We’re Proving Prostate Cancer Doesn’t Have To Be So Deadly

Ending the suffering caused by the vaginal mesh scandal

Shining a light on a dark corner of cancer research
Hello and welcome to TUF matters.

We have had an exciting and fun few months here at TUF. Supporter, Adrian Goldsmith, hosted a Charity Concert and fundraising auction, the Atlantic Seamen are finalising their preparations to row the Atlantic, we received support from the fabulous Stephen Fry, and saw great strides made in the fight against urology disease.

In March we were able to fund a series of excellent new research projects that we believe will make a substantial contribution in the fight against urology disease. This process also saw Professor John Kelly reach the end of his time as the Chair of our Science and Education Committee, handing the reins over to Mr Grant Stewart, an academic and clinical urologist in Cambridge, who is excited to drive us forward as we fund only those research projects with the greatest potential to save and improve lives.

We are, of course, a charity that is wholly reliant on support from people like you. Without it, we cannot do the work that we do. So, I’d like to extend a massive thank you to all who have given a gift so far this year, to those who sweated in lycra atop a bicycle on a sponsored cycle, to those who saw off blisters to run the London Landmarks Half Marathon, and to all of you who have contributed to our fight against urology disease in your own way.

With warmest wishes

Louise de Winter, Chief Executive
Leading the fight against urology disease

RESEARCH SCHOLARSHIP GRANTS

The start of 2018 saw research applications arriving on the TUF doorstep from urologists across the country who are looking to fund their vital research. These applications are marked by our Reviewing Committee and put in front of our Science and Education Committee, who make informed decisions about which research TUF should be funding.

In April we funded five researchers to start or continue their research to fight a variety of urological diseases from prostate cancer to bladder disease and pelvic cancer. Without support from people like you, research like this wouldn’t be happening. Here’s a sample of two of the applications that you helped fund.

DAVID ELDRED-EVANS
Imperial College London

David has received funding so that he can develop a new screening method for aggressive forms of prostate cancer. His research looks at new ways to screen for more aggressive forms of prostate cancer through the PROSTAGRAM trial.

The aim of the trial is to find an imaging technique for prostate cancer that would work like mammograms do for breast cancer. This trial will be the largest study of image-based screening tests for prostate cancer. It follows a call from the National Screening Committee for more research into alternative tests for prostate cancer after they described the current PSA test as “a poor test for prostate cancer.”

David has received the prestigious TUF Medal for this proposal. The TUF Medal is awarded to the best research application each year.

PRAMIT KHETRAPAL
University College London

Pramit is using his funding to monitor patients who have been discharged from hospital after undergoing surgery. More than 15 in 100 patients undergoing major urological surgery are re-admitted to hospital after being discharged to their homes and nearly a quarter of all deaths following major surgery occur during the first month after hospital discharge.

Going home after surgery poses a risk because doctors and nurses are not able to monitor a patient as closely. Pramit’s research will address this problem through the DREAM Path. Pramit is working with Apple and McLaren to see if devices like Apple Watches, smartphones and Fitbits can be used to track a patient’s health once they’ve left hospital.

Pramit has designed a HALO (Home And Locally Observed) Kit for patients to take home with them. The kit will provide blood pressure, heart rate, and temperature measurements as well as giving patients the opportunity to fill in a questionnaire through their smart phone. He hopes the kits can decide which patients need to visit the hospital or GP.

TUF PROVIDES CLINICS ONLINE

TUF have joined forces with talkhealth to provide online clinics for people across the UK.

The idea is a simple one; if you have a question about a health topic, join one of the online clinics and have your questions answered by a medical professional. The clinics take two forms: either a one-day ’Ask the Expert’ or an online clinic that lasts for a month.

So far, TUF has participated in clinics on Kidney Health, Bladder Health, and UTIs. We have a few more month-long clinics coming up on Prostate and Testicular Health in November and will be taking part in a few ’Ask the Expert’ sessions in September and December.

