Bringing follow-up to the forefront

Creating a lasting legacy

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

First I very much hope that you are keeping safe and well. We continue to live in uncertain times. When the pandemic first began last year we initially had hopes of it being over by summer, and then by the end of the year. Now it is becoming apparent that Covid is something we might have to learn to live with on an ongoing basis. Hospitals and GP practices have worked hard to make Covid-secure spaces and the message from urologists is clear: if you have any worries or symptoms please do not delay to seek help or advice. Good outcomes and quality of life depend upon early diagnosis so don’t hesitate if you have any health concerns.

In the meantime, despite the stresses and strains of 2020, TUF continued to support the urology community and made a number of research and training awards last year, funding 10 research projects and supporting over 100 trainees to take part in online lectures and tutorials via the RSM. Our TUF Warrior trainee programme also provided peer to peer support and mentorship opportunities for trainees.

As we move forward into (a hopefully brighter) 2021, I am conscious that none of our work would have been possible without your generous support. Thank you for continuing to help us make a difference and improve the lives of those suffering with a urology disease.

Louise de Winter, Chief Executive

Front cover image courtesy of Arun Sahai.
"Cake is the answer – who cares what the question is!"

March normally sees TUF supporters hitting their kitchens to take part in the TUF Big Bake but sadly coffee mornings and cake sales are not possible this year. So here’s the new plan…..

Got a friend who makes the best coffee and walnut cake? Do your friends swoon for your lemon drizzle? Want to know the secret of your aunt’s perfect scones?

Then this March we are asking you to please look to buy and sell favourite recipes among your friends and colleagues with payment taking the form of a donation to the TUF Big Bake Recipe Swap.

Making your donation could not be easier as we have set up a dedicated TUF Recipe Swap Just Giving page. Visit justgiving.com/campaigns/TUFRecipeSwap
Improving care and well-being across all urology

Every year TUF funds a variety of Small Research Projects. Open to nurses, clinicians and researchers, this award funds non-lab based projects that aim to make an immediate impact on patient care or well-being.

We funded three of these projects last year, across a varied range of subjects:

INVESTIGATING THE EFFECTS OF CHEMOTHERAPY ON MUSCLE-INVASIVE BLADDER CANCER

Richard Walshaw – University of Manchester / Christie NHS Trust

A tumour is not just made up of cancer cells but also a range of other things such as human cells (including immune cells) or proteins. This is known as the tumour microenvironment.

Patients with muscle-invasive bladder cancer are treated with chemotherapy followed by either radiotherapy or surgery to remove the bladder. Both treatments have similar rates of curing the disease, but the cancer returns in half of patients. This project aims to study the chemotherapy stage of the treatment, with the aim of finding what effect the chemo has on the tumour microenvironment. These results could then guide physicians on whether radiotherapy or surgery would have the better outcome for a patient.

Your support makes these important projects possible
VALIDATION OF A NOVEL PROM FOLLOWING GENDER AFFIRMING SURGERY

Tina Rashid – Imperial College Healthcare NHS Trust

Patient reported outcome measures (PROMs) have been proven to provide meaningful data and have been shown to effectively measure important outcomes for patients, such as quality of life. Tina Rashid’s project aims to create a validated PROM for gender-affirming surgery (GAS). GAS is performed around 500 times per year in the UK and current outcome measurements are either done ad hoc or are adapted from other surgeries. This makes it difficult to compare outcomes across different reports as all are using different tools. Tina Rashid’s project aims to fill this gap and improve post-operative outcomes for GAS.

SAVE THE BALL: A NATIONAL CAMPAIGN FOR EDUCATING YOUNG MEN ON TESTICULAR HEALTH

Nadine McCauley – various institutions

Nadine McCauley’s important project aims to educate young men and boys on the signs, symptoms, risks and responses to testicular torsion. Outcomes for testicular torsion can be quite poor, often due to late presentation. A lack of understanding amongst the affected population of boys and young men is a major cause and Nadine’s ambitious national campaign could help boys in future by educating them to understand the problem and see a doctor as soon as possible. For more information, turn to pages 6-7.
Testicular torsion is a painful condition where the testicle twists on its cord and cuts off the blood supply. It affects about 1 in 4000 males under the age of 25 each year, most commonly during puberty. Although testicular torsion is uncommon, it needs to be treated quickly when it happens.

“They have about six hours from the onset of pain to save the testicle. Once you get to 24 hours, it’s pretty much 0% chance of saving it,” says Nadine McCauley, a urology registrar at the Royal Glamorgan Hospital.
After doing an audit to see how long it took boys to present in A&E with torsion, Nadine found that there was often a significant delay.

“We were quite surprised because the average was about two days,” she says.

“We realised the problem was getting them to tell somebody that they had pain in the testicles, which is obviously embarrassing for young men.”

