

MINUTES OF MEETING No 31 Thursday 6th June 2013

VENUE – BURNLEY GENERAL HOSPITAL MACKENZIE THEATRE/LIBRARY 2-4 p.m.

25 people present including our two specialist nurses, Deborah Dobson and Debbie Hesketh, apologies for absence were received from Dave R, Steve L & Leon W. – Stuart M. Chaired the meeting.

1 new member Michael W. found out about the meeting through his Oncologist at Burnley. Stuart asked Michael if he felt able to tell the meeting about his diagnosis. Michael said that from his Biopsy he had 4 cores cancerous and 8 clear. He had come to speak to other people in the same boat as himself. Stuart told him to ask about his Gleason score when he next spoke to his Oncologist. Colin spoke to him about Hormone treatment and Deborah Dobson (Specialist Urology Nurse) said that she would talk to him and explain some of the facts to him. Stuart spoke to him about the buddy principal where people who had had various treatments could sit with him and go through their own experiences to help him make up his mind which route to go down.

Stuart informed the meeting that Colin O who lived in France had donated £40 to the Prostate Support Group.

Stuart then told the group about the Awareness Day which we held at Blackburn and explained that the group took buckets to collect for the scanner appeal for Burnley General Hospital which includes a mobile scanner for Lancashire. T Shirts were worn by the group (of which there were quite a few members present) and these had been paid for by Ted D. a member of our Support Group, Ted donated £50 for this purpose plus £50 for our group. Stuart explained that we do not know how much money was raised at Blackburn because the buckets were sealed and they can only be opened in the presence of an independent person. Stuart will send a letter of thanks to Ted.

Stuart introduced Colin Stott ('Doctor Colin') and also Colin Piddington, Colin P. is the Chairman of the Walnut Support Group based at Preston.

Stuart then informed the group of the speakers for the next two meetings. Doctor Parikh, Consultant Oncologist from Preston will speak at the next meeting (Thursday 4th July), this has been arranged by Deborah Dobson. Doctor Parikh will speak generally about Radiotherapy, but if anyone has any questions these could be submitted and incorporated into her general talk rather than her speak to people on an individual basis. At the August Meeting (Thursday 1st August) there is a speaker who is from an independent company, experts on legal solutions. His talk is entitled "Tax, Care and Toy boys," Colin S. from the Oldham Group said that they have had the talk and he thought that it was extremely good, briefly it covers financial affairs such as inheritance planning and all things taxed, etc. Colin also said that he thought it was very informative and there was no pressure on anyone in respect of sales and that it certainly will open your mind!

Stuart asked how many people had had different kinds of treatment and from the people present it was revealed there were 5 who had Prostatectomies, 7 Radiotherapy, 7 Hormone Therapy, 1 Active Surveillance and 1 person who had incontinence problems.

Dave M asked about the new proposed scanner and what it treats, he wondered if it was part of the biopsy procedure, Deborah confirmed that it is. Graham P. spoke about the fact that he knew

nothing about treatments when he was diagnosed and a general discussion took place about the way people are treated after they are told the life changing news that they have Prostate Cancer and about the state their mind can be in – especially if they have to drive home!

Moirira wanted to let people know that if they are interested in a topic on Prostate cancer where we have no literature, then let them (Eddie & Moira) know and they will endeavour to get some information or publication on it.

BREAK FOR COFFEE

After coffee the raffle was drawn and it made £32. Stuart made a plea for raffle prizes.

Colin Piddington then said a few words regarding trying to arrange a Prostate C. Regional Conference as there is not going to be one this year. He is prepared to co-ordinate it and said that he should be able to obtain a grant from Macmillan to fund a Conference if the group think it is the right thing to do and be prepared to send representatives. He then asked what we could do as a geographical area together. Deborah Dobson said that patient user voice is a strong one if directed appropriately and she wondered if a larger group could get some funding from Macmillan. It was decided that we would discuss it with other members of the group to find out if we wanted to have some part in a larger organisation.

Colin Stott (Doctor Colin) then gave an informative talk about new drugs etc. that are on the market. A new Hormone treatment is 'in the pipeline' but it may not suit everybody although it is looking promising and it could be another option when available. There's also research on a new Urine test for PSA which is giving good results. New treatments are being tested frequently but they will need to be approved by NICE before they can become available.

Colin then spoke about travel insurance and the new Euro health insurance card; the card tells you what you need, what you don't need and how Prostate Cancer can affect holiday insurance.

He has information on heredity prostate cancer and intends to talk on this when there is more time. As usual, the time had steadily crept up to 4.00 p.m. and as we can only have the meeting room until 4.00 p.m. we had to close the meeting and save this talk for another meeting.

For anyone who wants to read the Minutes of this meeting – a copy or copies will be at the next meeting so that people attending can read them

The meeting closed and the next meeting will be on 4th July (wear your stars & stripes) same venue, same time.