

AVPCSG Newsletter - Issue 7 : March 2014

In this issue:

Hale Leys final reminder

2014 AGM Report

Enzalutamide Petition

Relay for Life

PCUK Centres of Excellence

Article for Bucks Herald

Next meeting for partners – April 3rd

New Leaflet

Aberdeen University Research

Maypole dancing

MK Update

Next Lunch meeting

Hale Leys Final Reminder

Hale Leys is only next week! If you can come along to help out, with or without your partner, it would be appreciated. We have just about managed to secure at least one person per slot but this is with some members popping along twice. If you feel you could help out, even at this late stage please let Brian or Roger know.

This is how we stand today:



AVPCSG at Hale Leys Aylesbury 10-15 March 2014

DUTY ROTA

Day	10am - 12 noon	12 noon- 2pm	2pm – 4pm
MON 10 th	Brian Cole	Malcolm Way David Barrow	Malcolm Crawford John Masters
TUE 11 th	David Rogers	Jeremy Buckman Roger Wotton	Roger Wotton Errol Blackburn
WED 12 th	John Micklem John Sear	Peter Morton Bruce Cameron	Dennis Bone Brian Cole
THU 13 th	Gordon Taylor John Brown	Tony Lisk	Tony Lisk
FRI 14 th	John Davis Malcolm White	Leo Kyte	Ken Austin Peter Smith
SAT 15 th	Roger Wotton	Marc Ponsford Brian Cole	Brian Cole Peter Brannan & Sheila

Special Event : Meeting for our Partners!



We often talk about the important role of our partners, supporting us in dealing and living with the effects of prostate cancer. Some of us would say we underplay the contribution our partners make. We often forget they also need support and could value from meeting each other just as we sufferers do. There is no support for them and this has always been recognised by us and the local NHS trust.

Now we have a collaborative initiative underway between Buckinghamshire Healthcare and Aylesbury Vale Support Group, led by Emily Brown, a trainee clinical psychologist working with Buckinghamshire NHS Trust. You will see from the enclosed leaflet that Emily would like to set up a pilot support group of partners. The intention of this group is to be informal, with no structure, fund raising objective or commitment, but to come together in a confidential environment and

talk with others in a similar situation and get support.

To facilitate this, an initial meeting has been scheduled for **6.30 pm on Thursday 3rd April**, which will be hosted at Anne Barrow's home - Grassy Bank, Manor Road, Towersey OX9 3QS. Anne is happy to take phone calls to clarify any queries before the meeting (feel free to telephone 01844 215034).

We would like to encourage members to inform their partners of this opportunity to discuss and share their experiences in an informal and confidential get together. Emily and Anne would appreciate knowing how many would like to attend only for logistical purpose i.e. how many cups and car parking! The get together is designed to be informative and helpful. **Please make a note of the date in your partner's diary and let Anne know if you plan to attend (01844 215034).**

2014 AGM Report



At our AGM on 27th January we had 19 members attend – lower than we would have hoped but nevertheless we had an enjoyable lunch with a guest speaker, Robert Breakwell talk about the Hyperbaric Diving Bell at the Chiltern MS Centre. We discussed whether this might offer treatment to prostate cancer sufferers.

At the AGM proper we confirmed the continuation of Brian and Roger in the capacity of Chairman and Secretary respectively. John Brown stepped up to take over the role of Treasurer from John Davis, to whom Brian expressed grateful thanks from the group. Committee members Jeremy, David B and Bruce also offered to continue for the next year, and this was appreciated by all. Our finances have taken a battering this past year with heavy expenditure on publicity, the gazebo and other equipment. This has been necessary to relaunch the newly combined support group. Donations helped balance the books and we have a surplus of £1703. This will decrease significantly when pending costs for printing and Thame show are submitted. The good news is we have been successful with Brian's application for a grant from the Haddenham Beer Festival and we have received £500. Well done that man!

New Leaflet

You will find a couple of copies of our new leaflet enclosed with this newsletter. Once again Martin Dawe Design of Slough did the design and layout for us for free, and we used our funds to have a supply printed. We also have a stock of display cases for sending out stocks of leaflets to all the doctor's surgeries in our area. More about this later.

