

MINUTES OF MEETING THURSDAY 7th February 2013

Venue – The Mackenzie Theatre/Library, Burnley Gen Hospital 2-4 p.m. Chaired by Stuart M

31 people were present: There were 4 new attendees: Our thanks to Raymond H who donated £10 and Don who donated £5 to help with postage.

Stuart welcomed the new attendees and asked how they found out about the group. One found out through the Burnley Express, another through the internet, one by word of mouth and one through a feature in the Burnley Football Club match day programme (this latter one is the first through that source and shows that our promotion is starting to work). Stuart wanted to let everyone know that the main aim of our group is to help and support others with Prostate problems by supplying information and offering advice about where treatments and further help can be obtained: He also welcomed and introduced our two regular specialist nurses, Debbie & Deborah.

Stuart informed the group about notices of upcoming conferences; Pendleside Hospice are organising meetings on the 1st Tuesday of every month, 3-4pm for newly diagnosed Cancer patients and would like a representative from local support groups to attend as this would be of benefit to the Patients, the Hospice, and the Support Groups.

Prostate Cancer UK are campaigning at Accrington Stanley FC on Sat 2nd March as part of their season long campaign with the Football Association and wondered if we could get a minimum of 6 people to help out at the ground. Hazel said she had contacted P.C. UK about it and some of the members agreed to go and collect, it will give us the opportunity to hand out some of our leaflets. Eddie thought the small leaflet was a good idea because it goes straight into the pocket – whereas some of the other leaflets may be more bulky.

There's to be a Talk by Dr. J.P.Wiley who is the Consultant Radiographer at Christies Hospital on Sat 2nd March. (Dr Wiley is a specialist on Brachytherapy and Radiotherapy treatments). His talk will be about latest developments with these treatments. Some of the members are interested in attending this talk and will report back to the next meeting.

Colin then gave details of a conference to be held on 18th February at the Macdonald Hotel in Manchester organised jointly by the Prostate Cancer Federation & Prostate Cancer UK and he asked if any of the members would like to attend. This conference will be about how Prostate C. S. groups in the the NW and Prostate Cancer UK can 'pool' their ideas by working together.

Stuart asked about the on-line survey about Hormone Therapy and wondered if anyone had heard back from the firm conducting the survey. Colin informed the group that it has been put back a little.

Some of the new members told of their "journey" through the diagnosis of Prostate cancer. One of the new members reiterated that his wife had made him go. Again this shows the effectiveness of the ladies making the men confront their embarrassment and go for tests. Again it was discussed about men being bad about looking after or talking about their bodies. Colin told how early diagnosis is imperative and that Dr Wiley had told his own group that 22% are too late for active treatment and can only have palliative care. That's staggering!!!

One of the new members Richard spoke about his diagnosis and that he went immediately on Hormone therapy and half way through that he had an implant! He's not sure how it is going yet!

Stuart suggested that people with similar conditions could sit together with new members and to help by discussing how they had proceeded with their own treatments and to offer help as far as possible. Colin told of a group that was formed especially for people experiencing problems following Radiotherapy, it meets on the 2nd Wednesday of every month in Manchester. If anyone is interested he will give details. Deborah spoke about Radiotherapy and how different people react.

Graham said how important it is to keep a record of our own readings and appointments and keep notes. We must be able to recall our meetings and relative results – so write everything down!

Break for coffee. Colin then spoke about Prostate Cancer Support (NW). If members want a better “patient led” representation in Parliament then for just £15 they can fill a form in and send it off to Darrell at PCS (NW) and anyone who becomes a member will then receive all the booklets etc. and the monthly magazine. If a member of our group wanted a vote on anything we would have to be a member to vote. He thought it was a good idea to join and have access to all the information on Prostate Cancer. If anyone wants to join contact Secretary Stuart for details. Colin is also part of the Federation help line – manning the phone whereupon he will put people in touch with someone who can answer their queries and give them help. He told of a single man of 50, who lived at home with his mum and had contacted the help line. This man knew nothing at all about Prostate Cancer, PSA tests, or even the word ‘Advanced’. He only knew that his PSA was 5,000!!! This again highlights the case for getting information out to younger men and how imperative it is to be tested.

Something to think about **before** we have PSA tests. - don’t ride a bike or a horse or have sex! If you smoke the PSA reading is likely to come out lower – men with high body mass and Diabetics get lower readings.

Stuart spoke about a graph which he had kept of his PSA readings. This showed the overall behaviour of his PSA. Deborah said that Doctors can - at the ‘click of a button’ also see the same type of graph over the years of a patient’s PSA. Due to a personal experience he then stated how important it is for patients to keep records of clinical visits and discussions.

Stuart mentioned about our collection of library books for members and the pamphlets which he had ordered from Prostate Cancer UK – they are excellent and all are informative and the contents are explained in simple terms about all stages of Prostate Cancer. The library books are available to members and **must be booked out.**

At the next meeting, Tony Clarkson from the Sanctuary of Healing will give a talk of about 40 minutes on Complementary Therapies and how they can help with quality of life. Hopefully, at the April meeting we will have Gordon Birtwistle, Burnley’s MP, who has raised a lot of money for hospital equipment and Prostate Cancer is a subject close to his heart as a family member was treated for this condition.

It was suggested that a photograph of the Hospital building / entrance door that we use to access our meetings could be put on the newsheet and website, with a notice also on the door on the day of the meetings, new people have had some difficulty in finding the Mackenzie Theatre/Library.

The raffle made £39

THE NEXT MEETING; THURSDAY 7TH MARCH 2013, 2.00-4.00 P.M AT THE MACKENZIE THEATRE/LIBRARY, BURNLEY GENERAL HOSPITAL

