



Torbay Prostate Support Association

Serving men of all ages, and their partners, through a programme of support before, during and after diagnosis
Newsletter Autumn 2015 Issue No.42

Giftaid it Total £1554.24

We would like to Thank everone for there donations and to let you all now that we have recived via HM Revenue and Customs the above sum which is great news.

Important Message from our Treasurer

At our last trustees meeting our Chairman Peter Hosking announced that for personal reasons he would like to stand down as Chairman of TPSA. Many of you will be aware that Peter has been associated with the TPSA almost from its inception in 1999. Since that time he has held the position of both Treasurer and/or Chairman and has worked tirelessly for the benefit of the Association, its members and local Health Authorities. Amongst the many things he has achieved are raising substantial funds to aid the purchase of much needed hospital equipment, given presentations and represented members at various meetings as well as counselling newly diagnosed patients referred to him by Consultants at the Hospital.

Whilst Peter is still in post for the time being it is vital and imperative that we find another person to take on the role of chairperson. My plea to you, our members, is to help find such a volunteer. The incumbent need not have suffered illness associated with the prostate or have experience of prostate cancer. A partner, wife or any other person who wishes to give of their time in the voluntary sector would be most welcome. Maybe you know someone who can fill this role, someone for instance about to retire who wishes to fill their new found spare time. The position is unpaid but expenses associated with the role will of course be met.

Peter has stated he is willing to give whatever help and support is required to assist the new person for as long as necessary. The TPSA is a supportive organisation and is in a healthy financial state. To continue in this vein we need a replacement for Peter as soon as possible. If you know of anyone who can fulfil this role please get them to contact Peter direct or any Trustee including myself.

Darrell Fulford **Treasurer TPSA**

Message from our Chairman

The weather so far this Summer has been somewhat disappointing with the occasional recent lapses. We now of course look forward to the Autumn and I trust all will be well with you all and your families. We still look forward to the specific computer equipment to augment and improve on and identify very minute tumours. The delivery of this equipment is imminent and will of course substantially reduce the time the Consultants spend on each patient's data and information and at the same time be far more accurate reducing that time taken of 4/6hrs to perhaps 2/3hrs per investigation. All your donations will enable us to provide this obviously necessary facility. Please keep those funds rolling in.

I have to arrange another Talk. The last Talk was by Gill Dell Senior Urology Nurse Specialist was extremely well received and really appreciated. Bryan Sykes due to the serious illness of his wife has resigned as a Trustee. We all appreciate his efforts and work supporting the Association over the time he has been with us. We all do hope that things might improve for both Bryan and his wife or at least be easier and we will be thinking of them both.

Sincere Best Wishes

Peter Hosking,

Chairman

Are your contact details up to date?

When you first join TPSA, we ask you for contact details . These details often change over time but not many of you remember to tell us! If we do not have the correct contact details updates and news letters are not delivered so we need to have the correct details please.

PCUK branded survey via your NHS trust in August called 'Life After Prostate Cancer Diagnosis'

- This research aims to find out the impact of prostate cancer on everyday life by asking the only people who really know – men who've been there.
- Over the next three years, over 100,000 men in all four UK nations will get a survey through the post, or be invited to an interview.
- Some (but not all) men that have received a diagnosis between 1 and 3 years ago will be invited to take part by their local NHS organisation.
- It's really important that men take part because the answers from tens of thousands of men will help us persuade health providers to invest in services that men need, and by understanding what puts men at risk of a worse experience after diagnosis and treatment, we can better advise them before treatment and support them after.
- Men in England will start to receive surveys in August 2015. It's expected that men in Scotland, Wales and Northern Ireland will receive a survey in 2016.
- The research has been subject to a rigorous ethical review. Men's answers will be treated in confidence and the data will be analysed anonymously. Although we hope that you will choose to take part in this research, if invited, you don't have to fill in a survey if you don't want to, and if you do send in a survey, and then change your mind, you can withdraw your data from the study at any time.
- Prostate Cancer UK have funded an independent team of specialist health researchers, led by the University of Leeds and Queens University Belfast. They are supported by a user group whose role is to make sure that the research is aware of the needs and wishes of men with prostate cancer.
- The findings will be made public in 2017 and we aim to make sure that as many people as possible will know about them.
- If you have any concerns about prostate cancer or are seeking support you can call our Specialist Nurses free on 0800 074 8383, or you can read more about the study here <http://prostatecanceruk.org/research/life-after-prostate-cancer-diagnosis>

