‘Mammogram’ for prostate cancer

Countering stigma

Developing urology nurses

Ending the suffering caused by urology disease

theurologyfoundation.org
Hello and welcome to TUF matters.

TUF got off to a flying start this year with a number of developments and awards. You can read about plans for our TUF Trials Unit and some of the exciting projects we are funding under our new Innovation & Research Awards scheme. Our experts are currently reviewing a further 11 research projects ranging from prostate issues, male infertility, continence, UTIs, sexual health and testicular torsion. TUF is truly enabling all aspects of urological disease to be investigated, ensuring that patients can lead better lives.

I am pleased to announce two new Trustees: Mary Garthwaite and Hannah Warren. Both are extremely talented and bring a range of experience and ideas, we are very fortunate to have them.

We remain indebted to the many fundraisers who do so much to make TUF’s work possible. I’d like to highlight the enthusiasm of the trainees in organising and taking part in so many events to raise funds for TUF, while not forgetting our army of urologists and nurses who contribute so much in terms of their time, expertise and support.

But a particular ‘Thank You’ to all of you reading this issue, who take the time to get involved in the charity and who donate to the cause. You are making a huge difference to the lives of people living with a urological cancer or disease and are helping us to improve their treatment and care.

Louise de Winter, Chief Executive

Front cover image courtesy of David Eldred-Evans and the Prostagram team
We are asking you to STEP UP FOR TUF during Urology Awareness Month this September by virtually climbing a building or if you’re feeling ambitious, a mountain!

Climb the stairs at home, climb the escalator on the tube, climb the fire escape, climb the steps at your place of work and keep a count. Set up a JustGiving fundraising page on our Step Up for TUF Challenge page (justgiving.com/campaign/StepUpForTUF) and ask friends, family and work colleagues to sponsor you during the month of September.

The challenge can be done as an individual or why not put a team together and combine your totals to really “hit the heights”?

If you are of a competitive nature, why don’t you challenge a friend or another team to a race to the “summit”?

For more details visit theurologyfoundation.org/get-involved/fundraise/590-step and find out how many flights you’d need to climb to conquer Big Ben or Ben Nevis!

Every step you take will take us a step closer to ending the suffering caused by urology disease. So, please put your best foot forward this September!

justgiving.com/campaign/StepUpForTUF
Improving treatment and care across all urology

TUF launches Urological Trials Unit

We are delighted to announce the TUF Trials Unit (TTU) in partnership with The Centre for Healthcare Randomised Trials (CHaRT) at the University of Aberdeen. The unit will be led by Professor Graeme MacLennan, a medical statistician and Professor James N’Dow, a consultant urologist.

The role of the TTU is to identify promising and important research ideas from urology units and provide a team of medical investigators to bring those ideas to fruition. This approach will enable more high-quality urology trials to take place, leading to better care, quicker recovery times and fewer long-term issues. Successful trials are catalysts for change, provide potential for transformational discoveries and drive improvements in services.

The next stage is to seek applications to the unit and run a Dragon’s Den pitch process to identify which ideas to take forward. TUF is pleased to be working closely with the British Association of Urological Surgeons and representatives of the Royal College of Surgeons on this initiative. All parties are excited about the potential impact the TTU will have on the world of UK urology!

Fundraising to support the TTU continues, if you wish to donate please visit justgiving.com/campaign/TUFTrialsUnit

INNOVATION & RESEARCH AWARDS

This new award funds projects that take innovative approaches to address urological diseases and disorders. Opposite are some of this year’s:
Michael Hughes – University of Surrey  
*Mail-In cancer Diagnosis and Analysis by Dielectrophoresis – Bladder Cancer (MIRIAD-BC)*

Previous research has shown that electrical analysis of cells in urine allows diagnosis of bladder cancer. This study will develop this technique; optimising sample collection and analysis, identifying methods of grading tumours. The aim is that this will lead to a clinical trial.

Sarah Howles – University of Oxford  
*Defining the role of calcium-sensing receptor signalling in kidney stone disease*

Sarah’s team had previously identified 20 areas on the genome that are linked to kidney stone disease. This project seeks to further refine that data to improve understanding of stone disease and pave the way for innovative therapies.

