Ending the suffering caused by urology disease

Celebrating 25 years of The Urology Foundation

25 years of advances in care

A huge opportunity for our country

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

TUF in the time of coronavirus

Like everyone, The Urology Foundation has had to adapt to working from home over the last few months. This is nothing compared with the work of our medics and I would like to thank all urologists, nurses and researchers for the sacrifices they are making and the important work they are doing to help combat Covid-19. You can read about some of their experiences on pages 13, 16 & 17.

Much of our research and training has been suspended due to the pandemic, putting the future of those projects at risk. More worrying is the delay to patients in receiving their treatment or a diagnosis. To fulfil our mission to save lives and end the suffering, it will be even more vital for TUF to provide opportunities for research and training once the world reopens for business.

2020 is TUF’s 25th anniversary and we mark the occasion by revisiting some of our early grantees to see where they are now and how things have changed since they first started out. One of TUF’s objectives is to improve treatment and care, and the RESECT study on page 14 shows how that might be achieved in bladder cancer.

None of our work is possible without your generous support. Please help us to be there for the next 25 years to save lives and improve patient care.

Thank you and stay safe.

Louise de Winter, Chief Executive
A revised 2020 challenge for these challenging times
Will you support TUF with a Standing Order?

Earlier this year we launched our 2020 challenge to mark 2020 as The Urology Foundation’s 25th year. We asked people to run, walk or cycle and to raise £2,020 during the course of the year, to ensure that we can continue to fund the future of urology.

We had not foreseen what 2020 would bring and the extraordinary times that we are currently living through.

Whilst everyone copes with the effect of the pandemic, existing health issues have not gone away and many will be exacerbated by late presentation of patients, delayed treatment and disruption to medical research.

The need for us to continue to invest in research and training, and in the support that we offer to urology professionals to help them provide the best frontline care to patients, has never been more urgently needed.

We appreciate that in the current climate asking people to commit to raise £2,020 this year is not realistic, so instead, we ask if you would please give your support by setting up a Standing Order for TUF?

A regular gift, by way of a Standing Order, helps us to plan for the future and allows us to commit to vital urology funding in the years to come, knowing that we will have the resources to do so.

A Standing Order mandate to TUF to the value of £20.20 or £202.00 or £2,020 (or amount of your choice) to be paid either monthly, quarterly or yearly will help us to stand by urology professionals and continue in our work to save lives and end the suffering caused by urology disease.

You can set up your regular donation by completing the Standing Order form – or go online. For details please visit theurologyfoundation.org/donate
Increasing survival and quality of life

So far in 2020 TUF has funded research into a vast cross section of urology. From bladder and prostate cancer to incontinence and Posterior Urethral Valves (a condition that can affect boys in utero), TUF continues to support all urology across the whole country. Below is a selection of this year’s projects.

Going forward, TUF is making major changes to our programmes and funding, with an increased emphasis on trials and innovative research. Follow us on social media to keep up-to-date with these exciting developments!

THE CLIMATE TRIAL FOR PROSTATE CANCER

University College London

TUF will support all three years of this vital trial thanks to funding from the John Black Charitable Foundation. A team at UCL led by Professor Shonit Punwani, Professor Mark Emberton and Dr David Atkinson is hoping to create a paradigm shift in the use of MRIs for prostate cancer detection. MRI scans play a crucial role in the detection and diagnosis of prostate cancer. At the moment a scan takes 35-40 minutes and requires an intravenous injection. The UCL team hope to show that a different type of MRI scan can have the same results in just 3-4 minutes and with no injection. If successful, this could lead to a revolution in the availability and performance of MRI scanning for prostate cancer around the world.
DEVELOPING ALTERNATIVES TO VAGINAL MESH

Sanad Saad – University of Sheffield – TUF Scholar

Sanad Saad has been awarded a 2020 TUF Research Scholarship for his project that seeks to improve how we find materials that can be used for pelvic organ prolapse (POP) repair. Safer materials are urgently required and Sanad and his team hope to devise a novel in vitro test that can assess whether a new potential material would cause fibrosis (the formation of scar tissue, which can be very painful).

IMPROVING BLADDER CANCER SURVIVAL

Samantha Conroy – University of Sheffield – TUF Scholar

Samantha Conroy’s project aims to improve the outcomes of people with metastatic bladder cancer. Survival outcomes for people with metastatic bladder cancer have barely changed in 30 years and a major reason for this is the difficulty of treatment and the lack of treatment options. Samantha’s project aims to move past the one-size-fits-all nature of current and historic treatments by creating a rapid, pre-clinical test that will give a doctor an understanding of the specific sensitivities of each patient’s cancer and, therefore, guide them on the best possible treatment options.