Find out more at talkhealthpartnership.com

To show your support, visit http://bit.ly/WEEMUST and sign the petition.
The Atlantic Seamen are four men from Cornwall who have decided to do something truly remarkable to raise money for and awareness of urology disease.

In December they will start a journey that will see them row from La Gomera in the Canary Islands to Antigua & Barbuda on the other side of the Atlantic. The race is expected to take these men more than a month, during which time they will be expected to tackle sleep deprivation, salt sores, and all the extremes that come with ocean life. It will not be an easy task.

“I was flying off on holiday earlier this year and we flew over a body of water. Looking down you could see the supertankers going about their business way below, they looked tiny...we are a fraction of their size!! This made me think about the enormity of the task we have taken on, the ocean is bloody big! But I’m excited, this has been a dream for years and finally the reality is looming. We have had amazing support from family and friends as well as TUF. We are ready...as we will ever be!”

– Jonathan Davies

In December they will start a journey that will see them row from La Gomera in the Canary Islands to Antigua & Barbuda on the other side of the Atlantic. The race is expected to take these men more than a month, during which time they will be expected to tackle sleep deprivation, salt sores, and all the extremes that come with ocean life. It will not be an easy task.

“Trying to fit in family life with work commitments is difficult anyway, but then coupled with training and generating sponsorship, it has been incredibly tough. Personally, I can’t wait to get in the boat and start the row.”

– Andrew Berry

If you want to support The Atlantic Seamen as they prepare for this incredible journey, you can do so at theurologyfoundation.org/atlanticseamen
I’ve been given as much time as possible to spend with my lovely family

Starting a family is a delicate time; you have to adapt to challenging new routines, teach yourself to balance your livelihood with parenthood, and be confident that you can provide for your new family unit. The last thing you want thrown into that mix is cancer. The last thing you expect, at that time in your life, is that it would be bladder cancer.

This was the challenge that Richard faced. At 36 he was starting to adjust to his new role as a father when, in 2013, he noticed blood in his pee.

It was originally chalked up as a side effect of his marathon running and dismissed, but when the blood returned with a vengeance in 2016, he was referred to Mr Philip Charlesworth, a Consultant Urological Surgeon with an expertise in bladder and prostate conditions, who diagnosed bladder cancer.

“When Philip gave me the diagnosis it was a bit of a shock, particularly given that bladder cancer patients are usually a lot older than me.”

“My wife had broken her ankle a few months back, so she had been reliant on me to take care of the kids and ferry them about; it was a hard time to find out that I was now at the start of a really serious illness.”

“Still, it’s better to have found out and be taking action to deal with the problem than to remain blissfully unaware. It’s also very reassuring to be in the hands of a specialist like Philip, who really knows what he’s doing.”

Mr Charlesworth is the bladder cancer lead for Berkshire and South Oxfordshire, a position he has held since shortly after he arrived back from Los Angeles in 2013 where, thanks to funding from TUF, he had received training from one of the world’s foremost robotic surgeons, and experts in bladder cancer.

“The training I received from TUF has totally transformed how we treat patients in our region. Before I received the training we were performing predominantly open surgery, with robotic surgery only for prostate cancer. Now we perform over 250 robotic operations per year, including complex reconstructive operations, for example the formation of a new bladder using the patient’s own bowel, all done entirely robotically.

“Perhaps most importantly for our patients, their quality of life returns to pre-operation levels rapidly, and the long-term side effects of surgery are minimised. It is very pleasing as a cancer surgeon to be in a position to see our patients leave us with every chance at a normal life.”

Mr Charlesworth’s time in LA saw him learn from Professor Indebir Gill, a world renowned surgeon and key developer of the latest robotic surgical reconstructive techniques, including the techniques involved in the formation of an entirely new bladder, after removal of the native bladder due to cancer.

