Cancer and fertility
Becki McGuiness on living with the side effects of sarcoma treatment
First of all, I would like to say a huge thanks to each and every one of you who helped make Sarcoma Awareness Week such a huge success. There was so much going on, including The Big Picnic, the launch of our podcast series (see opposite page) and our Support Line heading off on a tour of the UK, where they met lots of patients, supporters and health professionals. There are updates on page 14 and 15.

As the winter nights draw in, and we increasingly think about staying indoors, I would like to give a round of applause to all the fundraisers who are still out there running, cycling and even climbing mountains! Sarcoma patient Dominic Paul climbed nine mountains in 12 days, can you believe it? He has written an account of his achievements on page 10. You’re an inspiration, Dominic, and we can’t thank you enough for all the funds you’ve raised.

Becky McGuiness is also raising awareness of the side effects of some cancer treatments, and on page 6 she tells her moving personal account of coming to terms with infertility in her 20s.

Elsewhere in the issue, we chat to patients who have volunteered to be part of ground-breaking research and give you a full round-up of the fundraising activities that continue to support our important research. It’s your donations and fundraising efforts that allow us to amplify awareness and change the landscape for everyone affected by sarcoma.

Please get in touch with your thoughts on the issue. And check out our new online store, sarcomauk.teemill.co.uk, which sells Sarcoma UK T-shirts, tops and totes!
During Sarcoma Awareness Week, Sarcoma UK’s Support & Information Team launched a podcast series based on the frequently asked questions we get asked on the Support Line.

Each episode answers questions on sarcoma from diagnosis to treatment through to follow-up. These podcasts also feature health and wellbeing topics looking at the psychological impact of a sarcoma diagnosis, as well as advice on living well beyond sarcoma.

The podcasts feature Helen Stradling, our Support Line Lead, and Claire Kelleher, our Head of Information and Support, discussing some of the main questions we get asked on the Support Line.

In episode 2, Helen explains the role of a CNS: “A clinical nurse specialist is your point of contact. These nurses are there to support you throughout all of your journey: through diagnosis, treatment and into follow up.

We know that a diagnosis of sarcoma is devastating, as with all cancer diagnoses, but I think the problem with sarcoma is the fact that people will not have heard the term sarcoma before, so this makes it an even scarier time for patients, families and also their friends. So your clinical nurse specialist is the person who’s there to support you through that time and help guide you through any information or support that you need and help to find that information for you as well, so that you’re not left to your own devices trying to gain information for yourselves.”

We offer advice to anyone touched by sarcoma whether you have just been diagnosed or someone you know is being treated for sarcoma.

No question is a silly question. Contact our Support Line on 0808 801 0401 or email supportline@sarcoma.org.uk.

Our podcast series covers a range of topics relating to sarcoma, but if you do have ideas of topics we may cover in the future, contact us at info@sarcoma.org.uk
Meet the fundraisers

From running for 24 hours non-stop to golfing challenges, iron women and great north running, this brilliant lot are changing the landscape for everyone affected by sarcoma.

**Cycling France**
Andrew Hutchinson took on l’Étape du Tour after his brother-in-law was diagnosed with sarcoma. It’s a cycling challenge following the route of one of the most taxing stages of the Tour de France – 178km long and climbs 4km. It took Andrew 9 ½ hours to complete. He raised over £2,000.

**Healy boys take over Richmond**
Eight members of the same family completed the Richmond Half Marathon in memory of their Aunty Sharon, who passed away earlier this year. Dan, Ronan, Dave, Dominic, Chris, Patrick, Frank and Conor wanted to honour their aunt, who they all remember so fondly.

The lads took over the course, with loads of family coming to cheer them on. After a fantastic day (and a few post-race beers, we heard!), they raised a phenomenal £9,300 – an incredible legacy for their aunt.

**Family football fun**
Lee Wood organised the second annual Family Football Day in support of his partner, Chloe. Together with support from local businesses and BBC news presenter, Nicholas Owen, he raised over £800 towards benefitting charities including Sarcoma UK.

**Prudential Ride London-Surrey 100**
Team Sarcoma once again stormed the 100-mile course, taking on testing climbs along the way. They raised an incredible £9,900, ensuring more lives are changed through ground-breaking research and personal support.

**Putterly brilliant ladies**
The Ladies at East Kilbride Golf Club organised a golf day incorporating a Big Picnic on the course and an excellently colour-coordinated raffle at the end. They raised £1,120.