Your support makes these important projects possible

We need your support

In these difficult times it is more important than ever that we support urology research, training and education. The Covid-19 pandemic has seen a drastic fall in charitable giving, but urology conditions and cancers will continue to be growing problems for the UK and Ireland.

TUF remains committed to reducing the suffering caused by urology disease, but we can’t do it alone.

Please donate by going to theurologyfoundation.org/donate
“It’s a huge opportunity for our country”

Mr Tim O’Brien has been a urological consultant for over 20 years and in June became the President of the British Association of Urological Surgeons (BAUS).

He shares with us the benefit he gained from a TUF visiting scholarship early in his career and how he hopes to make the UK the best place in the world for training urological surgeons.

“I started consulting at Guys Hospital in 1999, where they have a big practice in inherited kidney cancer surgery. There was a team in Cleveland, USA who were pioneering techniques on partial nephrectomy at the time and thanks to the visiting scholarship from TUF, I spent five days with them. We shared ideas and I could see how they did the surgery. That certainly helped
me to become much better and build the practice at Guys in that area.

“My research had been in bladder cancer, the TUF award got me going in kidney cancer surgery and it has since become my main focus.”

At the time of speaking, the UK was in lockdown due to the coronavirus pandemic. Tim highlighted how adapting to virtual consultations has accelerated change that will improve patient care.

“I run a practice in a rare disease called retroperitoneal fibrosis (RPF). Those clinics are now almost exclusively virtual. It’s far more convenient for patients and saves a lot of time and money.

“One of the challenges for people with rare diseases is that there isn’t uniform access to specialists. Our vision at Guy’s is to offer a virtual second opinion to anybody with RPF who wants it. A lot of the management depends on the imaging, and we can look at that in a meeting with our team of experts and give a rock-solid second opinion virtually.

“As someone coming into BAUS as the new President, it’s both a daunting and a thrilling time to be involved because there is a real desire to change.

“There’s tremendous opportunity for TUF and BAUS to work together. We want to develop research ideas together and get the best ideas developed as quickly as possible. If we do high-quality research, then British urology can change the world of urology.

“There’s been a massive programme of centralisation of complex surgery in the UK into high volume Centres of Excellence, which are of huge interest as places to learn and teach specialist surgery.

“One of the things I most want during my time as President is to develop the programme of fellowships for training of both UK-based and international surgeons in those specialist centres.

“It’s a huge opportunity and I’d like to see Britain as the number one country in the world for fellowship level training.”

Help us to invest in more visionary leaders like Tim, who are working to make urology treatment and care the best it can be. Donate today at theurologyfoundation.org/donate
In 2013, Jonathan Michelmore was diagnosed with benign prostatic hyperplasia, a condition where the prostate is enlarged and blocks the flow of urine.

At the age of 52, he was struck with “incredulity that I could have this condition at such an early age.”

Jonathan went to see his urologist, who offered him medication to avoid the invasiveness of surgery. This controlled the condition for a couple of years before he then opted for Urolift surgery, a new approach where small implants stop the prostate tissue blocking the urethra.

“This brought me another couple of years’ relief before the symptoms returned to uncomfortable levels,” says Jonathan. He then had a transurethral resection of the prostate, where some of the prostate is removed using a heated wire inserted through the urethra. While there can be long-lasting side effects from this surgery, thanks to modern techniques Jonathan was able to delay going through this procedure for four years.

Jonathan is now volunteering with TUF to help assess applications we receive for grants.

“I felt extremely grateful to the urology community for the skilled treatment and support shown to me through what were scary and unpleasant times. I wanted to find a way to give back something to the profession in a way that would benefit future patients and, when the opportunity to join the Scientific & Education Committee as a Lay Member arose I applied for it without a moment’s hesitation,” he says.
Andrew Etherington was diagnosed with prostate cancer in 1999 and had a radical prostatectomy performed by Professor Roger Kirby. This was done by open surgery, where a large incision is made across the abdomen. Now it is far more commonly done by laparoscopic or robotic surgery, which improves the speed of recovery after the operation.

The speed of recovery is important for many people going through surgery, and Andrew was especially keen as he was due to run the London marathon the next year.