To help tackle this problem, Nadine along with her colleagues started the Save the Ball campaign. They are aiming to reach boys aged 11-14 to explain what to look for and the importance of being checked quickly.

The campaign is developing lesson materials so that the topic can be easily taught in schools. Central to this plan is co-design, where children are involved throughout the process and provide ideas for the approach.

“In 2019, the government introduced compulsory PSHE lessons (Personal, Social, Health, Economic) in England, and I think it will be the same in Wales and the other nations eventually,” says Nadine.

“We worked with a school in South East London and they designed the basic layout of the PSHE lesson. That’s going for accreditation so it can be used throughout England.”

The project team is developing resources for the lesson, including a video, which the children suggested would help make the lesson more accessible. Nadine is doing a Masters in research looking at how to make the video design evidence-based.

“It’s not something that I normally would have expected as part of my medical career, but it’s been interesting. I’ve learned a lot along the way,” she says.

TUF is providing funding to support the project, including the production of the video and the co-design work.

“The final product will be assessed with focus groups again, and because it is a difficult-to-reach population, TUF funding is going to really help us to encourage young teenagers,” says Nadine.

“So part of the funding is going to help as a motivation for the kids to participate in something that they wouldn’t normally feel very comfortable talking about, for obvious reasons.”
During his professional career, Alex earned 31 caps for England, also playing for the British and Irish Lions, London Irish and Northampton.

“My father and uncle have both had testicular cancer at a similar age to me, so I’ve always been quite aware of checking,” he told the virtual lecture audience.

Thanks to his careful checking, Alex had previously noticed many years ago a change in the size of his left testicle. This turned out to be a hydrocele – a build-up of fluid that is harmless but made it difficult for him to notice changes when the cancer developed.

“That testicle had always been slightly bigger and slightly heavier than the other one and I just got used to that […] it wasn’t until it got alarmingly big, that I realised there was something wrong,” Alex said.

Alex had an orchidectomy to remove the affected testicle in November 2019, followed by chemotherapy in January 2020. He briefly went back to work as a rugby pundit at NBC in the US, when the pandemic halted professional sports.

“Being locked down for four months, I trained every day, I ate extremely healthily and I felt like I got back into peak condition,” said Alex.

That summer, Alex developed an acute pain in his abdomen and a CT scan showed a mass in his lymph node.

“I didn’t expect it to say that my cancer was back […] mainly because I felt so good. I was fit and strong,” he recalled.

Alex Corbisiero, the former England rugby star, gave the 2020 TUF guest lecture at the British Association of Urologists conference following his diagnosis of testicular cancer the year before. He is now working to raise money to support TUF research into the disease.

“I think it’s going to be a lasting legacy”
“But on the other side, I thought: I’m incredibly lucky I caught this now because the plan was probably not to scan until November, and the fact that it was already there in early August, where might it have spread to by November? In some ways it’s a blessing.”

Speaking at the lecture, he had just finished three cycles of further chemotherapy.

Alex is now working to raise £60,000 to support TUF research into improving the diagnosis or treatment of testicular cancer.

“My father and uncle have both had testicular cancer at a similar age to me, so I’ve always been quite aware of checking”

“...I think it’s going to be a lasting legacy,” he said. “There are men that are going to follow after me that go through this and if I can make the road for them easier to travel, it will be so worthwhile.”
Over 7,000 men have radical prostatectomies each year, where the prostate is removed to treat prostate cancer. However, because of the prostate’s delicate position in the body, the operation can lead to problems like erectile dysfunction or urinary incontinence.

“These men are usually happy with how the cancer treatment has gone, but there are patients with problems with erections, which are affecting their relations, quality of life and mindset. It’s the same with incontinence – they’re embarrassed to go out and meet friends. The number of times I’ve heard ‘my hobbies are out now’ or ‘I can no longer do…’, from patients for fear of leaking,” says Arun Sahai, a former TUF scholar and consultant urological surgeon at Guy’s and St Thomas’s Hospital.

“Too many patients come back years after surgery to seek help and some we never see. We are trying hard to change that and get patients seen in a timely fashion.”

Arun is working with a team of urologists at the hospital, including Majid Shabbir, consultant urological surgeon, and Findlay MacAskill, urology
specialist trainee and PhD student, to trial a patient pathway that puts cancer outcomes, erectile dysfunction and incontinence equally at the forefront of their care.

“Our cancer team have been wholeheartedly on board because their drive is exactly the same – they want to have the best functional as well as oncological outcomes for their patients. Now we have team members from functional urology, andrology and prostate cancer proactively involved in the ongoing follow-up of a patient from the outset, which wasn’t something we had before,” says Majid.

Over 250 men started the pathway in 2020. They are followed up at regular intervals for two years after the operation to monitor their cancer treatment and its impact on their quality of life, including questionnaires and even an interview with their partner.

