

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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THE MARCH MEETING

The AGM was held at the start of the meeting and was well attended. The AGM featured a report by the Treasurer and then a report by the Chairman Steve Allen. Steve arranged the election of Steve Murphy, Ted Goodhew, Derek Jackson, Keith Hunt and Chris Webb, and welcomed all these members to the committee and thanked them for joining.

Three members of the current committee came to the end of their terms and left the committee, these are Ian Forrester, Paul Sefcick (Secretary) and the chairman Steve Allen. Bill Forfar thanked these members for their contribution to the group, and presented some gifts as tokens of appreciation.

The AGM minutes will be posted to the web site for all to read.

Following the AGM, a set of six videos was shown, concerning the most unwelcome treatment side effects of ED (erectile dysfunction) and incontinence. The theme of the videos was the 'personal stories of real people'.

The first three videos concerned ED and were productions by the charity PCUK (Prostate Cancer UK). The videos were from a set of six produced by PCUK which are on a DVD that is included with their publication 'Prostate Cancer And Your Sex Life'. The videos gave short accounts of three men affected by ED and their efforts to overcome it.

Then three videos on incontinence were shown, again stories of men dealing with their incontinence. One of the videos concerned the AUS (artificial urinary sphincter) but was not very helpful. The chairman then gave a good account of the

AUS, and in response to a question, said that it is not possible to accidentally operate the AUS as it needs a moderate pressure to operate. He said that it was possible to feel the device in the scrotum when sitting on the edge of a chair, but this did not present a problem.

The videos led to some interesting comments from the audience and some accounts of their thoughts and experiences. There were some hilarious moments, particularly when a member gave us an insight into his personal life - let's just say that he was the envy of almost all of us!

Some comments were made about there being little information on the effectiveness of ED remedies (these include tablets (Viagra, etc), vacuum pumps, penile injections, MUSE and penile implants). It was suggested that the group could arrange some form of poll of its members on this subject and that could provide some useful information for members. It was said that a poll should be anonymous. The committee will look into how this could be arranged, and the questions that should be asked to achieve useful data.

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You can visit the Prostate Cancer UK website to order a free printed copy of the booklet 'Prostate Cancer And Your Sex Life' which comes with a DVD of the six videos. However you can see the six videos on Youtube at the following web page, where you can select each one of them in turn by clicking at the bottom right hand side of the page.

<https://www.youtube.com/watch?v=vNsvm8Sr1Bs&list=PL1E-4A2300jx70LsfqU7WyRERBExOrO-J>

You can also view or download the booklet at this web page:

<http://prostatecanceruk.org/prostate-information/our-publications/publications/prostate-cancer-and-your-sex-life>

The incontinence videos that were shown can be viewed again at these web pages:

<https://www.youtube.com/watch?v=2QUXIF73Jk>

<https://www.youtube.com/watch?v=XtjDJvAeqOU>

<https://www.youtube.com/watch?v=-eXwhE8IcYk>

PAST EVENTS

Earlier on the same day as the AGM, we operated an awareness stand in the Broad Street Shopping Mall in Reading. Many thanks to the volunteers. We were in a prominent position in the Mall and had an amazing result. With about four people in each of four shifts during the day, we spoke to 228 people, which is a huge increase (52%) on last year's total. These quantities were the numbers of members of the public who stopped to talk to our volunteers, not just to whom leaflets were given. We therefore anticipate that the message on awareness and early diagnosis will have reached many men who will hopefully benefit greatly from our efforts.

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The Lions PSA screening event was held on 11th March, and was very well organised. We had a few RPCSG representatives at the event. The evening was very successful, in that 692 men turned up for their PSA to be tested. Of these men, 642 received "green" letters which advised that the PSA was within the normal range, 16 received "ambers" meaning that the level was somewhat raised and that they should have further tests, whilst 34 received "red" letters meaning that the PSA level was of serious

concern and that a consultation should be arranged. It is thus probable that up to 50 men will be diagnosed with early prostate cancer with good prospects for a cure.

NEXT MEETINGS

The next meeting in April will for once, not be on the first Friday of the month as this happens to be Good Friday. Instead the meeting will be on Friday 10th April, in St Andrews church hall at 18:30, at which the guest speaker will be Liz Riddell, who is the Berkshire Cancer Centre manager. She will tell us about the work of the cancer centre.

The May meeting will have a talk given by Charlotte Robinson of the radiography unit at RBH, in which she will describe the work carried out in the unit.

The June meeting will feature a talk by consultant Mr. Paul Hadway. He is fairly new to RBH, having joined just over 12 months ago, and he has a particular interest in erectile dysfunction and operates a clinic for this condition.

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