According to Richard, Mr Charlesworth’s care has made all the difference,

“Philip has such a reassuring air about him; knowing that I’m in the hands of someone who has received such expert training has been a big relief. I have 100% confidence in him. I’m very grateful for the work that Philip has done to enable me to continue a normal life and to be given the opportunity to spend as much time as possible with my lovely family.”

Being diagnosed in his 30s makes Richard very young for a bladder cancer patient and Mr Charlesworth, thanks to his training in LA when he was in his 30s, is very young for an experienced bladder cancer surgeon. This uniquely young pairing are both keen supporters of TUF, and are hoping to fundraise for TUF in the near future by running a marathon together.

Thanks to support from people like you, Philip received training that is saving lives. Your money really goes a long way.

Bladder cancer normally affects people who are over 50.

In the UK, over 10,000 new cases of bladder cancer are diagnosed each year, making it the fourth most common cancer in men and 12th most common in women.

Nearly 5,000 people die from bladder cancer each year.

In just 4 hours, Philip, and other robotic surgeons like him, can remove a bladder and make a new one out of a patient’s bowel. It means that a patient can go on to live a normal life.

Blood in pee is the most common symptom for bladder cancer. If you’ve seen blood in your pee, see your GP right away.
Emma’s research follows on from the work of Naside Mangir, one of Emma’s colleagues, who also received funding from TUF. In the Spring 2018 edition of TUF Matters we gave you an insight into Naside’s work, which has produced a mesh that is made of a different material to the current mesh. It is made from a biodegradable polyactic acid (PLA) which has properties similar to the pelvic tissue and will integrate well within the pelvic environment. However, this biomaterial isn’t going to work on its own; it needs the patient’s stem cells to help the initial integration into the body.

Emma’s research builds on Naside’s research by discovering a way to aid the initial integration into the body by combining the PLA mesh with the patient’s own fat cells. Her aim is to bring this new mesh one step closer to being used on patients.

So far, Emma’s research has developed a completely new way of creating PLA scaffolds (the structures required for the mesh) with inbuilt tunnels that can house the patient’s fat cells. Her research has demonstrated that the tunnels are a suitable environment for the cells and she now has her eye on the next steps.

“I’m working on a new way to get stem cells from fat cells. I want to know whether we can extract the cells mechanically, without having to use enzymes or culture cells in an incubator. If I can manage that, then patients will only need one surgical procedure where fat can be extracted from the patient, processed in the operating theatre, and then combined with the PLA mesh and implanted into the patient’s pelvic floor.”

“We women are understandably concerned and deserve a treatment which has been rigorously tested and shown to improve their condition. At present I am engaged in the early steps towards this. If the combination of fat derived cells and PLA looks promising then it will require rigorous testing both in the laboratory and in animals before it can be trialled in patients.

“If successful, this research will open up a new treatment avenue for women who require pelvic floor repair.”

We are so pleased to see Emma progressing with this work. There has been too much suffering amongst women with vaginal mesh implants and, thanks to donations from our supporters, Emma and Naside are closer to providing a new reality for women the world over.

The use of vaginal mesh has become a controversial topic with some patients having huge trouble after their surgery. In April, MPs called for all types of surgical mesh surgeries to be paused and research has shown that the failed surgeries are costing the NHS millions. Thanks to TUF funding, Emma is looking for an alternative.
Simon's research aims to determine what genetic and epigenetic changes take place in the development of penile cancer. Specifically, Simon is looking to find out what the early changes are in an individual tumour and how they are responsible for the development of the cancer.

His hope is that, by understanding these changes, scientists can begin to devise new tests that can diagnose the cancer and new treatments which can target its vulnerabilities.

Simon told us, “This has been very exciting work! It has generated huge amounts of data on penile cancer that simply weren’t there before. Those data are currently being analysed, but the initial results indicate that there are extensive genetic and epigenetic changes in the early stages of the cancer.

