

PROSTATE CANCER PATIENT SUPPORT GROUP



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Hi everyone,

January 2019

Our last lunch at The Brickmakers was very successful and we were able to help a gentleman who now lives in France, has been on Active Surveillance but now needed more active treatment. Since the meeting he has told me how much he enjoyed the lunch and also how he benefitted from meeting others who had had the treatment regimes he was considering. This is what the Support Group is all about and it is so satisfying when it all works well.

EDUCATIONAL EVENING

Our educational evening is now on Wednesday 13th March and will be an 'Any Questions' session with Dr Carla Perna, a consultant oncologist and Mr Dimitrios Moschonas, a consultant urologist to answer your questions. If any of you have any questions that you would like to ask please let me have them and I will pass them on to the speakers. There will also be time for questions on the night. Do join us in the new Stokes Urology Centre (on the Royal Surrey County Hospital site) on Wednesday 13th March at 19.30. It is so good of these consultants to give up their time so I do hope for a good audience. Please support this event and bring along any friends who might be interested. The meeting is free but if you park at the Royal Surrey you will need to pay for parking.

PUB LUNCHESES

Our next two pub lunches are as follows

Wednesday 30th January at the Onslow Arms, West Clandon, GU4 7TE
and Thursday 21st February at The Brickmakers, Windlesham GU20 6HT

As usual please arrive between 12 noon and 12.15, order at the bar and we will all be served around 12.30 – 12.45

I apologise to those of you who get the newsletter by post as you will miss the first date. Hope to see you at Windlesham.

Our pub lunches are very informal and allow you to meet others with similar conditions and learn from their experiences. These meetings are light hearted, relaxed and friendly. Everyone welcome so please come along either by yourself or with your wife, family or friend. We also welcome unaccompanied ladies if their husbands do not want to come along. If you know of anyone who is worried about prostate cancer, whether or not they have it, please encourage them to come along and join us.

It is really helpful if we have some idea of numbers. Please let me know if you intend to come so we can notify the venues in advance.

GARDEN LUNCH

Once again we are holding a Garden lunch here at Merryacres on Thursday June 20th. Cost again will be £5.00 each and we will have a substantial buffet. I will give more information nearer the time but put this date in your diary now so that you do not miss it. On a law of averages it is time we had a really lovely day for this event!!

RESEARCH

I have only just received this request from Tackle, the organisation who support support groups. I appreciate this is very short notice so if anyone is interested you will need to act swiftly.

I appreciate it is short notice but we were asked today by Janssen pharmaceutical, one of our industry partners, if we could identify up to six of our members who might wish to participate in an exercise looking at where their PSA is rising even though they are on hormone therapy and have non-metastatic prostate cancer. Alternatively they may have previously not had metastatic prostate cancer while receiving hormone therapy but now have metastatic prostate cancer. Full details are given below

We are interested in hearing from men who meet either of the following criteria:

1. Men with non-metastatic prostate cancer who:

- • have undergone orchiectomy(a surgery to remove the testicles) **or***
- • are currently receiving long-term androgen deprivation therapy (ADT). Examples of ADT include bicalutamide, flutamide (Eulexin) , Leuprolide (Lupton), Goserelin (Zoladex)and Triptorelin (Decapeptyl)*

and

- who have been informed that their PSA levels are rising*

2. Men who previously had non-metastatic cancer and were on ADT, but have now been diagnosed with metastatic prostate cancer

If you meet the above criteria, are available on the 31st January 2019 and would like to be involved we would love to hear from you. Please contact Jordan Rankin at patientteam@its.jnj.com

We will be able to pay a small honorarium for your time and also to arrange and pay for your travel to and from the meeting.

There is also an opportunity to take part in a study to understand better a cancer patient's journey from initial diagnosis to treatment planning and therapy management in Europe. This study is carried out by SIS International via a phone interview of 30 - 45 minutes conducted by a professional moderator with compensation of £118. If you are interested, please complete the following survey to see if you are eligible: <https://www.surveymonkey.com/r/cancer-patient-study-europe>.

MAKING CONTACT

Remember even if you are unable to attend our meetings you are very welcome to contact us at any time. Please note that there is now a dedicated answerphone at the Urology Centre and this is the best way to contact me by phone, The number is 01483 406870 and if we are away someone will let you know when we will be back and able to contact you. I also have a new corporate e-mail:- supportgroup@prostate-project.net

This is the best way to contact me as I should receive these e-mails even if we are not around. Remember, if you do not wish to receive future newsletters from me please let me know.

Best wishes

Maggie (Swaden)

Email: supportgroup@prostate-project.net

Limitations on our use of your Personal Information

Your Personal Information is never used to send messages on behalf of third parties nor revealed to others unless there is a legal necessity. We never share Personal Information with other charities or any other third party.