The dye that could save lives

Celebrating 25 years of The Urology Foundation
Hello and welcome to TUF matters.

2020 is a very special year for The Urology Foundation. It is 25 years since our inception which came about when a group of urologists decided that it was time for urology to be lifted from the shadows of medicine and given the attention it deserves. TUF mission has always been to enable urologists and nurses to provide the very best care to all those affected by a urological cancer or condition. Looking to the next 25 years we will build on the breakthroughs we have made to the field of urology and continue to work towards ending the suffering caused by diseases of the kidneys, bladder, prostate and male reproductive system.

You can find out more about our strategic plans to invest in the future of urology on page 12, as well as see how your support is helping us to invest in lifesaving research and the training of urological surgeons. We also have an interview with consultant urologist Ben Eddy, on page 18, who talks about a very special Bike4TUF challenge that will see teams ride from around the country to this year’s BAUS Conference in Birmingham.

None of the work of The Urology Foundation would be possible without our generous supporters and I would like to take this opportunity to thank everyone who has donated, fundraised and attended TUF events over the last 25 years.

With heartfelt thanks,

Louise de Winter, Chief Executive
Set yourself the 2020 challenge

This year is our 25 year anniversary and to mark it we are asking our supporters to take up the 2020 challenge.

Through-out the year we would like as many as people as possible to pledge to raise £2,020 or more over the year and help fund the future of urology.

Whether you choose to do something you love or decide to undertake a challenge or a goal you want to achieve, do it to raise money for vital urology research and training.

How will you do your 2020 challenge?

This is your challenge, for you to complete in your own way. You set your goal, your rules (provided it’s legal) and pledge to raise at least £2,020 for TUF by the end of the year.

Perhaps you want to run or walk 2,020 miles over 2020, or want to throw a fundraising ball like no other for your friends and family. Maybe you’re a keen baker and can encourage colleagues to help you host 20 coffee mornings in your community. Perhaps you’re looking for your next adrenaline fix or have a novel new idea for fundraising – we need you!

Whatever goal or event you want to do, we need you to turn your passion or your goal into a fundraiser this year to help The Urology Foundation meet the challenges in urology healthcare. Every fundraiser helps us to fund life changing research, find new treatments, transform urology care and, ultimately, find a way to end urology disease for good.

Set-up your fundraising page today at everydayhero.co.uk/event/TUF2020Challenge or visit our website for more information
In 2019 The Urology Foundation funded seven more research projects to investigate a variety of urology diseases from kidney cancer to enlarged prostate and urinary tract infection. Here is a little look at just some of our research.

PROFESSOR NEIL DALTON AND MASSIMO GARRIBOLI
Evelina London Children’s Hospital and King’s College London St Thomas’ Hospital

Neil and Massimo are working to find biomarkers that will identify kidney blockages in children. Current diagnostics for congenital hydronephrosis are not good at predicting how the disease will progress and if the child will need surgery to prevent renal failure. The researchers aim to find proteins in urine that could be used to give a more accurate prognosis. They hope that this will prevent unnecessary surgery for those children who can be managed conservatively and avoid delaying treatment.

CHARLES SCOTT
King’s College London

Charles is studying the care for testicular cancer patients. Currently only about a quarter of men agree to cryopreservation of sperm or a prosthetic replacement. He will analyse the medical records to see if a patient-centric pathway, where men are given an additional week before surgery to address fertility and self-perception issues, will improve the uptake without causing harm by delaying treatment.

VEERU KASIVISVANATHAN
University College London

Veeru is looking at how to improve treatments for bladder cancer. Transurethral resection of a bladder tumour (TURBT) is the most common
Nurse of the Year 2019 award

Congratulations to Louisa Fleure, winner of the TUF/BAUN Urology Nurse of the Year award. Louisa, from Guy’s and St Thomas’ NHS Trust in London, received the prize for her work in providing information and support to men with advanced prostate cancer.

She set up the ‘Advanced prostate cancer club’ which offers a range of activities for men to come together, make friends and get support. “Some people don’t want to come to something called a support group – it sounds too touchy-feely,” says Louisa. She is keen to use the £1,750 grant to better engage people who are harder to reach.

Stephen Fry named as TUF Ambassador

Britain’s best-loved actor, comedian and writer, Stephen Fry has become an Ambassador for The Urology Foundation.

