Simulating Success

Evolving our research funding

Giving back to urology

Ending the suffering caused by urology disease
theurologyfoundation.org
Hello and welcome to TUF matters.

This will be my last introduction to the newsletter as, after ten years of leading TUF, I have decided to step down as Chief Executive and instead to undertake a part time role within the organisation, managing the programmes and grants as Director of Research and Operations.

I’m extremely proud of everything that we have achieved together over the last 10 years. When I first took up the reins in April 2011, TUF had two awards available to urologists: the Research Scholarship and Clinical Visit awards. Over the years we have massively expanded our programmes to include Innovation & Research awards, smaller research projects (open to urology nurses as well as urologists), a comprehensive robotic surgery training programme, trainee fellowships, the TUF Nurse of the Year Award, and other educational prizes. To this we can add our flagship TUF Trials Unit, and this year we will be adding more regional awards and fellowships. Opening some of our awards and training opportunities to nurses is also something of which I am extremely proud, and we look forward to working further with our colleagues in nursing.

TUF now has over 50 active research and training grants open covering the gamut of urology cancers and conditions, with a combined value of over £2.5 million. Truly we are the major ‘go to’ charity for funding research across the whole of the urology speciality and offering professional support. But we could not have done any of this without your support, so thank you.

Louise de Winter, Director Research & Operations
Introducing our new CEO

We are delighted that Rebecca Porta has joined the team at TUF as our new CEO.

Rebecca’s career in the voluntary sector spans over 30 years. She has worked for some of the UK’s leading health and medical research charities including The Multiple Sclerosis Society, The Migraine Trust, CancerBACUP (now Macmillan Cancer Support) and the British Lung Foundation.

She knows the urology world well, having led Orchid Cancer Appeal, the male cancer charity for over eleven years. More recently she oversaw the merger of two medical research charities and the launch of the new charity, Bowel Research UK. Rebecca is on the Board of Cancer52, an alliance of 100 organisations working to address the issue of inequality in rare and less common cancers.

Rebecca said: “It is a great privilege to be joining The Urology Foundation at a time when investment in research and support for our colleagues in the urology community has never been more needed. I am looking forward to leading the charity into its next stage.”
MULTI-MODAL RADIOTHERAPY IN PROSTATE CANCER

Yiannis Philippou, Clinical Research Training Fellow, University of Oxford

This study showed that treating prostate cancer with multiple combined treatments such as radiotherapy (RT), “focal” therapy and immune-mediated therapy in a sequential fashion at a pre-specified interval can result in enhanced tumour control, and sometimes cure, when compared with these treatments used alone. It also allows for reduced doses of RT which are known to cause important and often debilitating side-effects in men.

Further work is needed to fully understand the immune response and the ultimate goal is to test this hypothesis in men with prostate cancer in prospective and randomised trials in due course.

Every year TUF funds a variety of projects that aim to make an immediate impact on treatment and care. Below are some of the projects we supported in 2021:

DETORT: DETECTION OF TORSION BY REGISTRARS IN TRAINING

Testicular torsion is an emergency requiring urgent assessment, diagnosis and surgery to salvage the affected testis. However it is hard to accurately diagnose. Each year dozens of patients in the UK with testicular torsion lose their testis due to a failure in diagnosis, while thousands without torsion undergo unnecessary surgery.
This study aims to test whether the use of a rapid, bedside ultrasound, can accurately diagnose torsion, thus saving time and limiting the need for unnecessary surgery.

CHAPS STUDY: CREATING A GRADING SYSTEM FOR PAEDIATRIC BALANITIS XEROTICA OBLITERANS (BXO).

BXO is an inflammatory and progressive skin disease affecting the male genitalia, causing lesions and tightening, resulting in damage and pain.

No standard clinical grading system currently exists for BXO in boys. A grading system, that reflected disease severity and accurately predicted cases of BXO that relapse after intervention, would allow clinicians to identify high-risk patients and plan treatments accordingly. It would also provide a standardised means to classify BXO for future research, ultimately leading to better treatments.

