



Torbay Prostate Support Association

Serving men of all ages, and their partners, through a programme of support before, during and after diagnosis
Newsletter Spring 2015 Issue No.40

Message from our Treasurer

A few years ago, having seen a request in one of our newsletters, I volunteered to help our Chairman and other Trustees run the TPSA. I took on the role of Treasurer and all that that role entails. Over the last few years I have seen the Association go from strength to strength in terms of meetings its aims of supporting men diagnosed with prostate cancer together with their partners and also raising funds for much needed hospital equipment to help fight the illness.

However the continuation of the Association depends on volunteers and since I have been involved we have seen our number of volunteers and Trustees reduced to the point where we urgently need new faces to join with us enabling our good work to continue. We are all aware of the tremendous hard work that our Chairman Peter has been doing almost since the charity was formed and thankfully continues to do so. However it has been evident these last few months that we need more help from some members, partners or even friends to maintain the good work TPSA was set up for originally.

For a number of years we have sought someone to take on the role of Secretary, simply to take minutes of our bi-monthly Trustees meetings, prepare agendas and write the odd letter or two etc. Not too onerous a task yet we have not been able to secure anyone's services. We also need someone to fill the vacancy of Vice-Chairman. Through the medium of this newsletter I would ask, on behalf of the present Trustees, that if you know anyone who could help maintain the aims of our charity in any way whatsoever that you furnish the details to our Chairman as soon as you are able.

Thank you

Darrell Fulford

Trustee and Treasurer



Dear Group Members

Please see links below to a set of films which have been made about different kinds of support, knowledge and information that men with prostate cancer find helpful. Please feel free to share them, Many thanks to those of you who were involved.

Keep sharing: with Metro Walnut support group	http://youtu.be/73kp9feCZQE
Keep building: with Age UK	http://youtu.be/T_VbCGYsGCM
Keep healthy: with Focus on Food	http://youtu.be/XZqz5K9Qisw
Keep reaching out: with Black Health Initiative	http://youtu.be/FGgW35U9YLE
Keep fit: in the gym	http://youtu.be/AYhJUFycZJw
Keep talking: Men and Maggie's	http://youtu.be/S4mzu8xkMlg
Keep fit: with Prostate Cancer UK and Age UK	http://youtu.be/gOxq-GpVXm8
Joining a support group	http://youtu.be/PW5TyN8h67I

Cabazitaxel and the Cancer Drugs Fund

As you will have heard, the Cancer Drugs Fund (CDF) are proposing the withdrawal of 25 life-saving cancer drugs on March 12th, including one for the treatment of prostate cancer, Cabazitaxel. At Tackle we have joined a coalition of other leading cancer charities and together are campaigning for these proposals to be withdrawn. A petition has been set up here and we would encourage as many of our members as possible to add their name to the growing list. This is something terribly important to those patients for whom this offers possibly the only treatment option available to them. **Time is short, please send this round to your members as a matter of urgency Continued on page 2**

Cabazitaxel and the Cancer Drugs Fund

Dear Members,

This article is about the specific impact for prostate cancer patients - the proposed withdrawal of Cabazitaxel. This is a successful last chance drug for advanced prostate cancer patients who have exhausted all of the current advanced treatment options including Abiraterone and Enzalutamide. This is a real body blow to those patients who will need this treatment and have nowhere else to turn. Tackle is urging all of our members to contact their MP's at their Surgeries and confront them face to face on the implications of withdrawing Cabazaitxal. See the link below to find out contact details for your MP. If you are not able to do this, then please consider sending them a letter or email. A draft letter is attached for you to use. Time is short, Cabazitaxel is being withdrawn on March 12th. **If you have not already done so, please sign the online petition here**

<https://you.38degrees.org.uk/petitions/keepyourpromise?bucket=&source=twitter-share-button>

Tackle has joined with other leading charities and set out below is an action plan.

Timing February to March 2015

Objectives To rally support for the PM to halt the de-listing process and ensure NHSE and the pharmaceutical companies come up with solution.

- Target signatories – 100K
- Supplement petition with a communication plan which integrates both traditional media, online and social media using the #keepyourpromise hashtag.
- Petition delivery to No10

Target audience

- Cancer patients
- Carers family and friends
- General public

Take Action

- Sign the petition and communicate to your networks, friends and family using Facebook, Twitter, LinkedIn and other social media channels using the #keepyourpromise
- Write to your [MP](#) and prospective parliamentary candidates to ask them what they will do to ensure these treatments are still available.
- Write to your local newspaper

Tackle has been asked to take part in the following survey and would appreciate your help

"We are an independent market research agency working with independent researchers to carry out patient focussed research in the UK. We would like to interview men with Prostate cancer currently taking one of the following treatments **Abiraterone (Zytiga) **Enzalutamide (Xtandi)****

The research involves some telephone interviews; some face to face interviews at home on a day & time convenient to the patient and also some on-line interviews We are also looking for men who are currently or in the last 5years received the following treatment; androgen deprivation therapy (ADT) or complete androgen blockade This research involves a combination of telephone and on-line interviews. The research is about understanding, from the patients perspective, what impact PC has on men's lives; their family and friends and how their experience of treatment for this condition affects them. It is very much about understanding the patient journey from diagnosis to the current day and everything about how this has affected them at various stages.

