



“The Faucet”

Issue 1: Autumn 2020

Welcome to the first issue of “The Faucet”, the new quarterly newsletter about TAPS (Tamar Area Prostate Support). We plan to produce four issues a year, gathering useful information, advice, and stories from members into this new digital format, and we welcome your contributions to enhance the content with anything you feel will be of interest to the TAPS community.

HOT TAPS

With the Government imposing strict lockdown rules in March, our meetings had to be cancelled until further notice. Given the nature of our group, where face to face meetings allow us all to help one another, this has set us back. Since March we have tried to maintain contact using email and “Zoom” video conferencing meetings and, though these were well received by those who attended them, they were not widely favoured.

The Steering Group members are keen not to lose the momentum gained since our launch in 2018 but, until we all feel comfortable about returning to the Town Hall, Zoom meetings are better than nothing. In addition to our own meetings, we are also invited to join with those of the Plymouth and Reading groups. Notices of these are circulated a few days in advance.

Like the rest of the country we were hoping COVID-19 would be over by the winter, but there is no evidence yet to suggest it will not still be affecting us all into 2021. So in order to keep things ticking along, we will continue to hold occasional Zoom sessions. Alongside these, a Steering Group member will make brief direct contact with you by phone, just to see if there is anything you need, or anything that we can do, to support you regarding your prostate cancer over the coming months. Chris, Nigel, John, Paul, Harry, or Steve will be happy to chat about this, or just pass the time of day, when they call and they will of course identify themselves as members of the TAPS Steering Group first.

OPEN TAPS

You will have realized that the usual channels for advertising our group and our monthly meetings has also dried up (pun intended!) We have a small “advert”

placed in thirteen local magazines across the Tamar area, and although some of them have carried on, with digital versions, we have made no contributions to any of them since May. We are in regular contact with all of the editors and will restart sending “copy” once we have something more positive to say.

There is, however, some very good news to pass on. As well as this wonderful newsletter, we now have a great website, and you can find it by clicking on this link:

<https://www.tamarareaprostatesupport.org>

John Stewart did all the hard work to launch this website, and we are grateful to him for finding the time in his busy lockdown schedule to learn all there is to know about web design, content, and publication. John is now the “go to man” for web expertise! Please do have a look at the website and again your comments and feedback will be very welcome. You will discover historical documents and reports from previous meetings, a diary of upcoming events, and a reminder of how to contact the Steering Group.

OUTSIDE TAPS

In this section of the newsletter we will aim to cover any news from further afield, for example from Prostate Cancer UK (PCUK), Tackle, other support groups, and any medical or scientific news that might be of general interest.

PCUK is probably the best website to use when seeking information or help about prostate cancer. You can click on this link to access it <https://prostatecanceruk.org/> or call them on 0800 074 8383.

As we are now in Autumn, they and thousands of others will soon be supporting the 2020 Movember campaign. Here’s a link to the Movember UK website <https://uk.movember.com/>

Tackle is a great organization that supports both men with prostate cancer and support groups like ours. Look at their website here <https://tackleprostate.org/> and you can call them too on 0800 035 5302 if needed.

Tackle held its Annual Conference recently, which TAPS attended on Zoom, and the main topic for discussion was PSA testing. Academics, charities, the medical professions, and businesses are working together to improve the efficacy and speed of PSA testing in several positive ways. Future generations will soon begin to get the benefit from all the research now underway. One UK business, started by a renowned urologist, has developed a simple blood test machine that can be easily located in pharmacies, GP practices, etc where a PSA test can be taken and the results given 15 minutes later. Another speaker, a Professor at Imperial College, outlined the work he and his team are doing to develop “fast MRI scanning” that will reduce the need for unnecessary biopsies for men whose PSA levels have increased but their prostate has no malignancy.

Although we may not directly benefit from much of the research work currently underway, our sons, nephews, and friends will, and this work will provide

greater knowledge about prostate cancer, perhaps leading to better ways of helping those like us.

MIXER TAPS

In this section of the newsletter we will welcome new members, provide a forum for contributions from you, and spotlight any story from one or two members that may strike a chord amongst you. This issue contains one from Steering Group member Nigel, a big fan of Microsoft Excel.

Nigel writes: “I had a radical robotic prostatectomy in October 2016, having been diagnosed that August with a Gleason 9 tumour. The surgery was extremely easy for me, the robot was very kind, and I was in hospital for just one night. My surgeon, Anthony, is brilliant. Unfortunately, my PSA after surgery was not zero, and Anthony put me on a short dose of hormone therapy (Decapeptyl) to kill my testosterone and thus the minor traces of prostate cancer cells lurking somewhere in my body. I responded well to Decapeptyl and my PSA dropped to near zero. Since then I continue to have regular PSA tests to monitor the situation and they show the cancer cells are growing, but not in a way that worried me. Back in 2017/18 it took nearly 400 days for my PSA to rise above 2, before dropping back to near zero after hormone therapy. More recently it has taken just 165 days to go back above 2, indicating that the speed of the rise is increasing quite quickly. Anthony reassures me that I am on the bottom rung of a long ladder and that I will die of old age, and it looks like I’ll be on Decapeptyl or similar for the rest of my days. Anthony also tells me that there are other tools he can deploy, including new scanning techniques that might help detect where the cancer cells are in my body. However my current reaction to hormone therapy is positive and so he advises sticking to it for now. I share this because it demonstrates why it is important to track your own PSA test results. I do this using a simple Excel spreadsheet which means I can chart the changes over time. Anthony is a very busy guy and he loves my PSA chart because it shows him that I am actively managing my own journey which then forms the basis of positive discussions with him when things start to happen. If you need any help putting your test results onto a chart, I’m happy to help.”

CLOSED TAPS

Now that the summer is past, autumn weather well in control, shorter nights, and Christmas not far away, it’s easy to put on the cardie and slippers, turn on the TV, grab the whisky bottle, and moan when the dog needs to take you out for a walk. Or you can check out some of the information offered in this newsletter, talk to us when we call, and prepare for life getting back to normal once a COVID vaccine becomes available, which looks more promising by the day, and maybe in 2021. Our next newsletter will be out around the festive season.

From the TAPS team.