



# Torbay Prostate Support Association

Serving men of all ages and their partners, through a programme of support before, during and after diagnosis.

**E Newsletter Autumn/Winter 2022**

After a glorious summer the clocks have gone back and the nights are getting darker, but we can look forward to celebrating the festive season.

September saw us say goodbye to Peter Hosking, our late President and founder member. Over his 23 years running TPSA he was an inspiration to us all with his energy and enthusiasm and tireless desire to help others. He will be greatly missed.

Once again in this newsletter we look at a wide range of topics which I hope you will find informative and interesting.

## **Members' meeting & AGM**

In October we held our Members' meeting which was attended by approximately 25 members and guests. Over the past few months there have been lots of changes of personnel at Torbay hospital and we were delighted that representatives were able to join us.



### **Dr Helen Saxby, Consultant Clinical Oncologist**

Helen has returned to Devon having trained in London and, immediately before coming to Torbay Hospital in May this year, she had previously been working in Taunton. Helen said that she was very pleased to be at Torbay, it has been a very busy period. She is looking forward to being able to give the TPSA group an update in the future, particularly in the area of Clinical Trials with which Torbay are involved.

### **Emma Brooks, Manager at Torbay Hospital**

All the services relating to Prostate Cancer, are within her field of responsibility. She talked about the emphasis on enabling the Clinicians to provide the best possible services and the challenges of managing this within the budgets and guidelines set centrally.



## Miss Angelika Zang, Consultant Urology Surgeon

Angelika talked about the massive disruption caused to services by Covid. Initially staff working within Urology were scattered across many sites, including Dawlish. Very recently they have all been able to move into Paignton Hospital, which, although not ideal, does provide some better facilities than previously used by Urology in Torbay. It is hoped that the equipment (paid for by TPSA) enabling TP Biopsies of the prostate will be sited in Paignton from March 2023. There is currently a waiting list for these and the RD&E Hospital in Exeter are seeing some 'Torbay' patients to help reduce this.

Emma & Angelika answered questions from TPSA members, including treatment outcomes and the PSA tracker. From their comments it is clear that there is a lot of work taking place 'in the background' between Clinicians and NHS Managers across the South West Peninsular. It was very interesting to hear about the different 'Tracker' systems used and their views for the best way forward.

TPSA members emphasised how much they appreciated being kept up to date with this information and also offered to be involved in issues where 'the patient's voice' has particular value.



**Helen, Emma & Angelika agreed to return to future meetings to share items of specific interest to members of TPSA.**

## Health Connect Coaching presentation by Krystina Bones



We were also fortunate to have Krystina Bones from the Health Connect Coaching project who gave us an insight into this new project. Krystina introduced us to a member who had taken part in the support process who gave us valuable feedback on his experiences. For those of you not at the meeting here is a summary on the presentation

### **New NHS 1:1 coaching support service**

Are you managing well with your health condition and feel you want to give something back and support others? Then why not apply and get trained to become a volunteer health connect coach using your lived experience to help others. Alternatively, if you are feeling overwhelmed with your health condition and feel you would like some support from someone who "just gets it" then please refer to health connect coaching. To find out more about this collaborative programme available online via the comfort of your own home, please see our leaflet or visit our website <https://www.torbayandsouthdevon.nhs.uk/services/health-connect-coaching-programme/> for information and how to contact us.

## Meetings

Unfortunately, the planned Zoom meeting in November with Tim Dudderidge from Southampton Hospital, when he was going to talk to us about HIFU and Cryotherapy, had to be rescheduled to early next year.

However, we were pleased to welcome Ellyse Webb. She has just been appointed as a nurse practitioner in prostate cancer diagnosis and will be leading the nurse led Biopsy Clinics in Torbay. She is a local and is returning to the region having been in Southampton for some years. She described the plans she has for Torbay and also talked through some slides on HIFU and Cryotherapy.

## AGM Reports

### Summary of the reports:

#### Secretary

- We currently have 9 members on our postal contact list and 53 on our email contact list.
- Since the AGM last year, we have held 4 meetings by Zoom: and have circulated information about the National Partners' Group which meets via Zoom.
- We were very pleased to welcome Dr Anna Lydon, Consultant Clinical Oncologist, to a face/face meeting in April this year, and we had a very informative talk from the local Disabled Sailing Association in June.
- Although Zoom meetings have the advantage of enabling us to meet with people from many areas, and we had another one planned for November with Mr. Dudderidge, Consultant Urology Surgeon from Southampton, my guess is that members would prefer to meet face/face and feedback on this is welcome.