Stephen started supporting TUF after being treated for prostate cancer by TUF-trained surgeon Ben Challacombe in 2018. Since going public about his encounter with the disease, Stephen has contributed enormously to breaking down the stigma associated with urological conditions and encouraging people to see their GP when they spot symptoms.

He hosted a TUF Talk fundraising event in June 2019 with BBC journalist Jane Corbin, which raised over £9,000. Stephen has supported many other TUF fundraisers like the Atlantic Seamen and Bike4TUF team, as well as our Urology Awareness Month in September.

“I have special reason for supporting the work of The Urology Foundation. Everyone will benefit from the work of a urologist one day or another,” he said.

initial surgery for bladder cancer. However, it is technically challenging and has a relatively high recurrence rate. This study will collect data on 2500 TURBTs to understand the factors that lead to better quality surgery.
Matthew Perry was one of our first TUF scholars back in 1997. He was a first-year registrar and received funding from TUF to do a research project.

“I knew I wanted to do urology and I wanted to do some research to show my commitment to urology as a field,” he recalls.

“TUF funded me to look for a vaccine for prostate cancer. It was way ahead of its time, looking at immune responses to cancer. It’s all the rage now, but back then it was a bit of a punt.

“I was making a vaccine in a lab at St George’s and then giving it to men at the hospital. It was really hard work. I was learning a whole new set of laboratory skills and trying to understand what all the results were about.
“All of your medical training is about how you approach people and their problems. Then suddenly you’re in a completely different environment where you’re dealing with cells and cellular problems – how to keep them alive and how to kill them at the same time.”

Life skills

“If I had my time over, I’d do it all again. It was really interesting and informative,” says Matthew.

“The skills that I learned doing that, I still use now. That includes analytical skills, knowing how to look at scientific publications with the background knowledge of how all the tests work.”

Matthew now specialises in pelvic oncology, doing robotic surgery for prostate and bladder cancer.

“That research got me started with an interest in prostate cancer and cancer treatments overall. That really fired me up and put me on the track for the rest of my career.”

Matthew became a consultant at St George’s in 2005, where he learned to carry out robotic surgery when the hospital got its robot in 2007.

“I’ve been doing robotic urology ever since. I introduced the robotic cystectomy programme for bladder cancer at St George’s and then at the Royal Surrey in Guildford.”

Matthew now operates at the Royal Surrey, and over the course of his career he has treated many patients. “It must be a couple of thousand by now,” he estimates.

On your bike

In November, Matthew completed a 390 km bike ride across Costa Rica to raise money for TUF.

“I was thinking about the possibility of giving something back to TUF. Then the opportunity arose and it was the right time,” he says.

“It was hard – much harder than it seemed in the brochure! I’m not a cyclist, I had to buy a bike and do a fair bit of training for it.

“The first three days were pretty hard with potholes in the roads, and lots and lots of rain. Then the next three days were climbing over the volcanoes that divide the country. Of course the climbs were tough, but even the downhills were hard because of the gravel roads.

“It was really worthwhile. I’d consider doing it again, but maybe in a couple of years!”
“It’s a new normal”

Rob Powell was diagnosed with bladder cancer at the age of 54. He shares his experience and how he has managed the side effects of his treatment.

“The first sign was a few days before Christmas 2017. My wife Louise and I were doing some Christmas shopping, and I went to the loo and noticed blood in my pee. I knew immediately that it wasn’t right and it needed sorting.

“My GP sent me to see a urologist to have it investigated. Basically, I had a camera go where cameras should never go. You could see this mushroom-like tumour on the screen, and a biopsy confirmed that it was muscle-invasive bladder cancer. That’s not the news you want to hear.

“As far as they could tell, it was contained and we had caught it in the nick of time. Treatment started quite quickly with four cycles of chemotherapy to shrink the size of the tumour. Shortly after the chemo finished, I had a radical cystectomy to remove my bladder, prostate and some other bits.

“I opted for a urinary stoma (ileal conduit), where urine passes through a channel into a bag attached directly to your body. I chose not to have neobladder as I didn’t want to have to go through my body learning new stuff. I wanted to get on with my life.

“Bladder cancer doesn’t just affect you physically but mentally. Sexually, too – you have to find a new way of doing things, a new normal.

“When discussing my sexual function, I was referred to the urology nurses who have prescribed injections. Our sex life is not the same. The injections interrupt things, but we’re working it out for ourselves.

“My wife has been incredible through it all. My bladder cancer diagnosis didn’t just affect me, it had a huge impact on her.
“The operation had changed so many things in my life, and I didn’t want to let it beat me. I wanted to get back to things that I like doing. I was a keen cyclist previously, and so I decided to sign up to RideLondon.

