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Relay For Life



We have mentioned this event a couple of times and now is the time for you and your partner to sign up, come along as a member of AVPCSG and enjoy a free lunch! See <http://www.relayforlifeaylesbury.org>

With Brian on holiday he has arranged for one of his local friends Brian Bush to bring the gazebo and equipment over to the venue on Saturday. What we need are some volunteers to come over and help set up our gazebo in time for the start at 12 noon. It would be really nice if we could get as many local members and partners to attend the start and walk the course as survivors. A free lunch is then available afterwards. Roger will be there on the Sunday but if we could have one or two members popping in on the Saturday afternoon it would be really helpful, just in case we get anyone wanting to talk about our support group efforts.

If you feel you can come along please let Roger know as soon as possible by email (rwotton@btconnect.com) or by phone (01442 822161) as we need to give numbers to the organisers.

If you do plan to attend, please let us know if you can:

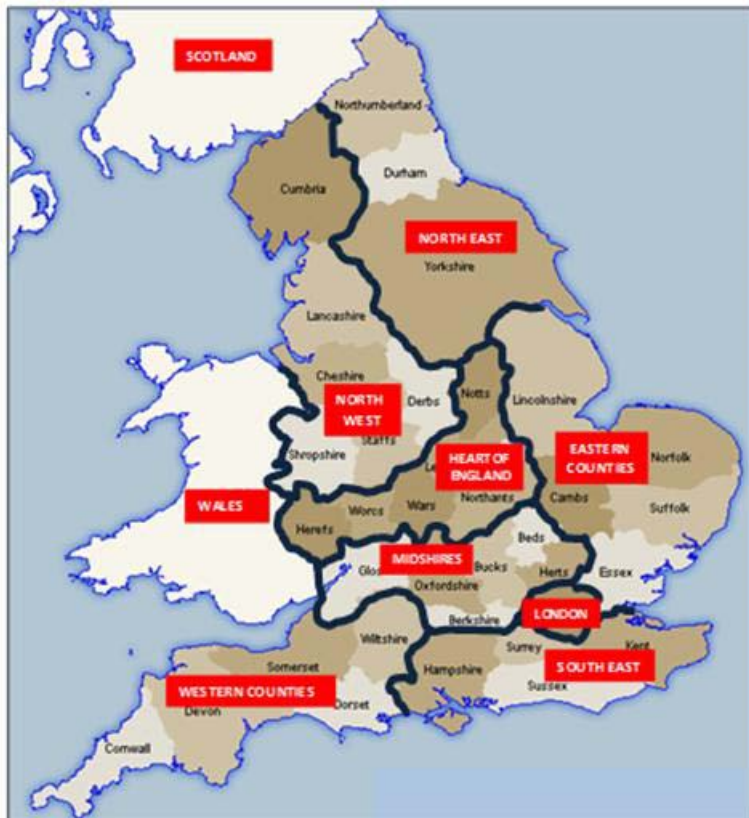
- a) Help prior to 12 noon to set up the gazebo/stall and/or
- b) Attend at 12 noon to walk the course and have lunch and/or
- c) Pop along sometime on Saturday afternoon to don a tabard and man the stall.

Here's hoping we can muster support to join the event. If we do not get enough support we will have to decline the event.





Federation News



The Prostate Cancer Support Federation has now set up 10 Regional groups, aimed at improving communication across the organisation and ensuring a better connection between grass roots and the Federation executive. Regional Focal Points have been established, and these are existing support group officers, so there is no overhead or additional cost in operating with this new structure. Our group is now part of the Midlands Region, along with Chiltern, Watford, Reading, Oxfordshire and Cotswolds groups. Roger has taken on the role as Regional Focal Point. The first meeting of focal points has already taken place and one of the early aims is to identify those hot topics or opportunities we feel the Federation should be working on as a priority. This will provide input to the next Federation National workshop in London in June. Both Brian and Roger will be attending this workshop representing Aylesbury Vale. As an aside, Roger has agreed to allow his name to go forward to be nominated as a Trustee of the National Federation.

