

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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Website: www.rpcsg.org.uk

THE APRIL MEETING

Graham Cook, the RPCSG Treasurer, hosted the April meeting and introduced the current committee to the audience. In addition to Graham himself, the committee comprises: **Beverley Skelton** - urology nurse who helped to found the RPCSG and arranges guest speakers.

Keith Hunt - support, deputy treasurer and fund raising.

Derek Jackson - support, and awareness stands.

Ted Goodhew - Deputy 'greeter' and membership.

Chris Webb - website manager.

Steve Parkinson - Newsletter editor and managing the Chairman's email.

Steve Murphy - Secretary and fundraising.

Carmel Howard - support and social events organiser.

Absent from the meeting due to holiday, was

David Priest - greeter and membership.

Graham explained that a chairman had not been appointed but it was hoped to eventually fill this post. In the meantime the group can quite easily continue under the management of the committee. The hosting of the group meetings will be done by committee members on a rota basis.

Graham then introduced two ladies to give a talk to the group, these were Liz Riddle and Shelagh Thomson. They both work in the Macmillan Cancer Information Centre, and Liz manages the centre and has some control over similar centres in other places including the Bracknell Health Space. The ladies gave a very interesting talk about the work of the Macmillan Cancer Information Centre, which is situated in the Cancer Centre in the Royal Berks Hospital. The talk was particularly interesting to me as my only treatment has been a prostatectomy (so far!) that was treated in either Greenland's Ward or Urology Procedures, hence I had no experience of the Cancer Centre, which is the

department of the hospital that delivers such cancer treatments as radiotherapy and chemotherapy.

Liz started by introducing herself. She works in the Macmillan Information Centre in Berkshire Cancer Centre and has worked for Macmillan for the past 8 years. Prior to that she was a urology-oncology nurse specialist for 8 years, then a bowel cancer nurse specialist for 8 years.

The aim of the Information Centre is to ensure that all patients, family and carers have access to high quality information on treatment and choices, and access to help and support. Information and support are the key factors for the Information Centre. The extent of information available to patients has improved dramatically over the years, which enables patients to make better decisions on their treatment and prepares them in advance of consultations.

Macmillan ensures that its information conforms to standards, is relevant, is up-to-date and available in appropriate formats.

The Information Centre is open from 10 am - 2 pm on Monday to Friday. There are 12 volunteers, and last year there was a total of 1500 contacts made either by visits or telephone. There are Information Points at West Berkshire Community hospital and Bracknell Health Space, and Liz would like to develop the Bracknell Info Point further.

Recognising the side effects of treatments helps patients to manage them, the main side effect being fatigue.

The Information Centre can direct patients to access help with many other aspects including finance, hair loss, holidays and insurance, dieticians and Community Services. Citizens Advice Bureau operates in the Cancer Centre to provide further assistance. Complimentary therapies will

start in June, comprising of aromatherapy, acupuncture, massage and reflexology.

Liz then gave some statistics on the demographics of the people who use the Information Centre services. The majority of contacts are by visits, and other contacts are by telephone, email etc. The majority of contacts are women, and most are in the age range of 55-79.

Liz then described the valuable work that the volunteers in the Information Centre provide, and expressed her gratitude to them.

Shelagh then introduced herself as the Project Manager for the Macmillan Berkshire Well Being programme. She works with Macmillan development managers in the provision of, and improvement in, services. The project is 15 months into a 2 year project. The aim is to provide support after treatment. It is patient oriented, and a big step forward has been the adoption of a form to help capture information and identify patient needs.

Physical exercise is a major contributor to recovery and improving outcomes and symptoms. There are four exercise areas across Berkshire, with sessions led by a specialist with a clinical nurse specialist in attendance, in a non-clinical environment. The exercises are tailored to each individual. A set of 12 sessions is free, then patients can buy further sessions at about £3-£4 each. Patients can obtain a DVD for home exercises, and can be advised on Walking for Health walks.

A module known as HOPE (Help in Overcoming Problems Effectively) starts next week and is a 6 weeks course of 2½ hours sessions, giving patients the tools to help their recovery.

Also available are educational rolling programmes on exercise, the impact of cancer on relationships, and information on the services available.

