lined up, and cancelled the Awareness day planned for March 2020.

Faced with the prospect of no group meetings for the foreseeable future we decided that the next best thing was to hold online meetings, and software called Zoom came to the rescue. This is an application that allows a large number of people to join in a meeting without leaving their homes by using devices such as tablets and laptops.

THE MAY MEETING.

Our first RPCSG meeting was held using Zoom on Friday 1st May and was very successful. There were 41 people who participated in the meeting, which was a Question and Answer session with Beverley providing the answers.

Beverley first told us of how the RBH is working in view of the coronavirus. Patients are being seen, many of them by telephone rather than face-to-face. Biopsies and MRI scans are still being carried out.

For PSA testing Beverley recommended arranging the tests via your GP, however at present there is usually a long waiting time at the surgery as most surgeries have a 'one person at a time' policy. Anyone having a problem arranging through a GP could contact Bracknell Healthspace or West Berkshire Hospital at Newbury.

Radiotherapy is still being carried out at both the RBH and the Bracknell Healthspace. Chemotherapy is being carried out at Bracknell only. Chemotherapy patients are advised to self-isolate and see a GP or a hospital if they develop any coronavirus symptoms

There have been no cases of coronavirus at Bracknell. It is thought not necessary to test staff as it may give a false sense of security.

At the RBH surgery for cancer will restart in about 2 to 3 weeks whilst non-cancer surgery will be somewhat later, e.g. for colo-rectal surgery it will be in about one month. In the case of surgery for prostate cancer a delay of a few weeks is not thought to be any detriment.

A recent decision by NICE (National Institute for Health and Care Executive) has enabled the drugs Enzalutamide and Abiraterone as treatments in the place of chemotherapy, previously they were not available for newly diagnosed men.

Beverley described the health risk if suffering from coronavirus following different treatments. If a person has had a radical prostatectomy in the last six weeks the body will still be recovering and a person should self isolate. The risk posed by coronavirus after the six weeks is no different from the rest of the population. Surgery for removal of lymph nodes may cause a little extra risk so particular attention to the isolation rules is advised. Similarly extra care is needed with treatment by Abiraterone, as it is a steroid. Normal radiotherapy does not harm the

immune system, however radiotherapy applied specifically to bones can slightly affect the immune system so self isolation is advised, and is also advised following radium 223 treatment. Chemotherapy affects the immune system so during treatment and for 12 weeks following the end of chemotherapy self isolation is recommended.

A member enquired about PSA tests being arranged at other locations and whether this could affect the PSA measurement. Beverley said that the measurement is not affected because the measurements are all carried out by the same laboratory at the RBH.

A member was due for a hormone injection on the same day as a PSA measurement and wondered whether the hormone treatment could affect the PSA figure. The answer is no, and a hormone treatment takes a while to take full effect.

Scans are still being carried out but because of the coronavirus extra measures such as distancing and the cleaning of equipment after each patient, the throughput is slower so fewer scans are able to be carried out.

Beverley advised a member who has had repeated occurrences of UTIs (Urinary Tract Infections) that the drinking of water is recommended to help prevent reoccurrences and cranberry juice can also help. Generally UTIs need to be treated by antibiotics.

We are very grateful to Beverley for her answers to the questions.

NEXT RPCSG ZOOM MEETING

We will hold a further RPCSG Zoom meeting of Friday 5th June 2020. The guest speaker will be Mr Philip Charlesworth who is a consultant surgeon at RBH. His talk will include information on the new anaesthetic template biopsies, SpaceOAR hydrogel, the results of Retzius sparing prostatectomies and how the Covid virus has affected treatments. This a great deal of interesting and useful information.

The meeting will start at 6:15 p.m. with Meet and Greet. At 6:45 p.m. Mr Charlesworth will give his presentation, but as he has a following appointment, his session will finish by 7:30 p.m. Invitations to the Zoom meeting will be sent to all members in early June 2020.