#### Treasurer

Despite the pandemic we have received a significant amount of donations, which will enable us to continue our awareness and support activities. Our expenditure has largely been in respect of the Prostate Health Awareness, PSA testing event in June. Key figures are:-

Opening Balance	£15,327.19
Income	£18,334.96
Expenditure	£5,435.85
Balance	£28,326.30

#### Chairman

Over the past year we have faced a number of challenges as we adapted to operating whilst living with COVID. We have continued to hold face to face and zoom meetings, have worked to maintain an effective relationship with Torbay Hospital (despite various changes of personnel and locations) and sought to develop the website. One of the most significant achievements being the PSA Testing events, raising awareness of Prostate Cancer and supporting early diagnosis through PSA testing.

During the coming year we hope to:

- Run 2 Prostate Health Awareness events in the form of PSA testing.
- Undertake a rebranding and updating of our support material
- Launch a new website which will be easier to maintain and dynamically update, together with a new Facebook Group
- Continue developing links with Torbay Hospital
- Continue working towards establishing an effective support mechanism for partners of men.

## November Prostate Health PSA Testing Event



Following on from the success of the first event in June, we have established these events as a cornerstone for raising awareness of Prostate Cancer and the support available from TPSA.

On 23<sup>rd</sup> November we held the second of our testing events with 323 men being tested at the event held at the Livermead House Hotel, Torquay. 16 received RED letters (youngest being 48) and 12 received AMBER letters (youngest being 43). Despite the dark and inclement night the event was a tremendous success. In addition to providing the PSA test it also gave us the opportunity to promote the support that TPSA offers. The number of people saying how useful they found the event

(especially as many said they had been unable or refused testing from their GP), was amazing. We heard from someone who was unable to secure a place on the last event but came to this one. He told us that his friend had been diagnosed with Prostate Cancer after the last PSA testing event and is now receiving treatment. Without our event it's unlikely that he would have been diagnosed.

Once again Wendy Symons and her team from Cornwall Prostate Health Awareness ran a professional efficient and well-coordinated testing facility with the support of nurses from the locality. A special thank you needs to go out to the Rotary Club of Preston (Torbay) members, for the exceptional way they continued to support us in marshalling the event. There is no way we could run these events without their support.



The event was largely funded by generous donations from the RAOB, Rotary Club of Preston (Torbay) and Richard Hudson (who ran the Exeter Half Marathon) for TPSA.

**We have provisionally pencilled in another event on 3<sup>rd</sup> May 2023 (when hopefully it will be warmer and less rain lol) and another on 8<sup>th</sup> November 2023.**

## Meet your new Trustees

### Mike Clay will support us with the Newsletter and Website editing.



Hi, I am Mike Clay and was diagnosed with Prostate Cancer in August 2020 right in the middle of the Covid pandemic. Following a poor-quality MRI, and a prostate biopsy, I was eventually diagnosed with some low grade cancer cells and put on Active Surveillance. Unhappy with this decision, and with a PSA of over 9, I sought a second opinion from the Focal Therapy Group in London who referred me to Mr Tim Dudderidge, Urologist, at the Spire Hospital in Southampton. Following a new MRI with a contrasting dye and a new biopsy, Tim advised I had a tumour, that was contained within the prostate, but not all the cells were low grade. Tim offered cryoablation of the tumour which was carried out in December 2020. I returned home the following day and recovery took around 6 weeks. Since then, my PSA has stabilized around the 0.9 to 1.0 level and I have annual MRI scans with a contrasting dye. I feel very lucky that I can still enjoy life and wish to offer help, support and advice to other local PC sufferers. In my view, it is the persistent rise in PSA that must be investigated, even if it is still below the NHS maximum level.

It is so important that we make all men aware of this cancer that has no symptoms in its early stages which is why I agreed to become a Trustee of the TPSA, so I can give something back to the PC community and bring awareness of the condition to men of all ages and the importance of checking PSA levels.

