

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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THE NOVEMBER MEETING

At the November we were very pleased to have Keith Cass MBE as the speaker, who was accompanied by a colleague Darryl Catton. Keith founded the Red Sock Campaign in 2007, with aims that include helping others, spreading awareness of prostate cancer, and informing men of the risks and benefits of being tested for prostate cancer. He is based in Cardiff, and has three sons and one daughter.

64 people attended the November meeting, and heard a very interesting presentation by Keith, who said he would talk about his experience of having the IADT treatment (Intermittent Androgen Deprivation Therapy, which is essentially periods of hormone treatment interspersed with periods of no treatment).

Keith said that he retired in 2006 and in that year was found to have a PSA level of 124. He had a full body bone scan, a CT scan and a transrectal ultrasound scan. A large tumour was detected that included the seminal vesicles, and the cancer had spread to other organs but not to the bones. In March of that year, he was offered a place in the Stampede trial, but rejected this on the grounds that he wanted to select his own treatment, not that decided by a computer. He was advised against having radiotherapy, as it was thought that it would kill too many good cells. Later in 2006, he was given a prognosis of a life span of 18 to 24 months.

He started courses of Zometa (a bone strengthener) every three months as well as hormone treatment. He suffered from side effects and carried out an investigation to find how many men suffered from each of them. He found a chart produced by a cancer charity that listed the quantities of men undertaking hormone treatment, who

experienced side effects, and found the following data:

PERCENTAGE OF MEN SUFFERING SIDE EFFECTS OF HORMONE TREATMENT:

Hot flushes	85%
Erectile dysfunction	82%
Loss of libido	80%
Tiredness/fatigue	70%
Weight gain	55%
Breast swelling	55%
Cognitive effects	45%
More emotional	45%
Joint pain	40%
Mood swings	38%
Feeling anxious	37%
Breast tenderness	30%
Less masculine	30%
Depression	30%
Muscle loss	28%
No self confidence	25%
Hair loss	20%
Osteoporosis	8%

Keith then sought a second opinion, and he advised the audience that anyone is quite free to take a second opinion should they desire. Among others, he consulted Mr Roger Kirby, who is the author of a book titled 'The Prostate - Small Gland, Big Problem'. He also spoke to Andrew Loblaw of the Sunnybrook Centre in Toronto, who has written a paper about IADT.

Keith told us of his personal history of undergoing hormone treatment and PSA levels.

Keith displayed a flip chart listing his experience of IADT along with his PSA readings, as reproduced below. He said that

undergoing IADT is a risk, but has the advantage of giving the patient some rest periods between the taking of hormones, during which the patient can have a degree of relief from the side effects.

Feb 2006	PSA 124
May 2006	Start Zoladex
July 2006	Start Zometa (bone strengthener)
July 2007	PSA <0.1
Nov 2008	PSA <0.1
Oct 2009	Start 1st IADT
Mar 2011	PSA 53.8
Feb 2012	PSA <0.1 2nd IADT
Sep 2012	PAS 12.0 End IADT
Aug 2013	PSA 0.3 3rd IADT
Apr 2014	PSA 17.0 End IADT
Jun 2015	PSA 0.9 4th IADT
Aug 2015	PSA 1.3

Keith's next PSA reading is due in January 2016.

Keith said that during IADT, Mr Loblaw advised that the PSA level should not be allowed to exceed a figure of about 10 to 15 during the 'rest' periods of IADT.

The prostate gland in childhood is about one fifth of the final size that it will be at puberty. Prostate cancer becomes clinically detectable around the age of 50 to 60, and it is possible that prostate cancer can develop over a period of about 20 to 30 years before becoming detectable.

Keith is on the board of 'Tackle', and is preparing a presentation on 'PSA testing - a way forward'. He will attend a meeting in Brussels in January to discuss alternatives such as K4 and PCA3 testing, and Free PSA.

Keith then displayed a table of the findings of autopsies of men who had not died of prostate cancer, listing the percentages by age group of those in which prostate cancer had been found. The source of this data is the NHS Prostate Cancer Risk Management.

PERCENTAGE OF AUTOPSIES FINDING PROSTATE CANCER	
AGE	INCIDENCE
20-29	8%
30-39	28%
40-49	39%
50-59	53%
60-69	66%
70-79	80%

These figures confirm the need for earlier testing.

A member asked about cramp. Keith advised some exercise before bed time, to avoid muscle contraction, which is the cause of cramp.

Keith said that he had suffered blood clots, which occur in 10-15% of men who are on hormone treatment.

Keith mentioned that he has helped many men, and gave an example of a 63 year old man who spent 16 hours per day in bed. Keith advised him to pursue the obtaining of Abiraterone after his consultant told him that it was not available. The consultant telephoned Janssen, the company that manufactures Abiraterone, and they agreed to fund a treatment. Within 24 hours of the treatment, the patient was able to walk easily outside his home, and in three months he could climb 'small mountains'.

Some of the figures that Keith presented were based on a report produced by the UK National Screening Committee, that can be seen at this link: [Legacy.screening.nhs.uk/policydb_download.php?doc=502](http://legacy.screening.nhs.uk/policydb_download.php?doc=502)

Keith was thanked for his very enlightening and helpful talk, and was presented with a gift of appreciation.

A DONATION TO UROLOGY PROCEDURES

During 2014 the committee thought that we would like to express our appreciation to the urology department for the excellent care

and treatment that many members have received from that unit. The staff in the urology unit said that there was an urgent need of a urine analysis (Urinalysis) machine, and the RPCSG committee decided to purchase one of these machines. The cost of this was a little over £400 and we donated the machine to the Urology Procedures unit earlier this year. It is now in use in Urology Procedures and has been a great benefit to them in carrying out their work.

The Urinalysis machine has many benefits over the older analysis machines. Quite importantly, it has an on-screen keyboard and the operator must type in the patients name before using it. The print-out that the machine produces includes the patient's name, ensuring a positive identification of the results to the patient. The machine also analyses samples automatically rather than the old method of subjectively judging by eye the colour of a sample against a colour reference strip. Hence the machine is much quicker and accurate than the old models, and can of course be used for samples from both men and women.

I would like to take this opportunity to express my thanks to Urology Procedures for the expertise and care that they have shown to many of our members.

There is a photograph below of the machine in use in Urology Procedures, with it's sample drawer open to receive a sample, followed by a photograph of a commemorative plaque that is now on display on the Urology Procedures notice board in the waiting room.



THE JANUARY 2016 GROUP MEETING

The January meetings are usually held as an informal gathering without any guest speaker. This is because attendance may be reduced because of the holiday season, and the meetings are held also for any new members that may want to attend. In 2016 we have the misfortune of the meeting being on New Year's Day. A deferral to another date was considered, but it was decided that we would hold the meeting as planned, in particular because any men newly diagnosed during December would expect there to be a meeting for them to attend. The January meeting will take place as planned from 18:30 and I hope that any member able to come to the church hall will do so.

DATES FOR YOUR DIARY

THE DECEMBER GROUP MEETING

The meeting on the 4th December will be our annual Christmas Social buffet meal, which is always a very popular and enjoyable event. Some detail of this event have been sent by email, which is that it will be in the St. Andrews church hall from 18:30 with the meal available from about 19:15. The drinks will be 'Bring Your Own' so please bring drinks for your own consumption. There will be a complimentary drink on arrival.

THE JANUARY 2016 GROUP MEETING

The January meeting will be on the 1st January 2016 at 6:30 p.m. in St. Andrews church hall. The meeting will be informal with no guest speaker, and a good chance to chat with other members. Refreshments will be available as usual.

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