Get your place on the 2018 team on our website: sarcoma.org.uk/get-involved/take-challenge/cycling/apply-place
Iron(wo)man
Rachel Hooper decided to take on the ultimate challenge in support of her good friend Sharon: a full Ironman. She swam for 2.4 miles and then cycled a whopping 112 miles before finishing with a full marathon (just the 26.2 miles). She dived into the water in the morning and crossed the finish line 13 hours later having raised over £4,000. We’re in awe, Rachel.

Great North Run update!
Over £6,000 has been raised by the 15 runners of Team Sarcoma at the 2017 Great North Run. They battled high winds on a chilly autumn day to complete the world’s biggest half marathon. And our cheering station staff weren’t the only ones willing them on!

Brendon Foster, founder of the Great North Run and British Olympian, sent them a special message of thanks and good luck: “Thank you to each and every Sarcoma UK runner. Your dedication and commitment is bringing sarcoma researchers one step closer to finding effective treatment for sarcoma. I am right behind you every step of the way, and wish you all a successful and enjoyable day here in the North East. Good luck Team Sarcoma!”

Turn to page 9 to see what one of our runners had in their kitbag.

Running for 24 hours
James and his brother Matt ran. And ran. And ran. They took it upon themselves to run for 24 hours without stopping, all in memory of their father. They chose a 7.5mile loop through their dad’s favourite town, Keswick, completing the lap again and again. All in all they raised almost £3,000 for Sarcoma UK.
Sarcoma and fertility

Becki McGuinness has been in remission for eight years, but still lives with the side effects of her sarcoma treatment every day. This is her story and the reasons why she set up her website Cancer and Fertility UK.

In the cancer community, you’d think everything should be thought about and put in place, but, unfortunately, fertility is being left off the agenda. In some cases, patients – especially when there is enough time and it would not be detrimental to their health – are not being offered fertility preservation, or even told what is available.

Not every patient will want to preserve their fertility, but everyone deserves a choice and access to information, so they can make an informed decision. A recent study by St Mary’s Hospital in Manchester found that fewer than 4% of female cancer patients have their eggs or embryos frozen before starting chemotherapy or radiotherapy. According to the same study, roughly half of 15 to 34-year-old women treated for cancer — around 4,000 a year — become infertile after their treatment.

The need for choice is why I set up Cancer and Fertility UK, I am campaigning for all those of reproductive age with cancer. I don’t just think about cancer, I think about reproductive health and also mental health. This is why I support Sarcoma UK because the charity is raising money to fund research, which may lead to kinder and less aggressive treatment for those with sarcoma.

I was 21 when I was diagnosed with osteosarcoma in my sacrum and spine – it’s an aggressive bone cancer. I knew there was a chance my fertility could be affected by treatment. But doctors explained what treatment I’d be having and told us there were no other options for my condition. We took them at their word – like most people do. I was led to believe there were no other option and also being advised that infertility “doesn’t happen to everyone” as a result. I had six months of chemotherapy, with all the stereotypical side effects – my hair fell out, and I was constantly neutropenic. Then came six weeks of daily radiotherapy.

It was during treatment that my early menopause began: my periods became infrequent and I started getting really bad hot flushes. I’d be on the bus, or at a social event, just sweating and sweating – and no one knew why. Then I was put on HRT (hormone replacement therapy) to tackle the symptoms. When my periods didn’t come back after treatment, I was referred to the Reproductive Medicine Unit, who took a blood test to check my hormone levels. I was just 23 when the test came back showing I was infertile.

After I had gone through the menopause, a fertility specialist told me that there had been enough time to save my fertility before I started treatment, but I feel like my choice was made for me. Being a young cancer patient is hard enough without the constant reminder that you are now infertile. There’s no
If you have concerns about the effect of sarcoma treatment on your fertility, call our Support Line on 0808 801 0401.

improving as the NHS had told him that his partner was not allowed to use his frozen sperm sample to have a child because they were in a same-sex relationship. Dean won an apology from the Human Fertilisation and Embryology Authority (HFEA) and HFEA provided a clarification of the rules to prevent discrimination.

Dr Channa Jayasena, a consultant in reproductive endocrinology at Imperial College London and Hammersmith Hospital, who helped provide the medical definitions for my website told me: “I firmly believe we should not discriminate against the LBGT community when it comes to fertility preservation. So, anyone biologically female should be offered egg freezing, and anyone biologically male should be offered sperm freezing. They have the same rights as anyone else when it comes to NHS freezing. There might be additional costs for IVF since they might need donor sperm or a surrogate etc.”

