

PHAROS

A beacon of hope in the darkness

Newspaper of the Reading Prostate Cancer Support Group (RPCSG)

Issue 26: July 2013

EDITOR'S FOREWORD.

The meeting on the 2nd August will be an 'Open Meeting', at which members of the group are invited to talk to the rest of the group about any aspect of their condition, including diagnosis, treatment and follow-ups. This invitation extends to all members, including our lady members, as we would appreciate hearing experiences from the ladies' points of view. The talk can be as short as you want, and as we would like to fit in several members on the evening, we suggest a maximum of 10 minutes each, thus giving time for the audience to ask a few questions afterwards.

If you would like to volunteer to be a presenter, please email or telephone the Chairman Steve Allen: (ChairmanRPCSG@yahoo.com, or phone 01189 266 747). We will be most grateful for any volunteers.

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'Prostate Cancer And Your Sex Life'

I thought that I would start this section with an attention grabbing title. This is in fact the title of a booklet produced by the charity Prostate Cancer UK. It is appropriate to mention this, as the guest speakers at our July meeting were Geoff Morris and Dawn Fishley, both from this charity, and they gave very interesting insights into their work. Geoff mentioned the fact that the charity has several publications, and these can be seen at this website: <http://prostatecanceruk.org/information/our-publications>

At the bottom of that page you can find an order form for a free copy of the booklet to be sent to your home address. I took advantage of this a few weeks ago, and

found the 70 page booklet to be very useful and comprehensive. It includes a DVD which consists of the stories of the six men that are referred to in the booklet, each story lasting for about four minutes.

If you cannot wait for your copy to arrive, or you prefer it electronically, you can download the booklet in pdf format by clicking near the bottom of the page on 'Download PDF'. The DVD stories can then be watched at this web site:

<http://prostatecanceruk.org/information/personal-stories/sexual-side-effects/bruces-story>

There are useful links on the left hand side of that page, to other topics.

If you do not have internet access you can telephone for publications on 0800 074 8383.

The booklets are free and the Prostate Cancer UK charity would be most grateful for any donation that you can send to them.

THE JULY MEETING (5th July 2013).

There were two speakers from Prostate Cancer UK, Geoff Morris who is a volunteer speaker, and Dawn Fishley who is a Community Nurse Specialist. They both gave very interesting and informative talks.

Dawn started by explaining that she spends about 40% of her time is raising awareness, and 60% involved in treatments. Her objectives are:

- To help patients to survive, with a better quality of life
- Support, and the effects of treatment
- Finding answers to the causes of prostate cancer
- Co-operating with other organisations

Some facts around prostate cancer are that there are about 40,000 diagnoses per year and 10,000 related deaths. About 200,000 men are currently living with the cancer.

Dawn's services include:

- Research funding
- Volunteer support groups
- Awareness and survivorship
- Identify high risk categories
- Empowerment – making people more responsible

A high risk group is Afro-Caribbean, and an issue is that generally this group does not readily seek testing. She advised that the best approach to this group is to visit them in places of congregation, e.g. churches and social groups. She talks more with Afro-Caribbean ladies than the men folk.

Prostate Cancer UK spends about £2.85m on research. Dawn's post is funded by Royal Mail.

Dawn said that she chose her position as it suited her ambitions and background very well. She had some early involvement in urology, and the post combines both teaching and nursing aspects.

Regarding screening, Dawn said that whilst the PSA measurement is accurate, it is not selective for cancerous cells and the lack of a definitive test is a reason for the lack of a national screening programme. PSA however is accurate for post-treatment. PCA3 and other tests have not yet been validated for screening tests.

Dawn then summarised by saying that she concentrates on diagnosis and treatment of prostate cancer, and managing the side effects of treatment.

Geoff Morris then addressed the group and explained his background and his reasons for involvement in the charity. He was diagnosed in 1999 quite by chance when his wife heard of the PSA tests. He had no symptoms, and after mentioning the test to his GP, was referred for a biopsy which found serious cancer, and which was confirmed by MRI and CT scans. His time from diagnosis to operation was three months, and he underwent a radical prostatectomy performed by Mr. Malone.

Upon retirement, Geoff joined the charity, in gratitude for the great help and information provided by them during his treatment. His roles have included reviewing brochures, work on the web site, participating in a Radio Berkshire broadcast, and public speaking and awareness. He has delivered more than 100 talks to date. His venues have included churches, bingo sessions, a sixth form college, a building site, Round Tables, golf clubs and BA at Heathrow. His aim is to let his audiences understand prostate cancer, but without scaring them. He finds that peer support is very rewarding, and the charity attempts to match patients with others having a similar diagnosis. Geoff has carried out lobbying at both clinical and political levels.

Geoff also mentioned the November Movement, which has donated a total of £12m over 3 years, and is committed to £27m over three years.

Geoff said that the main problem is people dropping out of the system, and the charity needs an IT system to help to prevent this.