### New Trustee - Gill Clay



I am married to Mike Clay and following his PC diagnosis, I am aware how important my support has been not only to his well-being, but also in supporting him through his treatment. Following a request at the recent AGM for more people to support the local TPSA Group, I offered my help as a Trustee. In this role I hope I can improve awareness of Prostate Cancer and the importance of PSA testing. Also I hope I can encourage more wives, partners and family members to become involved, as I believe they have an important role to play before and during treatment and may well welcome the opportunity to share their experiences in a friendly environment.

## Retiring Trustees

### Darrell Fulford

As a result of a family move from the area Darrell (our former Treasurer) has advised that he will stand down from his role as Trustee with effect from the end of December 2022. I know I speak on behalf of the other Trustees when I say the way in which he has supported TPSA over the past 12 years has been exemplary. The role of Treasurer in any organisation is a difficult one, ensuring we are fully transparent and up to date returns to the likes of the Charity Commission. This must have been particularly challenging during the years where we were involved in raising funds with the massive campaigns to provide equipment to the hospitals et al. We wish Darrell and his wife the very best for the future.

### Mark Smith

Mark has supported TPSA for a number of years with its IT infrastructure and the editing of our newsletter. During the COVID outbreak the way in which we kept in touch with our members needed to significantly change. Mark's support in organising zoom meetings, keeping the website up to date and keeping the newsletters coming, is very much appreciated. Thank you Mark and family, best wishes in the future.

## Fund Raising

We were delighted to receive an amazing donation of £5,000 from Margaret Tomlinson from the Tomlinson Family Trust set up in the name of her late husband Professor Martin Tomlinson who sadly died from Prostate Cancer earlier in the year. We also received a donation of £1,057 from the Dancing with Dennis organisation who collected from its members at their various dances around Torbay.

Additionally, we received further donations in the year of over £2,750 from the Rotary Club of Preston (Torbay) from their Sportsmans' Dinner and Golf Day. Additionally over £500 was received from the collection at Peter Hosking's funeral.

All these donations will be used to offer free PSA testing at our events in 2023.

## Rebranding

As people change and statistics become outdated, our support and publicity materials very quickly become redundant. Reprinting is costly and uses money that could be better spent on effective support. We have therefore commissioned some new Pull up Banners and awareness flyers with an updated message and generic contact details. In addition, we have launched a new Facebook Group (search for T.P.S.A.) and in the next few weeks will hopefully launch our new Website, so watch this space. We must thank Torbay Council Community Fund for granting us a donation of £500 towards the cost of our new website.

## How can you help TPSA

Our current Secretary, Clive Richoux moved some time ago to live in Exmouth but continues to support TPSA. We are looking for a successor. If you think you might consider taking over this role please speak to Clive or Ian to find out more

