

## MINUTES OF MEETING THURSDAY 3<sup>rd</sup> JANUARY

Venue – Mackenzie Medical Centre. Burnley Gen. Hospital 2 – 4pm

### Chaired Dave R.

20 people were in attendance. Dave opened the meeting and wished everyone a Happy New Year. He continued by reading some relevant points from the December minutes. He then informed the meeting that he had found a number of books and literature in a drawer which he had accrued during his time on his Prostate Cancer 'journey'. He said he thought that it would be a good idea to give them in for the group's library and suggested that if anyone else had suitable books they could do the same as this would help other members (particularly new members) gain information that could be of help to them.

Dave then talked about all the different pills (and potions) such as Viagra that are available online; he had a long list which he had printed out. Eddie asked why anyone would want to buy online and Dave said Prostate Cancer patients can go to their own GPs and are entitled to them free on the NHS. Stu then said that he had heard damning reports on radio and TV about some online drugs from abroad and that one particular programme told of how they were contaminated and were not even manufactured from authentic ingredients, some were highlighted as having been manufactured from animal parts!

Leon (our IT Guru) brought up the subject of having social events, he is keen to organise some guided walks because he is a keen walker himself and he found that walking helped him greatly following his surgery. He wondered if any other members were of 'like mind', if so anyone can contact him and he would organise suitable walks. Leon has put info on our website for anyone interested; go to - 'Social Activities' tab.

Glen S said he has a friend in Yorkshire who is very inhibited and does not like discussing his problems in the presence of women, particularly with respect to his prostate Cancer situation.\* (a little more of this later in the minutes). Glen also told us about the problems he had at Bradford hospital when he had his Prostate surgery, mainly with regards to the care and lack of attention to cleanliness, even arguing between Consultants! He said he had further treatment at Wakefield and his experience there was far better. He continued by talking about the troubles he had following his operation for having an artificial Sphincter fitted and that it had been a long time before it would operate correctly. He said he just wished that he had known about the Support Group before he had all his surgery and problems, it would have saved him a lot of trouble and anxiety.

Stuart talked about a man called John who he had listened to on Radio Lancashire, he was talking about Prostate Cancer and Stuart said he had been so impressed with what he had talked about that he contacted R Lincs for his Tele no. The man who is only in his 40s had recently been diagnosed with terminal Prostate Cancer and he has a wife and two young children. He contacted Stuart about a fortnight later and he is such a positive person that he has set up a website about himself and he is raising money for Prostate Cancer Charity. His website is [www.justgiving.com/John-ellison-CR](http://www.justgiving.com/John-ellison-CR) Stuart said that he intends to contact John again to ask him if he would like to attend one of our meetings.

Tony R proceeded to tell us that he had just recently been to see his specialist about his incontinence problem and is considering the possibility of an artificial Sphincter like Dave M & Glen S. Moira asked Tony if he wished that he had come to our meetings before he had had his Prostatectomy and he said definitely because he would have had far more knowledge and been more aware of all the alternative

options and treatments. He then told of the trauma he went through before deciding whether or not to tell his children that he had Prostate Cancer. Tony asked Glen about his operation because of his own situation, Stu also gave him Dave M's tel no.

\*Dave R. asked if we thought it would be of interest or benefit to have a meeting (or part of a meeting) when men can sit together to talk between themselves about any personal issues. The ladies present thought it was a great idea and that they would be happy to go and talk among themselves. Dave deferred this until the next meeting and suggested that we can debate then whether we have a complete men only meeting or a 'partial' men only meeting.

Tea and Coffee break was next and this was surprisingly a little more 'special' than normal because it was Stuarts 65<sup>th</sup> birthday on the day and he provided Haffners meat pies and Oddies egg custards which everybody enjoyed, like Xmas again! Stu said enjoy it because the cost was coming out of his first pension!

Following a short general discussion it was apparent that all the people who attended this meeting said that our group meetings were extremely helpful to everybody and that they were more comfortable knowing that all the others in the group are all in a similar situation.

Stuart talked about the **importance of patients keeping records**, particularly after his experience when he visited his Consultant for the results of a Prostate/Pelvis MRI Scan. He had two Scans because the the first one showed a 'shadow' on it, the Radiographer had said that it was advisable for him to return to have another one. When he went for the results of his Scans the Consultant only had the results of his first scan in his file, therefore based on that, he said 'we need to be doing something about this now'! Stuart then asked if he was referring to the first scan or the second one? - to which the reply was, 'have you had another Scan?', the Consultant then looked at his **computer** and saw the results of the second scan and he said 'this throws a complete different light on it, it's still the same as the 2009 results'! Apparently the shadow on his first Scan was due to some hemorrhaging following his Biopsy; he was told that it was likely to have been caused because the first Scan had been carried out too soon after the Biopsy. - To think that he could have been having surgery or treatment! The moral of this must be that **patients should make sure they keep their own records** and be responsible for themselves because there is a possibility that mistakes could happen. Stuart then showed his records and a graph of all his PSA tests since 2002!

Hazel told the group about the TV advert by Prostate Cancer UK featuring Bill Bailey with his sledge hammer to crack a walnut! It was noted that Prostate Cancer is the least supported in terms of funds.

Nigel D asked why the PSA test was not routinely offered to **all** men and told of his annoyance and anger that he was put off the test by his GP. If he had had the test at an earlier stage he would have been diagnosed much earlier and could have been treated before his Cancer had become more aggressive. Stu then said that the PSA test is not offered to all men because it is not a reliable test and it can lead to men having unnecessary trauma and Biopsies. Men over the age of 50 are entitled to a PSA test on the NHS.

Stu asked if anyone had any ideas as to how our group can move forward and to bring any ideas to future meetings. He also congratulated Leon for doing such a brilliant job of producing and adding all the information for the new website. Leon then said that he is going to issue everyone with a password to access the website and members can then add their own comments on it as well as looking at all the other excellent articles which are on the site.

Hazel asked Leon if he was still posting out newsletters to 19 members (at 50p each) and she said that quite a number of them do not come to meetings, posting newsletters probably creates a situation where people don't come because they get the information anyway! This would be looked into for the next newsletter.

Eddie told us that his Grandson had raised £850 for Prostate Cancer UK's Movember campaign – fantastic! He also said that we should be putting leaflets in Barbers shops and Steve L agreed, being a hairdresser himself.

Dave R said that he thought that it would be a good idea if the members told their own stories again and brought us all up to date with their PC journeys. Jennifer said we could do this as it would help to encourage new members to tell their stories, she said it would not then be as daunting for them in front of 20 – 30 people.

Dave concluded the meeting by telling one of his 'famous jokes' - about Viagra.

Apologies were received from Chairman Dave and Vice Chair Steve L who are unable to attend the next meeting.

The raffle made £20

**NEXT MEETING: THURSDAY 7th FEBRUARY 2013, 2-4pm, MACKENZIE MEDICAL CENTRE, BURNLEY GEN. HOSPITAL**