MEASURING URINE FLOW RATES OF PATIENTS REMOTELY

Lower Urinary Tract Symptoms (LUTS) affect hundreds of thousands of men, impacting on their quality of life, and waiting lists for in-person assessments have grown longer during Covid. The challenge has been how to make accurate clinical assessments in virtual clinics. This project is looking to develop a camera model that can recognise a standard, healthy urine flow rate and, therefore, enable a diagnosis and treatment assessment to be made safely and securely in a virtual clinic. This could potentially lead to thousands of hours saved attending clinics, and faster diagnosis and treatment.

TUF Urology Nurse of the Year 2021

We are delighted to announce Deborah Victor, of The Royal Cornwall Hospital, as the 2021 winner of TUF Urology Nurse of the Year Award.

Deborah was nominated by her consultant for:

• Starting a metastatic urology clinical nurse service, providing regular contact for patients;
• Helping patients to take part in a supported self-management programme;
• Training to do local anaesthetic transperineal prostate biopsies, thus significantly helping with her department’s caseload.

Deborah embodies the best qualities of nursing: a desire to do the best for her patients, and to continue learning and developing new skills to benefit those in her care.

The award comes with a £2,000 TUF education grant.
Last summer, Niyati Lobo spent six months at the University of Texas MD Anderson Cancer Center to do just that, thanks to a TUF Fulbright scholarship.

“As someone who hopes as a consultant to specialise in the diagnosis and treatment of patients with bladder cancer, I wanted to spend more time learning about the disease itself, the research that was happening, where the field was headed and what it would look like in the future,” she says.

Gene activity profiling of bladder cancer is helping researchers to identify molecular subtypes that show distinct responses to treatment. This could help to improve outcomes in people where the standard BCG treatment fails to treat non-muscle-invasive bladder cancer. As the largest cancer centre in the US, MD Anderson was an ideal place for Niyati to learn more about the future of bladder cancer treatment and get involved in their extensive research programme.

“I learned a lot about novel treatments for BCG-unresponsive disease. In the UK, we only have one option that is approved by NICE for us to use in patients unsuitable for cystectomy. However, MD Anderson and other institutions are currently investigating treatments that might eventually make their way across the pond,” says Niyati.
Niyati worked in the lab of Dr Ashish Kamat, a world expert in bladder cancer, where she did research into the validity of updated prognostic risk groups in BCG-treated patients, the efficacy of reduced dose BCG and sex-specific differences in oncological outcomes and treatment patterns.

“It was a really enjoyable experience. It was great to be in an environment where you had access to so many resources and to be mentored by someone like Dr Kamat. I am immensely grateful to The Urology Foundation and the US-UK Fulbright Commission for this incredible opportunity,” she says.

Niyati first became interested in bladder cancer as a medical student and was drawn to the way that the teams managed complex cases. She is currently a urology trainee at Royal Surrey County Hospital in Guildford, where she is getting a lot of experience in seeing bladder cancer patients and learning robotic surgery.

In October 2022, Niyati will join Guy's Hospital as a Fellow specialising in bladder cancer, where she plans to continue advancing research into the disease: “During my scholarship, I gained a lot of research skills and confidence in developing my own ideas and projects. I want to develop collaborations between the UK and MD Anderson, and I hope to do that next year at Guy's.”

Your donation today will be invested in urologists like Niyati resulting in more patients being able to access excellent urology care, theurologyfoundation.org/donate
As regular readers will know, TUF Matters normally contains an article about someone who has suffered from, or is living with, a urology condition. There are several very good reasons why we like to share these stories. A patient story resonates with people because it is authentic and because it makes the information about symptoms or the conditions very real. No longer abstract information, people now see a person like themselves, or their loved ones, and take notice. A story can provide an insight, hope and support for those going through a similar experience.

Humans have been sharing stories since man first sat around a fire, often not for entertainment but as a way of illustration, allowing people to easily absorb and learn. The Director of the
International Storytelling Centre says that “We are all storytellers. We all live in a network of stories. There isn’t a stronger connection between people than storytelling.”