“The DNA code within each cell provides the blueprint for how a cell should function. A genetic change is a mutation or change within actual DNA code. An epigenetic change is the change in the machinery which switches different parts of the DNA ‘on’ or ‘off’. Either type of change – whether within the DNA itself or the machinery that controls it – could potentially result in the cell becoming cancerous.

“Our research has also shown that some treatments only target mutations that occur in a small part of the cancer, which could quickly cause the treatment to fail and the cancer to recur. We therefore identified which mutations are present in all regions of a tumour, rather than only in one section of the cancer. This would enable us to devise treatments that target the whole cancer.

“The next step for the research will be to test the hypotheses we’ve already developed. We’ll start this by using a range of targeted and immune treatments in advanced penile cancer patients.”

The work that Simon is doing will provide evidence for the next generation of clinical trials within penile cancer. This means that new treatments can be tested and, as Simon told us, “Only by testing new treatments can the survival of patients be greatly enhanced.”

Simon’s experience with this research project has also brought him closer to the world of clinical trials, where he’s seen an area for significant improvement. This has led him to create a start-up called TrialSense, which aims to improve the ease and efficiency of clinical trials by providing new methods for collecting and analysing data on a totally new platform.

TrialSense aims to put patient care at the centre of clinical trials so that a patient’s quality of life can become the focus.

Penile cancer (cancer of the penis) is an exceptionally rare and often neglected, but devastating, disease. Due to its rarity, very few treatment options have been devised which means that patients are routinely being let down. Mr Simon Rodney is looking to change that with his TUF-funded research.
PS, could you tell us more about the forms of deadly prostate cancer that your research sets out to treat?

Prostate cancer is not a particularly deadly disease if it’s caught early enough. But, if the cancer is not caught early enough, it can spread to the bone, at which point your chances of surviving long-term decrease significantly.

If the cancer reaches the bone, patients will be put on non-curative treatments, like chemotherapy and hormone therapy.

What treatments are you hoping to provide?

Well, it’s been shown in previous research that surgery might improve survival if the cancer has spread to the bone. The problem with these prior studies is that the patients who go forward for surgery are the ones who are younger, fitter, and healthier, and so are more likely to do better anyway. These studies therefore don’t actually answer the question of whether surgery to remove the prostate will improve survival in men with prostate cancer that has spread to the bones.

To answer this question properly, we are conducting a study where some men get surgery and some don’t, but they all get the standard hormone therapy. The key to the study design is that who gets surgery will be allocated at random, so that the two groups of men can be compared fairly.

Why does surgery work for men in whom the cancer hasn’t spread, but doesn’t always work for men in whom it has spread?

Surgery on prostate cancer patients means removing the prostate. If the cancer hasn’t spread outside the prostate, then you’re completely removing the cancer when you take out the prostate. Hence, in most cases this will work.

However, if the cancer has spread to the bone, you won’t be removing all of the cancer when you remove the prostate. It may still work if the cancer outside the prostate is driven by signals sent from the cancer in the prostate itself. Therefore, by removing the prostate you cut off that cross-talk between the prostate and the sites of disease spread.

What are you hoping to learn from this?

I’m hoping the study will demonstrate that men and their doctors will accept randomisation to surgery plus standard care versus standard care only. This will then allow us to plan a future larger study to examine whether removing the prostate improves survival rates for men with early, lethal prostate cancer. I’m also hoping that the men who undergo surgery will maintain their good quality of life despite the major surgery they’ve had.

What are the next steps with the study?

We have 51 men from across the UK, who have prostate cancer that has spread to the bones and who have volunteered themselves for this study.

The next step is to randomise treatment for this group of men so that some receive hormones and others receive surgery on top of their hormones.

What could this study mean for treatment of the most deadly prostate cancers?

At the moment, one man dies of prostate cancer every 45 minutes in the UK alone. The majority of these deaths are among men in whom the cancer has spread.

