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Welcome from Brian



A very warm welcome to all our members. This edition of our newsletter will find many of you on holiday, and I do hope you have a relaxing and enjoyable summer break. Some of you may even be reading this on your iPad by the pool somewhere! Our recent lunchtime meeting was a major milestone in our development, as we approved a new constitution – see the article below. We also welcome two new members to our group – David Kew from Thame and Ron Knight from Aylesbury. We have taken the opportunity to provide you with an updated list of members distributed with this newsletter. If any details have changed please advise Roger. Happy reading!

Our New Constitution

This is something we have discussed previously and have now finally put in place. You will have seen this in the papers distributed for our recent support group meeting. Based on the model constitution supplied by the Charities Commission it outlines our purpose, the way we hold meetings, elect trustees, manage our funds and generally run the support group. It's something we also needed to put in place as we signed up to be a partner group with Prostate Cancer UK. We are pleased to announce this new constitution was unanimously approved at our recent meeting. It outlines the following purposes for our group:



- To promote and protect the physical and mental well-being of prostate cancer sufferers in the Aylesbury Vale area, through support, education and advice.
- To raise awareness of the general public in all matters relating to prostate cancer.

Trustees

Along with the new constitution, we have a committee of Trustees. The role of Trustees is to oversee the management of the support group, in the way that our committee has always done. We are pleased to say all of the existing committee members agreed to stand as Trustees until the next AGM, with the exception of Jeremy Buckman, who has elected to stand down in view of his other charitable commitments. Brian thanked Jeremy for his valuable contribution to the group over several years. If any member wishes to become a Trustee of our group please let Brian know and you will be most welcome.



Sign Up For Conversational Training



After a successful training pilot scheme run by the Hospice of St Francis in Berkhamsted we are opening this to members who wish to undertake the role-based training. It's all about having conversations with newly diagnosed men and their families. Those of you who have been involved in this will know it needs to be a dialogue that is both listening and respectful. Roger and Jeremy went on the pilot and spoke very highly of the event. It's non-confrontational, enjoyable and involves a couple of hours one evening at the Hospice in Berkhamsted. Some of you expressed an interest at our recent lunch meeting. If you were one of those or you are interested in attending, please get in touch with Roger and he will arrange the training.

NICE Decision

Some of you will be following the debate on the licensing of Enzalutamide and whether it can be offered to patients who have previously had the benefit of Abiraterone. We have had this latest news in from PCUK and it is clear the campaign is continuing.....



Access to Enzalutamide – an update on our campaign

After you and thousands of other Men United supporters signed our petition earlier this year, we hoped to be writing to you with good news. We hoped to tell you that the revised draft decision from NICE (the National Institute for Health and Care Excellence) to approve the drug enzalutamide without the outright restriction on its use after treatment with abiraterone would mean it would be available to all men who needed it. Unfortunately, this is not the case.

NICE has now [confirmed its decision](#) to approve enzalutamide, but the implications of this decision are not what we had hoped, or what we have been campaigning for together.

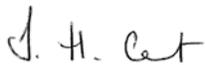
The wording of the NICE decision means the final say on whether to provide enzalutamide to men who have already received abiraterone is made by the organisation that funds the treatment. NHS England, which funds these types of treatments (in England), has decided not to fund enzalutamide for men who have had abiraterone. To put it bluntly: NICE has passed the buck and NHS England isn't paying.

This is an outrage and means that many men now have no treatment options left. Neither abiraterone nor enzalutamide are experimental drugs – they are both licensed and recommended for use on the NHS. But because they're quite new treatments, we don't know yet whether the order they're prescribed in makes a difference. We think that doctors need to be able to prescribe the medicines they think will be best for their patients, without fear that if they try one, another will then be out of reach.

If this decision affects you personally, our specialist nurses can offer support. Call them on 0800 074 8383.

There is one remaining chink of hope. [The Cancer Drugs Fund](#), which can be used to fund treatments in England that don't have NICE approval, met to discuss whether they would pay for enzalutamide for men who've already had abiraterone. We have strongly urged them to make the right decision for men, and we'll let you know what happens.