Travel and prostate cancer

Prostate Cancer UK have updated their fact sheet regarding Travel and Prostate Cancer which contains amongst other things information about travel insurance. This can be found on the following Link:-<http://prostatecanceruk.org/media/41624/travel-and-prostate-cancer-fact-sheet-updated.pdf>

Lunch time meetings

for any ladies or widows of men with prostate cancer

The prostate 'ladies' meet up for lunch once a month on the 3rd Thursday of the month. The prostate 'ladies' widows meet up for lunch once a month on the 1st Sunday of the month. Anyone welcome to join them for a meal and a good laugh!**Please contact Glenys on 01803 665280**



New FREE Telephone Number for the National Help Line Tackle has a new telephone number for our National Help Line: 0800 035 5302. The Board's view was that the existing 0845 number should be replaced with a free 0800 number to remove any disincentive to call the Help Line

Superfoods: The Real Story

Members may be interested in a recent Channel 4 Programme entitled Superfoods (series 1 episode 3) which did a feature on broccoli and its potential anti-cancer properties. According to the programme broccoli contains high levels of a substance called Glucoraphanin and when bitten releases molecules which in turn converts into Sulphoraphane. Whilst the TPSA cannot support or confirm the claims made by the programme makers the Internet provides a wealth of information about the properties of Sulphoraphane.

Prostate Cancer UK have updated there factsheet and booklet on sex and prostate cancer.

The factsheet is for men thinking about having prostate cancer treatment. The booklet gives more detailed information and comes with a DVD featuring six men talking about how they are dealing with changes to their sex life during and after treatment for prostate cancer.

We have included new information on:

- What problems men might have after each prostate cancer treatment and how soon they can have sex
- Getting treatment and the right support
- New treatments for erection problems: avanafil (Spedra) and Alpostadil cream.

The booklet and fact sheet are available to order or download on our website. To make sure that you have the latest version, check that the date on the back page is JAN2015.

Oracle Fieldwork Are asking men with metastatic prostate cancer who are currently taking Abiraterone or Enzalutamide either pre- or post-chemotherapy to take part in an online questionnaire lasting 30 to 40 minutes for which you will be paid. Those taking part will receive an honorarium of £35 for taking part and Tackle will receive a £20 donation for each person who takes part via this post. This research study is part of a multi-country study to obtain your views on treatment/potential treatment available. The research is conducted within strict guidelines and codes of conduct which guarantee your anonymity. If you are interested in helping with this study please contact Stella Frost at Oracle Fieldwork on 0161 284 889 or 07769 718 573 or email her at stella@oraclefieldwork.com

 **Come and play!**

**BAD
MINTON**



 If you are 16+ come join in and play we will be at:
Central Badminton Club, In Morgan Avenue, Torquay.
Tuesday Evenings between 7:00 and 10:00.

**WE LOOK FORWARD
TO SEEING YOU!**

Further information please call:

Richard: 01803 614779 | Paul: 01626 360392 | Pauline: 01803 606549

Central Badminton Club

At the last members meeting on 16th July our guest speaker emphasised the benefits in maintaining appropriate fitness levels during and post treatment. Some of our members already attend fitness establishments or partake in some kind of sporting activity. For those who are interested, the Central Badminton Club would welcome any of our members, wives or partners to join them on a Tuesday night for a friendly game. All abilities are welcome, just come along and enjoy the evening whilst at the same time maintain or increase your level of fitness."

Contact Details

Richard 01803 614779 Paul 01626 360392

Pauline 01803 605549

We would like to say thank you to Gill Dell Senior Urology Nurse & Specialist for her time at the last meeting at the Redcliffe Hotel. Gill outlined her responsibilities and work of her department which the attending members found very interesting and informative. We would also like to thank David Rundle who spoke as a patient outlining his own experiences to which so many of us there could relate.



The Speaker - Gillian Dell - Cancer Specialist Patient Speaker - David Rundle
Chairman Peter Hosking

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) Corbys, Ridgeway Road, Torquay TQ1 2HL**

Donor's details

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Date _____

Signature _____

Telephone No _____ (Acknowledgement of donations)

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

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Newsletter

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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