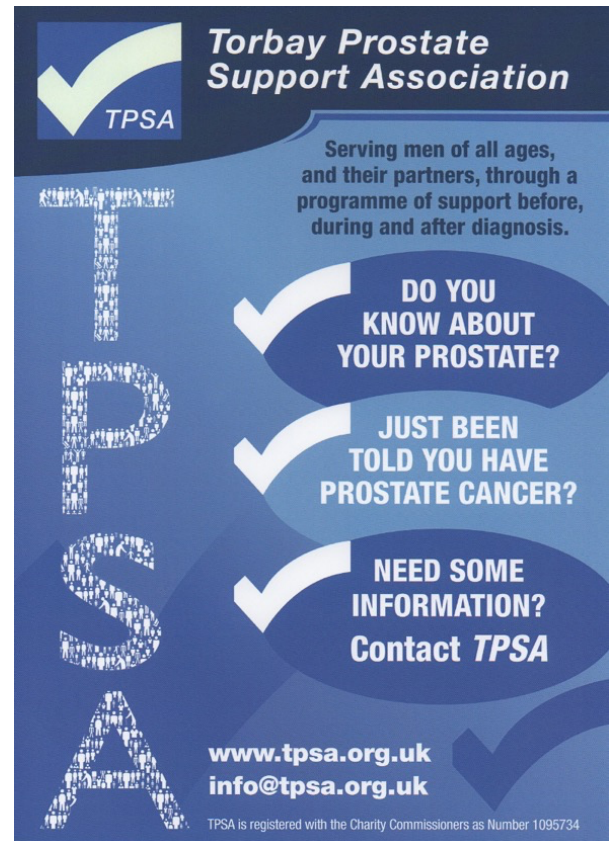
## Forthcoming meetings

On 8<sup>th</sup> February 2023 we are delighted to welcome back Helen Saxby who has kindly agreed to talk to us about developments at Torbay Hospital. This will be held at the Livermead House Hotel, Torquay. Commencing at 10.00 with coffee for a 10.30 start. Please confirm to Clive Richoux by no later than 20<sup>th</sup> January so we can ensure there is enough coffee and biscuits available. These will be complimentary from TPSA but donations will be appreciated.

## Our New Year luncheon

We are arranging this meal at the Livermead House Hotel, Torquay, (where there is ample free car parking), on **Wednesday 25<sup>th</sup> January 2023 meeting at 12 noon for our lunch at 12.30pm**. We would like to encourage you to bring your partners to this lunch. The hotel has given us a great price, but we need to advise them of your menu choices. Therefore, please let Clive Richoux know by 20<sup>th</sup> December 2022 if you would like to attend and advise him of your menu choice, and that of your partner or friend, by e-mail or post, and send him a cheque payable to "TPSA" for £25 for each person attending.

Attached to this newsletter is a menu for you to make your meal choice and details of where to send your cheque.



The flyer features the TPSA logo (a green checkmark) in the top left corner. The title "Torbay Prostate Support Association" is in the top right. The main text reads: "Serving men of all ages, and their partners, through a programme of support before, during and after diagnosis." Below this are three call-to-action boxes: "DO YOU KNOW ABOUT YOUR PROSTATE?", "JUST BEEN TOLD YOU HAVE PROSTATE CANCER?", and "NEED SOME INFORMATION? Contact TPSA". The bottom right contains the website "www.tpsa.org.uk" and email "info@tpsa.org.uk". A small note at the bottom states "TPSA is registered with the Charity Commissioners as Number 1095734". The background is dark blue with the letters "TPSA" in a large, white, pixelated font.



***TPSA** Christmas Menu at The Livermead House, Hotel*  
*On 25th JANUARY 2023 at 12 noon for our 12.30pm meal*

**STARTER**

- Smooth Chicken and Liver Brandy Parfait,  
Winter Fruit Chutney and Melba Toast
- Chef's Homemade Tomato & Basil Soup (V)
- Classic Prawn Cocktail with Brown Bread & Butter

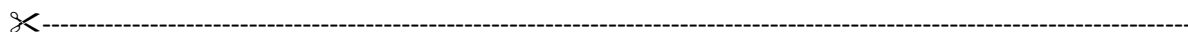
**MAIN**

- Traditional Roasted Crown of Torbay Turkey, Bacon Roll,  
Chestnut Stuffing, Madeira Jus
- Baked Fillet of Salmon "Bonne Femme"  
(White Wine, Mushroom & Shallot Cream Sauce)
- Tomato & Mozzarella Tart (V)  
with Basil Pesto

**Selection of Fresh Seasonal Vegetables and Potatoes**

**DESSERT**

- Cream Filled Profiteroles coated with Belgian Chocolate Sauce
- Livermead Home Made Christmas Pudding with Rum Sauce
- Fresh Fruit Salad with Devon Clotted Cream
- Coffee and a warm mince pie



Please complete and post the lower part of booking form to Clive Richoux, together with your **cheque payable to "TPSA", for £25 per member and guest** (if applicable), as soon as possible, so that we can confirm our booking to the hotel by 20<sup>th</sup> December. Please retain the top part of the booking form as a diary reminder.

**Send postal bookings with £25 cheque to :- Clive Richoux, at 20 Madeira Villas, Exmouth EX8 1QP**

<b>NAME (Member)</b> .....	Guest	.....
<b>STARTER</b> .....		.....
<b>MAIN</b> .....		.....
<b>DESSERT</b> .....		.....

**In conclusion we wish you all a happy, healthy and fun filled festive season and look forward to seeing some of you at our New Year meal, details of which are above.**

***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 trustees 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 trustees 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 newsletter should be of interest, there is no substitute for getting informed medical advice from your own GP, specialists and other medical professionals.*

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