“Roger asked me when I wanted to have the operation, and I said that as long as I’m ready for the marathon next year, we can do it now,” he says.

Fortunately, Andrew was able to get back to training quickly and Roger even joined him in running the marathon.

Andrew quickly became involved in fundraising for urology, saying: “I was in regular contact with Roger and other urologists after that, including cycling in Madagascar and walking in Malawi to raise funds.”

For 25 years TUF research and training has brought about changes which have made a very real difference to urology treatments. We funded Predict:Prostate, now a NHS approved tool for staging of prostate cancer patients, and supported research into Botox as a treatment for overactive bladder and incontinence, which has been adopted worldwide. We pioneered the introduction of robotic urological surgery in the UK.

We continue to look to the future, guided by research and clinical experts and our unique overview across the whole of urology, to set the right priorities allowing us to support programmes that will ensure the continuing development of all urology care.

Please support us to fund research and training that will deliver better urology care for patients of the future. Donate today theurologyfoundation.org/donate
Prof Abhay Rane OBE is a consultant urological surgeon, Vice President of the Royal College of Physicians and Surgeons and a pioneer of laparoscopic (keyhole) surgery in the UK. In 2000, he was awarded a TUF clinical visit fellowship.

“Early data suggested recovery from laparoscopic surgery was quicker and the patient stay was shorter than traditional open surgery so I visited Dr J Stuart Wolf, a pioneer of hand assisted laparoscopic surgery, at the University of Michigan as part of the scholarship. I managed to translate some of those skills to my clinical practice when I returned to the UK.

“As time went on, we took on more challenging cases and eventually set up a mentorship scheme, which was one of the highlights of my career.

“In 2006, I got involved in single-port surgery. That led to a procedure where we took a kidney out of a bellybutton, the first single-port nephrectomy in the world.

“Once we’d shown it could be done, the technique was adopted by a number of other
specialties and led to a dedicated single port robotic platform being developed a couple of years ago.

“TUF is special. We really do make a difference.”

“I was a member of the TUF Science and Education Committee which I really enjoyed, helping select talented young urologists for the research awards.

“I’ve been part of the TUF fundraising cycle rides since 2012 and several of my patients have been incredibly generous in their support, helping TUF to continue its vital work.

“TUF is special. We really do make a difference.”

Professor James Catto was a TUF Research Scholar in 2000. He is the first recipient of a NIHR Research Professorship to a urologist.

“I came into urology and wanted to do research, but was unsure if academia was my future. The TUF scholarship was enough to generate pilot data, pick up sufficient lab skills and make me competitive at a national level, enabling me to secure funding for my PhD, investigating the genetics of bladder cancer.

“I worked out one underlying mechanism was to do with changes in DNA methylation. This led to a clinical trial, looking at drugs that reverse changes in DNA methylation in melanoma, bladder and lung cancer.

“Throughout my career, my research has reflected the problems that I’ve come across in the clinic. As a consultant, I became concerned about BCG as the standard first line choice. This led to a trial called BRAVO comparing cystectomy versus BCG for high-risk non-invasive disease, and the use of ERAS protocols in Cystectomy care.

“We’re just finishing the iROC study, which is a TUF-supported clinical trial of robotic surgery versus open cystectomy and look forward to reporting on that soon”.

Will you help TUF be there for the next 25 years to support the next generation of inspirational urologists? Please donate today theurologyfoundation.org/donate
The 2020 Keith Yeates medal has been awarded to Sot Tolofari, a specialist urological trainee in the North West, for gaining the top mark in the Intercollegiate Specialty Exam in Urology. The prize comes with a £2000 travel grant from TUF, which Sot plans to use for a course at Aalborg University Hospital in Denmark.

Sot hopes to develop his skills for using robotics to perform nephrectomies – the removal of the kidney. So far he has mostly used keyhole surgery for this procedure and is looking forward to expanding his skill set.

“My initial plan was to go in June, but of course that was cancelled. I’m hoping to go later in the year. In Aalborg, I’ll be given experience at quite high intensity of doing robotic procedures. I’ve had exposure to it previously, but I’d like to get a much more in-depth understanding.”

In February, Sot became Chairman of the BAUS Section of Trainees and is responsible for representing urological trainee surgeons.

“It’s been a particularly challenging time with coronavirus – we’ve had to advocate for trainees being redeployed in and out of urology, having exams cancelled or not being able to complete their training,” he says.