I also want to raise awareness about how different types of cancer treatment, like radiotherapy to your pelvic area, can cause infertility. We also need to raise awareness of the difference between temporary and permanent menopause and what it means to you.

There should be more procedures put in place to ensure all cancer patients are referred to a fertility specialist as a matter of course. Professor Geeta Nargund from Create Fertility backs my campaign and my celebrity ambassador is Billy Billingham from Channel 4’s SAS WHO DARES WINS.

I recently organised a photo shoot for cancer patients of reproductive age around the UK to show the impact cancer and fertility/infertility has on a person. It should be their choice and people should be treated holistically.

“It’s taken me eight years to even be able to talk about the pain of infertility, to know there was time to preserve my fertility.”

Read more about Becki’s campaign at cancerandfertility.co.uk

chance for me now; once you’re infertile you can’t go back.

It’s taken me eight years to be able to talk about the pain of infertility, to know there was time to preserve my fertility. I thought cancer would have been my worst pain, it isn’t. I knew that I had to raise awareness, as a patient who had cancer and lost her fertility, to support others who still have a choice.

I was diagnosed with sarcoma in 2008, but it’s still happening. Journalist Dean Eastmond who recently passed away from Ewing’s Sarcoma shows us things still aren’t
Life-extending drug for GIST patients

We’re delighted to announce that the drug regorafenib is now funded by the NHS in England

Since 2015, we have been campaigning for the secure funding of this life-extending drug used to treat people with GIST. The news marks a major victory for people living with the most common type of sarcoma, who now have secure access to regorafenib through the NHS in England. The drug is currently available for treating GIST in Scotland and Wales.

The approval of this treatment is good news for people whose GIST cannot be removed through an operation. Regorafenib (Stivarga) is used to treat people who have GIST that cannot be operated on or whose sarcoma has spread to another part of the body. Typically, GIST is treated using the drugs Imatinib and Sunitinib. If these treatments have not worked, or have caused bad side effects, then regorafenib is an additional treatment option.

Regorafenib is a targeted cancer drug that can shrink the cancer or stop it growing for a period of time. It can also stop cancer cells from developing the blood vessels that they need to grow. Further good news, the drug has relatively few side effects when compared to many other treatments for sarcoma, so people with GIST now have a greater chance of maintaining a high quality of life.

“This is tremendous news for patients living with GIST in England”, says Prof. Ian Judson, Trustee at Sarcoma UK and former Head of the Sarcoma Unit at the Royal Marsden Hospital. "It draws a line under the uncertainty faced by the hundreds diagnosed each year with GIST as well as those already undergoing treatment. Now patients living with GIST have the vital reassurance that, should they need it, regorafenib is a viable treatment option through the NHS."

This is the second drug this year that has been approved by NICE (The National Institute for Health and Care Excellence) for the treatment of sarcoma. We also campaigned for the approval of olaratumab, which became the first new treatment to be approved by NICE since 2010.

Prof. Judson said he is “delighted we have secured this crucial decision that offers hope to those currently living with GIST. Alongside GIST Support UK, we’ve worked hard to provide evidence and challenge negative decisions since 2014.”

If you have questions about what regorafenib could mean for you, or about GIST, call 0808 801 0401 or email supportline@sarcoma.org.uk. Alternatively visit our website, sarcoma.org.uk/sarcoma-types/gastrointestinal-stromal-tumours-gist
What’s in my kitbag?

Jodie Hammond ran The Great North Run in support of her dad who was first diagnosed in 2016. Although treated successfully at first, his sarcoma came back at the start of 2017. Jodie is running to raise awareness and funds as she had never heard of sarcoma before her father’s diagnosis. These are all the bits she had in her kit bag on race day, along with some pieces of advice for those wanting to take on a running challenge...

**Warm, loose comfy clothes**
Some comfy clothes for after the event. When you are feeling all stiff and robbed of energy, you want something comforting like a hoodie and some jogging bottoms.

**Protein Bar**
It can be a long wait from when you have had breakfast to when you cross the start line. It’s good to have a nibble while you’re waiting for the starting gun.