“It’s about trying to get as efficiently through the rehabilitation pathway so you can go back to a normal life, rather than just living with the effects of the operation,” says Majid.

The team hope this work will yield valuable information and to identify risk factors that may predict incontinence and erectile dysfunction. With this evidence, the team can help men to make more informed decisions about their treatment options.

“Some of these guys come to us afterwards and say, ‘If someone had told me what impact the surgery would have on my life, from a sexual function point of view, I wouldn’t have had it or I would have considered other options,’” says Majid.

“We need to say ‘you’re going to have surgery, it can have an impact, but there are things that we can do to make it better and we are here with you every step of the way.’”
When Bradley Starr started to experience problems with his prostate, he knew who to call. Over twenty years earlier, when his father was being treated for prostate cancer, Bradley first met urologist Professor Roger Kirby. “My father, typical of his generation, wasn’t somebody who talked a lot about medical issues, but he did sit me down at the time he was seeing Roger and said ‘you need to know about this’. He actually had me come to the appointments with Roger to make sure I understood all about the prostate cancer, which was one of the best things that happened,” says Bradley, a marketing consultant from London.
Despite it being tough at times, he speaks very fondly of the cycle:

“I knew that my sponsors required that there was a degree of suffering involved! It certainly met that criteria with the temperature and the distance of 500 km.

“There were over 30 of us on the ride, and everyone looked after everybody else. You had that connection of all doing it for the same reason.

“It sounds a little bit corny, but it really was one of those life-changing events. I'd never done anything like that before.”

Two years later, Bradley did another TUF bike ride in Cambodia and Vietnam, and he is itching to do the next when it becomes possible again. With his family’s history of prostate cancer, he says supporting TUF is a bit like ‘an insurance policy’ for not only his future, but his two sons and others with the disease:

“I like that TUF is a relatively small charity and it’s efficient. It’s very much practitioner-led, so the urologists that I’ve met are actually driving the research and improvement in treatment that will make a big difference fairly quickly.”

Thankfully, Bradley did not have cancer like his father and grandfather before him, but was treated for an enlarged prostate. Bradley’s family had donated to TUF over the years, and during an appointment, he noticed a poster on Roger’s desk for the 2015 TUF bike ride across India.

“At that point, I actually hadn’t owned a bike since I was a teenager. I thought that just sounds crazy enough to be interesting,” he says.

After a trial run of being back in the saddle, Bradley signed up to the ride.

In addition to the money Bradley has raised by taking part in our cycle challenges, he has also donated his professional skills and time to work with the TUF team on fundraising proposals and materials. Do you have time and skills that you would like to “donate” to TUF? To discuss your ideas please contact Louise at ldewinter@tuf.org.uk
Supporting the next generation

At TUF working with, and inspiring the next generation, of researchers, urology and health care professionals is key to our mission to improve the nation’s urology health.

We have always been keen to support urologists early in their career and from this desire has grown the TUF Warrior programme.

Aimed at core trainees, clinical fellows and specialist registrars working in the field of urology, this extracurricular programme has been designed to demonstrate their commitment to urology while supporting TUF in its mission to better the lives of urology patients.

The programme takes between 6 to 12 months, and Warriors are asked to complete at least three charitable activities. Two fundraising activities on behalf of TUF and one activity that raises public awareness of urology health.

As part of the programme Warriors have access to a series of webinars offering support and development opportunities. These are overseen by Hannah Warren and Luke Forster, both TUF Warrior Alumni.

In 2020 we added the opportunity for TUF Warriors to choose a mentor. The mentors have kindly donated their time to this programme and include both urologists and non-urologists.

Depending on how each Warrior decides to complete the programme, they can further develop their teamwork, resilience, public speaking, management, event organising and networking skills.

The TUF Warrior programme has been established to promote a culture of mutual support and development and it has been a pleasure to watch the careers of past members of the Warrior programme as they have progressed. We are grateful to the many that have remained so actively involved with TUF and supported our work.

Help us to continue to support health care professionals at all stages in their career. Donate today theurologyfoundation.org/donate
TUF Nuts Tuesday – it could save your life

TESTICULAR CANCER IS 95% CURABLE IF IT’S CAUGHT EARLY

What’s the best way to ensure that you catch it early? To be aware of the symptoms and check yourself regularly so spotting any changes is easier. It could be a life saver!

TUF is encouraging all men in the UK to take part in our #TUFNutsTuesday campaign. We want men to undertake to check their balls for lumps and signs of testicular cancer on the first Tuesday of every month.

England and Lions rugby star Alex Corbisiero is a TUF Ambassador and keen to encourage men to take part in the campaign, knowing from first-hand experience (see pages 8 & 9) just how important is early diagnosis of testicular cancer. His upfront and positive approach is making a real contribution in getting the message out to a wider audience about the need for men to routinely check their balls for signs of testicular cancer and to get seen by their GP as soon as they feel any changes.

