



Torbay Prostate Support Association

Serving men of all ages, and their partners, through a programme of support before, during and after diagnosis
Newsletter Spring Newsletter Issue No.44

Hello One and All,

Welcome to another edition of our Newsletter as we now approach the spring as I write this missive. I trust you all are getting over the extremely wet winter and now look forward to some much drier weather. Dr. Anna Lydon has indicated that a new proposition is to be put to us and I look forward to hearing the details. As soon as I receive them I will be in touch and let everyone know the details.

We have been particularly fortunate to have received a magnificent total of **£6500** from four very generous benefactors:-

- The Dawlish Hospital League of Friends
- Torquay Boys Grammar School, "Davys House".
- The Tuesday Boys
- Preston Rotary Club

Thank you all for thinking of us. All your donations are truly appreciated and we were able to achieve our last target and are now working with Torbay Hospital to fund another project.

Sincerely

Peter Hosking,

Chairman

Prostate Cancer UK have launched four new on-line forums aimed at four specific groups of men (and their partners/families) with prostate cancer.

Dear Members,

Just wanted to let you know that Prostate Cancer UK have launched four new on-line forums aimed at four specific groups of men (and their partners/families) with prostate cancer. These are;

Young men still employed or not yet reached pension age

This is a section for younger men who are below state pension age, men who have young or dependent children, or for whom the option of having or not having children is a factor in their choice of treatment.

African & African Caribbean men

This is a section for African and African Caribbean men with prostate cancer. We know that although there are some dedicated support groups for African/African Caribbean men in the community we know that very few attend general prostate cancer support groups despite the high incidence of prostate cancer within the African/African Caribbean community.

Gay & Bisexual men

This is a section for gay and bisexual men with prostate cancer. We know that there are a small number of support groups across the country specifically for gay and bisexual men with prostate cancer but we know that there will be men who will find it difficult to attend these groups. We also know that the vast majority of men attending general prostate cancer support groups identify as heterosexual. We want to create a space where men can talk about some of the issues that are important to them but they may not be able to share in a face to face group.

Transgender women

This is a section for transgender women with prostate cancer. We know that transgender women with prostate cancer are unlikely to attend a face to face support group. Given the likely small numbers of people affected, an online community may be an easier way for people to share experiences and support with others.

We know that some of the younger men, African & African Caribbean men, Gay & Bisexual men and Transgender woman may find it difficult to access support from existing support groups for a variety of reasons. We also know that people benefit from sharing experiences and concerns with others who have had similar experiences and we wanted to offer a space where people can hopefully connect with others to do that. We are not blocking access for anyone else, but we respectfully ask those who don't self-identify as one of the four categories not to post on these forums in order to keep the space focused on those it's intended for.

The forums can be found here <http://community.prostatecanceruk.org/> under 'specific groups'. We will be trialling these groups over a 6 month period. Of course the non specific online community and forums are also still available [Http://community.prostatecanceruk.org/](http://community.prostatecanceruk.org/) As part of this community, you can talk about whatever you want, from diagnosis to dealing with treatment. Simply browse the conversations to join one, or start your own if you'd prefer. Its very easy to access and get involved in any of the forums by registering an email address and user name.

Presentation to Torbay Prostate Support Association By Davys House, Torquay Boys Grammar School



Peter Hosking gave a very informed Talk on Prostate Cancer to the whole of Davys House recently which was extremely well received by a very large audience. So many families have been affected by this dreaded problem and where it is so important that it is identified early. The head boy and his deputy were pleased to donate a cheque for £1500 to the Association which will go towards further essential items for the Torbay Hospital.

Advanced Prostate Cancer

Dear Members, I have been sent this email about advanced prostate cancer and although it is from the USA, it holds some very useful information.