**Ibuprofen**
To ease the pain for the travel home!

**Lip Balm**
My lips get so dry while running, so this is a must.

**Tiger Balm**
My number one saviour as my muscles are immediately sore after a long run – this is so soothing and instant relief!

**Vaseline**
My arm pits began to chafe! So it’s good to carry a mini pot – rub on during the run.

**Tissues**
A pack of tissues for when you cross the finish line, things could get emotional.

**Phone in a running bumbag**
I recommend carrying a phone in a running bumbag on race day. I forgot mine, which was a bad move, because trying to find my partner after I finished was a nightmare. It’s also good to tell your loved ones that you are safe and well after you have crossed the finish line.

sarcoma.org.uk

Connect • Sarcoma UK • Winter 2017
My sarcoma story started around two years ago when I noticed a small lump on my right shoulder blade. At first I thought nothing of it. It stayed the same size for a while, then suddenly over the space of a few months it began to grow at an alarming rate! It was at this point I went to the doctors and they told me it’s probably just a fatty lump. A few weeks later, I went for an ultra-sound. But it wasn’t until months later that I got my results, which meant being referred for an MRI scan. Then, within a week, I had an appointment at the Royal National Orthopaedic Hospital. From my first appointment with my consultant at the RNOH, a decision was made to simply remove the tumour, I was told not to worry though as it was most probably nothing “scary”.

After my first operation, I struggled with my right side for a week, then I started to get movement back and I was hoping I would never have to go back to the hospital again. I was told, after my operation, that if there was anything they needed to see me about, I’d be contacted in a month or less. I counted down the days. To my girlfriend Laura and my despair exactly a month later, I got a call from the hospital asking me to come back for a follow-up appointment. From this moment, I knew my fate, Laura and my family were still positive, telling me there was nothing to worry about, but for me the evidence was clear.

On the day of my appointment, I went to the hospital with Laura, my mother and little sister. When it was my turn to see the doctor, my name was called out by a Macmillan specialist nurse, and that was the last piece of evidence I needed. As soon as I sat down, the doctor was looking at my scans and he simply said: “I’m afraid I don’t have good news,” as these words left the doctor’s mouth, I saw Mum start crying. The doctor told me I had fibrosarcoma. I needed a second operation, where they would perform a scapulectomy removing part of the shoulder in order to prevent the spread of a tumour.

To this day, I’m still recovering from that operation, I don’t have full movement in my right arm and probably never will. I haven’t played my favourite sport, cricket, since my diagnosis, which is something I hugely miss. I’m currently undergoing something called long-term surveillance, which means no more treatment, however I do have to go to the hospital every three months for chest scans to check for metastatic spread.

Laura keeps me going, and I am so proud of myself for taking on my nine peaks challenge for Sarcoma UK. I wanted to prove to myself that I can still take on physical challenges, and I also want to help raise awareness and funds for the only charity in the UK that supports people with sarcoma. I hope others reading my story will be inspired.
Dominic Paul was diagnosed with sarcoma in November 2016 and underwent two operations to his right shoulder. To raise awareness of Sarcoma UK, he and his girlfriend Laura decided to take on the almighty challenge of climbing nine of the highest mountains in the UK in 12 days, raising more than £2000 in the process. This is the story of his diagnosis...

Dominic's peaks challenge for Sarcoma UK

Glyder Fawr
5 September 2017
Walk time: 7 and a half hours

Carnedd Llewelyn
6 September 2017
Walk time: 5 hours

Snowdon
7 September 2017
Walk time: 3 and a half hours

Helvellyn
9 September 2017
Walk time: 4 hours

Scarfell and Scarfell Pike
10 September 2017
Walk time: 4 and a half hours

Braeriach
13 September 2017
Walk time: 4 hours

Ben Macdui
14 September
Walk time: I will find out one day… we couldn’t climb because of bad conditions. But I will be back.

Ben Nevis
15 September 2017
Walk time: 6 hours

Are you doing your own challenge in aid of the charity? Let us know by email at fundraising@sarcoma.org.uk
We can help with fundraising packs, ideas and support through our communications team.
The patient side of medical studies

Ever wondered what it’s like to take part in a medical study? We spoke to two patients who were part of the International Kindred Study, the UK arm of which was funded by Sarcoma UK, to find out how they got involved.