If we can prove that surgery can stop or slow down the most deadly forms of prostate cancer, we could help millions of men with prostate cancer across the world. The results of this study are widely anticipated by urological and oncological societies worldwide, and it’s thanks to TUF that the UK leads this important work.
SPOTLIGHT ON FUNDRAISING AND WAYS TO GET INVOLVED

TUFheroes thank you!

The team at the Whittaker Lab took part in the Big TUF Bake and raised a delicious £100.00 to support urology researchers just like them.

Our first London Landmarks Half Marathon team raised an amazing £10,500 between them. Special thanks to Tom Stonier, John & Mark Tiner, Chris Blick, Sally Tierney, Tom Blair, Sanad Saad and Julian Stout of this year’s TUF running team.

Not content with training and preparations to row the ocean for us this December, the Atlantic Seamen raised an earseome £6,000 for TUF at their launch party in February.

In the splendour of the Cadogan Hall Adrian Goldsmith hosted a special gala concert, premiering his very own Piano Concerto No.2, and having a silent auction. The evening raised nearly £10,000 for urological research.

Grandfather David Plummer persuaded his former colleagues across five Santander sites to join him for a five-mile fundraising walk for urology cancer.

ARE YOU READY TO RIDE FOR RESEARCH?

PEDAL4CANCER: LONDON TO CAMBRIDGE, SUNDAY 16 SEPTEMBER

This 60 mile cycle is a fantastic way to get together with friends and family or team up with work colleagues and be part of this special cancer bike ride. It’s open to anyone 14 and over! The event is not timed and it’s not a race - it’s about having a great time, enjoying the challenge and raising funds for The Urology Foundation. Sign-up for your place by visiting theurologyfoundation.org/pedal4cancer

PRUDENTIAL RIDE LONDON-SURREY 100 – JULY 2019

DATE TBA - JULY 2019

Join our 2019 cycling team and channel your inner Chris Froome as you take part in the now iconic ‘festival of cycling’ with 25,000 fellow cyclists following the 100 mile route from the London 2012 Olympics. We have places in the TUF cycling team and we’d love you to be part of it, so sign-up today by emailing Sayara on sayara@theurologyfoundation.org

ULTRA CHALLENGES WALK IT, JOG IT, RUN IT!

THROUGHOUT THE YEAR

Tackle some of the most challenging routes over a weekend in aid of TUF. We have places in the South Coast Challenge, Thames Path Challenges and the Chiltern 50. Why not get a team together and push yourself on one of these exhilarating trails.

To find out more contact Sayara on sayara@theurologyfoundation.org

How you can get involved

Quite simply, without you our work into vital urology research, education and training would cease to exist.

It is thanks to you that we are able to lead in the fight against urology disease and make a difference to the thousands of people with a urology condition or cancer. Here are just some of the ways you can get involved to power our work.

FIGHT UROLOGY DISEASE FROM THE KITCHEN

TUF BIG DINNER OF THE YEAR, THIS NOVEMBER

Bring family and friends together for dinner this November and support the fight against urology disease. The Big TUF Dinner is simple, it’s fun, and it saves lives. Invite people over for a meal and collect donations for The Urology Foundation. Register your interest with Sayara on sayara@theurologyfoundation.org

OTHER WAYS TO DONATE

LEAVE A LEGACY

Leaving a gift in your will, no matter how big or small, is a touching way to be part of the fight against urology disease. Your gift will help fund ground-breaking research into all urological conditions and diseases, their causes and new treatments.

Visit our website to find out how to do this.

Whether you choose to host a big pub quiz, set-up a cycle marathon at work or run a series of cake stalls through the month, every bit of fundraising you do will make a difference. Spread the word and encourage friends, family and colleagues to join the Big 5 challenge as the more money we can raise the quicker we can reach our goal.

Sign-up at everydayhero.co.uk/event/Big5 or contact Sayara for more information.