“I came across The Urology Foundation on the RideLondon site as one of their affiliated charities. It was a no brainer to sign up to raise money for them.

“TUF helps the people who helped me. I was lucky – if I can help others receive the same treatment and care I had, that would be great.”

Surgery to remove urological cancers can have a long-lasting impact. There are many delicate muscles and nerves in the area that may be damaged during surgery.

For many men, this may lead to erectile dysfunction. There are support services available for erectile dysfunction, which can offer treatments and products to help. In women, it may cause vaginal dryness. Urinary incontinence is also a common side effect. This may be short-lived, as the muscles repair after surgery, or permanently require aides, such as pads. Getting used to these changes can take time. TUF is looking to fund research or innovations which can help to improve quality of life for urology patients.

If like Rob you would like to raise money for The Urology Foundation and make a difference to those affected by urology disease, visit theurologyfoundation.org/get-involved
“If you are catheterised for more than two weeks then you virtually have a 100 per cent chance of getting a UTI,” says Professor Toby Jenkins from the University of Bath.

Catheterisation is very common – about 1 in 5 patients in hospital will have a small tube inserted into their urethra to collect urine in a bag attached to the leg. This may be for a short period following surgery, or longer-term to manage urinary incontinence.

Thanks to your support, Toby is using funding from TUF to test a bright idea for detecting the most dangerous UTIs as early as possible.

“There really nasty UTIs are the ones where the bacteria block the catheter,” he says. One in particular, called Proteus mirabilis, creates small crystals which can stop the flow of urine in the tubing.
“This is very, very dangerous because it can be asymptomatic for patients, who don’t realise the catheter is blocked. The urine backs up into the kidneys, causing kidney failure, sepsis and death. That is probably the most serious outcome from a UTI.”

It’s thought that 3,500 people in the UK die each year from sepsis caused by catheter-related UTIs. Toby has developed a new product that releases a brightly-coloured dye into the leg bag if the catheter is about to be blocked.

It relies on the fact the pH, or the acidity, of the urine changes when there is a Proteus infection. So he has wrapped a green dye in a special plastic that dissolves when the pH rises.

“We can see the colour change in the leg bag 12 hours before the catheter blocks,” says Toby. “We’re lucky that we have such a simple early warning system for when things go wrong.”

He and his team refer to the package of dye as a lozenge “because it looks like a lozenge sweet.”

“We might change the dye to blue as it should be easier to see – your urine really shouldn’t be blue!”

**Future steps**

“The Urology Foundation funding has been fantastic, because it’s allowed us to set up a clinical study where we can do off-patient testing of the lozenge. We’re recruiting patients and asking them to donate their urine bags when they’re full,” he says.

“We’ll test our lozenge in real patient urine to see if it changes colour, we’ll do microbiology to look for Proteus mirabilis in the patient urine and we’ll look at the reported outcomes for that patient in the following week to see if they experienced a blockage or not.”

Toby thinks that the main advantage of this approach is that it will be very cheap to produce, only 5p each. If this TUF-funded project goes well, then he hopes to start a large-scale clinical study in the next two years. “It does require a commercial manufacturer to do the next step – upscaling the production of the lozenge. Once that’s done, we’d like to do a very large clinical study with potentially thousands of patients.”

Help us invest in researchers like Toby so that together we can save live. Donate today theurologyfoundation.org/donate
Investing in Urology for the Future

This year we are celebrating 25 years of TUF. While this is an excellent opportunity to look back on our past achievements, we are also using this year to look forward and launch our appeal to fund urology for the future.

The burden of urological disease is expected to grow as the population ages, leading to major morbidity and quality of life issues for urology patients and placing a growing burden on the healthcare service.

Having consulted with many experts in the field, we know what must be done to ensure that patients have better outcomes and that urology doctors and nurses are supported to deliver the best possible care.

Our 2020 appeal fund will put the building blocks in place to meet these crucial challenges:

- Finding tests for urological cancers that lead to faster diagnoses, as we know that survival prospects depend on how early a cancer is picked up.
- Making treatments more effective and kinder, and developing better devices for patients living with long term and debilitating urological conditions, giving them a better quality of life and their dignity.
- Ensuring that urological doctors and nurses have access to the latest research developments and technological innovations so that patients benefit faster.
- Developing the next generation of urological experts who can meet the challenge of the increased burden of disease and who put excellence of care at their core.

