



Torbay Prostate Support Association

Serving men of all ages, and their partners, through a programme of support before, during and after diagnosis
Newsletter Summer 2014 Issue No.37

Challenge NICE on enzalutamide

NICE decision on enzalutamide limits options for men with advanced prostate cancer. We've recently heard that NICE have reversed their draft decision on enzalutamide to make it available only to men who haven't previously been treated with abiraterone, and we need your help to change their mind!

This decision places a tremendous burden on doctors, who must now consider - without knowing which treatment will work better for a particular man - that if they prescribe abiraterone, they are ruling out the possibility of enzalutamide later on. This is an unnecessary complication for men whose options are already limited, and will come as a huge disappointment to those men for whom abiraterone hasn't worked, as they learn they've reached the end of the road in terms of possible treatments.

Please help us to get this restriction removed by responding to NICE's public consultation with your own comments on why enzalutamide should be made available to all men with advanced prostate cancer after chemotherapy – regardless of whether they've already received abiraterone. To make this easier, go to www.prostatecanceruk.org/challenGENICE for more information about the consultation and a step by step guide of how to Sign and share our petition. This will take less than two minutes, but could make a huge difference to the men affected by this decision..

Please also encourage your support group members and other relevant contacts to submit comments to the NICE consultation too.



The poster features a large, stylized musical note (treble clef) in dark brown and orange tones, set against a textured, light brown background that looks like aged paper or wood grain. Overlaid text includes:

- Mid Summer Evening of Music**
- In Aid of Torbay Prostate Support Association.**
- The Chordettes** Ladies Close Harmony Chorus
- Torbay Police Choir** Male Voice Choir
- & Guest Artists**
- Saturday 12th July**
- Central Church Torquay**
- 7:30pm**
- Entrance by Programme: £7.00**
- More Details Contact:**
- Jane Barry: 01626 203901
- Keith Meager: 01626 335623

TPSA logo and Registered Charity: 1095734 are visible in the bottom right corner.

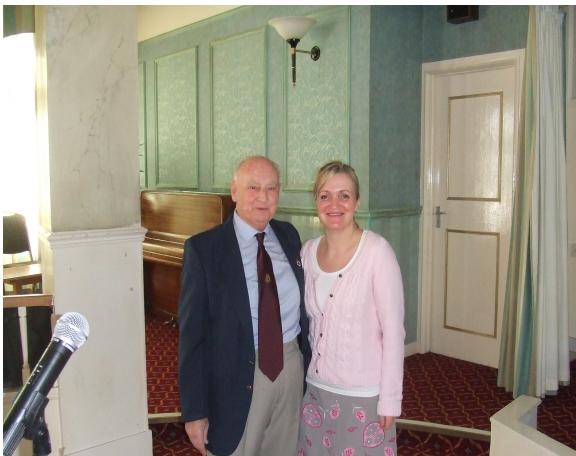
Watchful waiting fact sheet available online from Prostate Cancer UK

We've updated our information on watchful waiting for prostate cancer.

This is a way of monitoring prostate cancer that isn't causing any symptoms or problems. The aim is to monitor the cancer over the long term, as prostate cancer is often slow growing and may not cause any problems during a man's lifetime. However, men can start treatment at any time if they do start to get symptoms.

The Watchful waiting fact sheet is available to download, or you can order it on our website. As always, it's been updated with the latest available evidence, and has been checked by men with prostate cancer and health professionals. <http://prostatecanceruk.org/information/prostate-cancer/treatment/treatment-choices/watchful-waiting>

Emma Meckiff BSC. Hons.
Head of Pre TreatmentTorbay Hospital
Intravenous Contrast and Planning of Prostate
Cancer AT THE Redcliffe Hotel.Paignton Thursday
27th February



CAN YOU HELP ?

Dear TPSA Members, Angélique du Toit asked us to circulate the following message to TPSA members.

I am in the process of writing a book on the experiences of cancer patients and their families and in particular prostate cancer patients. I would very much appreciate your help. I can be contacted angelique.daviesdutoit@gmail.com

In this research I am not seeking the technical and medical information, but more of a lay person's view. I am more interested in the personal effects and how this impacts on their lives and that of their families. Thank you in advance for your support and if you need further clarification from me, please let me know.