Following Mr Charlesworth's session there will be an informative talk by Tessa Higgins of Macmillan Cancer Support for about 20 minutes and she intends to include a short video about the exercise sessions that she arranges. Then the meeting will continue as an open forum.

See below for some information about joining her exercise classes.

EXERCISE SESSIONS

You are probably aware that before the virus pandemic occurred, Tessa Higgins of the Macmillan Cancer Support organised exercise sessions at gyms on Mondays, Wednesdays and Fridays. Now that the gym sessions can no longer continue due to the virus situation, Tessa has arranged for online sessions using Zoom. Several of our members take part in these online sessions and find them great fun and valuable exercise. If you would like to take part in these just send an email to tlhiggins@hotmail.co.uk and include your telephone number. Tessa will telephone you for a brief discussion on the state of your health with respect to the exercise sessions, and will then send a Zoom link for you to join in the sessions.

SUPPORT AND HELP

On account of the coronavirus situation making personal contact impossible we have put a couple of new methods of obtaining help and support for our members.

We have set up a new telephone number that members are welcome to call for support, help or information. On calling the number you will be automatically switched to one of our committee members who will help you. The number is **0118 357 0482**.

We have established a new email address that can be used for questions concerning medical matters or problems, this is rpcsgmedical@outlook.com. Beverley will regularly monitor this email address and reply to you.

A MEETING ON HORMONE TREATMENT

On the 21st May 2020 Andrew held a Zoom meeting on the topic of Hormone Treatment. This meeting was open to RPCSG and another group and had a total participation of 27 people. Andrew gave a very informative description of how the body manufactures and controls the production of testosterone and how various hormone treatments interact with and modify the process. There was much interaction with the participants and many questions asked.

Many thanks to Andrew for arranging this very interesting talk.

COFFEE MEETINGS

Before the coronavirus arrived we had held several coffee mornings at The Mill at Sonning and these were very popular occasions, being a great opportunity to chat to other members about almost anything. To replace these occasions we decided that we would try a virtual coffee occasion using Zoom. Such a coffee evening was held for the first time on Friday 22nd May 2020 starting at 6:30 p.m. and there were 14 participants. The event was successful and enabled the participants to have some interaction and chat amongst themselves.

We intend to another hold another coffee evening on Friday 19th June 2020 at 6:30 p.m.

PARTICIPATE IN SOME RESEARCH

The following is a message from member Steve Allen:

Dear RPCSG Members,

In addition to being very closely involved with Prostate Cancer UK, I am also very involved with Tackle Prostate Cancer. I am their Patient Representative on a number of national bodies such as NICE and the Scottish Medicines Commission. From time to time, like Prostate Cancer UK, I am approached by various pharmaceutical companies who wish to have contact with patients and gain from their input. I have recently had one such request.

The company concerned would like to speak with men who have advanced / metastatic prostate cancer with still a rising PSA. Patients may have already had treatment with hormones, chemotherapy, and possibly Abiraterone / Enzalutamide in addition. The company are keen to know more about living with metastatic prostate cancer with an elevating PSA. They would like to get insights into what that has been like for the patient and his family, and where they turned for hope and information.

The company concerned are involved with Gallium68 PSMA scanning – currently the most sensitive scan for detecting recurrences of prostate cancer. They are also involved with treatment of advanced prostate cancer using a radio-isotope, Lutetium 177. This is taken up specifically by prostate cells and is being advocated for use in prostate cancer that has spread and is no longer responding to other treatments. This would be a very informal sort of chat via a video link. I would be happy to also be part of that chat if it made things easier.

If you wish to take part please do get in contact with me :

drstephenallen@btinternet.com.

Steve Parkinson
Newsletter Editor.

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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.

5th June 2020 will be a Zoom meeting with a guest speaker Mr Philip Charlesworth.

Following Mr Charlesworth there will be some information from Tessa Higgins about her online exercise sessions.

19th June 2020 will be an RPCSG coffee evening at 6:30 p.m.