We have big plans to help achieve these goals, including funding more research scholars, supporting research into AI and genomics, developing a mentor network for nurses and doctors, and providing training bursaries for urology nurses.
Shop online?
Raise money for TUF at the same time

Register with easyfundraising and you can raise free donations for The Urology Foundation every time you shop online.

There are over 4,000 shops and sites who will donate to us, including all the big names like eBay, John Lewis & Partners, Argos, ASOS, Expedia, M&S, Just Eat, uSwitch and many more! This means you can raise donations for us no matter what you’re buying – at no extra cost to you.

So whether you’re looking to book your next holiday, update your wardrobe or order a take away, your online shop could fund the next breakthrough in urology patient care.

What’s more, add the easyfundraising Donation Reminder to your browser or shop through the app on your phone and you can ensure we never miss out on your support when you shop online.
Day in the life of a director of robotic surgery

Robotic surgery has transformed the way that we treat urological diseases. However, it requires a different set of skills for the surgeons carrying out the procedures. Naeem Soomro, Professor of Urology at Newcastle University and Director of Robotic Surgery at Newcastle Hospital, has helped to train new surgeons for TUF for many years.

“It has been a lifelong ambition of mine to train surgeons and develop training facilities,” he says.

“I became a consultant 25 years ago. I developed keyhole, or laparoscopic, surgery at that time in our department. As a part of that, I spent six weeks in the United States and then I visited many centres in France to look at how they train surgeons and see their training facilities.

“That gave us the idea that we must have a similar training centre in the UK, so about 15 years we developed the Newcastle Surgical Training Centre.

“Our association with TUF is very long-standing. TUF has supported us to run robotic urological courses over many years, and helped us train urologists and surgeons in training in robotic urological surgery.

“Our trainees come for a two-day course and they go through two hours each of hands-on training where they sit at the console and work on cadavers.
“TUF has funded urology training for a very long time, and for robotic surgery it has been vital. When we go to other specialties, they want to know how we have done so well in urology!”

“When I’m operating, I start at the hospital at 7:30 am and finish by 6 pm – it’s a long day. But using robotic surgery allows me to do long operations without getting too tired,” Naeem says.

“On other days, I’d be in our clinic to see patients. I talk to our nurse practitioners who want to take advice on patients that they have seen. I’ll do rounds for patients who have already had operations, or are coming for operations.”

Naeem holds a number of other roles, including reviewing surgical research in the region. He is also the lead in robotic and digital surgery at the Royal College of Surgeons. This requires meeting with many different national stakeholders, including the Department of Health to inform and advise on policy.

“In my current role at the RCS, we are looking at how to train the surgeons of the future. In my time, all the training was based on patients where you assisted your consultant. When laparoscopy started it allowed people to start in the lab and become competent at that and then go on to assist surgeons,” he says.

“Gradually, simulations started. At first, it was very basic, you just worked on inanimate objects but now the simulators have become much more complex and provide feedback.”

In the future, Naeem believes that augmented reality could help to take this even further.

“It will be a very different world. People could have a Hololens [virtual reality headset] and think that they are doing the actual operation.”
SPOTLIGHT ON FUNDRAISING AND WAYS TO GET INVOLVED

TUF heroes thank you!

We would like to say a very big thank you to all those who undertook wonderful feats of fundraising to support our work.

Rob Powell, Mike Ng and the Halliwell family delivered some pedal power to complete the Prudential RideLondon challenge. TUF Warrior and urology core trainee Sam Folkard cycled 200 miles through sun, wind, rain and hail to Japan’s northernmost point on Hokkaido Island. Led by Oliver Holman medical students from Imperial College London scaled the Three Peaks in 24 hours. Just shy of his personal best James Kirkpatrick completed the Amsterdam Marathon. The 30-strong Bike4TUF team rode 300 miles from London to the Loire Valley and 41 cyclists completed the 390km TUF Cycle Costa Rica challenge. George Choa took a break from shaving and grew a TUF Tache in November. And finally, ending the year on a high, Paul Middleton walked 110km.

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 work towards ending the suffering caused by urology disease and make a difference to the thousands of people with a urology condition or cancer. Here are just six ways you can get involved to power our work.

1 TUF 2020 CHALLENGE

Celebrate our 25 anniversary and pledge to raise £2,020 over 2020. You decided the challenge, or series of challenges, you want to achieve through the year.