Enzalutamide Petition

Many of you will be aware of the campaign to overturn the NICE decision to limit the use of Enzalutamide, a life saving prostate cancer drug for those with advanced forms of the disease. We received this note from the Prostate Cancer Support Federation.

tackle
prostate cancer

Dear Roger

The battle to get NICE to change its mind over Enzalutamide continues. Prostate Cancer UK, with support from Tackle, have set up a petition for NICE to reverse the proposed decision not to allow Enzalutamide to men who have already had Abiraterone.

Please ask your members to support this petition by going to <http://tinyurl.com/ohvq99o> and signing it.

We must keep fighting for an early reversal of this cruel decision which has, at a stroke, dashed the hope of hundreds of men who, unable to tolerate Abiraterone, were waiting and early release of this new drug, which, as latest trials reported today show, has shown some "spectacular" results.

Best wishes

Sandy Tyndale-Biscoe

Hon Chairman

Aberdeen University Research

Core Outcomes for Localised Prostate Cancer Research: Patient Involvement Required

For those of you interested in participating in a research study, the University of Aberdeen is seeking people to help by completing a questionnaire. We mentioned this to those who attended the AGM. If anyone else is interested please contact steven.maclennan@abdn.ac.uk

It is for those men diagnosed with prostate cancer during the last five years. It only takes 15 minutes to complete the questionnaire.

Relay For Life 5th to 6th July



Cancer Research UK are organising a "Relay for Life" event at Aylesbury Rugby Club from noon on **Saturday 5th July**. This continues for 24 hours until noon on Sunday 6th. There is an opportunity for us to take part as survivors and take the opening lap, for which you will receive a T-shirt, special lunch and high tea for free!

Check out further details here : <http://www.relayforlifeaylesbury.org>

We are making a small donation to the cause. We will be erecting our gazebo on the day and will be asking for names of those who wish to participate. This will be discussed further at our next lunch meeting. Make a note in your diary now!

Maypole Dancing



On Saturday 3rd May there will be May Day dancing around the maypole in Haddenham and we normally see a good crowd gathering. There will be a few gazebos from other organizations up for a couple of hours or so. We plan to erect our gazebo and wave the flag. We only need two or three members to volunteer to man the stand for a couple of hours. It's all good fun with a beer tent and barbecue stand etc. Can we have volunteers please? - **names to Brian**

PCUK Centres of Excellence

We received this email from Prostate Cancer UK:

Movember and Prostate Cancer UK, working in partnership, have announced the launch of 2 Centres of Excellence supporting research into prostate cancer, one in Belfast-Manchester and one in London. More information about the Centres of Excellence can be found here, with a short video: <http://prostatecanceruk.org/research/movember-centre-of-excellence>

If this link does not work for you, go to the PCUK web site www.prostatecanceruk.org click on the tab "Research" and you will see the article.

Milton Keynes Update



Roger and Brian visited the urology department at Milton Keynes General Hospital to meet Emelda Moos, the urology lead nurse and Mr Leslie, one of the consultant urological surgeons. Diagnosis is carried out at MK but surgery is done at Oxford. There is no support group in MK and yet they have some 600 prostate cancer referrals a year and they do 10 biopsies a week. We shared with them how a support group could work and what is necessary for success. They are very keen to start a support group locally. Emelda is going to call an initial meeting of recent patients and we said we would help in sending a couple of our members along, as well as contacts from the Oxfordshire and Watford support groups.

Bucks Herald Article

Brian penned a short article for the local paper to coincide with Awareness Week and we gave the paper a picture of our gazebo – look out for the article!

Next Lunch Meeting

Make a note now in your diaries – our next lunch time meeting will be **Monday 28th April** at the normal Thame Football Club venue from 12 noon. This time we have Peter Seaton, an old member, joining us to speak about his work on “The Prostate Project” in Surrey.



Brian Cole
Chair, Aylesbury Vale PCSG



Roger Wotton
Sec., Aylesbury Vale PCSG

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