Hannah Warren - Royal Free Hospital / UCL  
*Sestamibi Kidney for the Assessment of renal Neoplasms (SKAN)*

This project will evaluate existing and novel diagnostic imaging techniques in the assessment of small renal tumours, with a view to reducing unnecessary invasive diagnostics and management in patients with benign disease.

Prasanna Sooriakumaran – UCL Hospital / Royal Berkshire Hospital  
*RESTART*

This study is a randomised controlled trial which aims to evaluate a technique called Retzius-sparing robot-assisted radical prostatectomy (RS-RARP) to see if it achieves better post-operative urinary incontinence outcomes for patients than the standard technique. Funding for this project is thanks to the John Black Charitable Foundation.

Introducing two new TUF trustees.

Ms Mary Garthwaite was a Consultant Urologist in Middlesbrough specialising in functional and reconstructive surgery and neurourology. Her expertise is in the management of benign, chronic disorders of the bladder. She served on the BAUS committee of Female, Functional, Neurological and Urodynamic Urology Section until her retirement from clinical urology in 2019.

Ms Hannah Warren is a trainee urologist in London with an interest in kidney cancer. She is also a committee member of BURST, a trainee-led research collaborative. Before joining the board, Hannah led the TUF Warrior Programme and was a supporter of TUF through sponsored events and sporting activities.
Despite a traumatic experience from a urological condition as a child, Henrique Fonseca is now a urology clinical nurse specialist in Dublin. He will be taking part in the TUF Machu Picchu challenge trek to raise money for TUF’s work.

As a young boy in Portugal, a chance scan revealed a potential obstruction in one of Henrique’s kidneys. He went through about ten years of investigations, including a urodynamics test at the age of 12.

“I was probably one of the first kids to have this test in Portugal at the time. I didn’t give my consent. They grabbed my legs and arms and they forced me to do the urodynamics. It was a very traumatic experience,” he recalls.
Eventually, Henrique had surgery on his kidney and he says that the nurses at the paediatric hospital were ‘amazing’ in helping him feel comfortable. It was during that hospital stay that he discovered he wanted to be a nurse.

Henrique had no intention of working in urology, but job opportunities came up that led him down the path to specialising.

“I find it a bit funny how urology brought me back to the field. I always feel very empathetic with the patients. I believe that this was a chance for me to deal with my experience in urology and take the best of it and use it as a super skill,” he says.

“Some people will get really stressed and will not cope the way that other people can. As a nurse, we have a job to recognise these people and work with them in terms of clear explanation. I think people need to be informed in different ways.”

Being a male nurse in urology, he noticed that he was getting more and more questions from male patients about erectile dysfunction. Henrique then decided to complete a post-graduate qualification in human sexuality.

“I developed a nursing consultation in sexual health with a focus on erectile dysfunction. I was a bridge between the consultants and the patients; I did all the education in terms of lifestyle alterations, vacuum pumps and intracavernous injections, mostly for men after prostate cancer,” he says.

“They felt like it was the first time they had someone they could talk to about sex without any problems. I could feel that it made a big difference for them.”

During lockdown, Henrique found that walking helped his mental health. When he came across TUF’s challenge trek to Machu Picchu (now rescheduled to March 2022), he jumped at the opportunity.

“It was joining the walking part of me, combined with the opportunity to raise money and awareness for urology care. So it was pretty much obvious that I had to participate in this adventure.”
Using social media to counter stigma

At the age of 24, Laura Piercey found that her bladder suddenly stopped working. This meant that she would constantly need a catheter to empty it.

She was given a suprapubic catheter, which is inserted directly into the bladder through the abdomen. About every four months, the catheter falls out, leaving Laura with no way to empty her bladder. When this happens, she has to go straight to the hospital as an emergency case and have a new one surgically fitted. However, it is the daily challenges that make life difficult for Laura.

“I think the number one thing for my day to day is making sure that I have toilets accessible to me. I don’t actually have any sensation for when I need to drain my catheter, and the leg bag can fill up quite quickly,” she says.

“It’s also about managing people’s expectations. I think that has been a real barrier because a lot of people are not necessarily aware of what a catheter is and why people have it. I feel like there is still a lot of stigma surrounding catheters.”