TUF has recently sponsored urology webinars from the Royal Society of Medicine so that they are free to trainees. Sot says that he is grateful for the support that TUF provides:

“There are a number of different things that TUF offers to trainees. It’s a useful resource for education and training, and it’s a useful link between patients and doctors.”
Impact of COVID-19 on trainees

Sophie Rintoul-Hoad is a urology trainee at St George’s Hospital, London. Here, she describes her experiences of working on a COVID-19 ward:

“We got an email in late March asking if we had any ICU [Intensive Care Unit] experience. I realised that I didn’t have the right skills, but I’m very happy to try and learn.

“Because everything was disrupted, it made it quite a challenging time personally and professionally. Everything that you’ve known and worked for changed overnight – our exams were postponed and our training sessions were cancelled.

“I got an email on a Saturday saying that I’d been selected and I was redeployed on the Monday. Those of us who had no ICU experience did four days of shadowing first. We started after Easter and once my routine was established, the days and nights passed by.

“With help from ICU consultants and nurses, I soon became familiar with the assessment and management of patients with COVID.

“One of the nice things in the ICU was eating lunch together. It meant that you got to know your team better, both doctors and nurses, especially when you’re in full PPE all day. It was only at lunchtime and we took our masks off that I realised that one of the team was somebody that I play touch rugby with.

“There were about a hundred junior doctors who went through the same experience at St George’s. You really felt like you were being part of something bigger. I’m so pleased that I did my bit, but let’s hope that nothing like it ever happens again.”

TUF continues to support urology trainees through its TUF Warrior programme, providing professional development and funding training opportunities.
Improving bladder cancer treatment internationally

The main form of surgery for non-muscle invasive bladder cancer is transurethral bladder resection, or TURBT, where the surgeon uses a heated loop to scrape away the cancer.

“We know that if you follow evidence-based guidelines, then you get good results,” says Dr Veeru Kasivisvanathan, a urologist and academic clinical lecturer at University College London.

With the help of funding from TUF, Veeru is running a study called RESECT that will help to improve the delivery of bladder cancer surgery.

“We want to identify whether people are meeting certain criteria for performing TURBT and post-operative care. That will allow us to give feedback to surgeons around the world on how they are doing. Hopefully, they will be able to understand how they can improve their performance and adherence to the guidelines,” he says.

“One of the quality indicators of the surgery is whether or not you obtain muscle in the resection. That’s really important to understand how far the cancer has spread and what treatment is needed. If you don’t have muscle it means the operation may need to be redone.”
A couple of previous small-scale studies have shown that some guidelines are not always followed, including the use of chemotherapy straight after surgery.

“We know from previous studies that giving intravesical chemotherapy will reduce recurrence rates significantly. We’re talking about 10-20% in 5 years” says Veeru.

The RESECT study also hopes to find out how many surgeons are offering this chemotherapy and why some of them might not be.

“They might not have availability of the product, they may not understand that they’re supposed to give it, or it might be that they have different evidence on which they’re basing their management. We’ll be able to understand those reasons so that we can address the issue,” he says.

The study is aiming to recruit around 2000 people having TURBT from the UK and around the world.

“We can look for new associations between how the procedure is performed and what will give you a better outcome afterwards. The scale of this study really allows us to investigate some meaningful questions.

“The funding from TUF helps us to cover costs of some of the core aspects of the study, for example statistical help, methodological help and the data management.”

RESECT was born out of a previous study, also supported by TUF, called IDENTIFY, which looked at the diagnosis of bladder cancer.

“That helped us to establish the network, which allowed us to look at this further,” says Veeru.

“There are very few registries that show people how good their TURBT is. We want to provide that opportunity to improve care in this area.”
The future of urology practice

The Covid-19 pandemic has forced a number of changes in the way that we work, one being fewer face-to-face consultations.

Speaking in May, Mr Duncan Summerton, the former President of BAUS and urologist at Leicester General Hospital, and Mr Luke Forster, a urology trainee at the Royal Free Hospital in London, share how they have adapted their approach to patients and how they think this will change urology practice in future.

Luke Forster: We are still doing urgent cancer referrals in person because they have to be examined. Everything else has been over the telephone. That’s very challenging as so much of being a doctor is eye contact with your patient, so some of that non-verbal communication is missing. You’re explaining something sensitive or complex and not necessarily getting that feedback from looking them in the eye.

Duncan Summerton: I think going forward there will be a hybrid clinic. It will be mixture of telephone or video consultations with patients and just those people who really have to be seen coming in.