Asking people to describe their experiences enables audiences to hear information in a way that reading dry facts and figures does not. Whilst statistics are important, stories have the power to motivate and make a difference, affect others’ viewpoints and behaviour.

We talk a lot at TUF about the importance of breaking down the taboos associated with urology health, encouraging people not to delay seeking professional advice because they are embarrassed. Seeing other people speak in a very matter of fact away about their conditions can help others to hold much needed conversations.

Working to create better patient journeys and best outcomes is at the heart of all we do at TUF, therefore it is important to us that patient voices are heard and can help others.

If you or a loved one have experience of a urology condition, whether ongoing or resolved, we’d love you to share your stories. To talk about your experiences – the symptoms, how you felt, from first doubts to treatment and outcome. What lessons you have taken from your journey and what advice you would pass on to others.

By sharing experiences, you will inform, teach and bring hope to others.

If you would like to share your story, in our newsletter, website or social media, please contact Serena on swyman@tuf.org.uk or call her on 01449 737971 to discuss.
"I remember building the first simulator for keyhole surgery of the kidneys in 2002. So we have a long history of trying to simulate operations away from patients, so that it is much safer by the time we actually perform them," says Professor Prokar Dasgupta from Kings College London.

The complexity of modern keyhole operations led to the uptake of simulation to help trainees get to a suitable standard in a safe environment. This approach was influenced by the use of simulators in aviation and the military. However, a lack of robust evidence for patient benefit has hampered the uptake of simulation-based training and not all trainees get this experience before operating on a patient.

"Urology was the first surgical specialty to put simulation on the curriculum in 2014, but it never became compulsory," says Prokar.
With funding from TUF, Prokar and his colleague Dr Abdullatif Aydin set up an international trial, called SIMULATE, to gather evidence on the impact of simulation training. Half of the 65 urology trainees taking part were trained traditionally and half received additional simulation training.

The trainees were monitored through their proficiency with a ureteroscopy procedure, where they pass a telescope through the patient’s urethra and bladder into the ureter and kidney. This procedure is commonly used for treating stones.

“An expert panel felt that this was an operation which most trainee surgeons would need to learn to become a consultant,” says Prokar.

Over the course of the trial, trainees across Asia, Europe and North America performed over 1,100 procedures on patients. The results, which were published in the journal European Urology, showed that those who received simulation training reached a higher level of proficiency on average, with fewer minor and severe complications.

“For the first time, we’ve demonstrated that it’s not just a confidence booster; it actually makes a massive difference to patients. There’s been a very warm welcome from across the surgical community regarding our results because it’s an example for most surgical specialties,” says Abdullatif.

The team plans to do further research into the surgical impact of newer simulation methods and non-technical skills, such as leadership and communication.

“Educational trials like this are very difficult to get funding for, but The Urology Foundation put their faith in us. We were very grateful for that because, without that funding, this trial would not have happened,” says Prokar.

“We owe it to our patients to provide the best care that we can, by the best-trained surgeons. I think the next challenge would be the implementation of this in the UK and other parts of the world.”
The TUF Science and Education Committee (SEC) is a core part of our efforts to ensure that the generous donations from our supporters have the greatest impact for patient care. This panel of experts works to identify the most effective funding programmes and the best applications.

The committee is chaired by Grant Stewart, Professor of Surgical Oncology at the University of Cambridge and an Honorary Consultant Urological Surgeon at Addenbrooke’s Hospital, Cambridge. He joined the SEC in 2014 and became its chair in 2018.

“I recognised that TUF was the only charity that funds research across the whole of urology and I wanted to be involved in the process,” he says.

During his tenure, Grant has overseen significant changes to the TUF funding programme, including the new TUF Trials Unit, developed with colleagues from the British Association of Urological Surgeons (BAUS). This was inspired by a similar model adopted in orthopaedic surgery that led to several significant clinical trials.

“We wanted to support the very best research that would change practice, so we needed to support trials. The idea is that urologists can come to the TUF Trials Unit with an idea, get advice on it and then turn that idea into an excellent funding application. If it gets funded, then the TUF Trials Unit will help the researchers run the trial,” says Grant.