Laura uses Instagram (@didusehercatheter) to share what life with a catheter is like and connect with others in a similar situation. She hopes that it will help to break down the stigma that she has encountered.
“I felt quite isolated, and I thought that social media is a place where you can voice your own experiences. I was just so astounded at how many young people, and especially young women, have suprapubic catheters that were almost too afraid to share their own experiences,” she says.

Laura decided to fundraise for TUF undertaking a one day 51 km walk this June in the Lake District. Even training for the walk was extra challenging due to the toll from regular infections, medication and being regularly in and out of hospital.

“Hiking is something I enjoyed before I acquired my catheter and I was able to do it without any issues,” she says.

“The challenge was both mentally and physically challenging, but it’s something to show myself that I actually can do it and I can push through those barriers.

“I feel that urology is largely underfunded across the health sector – that’s from my own experience and from caring for my grandfather, who had bladder cancer. He had a catheter and he used resources from The Urology Foundation. I just thought, what a great charity to provide resources for people in their time of need.”

You can still show Laura your support by donating at justgiving.com/fundraising/50kpeakdistricthike
The search for an equivalent of the mammogram to screen for prostate cancer is a step closer as TUF researchers demonstrate the potential of a new short MRI scan.

The big challenge in creating a screening programme for the disease is detecting dangerous cancers without leading to more men needing biopsies. As biopsies are painful and risk causing an infection, tests need to minimise the number of false positives.

The current first-line test for prostate cancer offered by GPs detects levels of the protein PSA in the blood. However, this has a high false-positive rate.

The new 15-minute scan, dubbed a prostagram, does not lead to more men having a biopsy than the PSA test, and it appears to be better at
detecting aggressive cancers. Over 400 men were screened in the trial, and 11 cases of clinically significant cancer were seen by MRI, while only 7 were seen with PSA. The prostagram will need to be tested in a larger trial with thousands of men screened to verify its improved detection.

Prostate cancer has a high survival rate if it is caught early, however many men do not experience symptoms until the cancer has spread and is incurable. It is hoped that a screening programme would catch aggressive cancers before this stage.

The trial led by researchers at Imperial College London was part-funded by TUF, enabling the scans to be tested in a second centre at Mount Vernon Hospital to verify its generalisability.

The trial compared different thresholds for the MRI scan to define a positive case. Each scan was graded out of five, and the researchers found that a score of four or higher avoided too many men needing a biopsy unnecessarily.

“With a score of 4-5, you would biopsy the same number of men as PSA, but PSA was missing a lot of cancers. The MRI identifies a good proportion of them, much better than PSA,” says Dr David Eldred-Evans, the lead author of the study and research fellow at Imperial.

A prostagram scan would be more costly than a PSA test, however David hopes that its improved accuracy would make up for that: “If you have to do it less frequently, even though the test is more expensive, it can become cost-effective.”
“I had been aware of TUF for essentially as long as I’ve been interested in urology. They are prominent in British urology through sponsorship of trainee education and fellowships, but also fun events such as the Fun Run for TUF organised by trainees that takes place in June,” she says.

In 2018, Hannah signed up to the TUF Warrior programme, a scheme for junior doctors who are interested in urology but haven’t yet specialised. Members of the programme can improve their career development skills and raise money for TUF.

“It’s obviously a fantastic thing for TUF as a way to raise much-needed funds. But the Warriors also get a lot out of it, through networking and establishing a group of like-minded professionals in their early careers,” says Hannah.

“Because you may not necessarily work in an area where there’s much urology going on, it can be difficult making those connections but TUF can provide these opportunities. You end up meeting people who can really nurture your onward career."

Hannah is now leading the TUF Warrior programme, and this year became a trustee of TUF. She wants to ensure that the charity is as relevant as possible to early career trainees.

“I very much see that as my role – I want early career urologists to feel that TUF is their charity,” she says. “For TUF to be able to deliver in supporting urologists, TUF in turn needs support from urologists at every level of their career.”

You can help TUF to support early career urologists: urologyfoundation.org/donate

Hannah Warren is one of the newest members of the TUF board of trustees. She is a trainee urologist in South London with an interest in kidney cancer.
Setting up a Facebook Fundraising page in aid of TUF

Is easy to set up

Is easy to share with friends and family to ask them to donate

100% of all donations come directly to The Urology Foundation

Raises much needed funds that make a real difference to our ability to continue to support cutting edge research and training.