PCUK News



Now that we have become a partner organisation with Prostate Cancer UK we are able to benefit from a number of additional services. These include training opportunities, membership of advisory panels, branded publicity material, free public liability insurance, grant aid, etc. In fact we have applied to PCUK for a grant towards our web site development and for leaflet printing costs. In return we are asked to acknowledge the connection with PCUK and be expected to run our group in line with good practice – something we will be discussing at our next meeting on July 21st. We hope this partnership develops for the benefit of our members.

Web Development



At last we have made progress on the development of our own dedicated Aylesbury Vale Web Site. We have secured some help in getting the site set up, and we are setting up the hosting and support. We plan to be able to update and maintain the site ourselves which will make it much easier to keep it current and interesting. The web address will be www.aylesburyvaleprostatecancer.org.uk. It may be a bit of a mouthful but the committee felt it hit the spot. Watch this space!

Enzalutamide Success

There is some excellent news on the enzalutamide front. PCUK, working together with Tackle Prostate Cancer (the Federation) have succeeded in lobbying for wider access to this important drug. You will be aware that the government's advisory body NICE was planning to withhold the end of life treatment enzalutamide from patients who had already been treated with abiraterone. This unfair decision has been reversed, not least because of the efforts of both these bodies and all the support group members who signed petitions. PCUK made the following announcement on 9 May:



“Thanks to the 13,500 of you who stood with us to challenge NICE, we're thrilled to report that NICE has removed the outright restriction on the use of life-extending enzalutamide after treatment with abiraterone, saying there is no clinical reason for it. By coming together as Men United and with Tackle Prostate Cancer we made our voices heard.

“This is good news for men with advanced prostate cancer, who have so few treatment options. But NICE's decision isn't an outright recommendation, either. We believe men should now have access to enzalutamide even if they've already had abiraterone, but we need to make sure this is followed through. Read the full story and find out how you may be able to help: <http://prostatecanceruk.org/challengenic>”.

Leaflets in GPs Surgeries

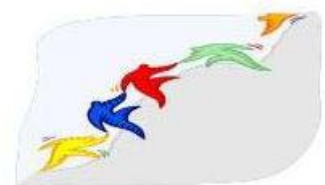


Now that we have a stock of tri-fold leaflets and display cases, we would like to target all the 50+ GP surgeries in our catchment area and help raise awareness by placing the leaflets where men might read up about prostate problems and seek help if required.

Brian handed out some of these to those who attended the lunchtime meeting last month. If any member would like to target their own surgery please get in touch with Brian to co-ordinate distribution.

Chiltern Group Support

Bruce continues to liaise with the Chiltern Group and we have much to thank him for, particularly as he has secured some further financial support from them. They have kindly agreed to help us by funding leaflet production up to the value of £500. This is a tremendous boon to us as it will allow us to produce a quality leaflet for the partners of those with prostate cancer. Our thanks to Bruce and the Chiltern Support Group for their generosity.



Hospice of St Francis



You will be aware we have been working with the hospice, based in Berkhamsted, to explore closer links with the prostate cancer community. Jeremy and Roger attended a pilot training programme (see latest edition of “Prostate Matters”). We are planning to ask members from the hospice to attend our next meeting in July. In the meantime Tina Smith, the specialist prostate cancer nurse based at the hospice, is surveying the outpatients departments at Watford and Hemel Hempstead to see if there is a need for support in their area.

Milton Keynes Update



In the last newsletter we mentioned the contact with Milton Keynes General Hospital. The urology department there has sent out invitations to recent prostate cancer patients asking if they would find value in forming a support group. If this results in sufficient interest both the Oxford support group and Watford support group have offered to join us in helping MK establish their own group. If this comes to fruition they will join the Midshires region of the Federation.

Thame Show



Don't forget the date for your diary – **Thursday 18th September**. It's the Thame & Oxfordshire County Show and once again we will be represented. This is our premier event of the year and we are hoping for a grand turnout. More details to follow.

Next Lunch Meeting

Make a note now in your diary for our next meeting on **Monday 21st July** at Thame Football Club from 12 noon. This meeting will incorporate an Extraordinary General Meeting to agree our new constitution and to elect trustees. This is an important meeting and we would like to see as many members attending as possible. Please do make the effort to come along if you can.



Brian Cole
Chair, Aylesbury Vale PCSG



Roger Wotton
Sec., Aylesbury Vale PCSG