Chairman's Report May 2014

Dear All,

Our latest project (purchase of Intensity Modulated Radiotherapy Treatment Equipment) has at last been installed and is functioning very well indeed. Everyone involved including the patients are extremely pleased with the results – Thank you all that donated to this project. The official presentation as I speak has not yet been arranged but we expect it to have taken place by the time you receive this Newsletter. We are still looking for a secretary please contact me or a member of the committee if you can assist us

We are as always looking for new ideas for the Newsletter and Website – if you feel you may have a story to tell of your experiences with Prostate Cancer from the beginning to the present time why not share it with us all. Many of us have gone down different roads with this problem and you could well be helping someone out there who is worrying needlessly. Please think about it and contact myself or the Newsletter Editor. Members, family and friends at our last members meeting really enjoyed an excellent presentation by Emma Meckiffe, based at Torbay Hospital. We have now arranged our next Members meeting, again at the Redcliffe Hotel – a poster is attached giving the full details please display prominently.

The speaker will be Yvonne Trace a Support Group Development Officer at Prostate Cancer UK, who will be describing the purpose, benefits and her work with groups throughout the country.

A very advanced notice – please place a note in your Diary now – The Torbay Police Choir together with the Cordettes Ladies Choir are to put on a concert in aid of the TPSA on Saturday evening 12th July at Central Church Torquay. They are excellent performers and we need your support – thank you. We will keep you posted – tickets will be available in advance and on the night. In the meantime please display the attached Poster in a prominent position – perhaps in your Doctor's surgery. Again please let us know if you would like to receive your Newsletter by email since you will all appreciate that the cost per year is rising and on top of the printing, postage costs are a real consideration. Your help in this context would be very much appreciated.

Peter Hosking,
Chairman

MEMBERS CORNER

Dear Members

I have for many years also been a member of PCaSO, a prostate support organisation based in Hampshire, where I had my laparoscopic prostatectomy operation performed by Chris Eden. I have found them to be an extremely professional and well informed organisation who appear to have access to some of the top personnel, information and articles.

I found their information pack given to new members to be very good and I believe that this has been updated considerably since I joined. You can obtain access to them via their website www.pcaso.org or by contacting their Publications and Newsletter Editor, Ian Graham-Jones on 01243371128 or www.publications@pcaso.org.

From their website you can access copies of their newsletters and I think that they are all well worth reading together with their Issue 46:February 2014 with details of The 'Riskman' Trials, A review of PSA Apps and Comments on PSA testing under the article 'Knowledge Empowers. I hope that the enclosed may be of some interest to you. Thank you all for your good work.

Regards
Howard Richards

TORBAY PROSTATE SUPPORT ASSOCIATION
Charity no. 1095734
NEXT TALK IS BY
Yvonne Trace
Support Group Officer Prostate Cancer UK
Work with Local Groups And Patients
AT THE Redcliffe Hotel.
Paignton, Sea Front
Thursday 12th June 2014
1000 for 1030hrs
EVERYONE WELCOME (Not Just Members)
Please display this notice to encourage your friends & neighbours to come and support us. Why not display copies of this notice in your local shops or libraries & Doctors' Surgeries?
Best of all - be sure you turn up yourself

Can we draw members attention to the Watchful waiting fact sheet available on line from Prostate Cancer UK

Watchful waiting

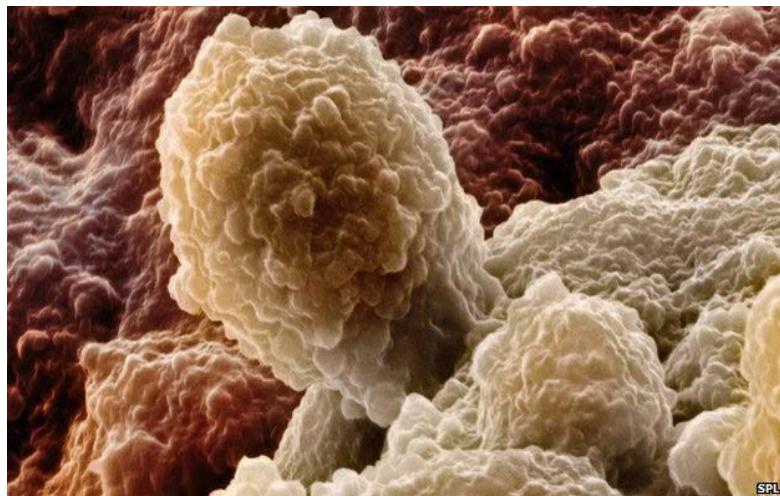
Watchful waiting is a way of monitoring prostate cancer that isn't causing any symptoms or problems. The aim is to keep an eye on the cancer over the long term, and avoid treatment unless you get symptoms. Prostate cancer is often slow growing and may not cause any problems or symptoms in your lifetime. And many treatments for prostate cancer can cause side effects. For some men these side effects may be long-term and may have a big impact on their daily lives.