Although a huge disappointment, this result for men with prostate cancer highlights the need for Men United to keep taking the fight to the organisations and individuals who make the decisions that affect so many men's lives. We're certainly not resting on our laurels, and are already planning our next move depending on the decision made by the Cancer Drugs Fund. Thank you again for your support so far, and keep an eye out for our next appeal for your help.



Dr Sarah Cant, Director of Policy and Strategy

Recent Grants & Donation



We are happy to report our finances are looking up. Not only have we received a £500 donation from Haddenham Beer Festival and a further £500 donation from the Chiltern Support Group for publication printing we have been awarded at £990 grant from Prostate Cancer UK. This was as a result of our submission to fund development and support for our new website and our campaign to target all local doctor's surgeries to raise awareness of prostate cancer. Our thanks to Brian for facilitating the beer festival money, Bruce for the Chiltern donation and Roger for making the case to PCUK. Although we have had to fund our pitch at the upcoming Thame Show, we are in a strong position to support future awareness campaigns.

Federation News

Brian and Roger attended the National Federation AGM and Conference at Twickenham in June. We discussed the importance of staying in touch with local groups and priorities going forward. We expect to see a more regional focus emerge. We are pleased to say that Roger, our group secretary was elected to the National Board as a Trustee. He still plans to devote as much time to our local support group but it will give us an insight as to what is going on elsewhere in the Federation.



One of the regional initiatives we are following up in the "Midshires" region is helping Milton Keynes set up a support group. Brian and Roger made a visit to patients at the Linford Wood Medical Centre in MK to talk about how our group operates. As a result we may see a couple of new members join us from the Leighton Buzzard area. Secondly, Brian, Roger and John Hazell from our group, together with George Goldsmith, Chair of the Oxfordshire Support Group attended an inaugural support group meeting for patients at Milton Keynes General Hospital. Arranged by the urology nurse at the hospital, it was attended by some 25 patients. We discussed the value of having a support group and shared some of our experiences. They plan to meet again in 6 weeks time and we offered to continue to help where we could.

Travel Insurance



Just a reminder for all of you going on holiday. If you are having trouble arranging travel insurance the Federation has negotiated travel insurance for men with prostate cancer and pre-existing medical conditions. You can find details at www.justtravelinsurance.com. If you are interested and want to know more, give them a call on 0800 231 5532. JustTravelCover.com is open 9am -8pm Mon-Fri, 9am-4pm Saturday and 10am-4pm on Sundays. Please quote reference "Tackle". For each policy sold, a small donation is made to the Federation.

Friends of The Vale

One of the main aims of our group is to help others diagnosed with prostate cancer. We often get referrals from Joe at Stoke Mandeville to speak to newly diagnosed patients. It would be a great help to us if we had a list of names of group members who would be willing to share their experiences of a particular treatment. For example, Dennis Bone recently kindly agreed to telephone a newly diagnosed patient considering Brachytherapy. If you feel you could do something similar based on your specific treatment, please let Roger know for one or more of the following: Active Surveillance, Radical Prostatectomy, External Beam Radiotherapy, Brachytherapy or Hormone Treatment.



Newsletter

Thame Show

Don't forget the next major event for us is the Thame Show on Thursday 18th September. We will be manning our normal stand and anyone who volunteers to help on the day will receive a free entrance ticket. This is a great day out and an opportunity to really spread the word about what we do and raise awareness locally. Roger will be sending out the rota shortly, so try and free up a couple of hours to help on the day.



Future Events

Looking further ahead, our next lunchtime meeting will be on Monday 6th October. Venue to be agreed. We are also arranging an evening with partners at Stoke Mandeville Post Graduate Centre to hear from Mr Neil Haldar who many of you will know. This will be a great opportunity for Q&As on lots of topics. This is likely to be late October. Finally, we will be having our Christmas lunch party at Brian and Hazel's home once again. Date to be advised.

Brian Cole
Chair, Aylesbury Vale PCSG

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