LF: Hospitals have quite big catchment areas, so patients are sometimes travelling one or two hours to come to the hospital. It can also be expensive.
for parking or taxis. It would be much better for some people to stay at home and have a phone call to discuss the issues. A lot of the time, it’s reassurance or reinforcing messages that you’ve already discussed.

**DS:** Another good benefit is that a telephone or video consultation can be recorded as well. It’s been shown, I think, that patients take in on average about 10-15% of the information you give them during the consultation. So I think for the patient to have a recording and be able to go back over what was discussed is probably a benefit.

**LF:** I think if you’ve had exposure to doing telephone and video consultations as a trainee, then you’ll be better prepared as a consultant. When we come through medical school, there’s a big emphasis on communication skills and we go through role plays to simulate difficult conversations. Perhaps there needs to be new modules where you’re looking after patients over the phone.

**DS:** Normally when you’re given a diagnosis, you then have to go outside into a waiting room full of strangers and deal with the emotional repercussions of that. It might sound a bit impersonal doing it over the telephone, but if this is a dedicated one-to-one video call where the doctor can see the reaction of the patient, then it might be better for them to be in the comfort of their own home with a supportive relative or friend. If it was me, I’d actually prefer to hear bad news like that.

“**At medical school we go through role play to simulate difficult conversations. There needs to be new modules for looking after patients over the phone.”**

Help TUF to continue to support professional development and patient care. [Theurologyfoundation.org/donate](http://Theurologyfoundation.org/donate)
SPOTLIGHT ON FUNDRAISING AND WAYS TO GET INVOLVED

OUR TUFheroes THANK YOU!

To all the professional urology community for their outstanding work during this COVID crisis. For those who have been pulled on to the front line and those still working in their departments to ensure the continuation of urology care.

To Anna Concannan who got sponsored to give up chocolate for our ‘Free From’ February Challenge. To Roland Morley, Simon Lord and Alexandra Troubridge who all undertook a 2.6 challenge in April raising £1,300. To Adrian Joyce for organising a fantastic (pre COVID) Beatles Night that raised both awareness and £4,000 and Ben Challacombe and Jake Hepworth for setting up birthday donation pages on Facebook. To BSoT for organising a virtual run in June and the 90 people who took part raising over £2,000.

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

THANK YOU!

Dates for the diary

BIKE4TUF
The postponed Bike4TUF ride to Birmingham will now, subject to Government guidelines at the time, take place on the weekend of 19 – 20 September.

UROLOGY AWARENESS MONTH
To celebrate Urology Awareness Month in September please “Step Up For TUF” and join our virtual step challenge.

TUF BIG DINE
We are asking people to host a lunch or dinner for the TUF Big Dine in November

WINE TASTING DINNER
Our postponed Wine Tasting Dinner will now take place on 19 April 2021.
25 Ways to Fundraise for TUF

1. Always a favourite – hold a quiz (which you can also do online)
2. The easyfundraising.org.uk website enables you to shop at over 2,700 online stores and raise free donations at no cost to you
4. Celebration donations - ask friends and family to donate to TUF in lieu of birthday or wedding presents
5. Send a Your Big Day video to someone for a special anniversary
6. Been wearing casual clothes for months in lockdown? Then put on your finery and host a “Glad Rags” day
7. Set up a Standing Order to TUF
8. Send a greetings card that raises a donation – visit charitycards.org
9. Raise a glass at our Wine Tasting Dinner on 19 April 2021
10. Get sponsored to quit a bad habit
11. You don’t have to wait for TUF’s Big Bake in March to raise money with your cakes
12. Join our Machu Picchu Trek 1 – 10 October 2021
13. Sell your crafts – been busy in lock down? Sell your wares online and donate the profits
14. Take up a challenge for TUF
15. Get a TUF Collection Box – one for an office collection or at home for your loose change
16. Give in memory
17. Join the Big TUF Dine this November
18. If you hunted out your old board games in lockdown put them to good use with a “Game a thon”
19. Suggest TUF as your company’s charity of the year
20. Organise a charity Golf Day
21. Give a Car (yes really!) raises money for UK charities by scrapping and selling old cars
22. Challenge the kids to a Keepie Uppie challenge
23. Enrol for Payroll Giving.
24. Give Gift Aid on your donations
25. We are always looking for new ideas so let us know yours

FOR FULL DETAILS ON ALL THESE IDEAS AND MORE PLEASE VISIT theurologyfoundation.org/GetInvolved
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:

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Events Manager
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