To set up your page

- Go to the homepage of your Facebook account
- Select the “see more” button from the menu on the left-hand side
- From these further options scroll down to Fundraiser
- The fundraiser page has links to FAQ’s and at the top of the page a box asking you to select your charity
- Type in The Urology Foundation and the system will set you up a template TUF fundraising page ready for you to edit and personalise.

A Facebook birthday or celebration fundraiser is a gift that will support research into urology conditions and diseases, improving the lives of urology patients.
Developing skills for urological nurses

Having been a nurse for 32 years, including 21 years within urology, Clare is well-positioned to help the association navigate a changing world. She is on a mission to sell urology as an exciting specialty for nurses, sharing practice and initiatives nationally.

Attending the BAUN conference a few years ago, Clare was looking for a fresh challenge.

“I sat there in the audience listening and thought: ‘This is something that I would like to get involved with. I’d like to give something back,’” she says.

New techniques in urology over the last 15 years, such as robotic surgery, have reduced hospital stays for patients and led to a loss of urology-designated wards. This, Clare says, has reduced nurses’ exposure to urology and there is a need for a national effort to encourage nurses into the specialty.

“That’s really why I wanted to become involved with BAUN as an association. As I sat there in the audience, I never actually saw myself as being President,” she says.

For her, the development of her team is critical so that they can offer high-quality care to the
patients they look after. In her role as President, she aims now to support other urology nurses across the country to extend their knowledge and skills. In particular, she is keen to develop leadership skills in urology nurses to take a more prominent role in identifying and leading service improvement.

“Until you’ve got that leadership element within a urology specialist nurse service, it’s very difficult for nurses to drive forward their own services,” she says.

Clare highlights TUF as being a fantastic source of support for urology nurses: “This is what we need as an organisation, for our nurses to be able to access development support and grants.”

Clare is very passionate about urology and its possibilities for nurse-led services: “We’re very fortunate within urology because it is well-recognised that you need specialist nurses and that what they bring to the service is incredibly valuable.”

The Covid-19 pandemic has brought a lot of changes to health care. As Clare took on the role of President, she was redeployed to the ICU, taking her out of her comfort zone on both fronts. However, new ways of working through the pandemic has made it easier to redesign services, says Clare:

“Covid has provided lots of opportunities clinically with urology services, and now is a fantastic time to share these initiatives that have been developed all around the country.”

You can help Clare and TUF to support more urology nurses by donating theurologyfoundation.org/donate
Without you, our work into vital urology research and training would cease to exist. Your support enables us to make a difference to thousands of people with urology conditions and improve their quality of life.

To sign up for any of the events, or to find more ways to get involved, visit theurologyfoundation.org or email fundraising@theurologyfoundation.org

100 minutes of exercise on the Sunday. Between them they raised, with the added Gift Aid, an amazing £932.

To Laura Piercey (see p 8) who undertook the Lake District 51km challenge and to date has raised over £720.

We are so grateful to BSoT (the trainee section of the British Association of Urological Surgeons) who this June organised a second BsOT Fun Run for TUF. They asked their membership to walk / swim / cycle etc during the week of 17 June and donate to TUF. Some 67 people took up the challenge and included activities such as paddle boarding and boxing. Between them they raised over £2,300 with Gift Aid. A HUGE THANK YOU to everyone who took part.

To those that gave with love in memory of Geoffrey Cave-Wood, Ted Clucas, Susan White and Mr Armstrong.

To Ben, Joyce, Matthew, Robert and Gale for setting up birthday donation pages on Facebook in aid of TUF.

Last, but not least, to our wonderful trustees Mr Andrew Moss, Mr Duncan Summerton and Baroness (Laura) Wyld who recently retired from TUF Board. We remain grateful for your support, input and advice over the years and hope you enjoy watching TUF continue its work.
How you can get involved

Italy to Slovenia Bike Challenge

Come and join TUF supporters in September 2022 and cycle from the sparkling Adriatic Sea to the grandeur of the Alps on this wonderful two-country challenge for The Urology Foundation.