If you decide to go on watchful waiting, you won't have any treatment unless you get symptoms, so you'll avoid these side effects. Many men on watchful waiting never need any treatment for their prostate cancer. But for some men, their cancer may grow more quickly than expected. If your cancer does grow more quickly than expected and you get symptoms, you can start treatment to control the cancer and help manage symptoms.

What other treatments are available?

www.prostatecanceruk.org/information/prostate-cancer/treatment/treatment-choices

DNA prostate test 'will predict deadliest cancer risk'



DNA testing can predict which men face the highest risk of deadly prostate cancer, scientists say. The team at the Institute of Cancer Research, in London, say men could soon be offered genetic screening in a similar way to breast cancer in women. They have shown 14 separate mutations can greatly increase the odds of aggressive prostate cancers, which could form the basis of a test.

DNA prostate test continued:-

Prostate Cancer UK said such testing could "revolutionise" care for men. Prostate cancer is the commonest cancer in men in many countries, including the UK - where more than 40,000 people are diagnosed each year. But not every patient has, or needs, invasive therapy that results in severe side-effects. Identifying which men will need treatment - those who are likely to develop the most aggressive and deadly form of the cancer - is a huge challenge.

Danger genes

The researchers took blood samples from 191 men with prostate cancer and at least three close family members with the same condition. Each was tested for risky mutations - this included the BRCA genes that are involved in repairing DNA and already linked to breast and ovarian cancers. The results, published in the British Journal of Cancer, show that 7% of the men had one of 14 high-risk mutations. The researchers said that it was also these men who had the aggressive prostate cancer that had started to spread around the body.

One of the researchers, Dr Zsophia Kote-Jarai, told the BBC: "I can see in two to three years offering screening to men with prostate cancer and to men worried about their family history." However, she said it was unlikely these men would immediately opt to have their prostate removed

'Exciting'

However, the screening is not ready yet. The research group is already running a larger trial involving 2,000 men and testing 192 genes.

Dr Iain Frame, the director of research at the charity Prostate Cancer UK, said: "We urgently need to understand more about which men are at risk of developing prostate cancer, and in particular aggressive forms of the disease. "Genetic testing to predict risk could revolutionise how we treat the 40,000 men diagnosed with the disease every year in the UK. "These results are exciting as they add to the growing weight of evidence that men with a family history of prostate cancer who possess certain genes may be at higher risk, providing us with another crucial piece of the jigsaw."

Disclaimer

From time to time in the TPSA newsletters we provide information about developments in the diagnosis and treatment of prostate cancer, research articles, documents, presentations and other interesting materials. However, the TPSA Executive and the editor of this newsletter do not have the medical expertise required to make an informed evaluation of the conclusions and recommendations presented in such materials, and we have not verified such conclusions and recommendations through appropriately qualified medical professionals. The information presented in this TPSA newsletter must not be interpreted as being endorsed or recommended by the TPSA Executive or the editor. Any recommendations made in such materials may not be applicable in your particular case. Before implementing any recommendations made in the materials that are reported, it is essential that you obtain advice from appropriately qualified medical professionals. The view of the TPSA Executive is that no two prostate cancer cases are alike and that no single treatment option is better than any other in all cases. While the information in this TPSA newsletter should be of interest, there is no substitute for getting informed medical advice from your own GP, specialists and other medical professionals.

Giftaid it



Torbay Prostate
Support Association

Gift Aid declaration –for a single donation

Please treat the enclosed gift of £_____ as a Gift Aid donation. I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for the current tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities and Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for the current tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I have given. **Please forward completed forms and donations to Darrell Fulford (Treasurer) Corbyns, Ridgeway Road, Torquay TQ1 2HL**

Donor's details

First name & Surname _____

Full Home address _____

Postcode _____

Date _____

Signature _____

Please notify the charity if you want to cancel this declaration Or Change your name or home address

No longer pay sufficient tax on your income and/or capital gains

If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

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Subscribe to our newsletter by email or post. Please include your name, mailing address, phone number and email address to newsletter@tpsa.org.uk and please indicate your preference (**POST or EMAIL**)

Email preferred to keep cost down.

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