'Relate' offers its services to patients referred to them.

Psychology sessions for carers, and coffee mornings are due to be launched soon.

Shelagh made some leaflets available for anyone to collect.

Liz then invited everyone to join a User Group for cancer patients, whose objective is to act as a patient voice for cancer patients and carers,

positively influencing cancer care delivery and planning, by looking at the services and literature and proposing improvements. If anybody is interested in joining this User Group, please contact Liz.

Some audience members expressed their appreciation of the Berkshire Cancer Centre and the help given to them by the Macmillan Information Centre.

A gift of flowers was presented to the speakers as a token of appreciation.

LET US KNOW WHAT INTERESTS YOU

The committee would very much like to know what sort of events you would like to have at the group meetings. Are there any particular speakers that you would like to see? Or particular topics for presentations? We usually have speakers giving a presentation on topics related to prostate cancer, however we wondered whether you may like an occasional meeting with a topic on a completely unrelated subject, for example travel insurance, or a hobby topic such as photography. Please speak to any committee member or email the chairman on mailbox chairmanRPCSG@yahoo.com with any suggestions that you have; all comments and ideas will be greatly appreciated, and will help us to provide you with interesting group meetings.

DATES FOR YOUR DIARY

THE MAY GROUP MEETING

This will be on Friday 1st May at St Andrews church hall at 18:30, when the speaker will be Charlotte Robinson of the radiography unit at RBH.

THE JUNE GROUP MEETING

This will be on Friday 5th June and the speaker will be Mr. Paul Hadway from the RBH, and his talk will include erectile dysfunction and the clinic that he operates for this.

PCSF AGM and CONFERENCE

On the 16th June 2015 the PCSF (Prostate Cancer Support Federation, usually known as

'Tackle') will hold their annual conference and AGM. The event will feature two speakers, whose subjects will be:

- 'Stampede' - the first results of a trial of combined therapies for metastatic prostate cancer.
- Prostate cancer issues from the Primary Care perspective.

This annual meeting is free for all members of support groups, and will be held in the Nicolson Building in Edgbaston, Birmingham. Some of our members have attended previous sessions and found them very interesting and a useful way of collecting information and meeting members of other groups. Full details of the event including attendance booking and travel can be found in the following web page. Please attend if possible, I am sure that you will find it of great value.

<http://tackleprostate.org/2015-agm.php>

THE JULY GROUP MEETING

This will be on the 3rd July. Details will be available later.

SUMMER SOCIAL

The Summer Social will be in the evening of 15th July 2015 at the Calcot Hotel, the same place as last year, which was a very suitable and popular venue. You will receive more details later on such things as the menu.

RACE FOR LIFE

This will take place on the 26th July 2015 in the Newbury showground, and we will run an awareness stand there. It is a fund raising event on behalf of Cancer Research UK so is for a very worthwhile cause. It is a mainly a run of 5km, although walking and dawdling are adequate! The theme of the event is 'Boys Beating Cancer' as the participants are male only. Of course all members' families are welcome to come and support them. You can find more detail of the event in the following two web pages. Please come along for a fun day out in aid of a good cause.

<http://www.boysbeatingcancer.org/about>

<http://www.boysbeatingcancer.org/event-information>

A RECENT REPORT - INCREASED CANCER RISK TO DAUGHTERS

There was a story in the press recently that may cause some concern. It said that research has found that the daughters of men who have suffered from prostate cancer, have a raised probability of contracting breast cancer.

An American study of 78,000 women found that those whose fathers, brothers or sons had prostate cancer, had a 14% greater risk of breast cancer. The study was carried out at the Barbara Ann Karmanos Cancer Institute and Wayne State University School of Medicine, and was published in the journal Cancer. It is believed that prostate and breast cancers are caused by the same faulty gene being passed down.

You can read more on this report at this web page:

<http://www.dailymail.co.uk/health/article-2985758/Prostate-cancer-raises-breast-risk-daughters-Women-s-risk-increases-14-father-brother-suffered-disease.html>

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Finally, if anyone no longer wants to receive emails from the group (newsletters, chairman's messages, etc) please send an email to the chairman's mailbox chairmanRPCSG@yahoo.com requesting to unsubscribe.

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