

Minutes of meeting Thurs 2nd Feb 2012, 2 – 4pm
Venue - Conference Centre, Pendleside Hospice

Helen Mcvey from the Hospice and Julia O'Neill introduced themselves to the meeting and reaffirmed that today's room is only temporary (for this and the March meetings), the room we used for the January meeting will be available again from April to the end of the year. They said that they really want to support and be involved with our group and hoped that we form a good 'partnership'. Joanne who often attends our meetings and is a Hospice Volunteer helper will be available to 'meet and greet' members and assist us wherever possible.

32 people attended this meeting incl. 2 new attendees - Bill and Clive and our regular visiting professionals. We thank Martins sister Sam for helping organise the seating and assisting with the setting up of the film equipment.

It was suggested that it would be beneficial if all members signed in and gave their contact numbers, they could then be contacted with the offer of help or support should they become ill, we will also be able to mail them about meetings and other interesting information.

Martin opened the meeting by announcing that our guest speaker Mike Murphy from Janssen would not be attending due to news which had just been announced this morning. Janssen are the manufacturers of Zytiga (Arbiterone Acetate) N.I.C.E. (National Institute of Clinical Excellence) have decided that due to cost they would not be financing the drug. This drug has been extremely successful in reducing the effects and pain of Prostate Cancer and has been one of the most successful to date. It has been proven that it extended the life of the patients who had been using it. Colin gave information about the benefits Zytega had given to patients and said that we should all get together and lobby to try to get the decision reversed. He said that there is a website where people can comment on the funding issue and state their opinions or objections. **Website: <http://guidance.nice.org.uk/TA/Wave26/4/consultation/DraftGuidance>**

Colin then informed us about a conference at the Christie Hospital Manchester, organised by Prostate Cancer Support N.W. The Conference is this coming Saturday 4th Feb., 1-30pm/4pm. Doctor John Logue who is the Director of Clinical Oncology at the Christie will be speaking about the advances in Clinical Management of Prostate Cancer.

Martin showed some short films on the 'big screen' 1 - Billy Connolly 'making light' of his Prostate tests at the Doctor's and men's concerns and fears when having to visit their doctors, very amusing! 2 – A short film about Androgen Deprivation Therapy and how much men know about their Prostate, this film highlighted just how many men don't know where their Prostate is or what it's function is! - The normal prostate is a small, squishy gland about the size of a walnut (20 milliliters). It sits under the bladder and in front of the rectum. The urethra—the narrow tube that runs the length of the penis and carries both urine and semen out of the body—runs directly through the prostate. The rectum, or lower end of the bowel, sits just behind the prostate and the bladder.

Sitting just above the prostate are the seminal vesicles—two little glands that secrete about 60% of the substances that make up semen. Running alongside and attached to the sides of the prostate are the nerves that control erectile function.

An interesting discussion between members then followed and once again, as stated at all the meetings, it was very apparent that men do not talk about their ailments, particularly in respect of their Prostate and other male sexual issues.

Stuart said he had been told by his Consultant that more younger men with the Cancer are now attending his clinics, this was also confirmed at the meeting by Clinical Specialist's Debbie Hesketh and Deborah

Dobson they said it could possibly be due to more publicity or awareness and the possibility of more men seeing their Doctors about the PSA test, the reasons are unsure at the present time. Debbie and Deborah said that the title of the Well Man Clinics (historically run by GP surgeries) seems less popular of late. This may be due to a change in the clinic title or format run by GP surgeries. GPs may well perform 'stand-alone' tests and investigations brought about by the concerns of the patient. If you have any queries about clinics in your area ask your GP's surgery for advice.

Debbie and Deborah were asked why PSA tests still continued after the Prostate has been removed (Radical Prostatectomy), they said the main reason is because microscopic Cancer cells can travel in the blood and could have spread prior to surgery, also there is a small possibility that some may not have been completely removed during surgery and this could cause a higher PSA reading. BPH (enlargement of the Prostate) can also be a cause of higher PSA readings. Colin said that the PSA test is not a "good" test but there is nothing better at the present time the biopsy is another means of determining the state of the cancer or whether cancer might be present.

Stuart explained that his Consultant has arranged for him to have a biopsy in 6 months' time rather than his usual 6 monthly PSA test. This is because his PSA has remained stable since he was diagnosed in 2007 and his previous two biopsies have been the same with a Gleason score of 3+3 = 6 in two cores. In August he will have been on Active Surveillance for 5 years and has been having PSA tests since 2002. His Consultant has told him that if the PSA and Biopsy results are no worse he can be signed off, although he can still have his PSA tested by his own G.P. Stuart doesn't feel too convinced about this because as we all know the PSA alone is not a good indicator in respect of how the Cancer may be behaving.

Dave said he had mentioned the PSA test in the changing room at the leisure centre he attends, there were 7 or 8 men in at the time, probably between the ages of 50 – 70 and they did not know what the PSA test is! Dave also told us that he had just had his consultation on Tuesday at Stepping Hill Hospital in respect of solving his incontinence problem. He is now awaiting confirmation about having an operation to have an artificial Sphincter fitted although he is concerned that it may be dependent on area funding.

Brian told us about a book he had read from corner to cover which he had found invaluable when he had to make his decision about which treatment to have. He said in his opinion it is better knowing than not knowing, particularly when making what could be a life saving decision. Brian chose Radiotherapy and he had just finished the treatment. The book is called Tool Kit.

The raffle raised £40 and £5 was donated to the Hospice to cover the cost of tea and coffee etc.

Next meeting: **Thursday 1st March. The Conference Centre, Pendleside Hospice, 2 – 4pm**

Note for Diaries: Local Consultant Urology Consultant, Mr. M. Pillai will be the guest speaker at our May meeting and will inform us of recent advances for the treatment of Prostate Cancer.