There were then some questions from the audience, at which Geoff provided some more detail:

- The charity uses benchmarks to see how volunteers are being used
- Prostate Cancer UK does not have any retail shops, unlike some other charities.
- The majority of calls that the charity receives are about the prostate, or recent diagnoses.
- There are about 40 'markers' that can be used to track cancer, but their relevance is still being researched.

Dawn and Geoff were thanked for their very interesting and informative talks. Dawn was presented with a bouquet of flowers, and Geoff with a bottle of 'prescription', as a token of our appreciation.

CONGRATULATIONS

Hearty congratulations are due to our Chairman Dr. Steve Allen and his wife Sylvia, on achieving their 40th wedding anniversary on the 7th July. This conveniently happened to be a Sunday, and

Steve and Sylvia were invited on the day by their children to a much enjoyed celebratory meal. They were then lured to a village hall, where a large group of friends and relatives laid in wait for a surprise anniversary party. This was a very well kept top secret, expertly arranged by the children, and was greatly appreciated by Steve and Sylvia, to such an extent that Steve gave an impromptu speech! There is no holding him back. Thanks also to the weather, which was absolutely perfect, sunny and warm. Very best wishes to Steve and Sylvia for the future.



Steve and Sylvia at the party

FUTURE MEETINGS

The plan for future meetings is as below – this is provisional and confirmation of each event will be sent out shortly before each meeting:

2 August 2013: An open meeting. Any person willing to give a short presentation is most welcome to do so – please see the Editor's Foreword for details and to contact the Chairman as soon as possible so that a schedule can be devised for the evening.

FUTURE EVENTS

It is planned to again have a presence at the Earley 'Green Fair' on 3rd August 2013 (I mistakenly gave the wrong date of the 8th in previous newsletters). We will need volunteers to help to man the stand and promote awareness of prostate cancer. The format will be similar to that of the Awareness Day held in March 2013, whereby

a few volunteers at a time will do a shift of about two hours, the task being to engage with as many people as possible to inform them about prostate cancer, and thus hopefully helping to save lives as more people become aware of this cancer and its symptoms, and the role of PSA testing.

If anyone would like to volunteer for a session, please contact Ivan on ivanpeacock@btinternet.com

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The RPCSG group will be holding the Summer Social on August 22nd at The Moat House Hotel, Sindlesham on Thursday 22nd August. The cost will be around £18 per head. All are warmly invited; this event has proved to be very popular in the past, with members enjoying the opportunity to chat with each other in a pleasant and informal social setting. Please contact the Chairman if you would like to be included.

NEW MEMBERS.

We welcomed one new member at the July meeting.

It is always good to see new members at our meetings, and we wish our new members well and invite them, and indeed all members, to get in touch with any of the support contacts below should they want to discuss any matter relating to prostate cancer.

SUPPORT CONTACTS

For any member who would like some help or support from the Group, or simply would like to chat with someone – perhaps another member who is or has been in a similar situation – any of the members below can be contacted:

Steve Allen	01189 266 747
Ian Forrester	01189 789 857
Keith Jackson	01189 842 999
Paul Sefcick	01635 34778
Graham Cook	01189 691 668
Steve Parkinson	01189 785 268

RPCSG WEB SITE

Laurie Fineman has completed 5 pages of the web site, and after he has gone through a first round of comments from a limited number of people, Laurie intends to give a live demonstration of the site at one of our future meetings, to be announced.

INTERESTING ARTICLES

I am sure that most, if not all of us are aware that a Vacuum Erection Device is one of the methods of penile rehabilitation following prostate treatment. One manufacturer of these devices includes the warning "Do not use whilst driving". This is indeed good advice, but someone in Slovakia must not have seen this warning. Below is a link to the story (published 12 September 2006) – I wonder what he wrote on his accident report?:

http://www.theregister.co.uk/2006/09/12/slovak_pile_up/

For anyone without internet access, here is the story:

A Slovak driver who ignored a give way sign and crashed into a bus was subsequently extracted from his car unconscious, half naked, and "with a vacuum pump on his penis", Channel 4 reports.

The unnamed 42-year-old was driving his old Citroen in the Slovak town of Levice when the accident occurred. Police officer Peter Polak told Reuters: "It's very likely he had auto-sex while driving: it is a matter of investigation. After the accident he was found lying in the seat, his pants were off and it [the pump] was placed on his penis."

Unsurprisingly, Polak added: "I've never seen anything like this, nor have my colleagues."

The man was taken to hospital with "head injuries", the report concludes. ®

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You may have seen in the media that Sir Michael Parkinson has prostate cancer. He was diagnosed in May 2013 following a routine medical, and is undergoing external beam radiotherapy. The following is a link to a report about him; there are several other reports that you can find by searching the internet:

<http://www.guardian.co.uk/media/2013/jul/07/michael-parkinson-reveals-prostate-cancer>

FINAL NOTE

Please note that capital letters in email addresses are for readability only and can be typed in lower case when sending emails.

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DISCLAIMER

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