Advanced Prostate Cancer is what actually kills the men in our prostate cancer survivor community. That's why, in 2007, we started <http://advancedprostatecancer.net>. Updated five days per week, the Advanced Prostate Cancer website has grown into the English speaking world's most authoritative patient facing prostate cancer website, with over 3 million unique visitors every month. And most of those come from the UK. So, starting today, we have parsed out a separate section just for readers from England, Northern Ireland, Scotland and Wales. For faster access, our UK version is [viewable at http://advancedprostatecancer.org.uk](http://advancedprostatecancer.org.uk) Advanced Prostate Cancer is entirely patient developed and maintained, compliments of the prostate cancer survivor support group, Malecare. Please add or update your resource list to include www.advancedprostatecancer.org.uk and share with your group members and all who care about men fighting prostate cancer.

Advanced Prostate Cancer killed my Dad, Grandpa and Uncle, and might kill me. I joined our prostate cancer support community because I don't want my wife to cry because I might die from prostate cancer. I want her to know that I'm fighting it with full vigor and force. And the information written every day on Advanced Prostate Cancer is part of my armor. I hope you agree and will join me in spreading the word about this resource.

Kind regards,
Darryl
Darryl Mitteldorf

Free PSA Blood Tests

The Trustees are considering the possibilities of setting up a new system whereby we will be able to provide free PSA blood tests to the male population of the area we cover and help to identify the Cancer before it becomes out of hand and to enable the consultants to get some control before it is too late as so very often happen. However to get it off the ground we will need some very keen volunteers to help us to help others. Volunteers are invited to attend our meetings and learn more about this scheme which is already successfully operating elsewhere

Tackle prostate cancer

“Track your PSA” tool

Here is an opportunity for those patients interested in following their prostate treatment history. A urologist based at Cambridge that we have worked with before has developed a PSA Tracker. This is a simple tool to empower patients who wish to follow their progress, and it supports regular monitoring and tracking. You are able to enter PSA results, treatments and reminders, as well as viewing trends over time. It is also possible for you to allow health care providers to view your data, should you wish to. Under trial for the next two months, the developers have offered it to any members of Tackle who wish to assess its value and help with feedback. Take a look at the video about the tool at: <http://trackmyspsa.com/video/standalone/>

Username **TMPSA**
Password **video2015**
This is case sensitive.

If you would like to try this out please email Jenna at jmk66@medschl.cam.ac.uk or Lorraine at lorraine.starling@addenbrookes.nhs.uk and they will register your interest and advise how to access the tool.

The STAMPEDE prostate cancer trial: docetaxel and zoledronic acid results for patients

Read the article about them at:-

http://www.ctu.mrc.ac.uk/news/2015/early_chemotherapy_improves_survival_for_men_with_prostate_cancer.

The results show that having early chemotherapy with a drug called docetaxel (when starting long-term hormone therapy) can improve survival by an average of ten months.

The MRC Clinical Trials Unit at UCL have produced a short film exploring the results of the STAMPEDE prostate cancer trial. It was created especially for patients. We would be very grateful if you would share it with the members of the Torbay Prostate Support Association and others you know who may be interested. The film can be viewed online, or downloaded for offline viewing at <https://vimeo.com/mrcctu/stampederesultsforpatients>.

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

Disclaimer

From time to time in our 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 Trustees 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 newsletter must not be interpreted as being endorsed or recommended by the TPSA Trustees or the editor. Any recommendations made in such materials may not be applicable in your particular case.

Gift Aid declaration –for a single donation

I want to Gift Aid my donation of £_____ and any donations I make in the future or have made in the past 4 years to: **TPSA**. 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	01803	363028
Darrell Fulford (Treasurer)	treasurer@tpsa.org.uk	01803	292171
Ray Matthews	ray@tpsa.org.uk	01803	606915
Carole Hooper	carole@tpsa.org.uk	01803	329044
Robin Causley	robin@tpsa.org.uk	01803	311407
Ernest Bartley	Ernest@tpsa.org.uk	01626	866936
Mark Smith (Newsletter Editor)	newsletter@tpsa.org.uk	01530	481802
Mark Smith (Website Editor)	website@tpsa.org.uk	01530	481802