NAME: Grant Stewart

PROFESSION: Professor of Surgical Oncology at the University of Cambridge and an Honorary Consultant Urological Surgeon at Addenbrooke’s Hospital, Cambridge.
The Trials Unit is being run by a team in Aberdeen, who hope to become the go-to centre for urological trials. The unit is already working with several trials to test interventions, including using a stent after a ureter investigation to deal with stones, removing lymph nodes in prostate cancer and doing partial nephrectomy for small kidney cancers.

Another significant change has been introducing the Innovation and Research fund to support new ideas at the early stages. The scheme received so many excellent applications when it was launched last year that TUF secured extra funding to support an additional three projects.

“Whilst background research is required to show a research idea could work, we recognise the importance of innovation and getting new ideas off the ground. We want people to come forward with great ideas, and we are willing to put money into reasonably high-risk projects as long as they have a clear route to impact positively the care of patients with urological disease,” says Grant.

TUF continues to support the urology community through several schemes, such as the Smaller Research Projects fund and our education and training programmes. In the near future, Grant says, TUF aims to introduce new regional awards: “We want to ensure that every region of the UK feels that they have a stake in the charity and can interact with us.”

**Help us to invest in researchers working in the field of urology and work together to save lives. Please donate at theurologyfoundation.org/donate**
As the founder of a medical devices company, Charles has worked closely with urologists over the years in supplying technology that allows them to deliver better care to patients.

He was first introduced to TUF by Abhay Rane, a consultant urologist at East Surrey Hospital and former TUF scholar, after working together on research into technology for treating ureteric stones. Abhay invited him to join the Cycle India ride in 2015 to raise money for TUF.

“The people in India were wonderful receiving the 35 cyclists tromping through their villages. They came out of their homes and would be very gracious and supportive. It was tremendous to be able to enjoy all of the camaraderie and the fun of the group,” he says.
The experience of the ride had him hooked, and a few years later, Charles signed up again to cycle across Costa Rica, this time including his son George.

For Charles, this brought together his interests in philanthropy and supporting urologists: “My business is connected closely to urology, providing surgical and medical devices for use during operations. I was interested in giving back to the scientific community after running a business that’s been very supportive of myself and my family.”

Having made a number of philanthropic grants over the years to the local community in Cornwall, he decided to structure his donations through the Charles Reynolds Foundation, which has supported local projects to tackle intergenerational poverty.

“I wanted to do something within urology in a similar way that allowed me to grant money to worthy causes. But it’s very difficult to attract applications, and then have the wherewithal and time to sift through them and make serious decisions about the funding,” says Charles.

In this regard, TUF was well-placed to help with its existing systems for awarding grants, including regular grant rounds, a strong reputation within British urology, an extensive peer-review process and panels of experts. Making the most of this infrastructure, Charles agreed last year to donate £150,000-£300,000 through his foundation to TUF to support additional urological research and training over the next three years.

That isn’t all that Charles is doing to support TUF. Later this year, he will be joining the TUF ride for the third time in Slovenia, bringing his daughter along as well, he says: “Hopefully my children, George and Liberty, will aspire to continue donating to TUF as they develop the business with me.”

If you are interested in learning about the different ways you can work with TUF to support advances in urology please contact Rebecca Porta – rporta@tuf.org.uk
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

Enormous congratulations to all the Bike4TUF Team, and their support crew, who rode 250 miles from London to Birmingham in September raising an amazing £36,000.

In October Robert Barton took on the ASDA Foundation Yorkshire 10 Run in memory of his close friend, and much respected urologist, Marek Miller and raised £865.

October also saw Sue Macpherson pull on her running shoes to take part in the Royal Parks Half Marathon which she ran for TUF because of her desire for better care and treatment to be available for those suffering with bladder and prostate cancer and raised £330.