For more ways to support TUF’s work visit theurologyfoundation.org/get-involved or contact Sayara on 020 7713 9538
Ashwin Sachdeva’s research proposal won him the prestigious TUF Medal back in 2015. He has now been studying prostate cancer at Newcastle University for the last few years. Here’s a short update on what he has found, both in and out of the lab.

Ashwin set out to understand the role played by mitochondria in the progression of prostate cancer. His goal is to help improve the treatment of men with prostate cancer.

**What are mitochondria?**

There are hundreds of thousands of mitochondria in every cell in our body. They act as a “biological battery” by playing a crucial role in producing energy for the cell and contain their own DNA to generate the required machinery for this process. This DNA accumulates errors as a part of the normal ageing process, which may eventually influence the normal functioning of cells.

**How does this relate to prostate cancer?**

Ashwin had a theory when he started the research: that prostate cancer is more likely to affect older men because the mitochondria in their prostate cells collect these DNA errors and function abnormally, as compared to cells in prostates from younger men.

**Was this found to be the case?**

No. In fact, his preliminary results suggest that defective mitochondria (those that have errors in their DNA) may actually slow down the progression of prostate cancer.

**What’s the next step?**

As with any scientific hypothesis, the next step is to undertake further work to confirm these early findings and unpick the underlying mechanisms. Ashwin’s hope is that by developing or repurposing drugs to specifically damage these “batteries” within cancer cells, we may be able to help slow down the progression of prostate cancer in patients in the future.

**Outside the lab**

Ashwin has teamed up with the School of Fine Art at Newcastle University to take part in a project called Valence, which aims to bring together artists and scientists to help communicate scientific research to the public. Ashwin has been working with Katie Antoniou, who has incorporated the scientific process to develop art work inspired by images that scientists see under a microscope.

“As researchers, we become used to looking under a microscope and we often don’t step back to appreciate the beauty that lies in the scientific images we generate.”

The artists have turned these scientific images of cells and tissue samples into works of art, which have been exhibited across Newcastle. These science-inspired art exhibitions have provided a chance to speak with members of the public about the prostate and prostate cancer.

Gladsly, I’ve also been able to tell them about the recent advances in this area, as we continue to improve our understanding about its biology, diagnosis and management. For me, this has been a perfect opportunity to complement the work of charities like TUF in raising awareness of prostate cancer.”

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**TUESDAY 18 SEPTEMBER**

**Vintner’s Wine Tasting Dinner with Jane MacQuitty**

Following the success of our previous wine tasting dinners, we are delighted to announce that Jane MacQuitty, author, broadcaster and wine critic for The Times, has very kindly agreed to host one for us in September.

The event will take place, appropriately, at the historic Vintners’ Hall. The evening will begin with a drinks reception in the drawing room, followed by three course meal downstairs in the splendid Livery Hall. Each course of the dinner will be accompanied by two different wines in order that you can compare, contrast and judge for yourself.

Whether you are a wine connoisseur or a novice, join us for what promises to be another entertaining and lively evening.

For more information on any of the above events please email Serena at swymans@theurologyfoundation.org
Thank You

We’re making great progress every day as a result of our investment into urology research, training and education.

Your support enables us to keep our work going and improving treatment for the people affected by a urological condition or disease who need it most. This work would simply not be able to happen without you.

Further information

If you would like any further information, or indeed would like to host a fundraiser for The Urology Foundation, please call:

SAYARA MUTHUVELOE: Fundraising Manager
t: 020 7713 9538

SERENA WYMAN: Events Manager
t: 01449 737 971

Get your tickets today by contacting Serena at swyman@theurologyfoundation.org

This September, TUF is hosting a wine tasting dinner with author, broadcaster, and wine tasting critic for The Times, Jane MacQuitty.

The event will take place at the historic Vintner’s Hall on Tuesday 18 September. The evening will begin with a drinks reception in the drawing room, followed by a three course dinner downstairs in the splendid Livery Hall.

All the money raised will go towards our fight against urology disease.