2 MARCH INTO SPRING

With the cold winter months behind us (we hope) you can clock up the steps over March, April and May. From one mile family rambles to 200 mile solo challenges your sponsored walk will help fund vital urology research and training.
3 BIKE4TUF
This year the Bike4TUF are planning a special ride to this year’s BAUS conference in Birmingham to celebrate our 25th anniversary. See page 18 for more information.

4 RIDE FOR RESEARCH AT THE RIDE LONDON 100
Join our 2020 cycling team at the iconic ‘Festival of Cycling’ on Sunday 16 August. Riding the 100 mile route from the Olympic Park to Surrey and finishing on the Mall

5 TREK MACHU PICCHU
With urologists, nurses, patients and supporters the TUF trek to the lost Incan city in Peru is set to be an unmissable experience of lifetime. Taking place from the 18 – 27 September this tough challenge will be one you won’t forget.

6 DONATE YOUR DAY
If you have a special day coming up you can support us while you celebrate. Whether it is your birthday or wedding day you could ask for TUF donations instead of gifts or selling our pin badges to your guests.

If you would like to sign up to any of the above, or to find out more ways to get involved, visit our website or email fundraising@theurologyfoundation.org or call 020 7713 9538

Whip Up Your Fundraising
Gather your friends, family and colleagues and raise some dough for The Urology Foundation with the Big TUF Bake this March.

Gather your friends, family and colleagues and raise some dough for The Urology Foundation with the Big TUF Bake this March.

You could do it in the form of a bake sale or an afternoon tea and use the opportunity to let everyone know why you have chosen to support The Urology Foundation.

And as well as asking people to donate in returned for your baked delights you can (self) raise even more money via a ‘Guess the Weight of the Cake’ competition.

Start planning your Big TUF Bake today theurologyfoundation.org/BigTUFBake
Bike4TUF rides out again

This summer, the Bike4TUF ride will set out for the seventh time having already raised over £200,000 to support TUF’s work.

Ben Eddy, a consultant urologist at East Kent Hospitals Trust, set up the ride as a way to repay TUF for its support. In 2012, he and his team were awarded a grant to visit a robotic surgery unit in Nashville in the US.

“We were just starting our robotic service and it helped us to get up and running. It allowed our team to see a world-class centre and really understand their roles,” he says.

The first bike ride was launched later that year with urologists, patients and nurses cycling from Paris to Canterbury.

“We aimed to raise £18,000 to repay TUF for the grant. We raised £16,000 – just a little short – so we thought, OK, we’ll do another ride next year. It carried on from there,” Ben recalls.

“This year, for TUF’s 25th anniversary, we are going to bike to BAUS in Birmingham on 13th and 14th June. The plan is to have different teams from around the country cycling in and meeting on the Saturday night, and then everyone coming into Birmingham together on the Sunday.

“We would welcome anyone who wants to set up their own team to cycle in and meet us on the Saturday. We have shirts and water bottles that we can provide. It’s open to all abilities and it’s a sociable event.

“We’ve had great relationships with industry over the years too, particularly Intuitive Surgical and Boston Scientific, with teams taking part and raising money for TUF.

“We raised nearly £70,000 last year with a cycle to the Loire and our ambition is to raise even more this year.”
The lasting power of a TUF Legacy

Your TUF Legacy will help millions of people affected by urology and ensures we can continue to make a difference to the lives of so many in the future.

If you would like to leave a gift to The Urology Foundation please make sure your solicitor, or will writer, uses our full name, address and charity number in your will to remove any doubt about our identity.

The Urology Foundation, a registered charity in the UK no. 1128683.
Registered office: 1 – 2 St Andrew’s Hill, London EC4V 5BY.

Urology disease can affect everyone from children to grandparents. But by leaving a gift in your will you can help The Urology Foundation continue its crucial work in the years ahead. With your TUF Legacy we can plan ahead and invest in key research and training programmes that will help end the suffering caused by urology disease quicker.

Over the last few years legacies have been fundamental in allowing The Urology Foundation to revolutionise the way in which urological surgeons can be trained in the UK. This has ensured that more patients have access to new surgical options that provide better recovery times and better patient outcomes.

Gifts in wills are crucial if we are to continue to support the development of vital research and training that will lead to the very best urological care and treatment for all those in need.

If you are considering leaving a gift to The Urology Foundation in your will, thank you.
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:

SAYARA MUTHUVELOE: Fundraising Manager  t: 020 7713 9538

SERENA WYMAN  Events Manager  t: 01449 737 971