When consultant urologist, Giles Hellawell’s daughter, decided to take on the Winter 3 Peak Challenge of climbing Ben Nevis, Scafell Pike and Snowdon he decided to join her to raise funds for TUF. Over a long weekend in November, in weather from sunshine to snow and sleet, they hit all the heights with Giles raising £878.
Bike4TUF

Findlay MacAskill, a specialist urology registrar, who took on the Hackney Half Marathon and came in with a great time of 1 hour 44 minutes and raising £717 for TUF.

Joanne who set up a Just Giving Fundraising page for her father’s birthday that raised an amazing £670.

To those who gave with love in memory of Marek Miller, Spencer Derek Coad and Ron Plummer.

In November, 120 of our supporters finally gathered in person for the twice postponed Wine Tasting Fundraising Dinner with TUF Patron Jane MacQuitty. It was a hugely enjoyable evening and our thanks to Jane, The Vintners’ Company, Majestic Wine, auction donors and everyone who made the evening possible and helped to raise a fantastic £38,000 to power our research programmes.

Dates for the Diary

JUNE
10 - 12 June - Bike4TUF

SEPTEMBER
1 – 30 September
Urology Awareness Month
10 – 16 September
Italy to Slovenia TUF Cycle Challenge
Plus a whole range of fantastic Ultra Challenges, more of which on page 18.

Please see the website for more details on all these events or email Serena at swyman@tuf.org.uk

The ever-popular Bike4TUF fundraiser will be moving back to its normal June date and planning for the 2022 ride is well underway. The ride will take place Friday 10 – Sunday 12 June 2022 inclusive and we look forward to welcoming back old friends and meeting new riders.

This year the route is expected to take in some beautiful, Welsh, scenery before concluding at the site of this year’s Annual BAUS Congress in Birmingham.

If you would like to be sent more information about the plans for Bike4TUF2022 as they come hot off the press, then please contact Serena at swyman@tuf.org.uk
Are you someone who is looking to get involved with a challenge event at an entry level? Or perhaps you are a keen walker or runner looking for a real challenge. If so, there is sure to be an Ultra Challenge for you!

TUF is delighted to be a charity partner with Ultra Challenges, giving our supporters the opportunity to raise funds for us in events in some of the most beautiful parts of the country. The 14 unique events make up some of the biggest and best series of treks and runs available.

Walk, jog or run. 100k, 50km & 25km challenges, there is something for everyone and there is a range of registration and charity sponsorship options available to you. Why don’t you join some of the 90,000 adventurers who have taken on an Ultra Challenge, raising over £33 million for charities.

Whichever challenge you choose, you’ll get full support from the Ultra Challenge team so you can set a new goal, enjoy the great outdoors, push yourself and raise money for TUF.

You can find out more about all the events and sign up by visiting either the events calendar on our website theurologyfoundation.org or visit ultrachallenge.com
Two for one

TUF ran its first Cycle Challenge in 2008 and this biannual event has become a firm favourite and a key fundraiser for the charity.

Participants on the challenges, who are affectionately known as Tuffers, are a mix of doctors, patients and supporters. Everyone involved has the connection that they are undertaking the challenge for the same cause and it creates a very real camaraderie that lasts much longer than just the ride itself.

For our next cycle challenge, the Tuffers will be pedalling from the sparkling Adriatic Sea in Italy to the paradise of the Slovenian Alps in a stunning two-country ride.

Starting off on the idyllic Italian island of Grado, the route will range from the sea shore to snow-capped peaks and across the border to the forests, lakes and green capital city of Slovenia. There will be spectacular mountains and swooping valleys, lush alpine meadows, chocolate-box local settlements and the mystical Triglav National Park. In addition, riders will enjoy two nights at the crystal clear Lake Bled, famous for the tiny island and castle at its heart.

The adventure finishes with a chance to explore the amazing capital of Ljubljana, one of the world’s greenest cities.

This once-in-a-lifetime bike ride will raise vital funds for TUF. Every push on the pedal and every penny you raise will go a long way to support people affected by urological cancers and diseases.

To find out more, and sign up to join Team TUF visit www.dream-challenges.com/challenges/the-urology-foundation-cycle-italy-to-slovenia-2022/
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