If you feel any hard lumps or other changes, or have aches in your testicles don’t delay, make an appointment to see your GP.

England & Lions rugby legend
ALEX CORBISIERO
is an Ambassador for
TUF NUTS TUESDAY
because he knows the importance of catching testicular cancer early

So make the first Tuesday of every month your #TUFNUTSTUESDAY

How to check

Check yourself regularly

The warmth of a shower relaxes your testicles

One at a time, gently roll a testicle between your thumb and fingers checking for any lumps or changes

If you feel any hard lumps or other changes, or have aches in your testicles don’t delay, make an appointment to see your GP.
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

To the professional urology community who are working under extraordinary circumstances to ensure the continuation of urology care during the ongoing Covid-19 pandemic.

To Thomas Newman, Abida Sultana, Akshay Narayan, Shaun Humphries, Ashfield Health and Urology & Incontinence Care who all literally stepped up and raised £1,970 as part of the inaugural Step Up Challenge for TUF during September’s Urology Awareness Month.

To Simon Lord who ran a marathon to mark the 10th Anniversary of his successful treatment for prostate cancer and raised over £200 for TUF.

To the riders and organisers of Bike4TUF who rapidly adapted their itinerary, route and plans to comply with the Government “rule of 6”. Not to be deterred our 26 riders organised themselves into separate groups and rode in their local areas and raised a truly amazing £46,194! A huge thanks to all their donors and corporate sponsors BXT Accelyon, Santander and a big shout out to the main sponsor Intuitive Surgical. Thanks to all involved for showing what teamwork can achieve and how together you can make a difference.

To all those that gave with love in memory of Clive Rigby, Mr Birch, David Watts, Cliff Evans, Barbara Old, Callum Palmer and Raymond Layzell.
To Cath Sutton, Katie Highton, Matt Watt, Ina Ologenau, Emily Hamilton and Deborah Evans who set up birthday donation pages on Facebook in aid of TUF.

To everyone who donated to the TUF Trials Unit appeal and to The Hadley Trust who match funded those donations.

To those that raised a glass and joined the TUF Team for a Virtual Gin Tasting Fundraiser with Pinkster Gin in December and to Pinkster Gin who donated a percentage of the post event sales to TUF.

To Alex Corbisiero for donating the profits from his charity t-shirt sales to TUF, (order yours at onlymotif.com/teamcorbs) and for setting up a Just Giving Team Corbs Against Testicular Campaign page to raise funds for a TUF research study into the disease. justgiving.com/campaign/TeamCorbsAgainstTesticularCancer

To those that kindly bought and sent TUF Christmas cards.

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

Raise money while you shop online

Shop online with over 4,400 well known retailers via the easyfundraising website and a percentage of what you spend is passed on to TUF at no additional cost to you. Retailers include Amazon, M&S, Tesco, John Lewis, eBay, Just Eat, Sky and many more.

Please register to support us today at easyfundraising.org.uk/causes/urologyfoundation
THIS YEAR

Regular donations are extremely important to TUF as it helps ensure that we have the funds available when they are needed most. Knowing we have regular structured income helps with our cashflow and gives us the security and confidence to capitalise on opportunities that will make a positive difference to the nation’s urology health. You can quickly and easily set up a standing order via our website theurologyfoundation.org/donate

March

This March we are asking TUF supporters to buy and sell favourite recipes among their friends and colleagues with payment taking the form of a donation to the TUF Big Bake Recipe Swap. It couldn’t be easier just visit JustGiving.com/campaigns/TUFRecipeSwap

April - September

TUF is delighted to be working with Action Challenges again in 2021. Between April and September there are 14 different challenges taking place around the country.

Walk, jog or run. There are continuous 100km challenges, a 2-day daylight 100km with camping, 50 km Half and 25km Quarter challenges and a few 10km tasters, so there is an Ultra Challenge for everyone.

April

It is with regret that, due to the ongoing pandemic, we will be postponing the Wine Tasting Dinner with Jane MacQuitty scheduled for 19 April. We are contacting all bookers directly.

June

Following the success of the Pinkster Virtual Gin Tasting in December we will be joining forces later this summer for a Pinkster Cocktail Class. Want to join the party? Then please contact Serena on swyman@tuf.org.uk or keep an eye on our social media.

September

Bike4TUF 2021. Plans are afoot for this year’s Bike4TUF in September. If you would be interested to receive more information as it comes hot off the press and book your place, please contact Serena at swyman@tuf.org.uk

October

TUF Trek to Machu Picchu – One not to miss and it would be great if you could join us – please see back cover for full details.

For full details and to be inspired visit theurologyfoundation.org/get-involved/events
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:

SERENA WYMAN
Events Manager
t: 01449 737 971

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

Trek To Machu Picchu

1-10 October 2021

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.