Kicking off on the Italian island of Grado, you’ll ride from the sea to snow-capped peaks and cross the border to the forests, lakes and green capital city of Slovenia. This route will take you up and down through spectacular mountains and swooping valleys, past lush, alpine meadows and include a night by the crystal clear Lake Bled.

Join this once in a lifetime bike ride where every pedal pushed will support people affected by urology disease.

For more information visit theurologyfoundation.org/get-involved/fundraise

Dates for the Diary

**SEPTEMBER**
1 – 30 September
Step Up for TUF / Urology Awareness Month

10 September
Thames Moonlight 10 Walk, in association with Action Challenges

11 – 12 September
Thames Path Challenge, in association with Action Challenges

17 – 19 September
Bike4 TUF

25 September
Chiltern 50 Challenge, in association with Action Challenges

**OCTOBER**
30 October
London Halloween Walk, in association with Action Challenges

**NOVEMBER**
2 November
TUF Wine Tasting Dinner with Jane MacQuitty at the beautiful Vintners’ Hall.

**2022**
18 – 27 March 2022
TUF Machu Picchu Trek

10 – 16 September 2022
Italy to Slovenia TUF Cycle Challenge

Please see the website for more details on all these events or email Serena at swyman@theurologyfoundation.org
Our urology health is vital to our quality of life. But diseases and cancers of the kidneys, bladder, prostate and the male reproductive system are becoming more prevalent and devastating the lives of millions of men, women and children in the UK.

This September we will focus not just on raising awareness but on breaking down the taboos and attitude of silence around urology conditions. With 50% of the population likely to be affected at some point in their life, this is something we need to be able to talk about.

We will be encouraging people to take charge of their own urology health through lifestyle tips and being aware of the signs and symptoms of urological diseases. The one message that we want to drum home is that if you notice any changes in your body or toilet habits you should talk to your GP. Early detection and treatment with so many conditions are key.

During the month we will be sharing information through our website and social media from patient stories, professional insight, bitesize guides on a variety of urology conditions, health tips and advice.

In order for TUF to continue supporting cutting edge research we need to have the funds. Therefore, we are asking people to take the opportunity to fundraise for us. Whether you take part in our Step Up for TUF challenge, or organise your own fundraiser, please support TUF this September so that we can support vital research into the best future treatments and care for urology patients.

Take the opportunities offered by Urology Awareness Month, and the conversations that the campaign generates, to fundraise for future research.

For more information, go to: theurologyfoundation.org/get-involved/urology-awareness-month
It’s time to Bike4TUF!

We are delighted to announce our annual Bike4TUF cycle and although Covid has made it harder for group events to take place, it has not stopped determined urologists and patient supporters from getting on their bikes in support of the charity.

This year’s three day ride will take place from Friday 17 – Sunday 19 September 2021 and cover some 240 miles.

Two groups of riders will set off from London and from the Manchester area, and meet in Northamptonshire for dinner that evening. Saturday will consist of a scenic but hilly ride through beautiful Cotswold and Warwickshire countryside. The ride will conclude in central Birmingham on Sunday.

The first Bike4TUF was held in 2012 at the instigation of consultant urologist Ben Eddy from East Kent Hospital Trust to repay the support TUF gave him and his team. A TUF grant enabled them to visit a major robotic centre of excellence in America. “We were just getting started in our robotic service and it helped us to get up and running” he says. Ben is still passionate about supporting TUF’s work and continues to take the lead on this popular annual fundraising event.

We look forward to seeing our regular riders once more and to welcoming new riders to the Bike4TUF family.
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 improve 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:

SERENA WYMAN
Fundraising & Events Manager
t: 01449 737 971

Trek To Machu Picchu
The lost city of Machu Picchu sits on the bucket list of many and with good reason; it’s simply breath-taking. So join other TUF supporters on the trip of a lifetime on this gruelling yet rewarding, challenge that follows the spectacular and uncrowded Ancascocha trail, surrounded by snow-capped mountains, raging rivers and remote mountain communities and make memories that will last a lifetime.

If Charity Challenge cannot operate a challenge in the host country due to Covid-19 they will offer you a number of options including postponing / joining another challenge / refund. See website for full details.

For full details visit
www.charitychallenge.com/expedition/3064/Trek-to-Machu-Picchu

RESCHEDULED DATES
18-27 March 2022