The interviews would last for 30- 90mins (depending on type of interview) and be carried out within the guidelines of the Market Research Society and British Healthcare Business Intelligence Association codes of conduct. This guarantees the anonymity of anyone taking part in this type of research. At no time would we advise on the condition; pass comments about treatment or discuss any other condition they may have.

The research studies has been commissioned by companies in the pharmaceutical industry in order to gain the views of what are ultimately their end customers. The research provides the company with a much greater understanding of how this condition affects men and their families and friends but also how taking whatever treatment they have experience with, also affects them and the people around them. The report is used to educate researchers; marketing teams and communication teams in the oncology departments about what it is like from a patients perspective to have this condition. This in turn creates a better understanding of the way these companies provide not only the drugs they develop but the information leaflets or booklets they provide with their drugs or in clinics. As you know, pharmaceutical companies are not allowed to speak to patients directly but gain second or third hand views on how this condition affects them or how their drug treatment affects them from doctors or nurses working in this area. They are used to looking at clinical trial data but this does not give a personal view of real life patients with this condition. To have information "from the horse's mouth" is invaluable insight that hopefully benefits all concerned

In appreciation of their time the people taking part will receive a cash honorarium of £30-£60 depending on the type of interview they take part in. In some cases we may also want to interview the wife/partner of the gentleman taking part and they would receive the same honorarium. We would also make a donation of around £30 to Tackle Prostate for each person who takes part in an interview that came via your organisation.

If you wish to take part please forward contact details to newsletter@tpsa.org.uk

At the last members meeting held on 22nd January members and friends were once again privileged to hear Mr. Robert Mason give an interesting talk about the latest developments in the treatment of prostate cancer. Mr Mason, a leading urologist at Torbay Hospital, explained treatment known as Robotic Radical Prostatectomy. He informed the meeting that treatment and removal of the prostate gland by use of this new process was surgically more accurate and therefore more beneficial to the patient.



Mr. Mason, always an interesting and much welcomed speaker, was thanked by our Chairman for giving up his valuable time to enlighten members and the other attendees.



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

Whilst this treatment had been in use elsewhere in the UK it was now available, in suitable cases, on a more local basis. Mr. Mason went on to explain how he had now received training in the use of the 'robot' and showed a short film of the procedure. He then welcomed questions from the floor, which generated much interest.

New to the News letter is Peter,s Quiz

Peter's Quiz For October and answers

1. In Aussie slang what is a Donnybrook?.....**A fight**
2. Which Emu sits on the eggs?..... The male
3. Who wrote Huckleberry Finn?....Mark twain
4. What is the birthstone for February? Amethyst
5. What does the King of Spades hold in his hand?.....A sword
6. Which street does Oscar the Grouch live in?.... Sesame Street
7. Which car company's emblem is three diamond shaped figures?....Mitsubishi
8. Which "ology" is the study of the nervous system?.....Neurology
9. What did Jack of beanstalk fame swap for 5 beans?.....A cow
10. What were the first words A.G. Bell spoke into his experimental telephone?

Was it " Can you hear me mother?"

NO... It was Mr Watson come here I want to see you

TORBAY PROSTATE SUPPORT ASSOCIATION

Charity no. 1095734

NEXT TALK IS BY

Dr. Anna Lydon

Consultant Clinical Oncologist

Torbay Hospital Foundation Trust

Up to Date Review - Prostate Cancer

Treatments

AT THE Redcliffe Hotel.

Paignton Sea Front

Thursday 23rd April 2015

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 and bring a raffle prize.

Giftaid it



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 _____

Telephone No _____ (Acknowledgement of donations)

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. **Please note that, to keep costs down, acknowledgement of donations will not be sent unless you include a Stamped Addressed Envelope. We will Acknowledge donations via the telephone if your telephone number is entered above.**

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.

Trustees

Email Address

Contact telephone numbers

Peter Hosking (Chairman)	chairman@tpsa.org.uk	
Darrell Fulford (Treasurer)	treasurer@tpsa.org.uk	01803 292171
Carole Hooper	carole@tpsa.org.uk	01803 329044
Ray Matthews	ray@tpsa.org.uk	01803 606915
Robin Causle	robin@tpsa.org.uk	01803 311407
Bryan Sykes	bryan@tpsa.org.uk	01803 660410
Mark Smith (Newsletter Editor)	newsletter@tpsa.org.uk	01530 481802
Mark Smith (Website Editor)	website@tpsa.org.uk	01530 481802

Disclaimer: The information and opinions expressed in this Newsletter are not an endorsement or recommendation by the TPSA or the Editor for any medical treatment, product, service or course of action. For medical, legal or other advice, please consult appropriate professionals of your choice. TPSA is registered with the Charity Commissioners as Number 1095734