Emma McCloskey, 34 years old

“I was diagnosed just over five years ago, it was liposarcoma in my right thigh. Not many people have heard of sarcoma, but I had. My colleague actually passed away from the same kind that I had. One of my immediate thoughts when I found out, was that I thought I would lose my hair. No one in my family had ever had cancer, so I knew that is the stereotype everyone thinks of. In fact, my treatment first of all was just surgery, so people were often shocked when I told them I had cancer – I still had my hair!”

“All my family took part too: my mum and four siblings. Some were able to do it by post, as my brother lives in Edinburgh. My sister came into the hospital with me and did it there.

“I know not every patient wants to take part in these studies. I guess they want to block it out and not get involved. I don’t really understand that mentality, but I guess everyone deals with a cancer diagnosis differently. I think even if just one person benefits from something then it is worthwhile – although no one should ever be forced to take part, of course. I would just never want anyone else to go through what I have been through. I also think of the research from, let’s say, 20 years ago that has helped me today. Helping future generations is what really motivated me to take part, and I hope that will motivate others too.”

Judy Bright, 59 years old

“In 2011, I was diagnosed with uterine leiomyosarcoma. And a few years ago, doctors at the Royal Marsden in London asked me to take part in the study. I was told taking part wouldn’t necessarily benefit me, but it might help my family in the future. That is what motivated me to be part of it.

“These kinds of studies are so important for the future. Researchers will gather information from people, so they can find patterns and connections, which will one day lead to a cure. Doctors suggested that a member of my family should take part in it too. So my husband volunteered – even though he has a phobia of needles, he got over those nerves for the greater good. He doesn’t have cancer, but that is the whole point of the study, they need to gain information from people who do and don’t have cancer.

What is The International Sarcoma Kindred Study?
The International Sarcoma Kindred Study (ISKS) has been set up to identify, validate and quantify genetic risk in patients with adult-onset sarcoma. This is an international initiative, with nine major international sarcoma centres in USA, Europe and Asia taking part, to ensure genetic diversity. This gives sarcoma patients and their families the opportunity to take part in, and potentially directly benefit from, this first-of-its-kind-in-sarcoma study. The study will be of direct and immediate benefit to patients in the investigation and identification of their risk of developing further sarcomas or other cancers, and the associated risk to their family members. All participants will be offered full support and referral to counselling services. Sarcoma UK has funded the UK arm of this study for two years, recruiting patients at the Royal Marsden Hospital and University College Hospital London.
"I think they needed a family member to see if the cancer is related to any environmental factors. Of course, for the most part, we have been eating the same foods, we have been to the same places and we live in the same house."

"All we had to do was give a blood sample and fill in a detailed form. There were lots of questions about our family histories and genetics – luckily my mother could answer the questions that I couldn’t."

"I won’t know anything about the study for a while. But the research is trying to find out if people who have sarcoma have a genetic fault, like the breast cancer gene, which may make us more at risk of getting cancer. If they prove this and I have this gene, my children – who are 37 and 38 – can find out if they have it too – if they choose to."

"At the moment, there just aren’t enough people taking part in these studies, without enough people, doctors just can’t prove anything. I will willingly take part in any study, even if I know I won’t benefit. I just think about those patients who might be cured in the future."

Visit sarcoma.org.uk/research for more information. If you would like to get involved with sarcoma research, give our Support Line a call on 0808 801 0401.
Sarcoma Awareness Week Update

A key week in the Sarcoma UK calendar, and we would like to say a huge, huge thanks to everyone who contributed to our SAW and Big Picnic! So much awareness and funds raised, transforming the future for everyone affected by sarcoma.

This is the first time the Big Picnic took place, and we’re thrilled that so many supporters across the UK held picnics during Sarcoma Awareness Week, raising about £20,000 in the process. Well done to all! Packs contained an exclusive poster and badges designed by artist Magda Archer and a branded picnic mug.

We also welcomed more visits to our website during Sarcoma Awareness Week, with the dedicated Sarcoma Awareness Week page being the fifth most visited page that week! We also saw lots of you head to our social media pages, including Facebook, Twitter and Instagram, where you commented and shared some of your own Big Picnic photos. There were also five features in the local press.

During the week, the Support Line on Tour met with more than 100 patients directly, who had either heard of us and used the Support Line or were interested in finding out more. We also spoke to people who weren’t sarcoma patients but were interested in what we were doing.

We participated in three patient events with local support groups: at the Boom Foundation in Northern Ireland, the London Support Group picnic, and the Oswestry support group who held their picnic next to the Sarcoma UK information stand as well as a staff picnic on the ward.

Next year’s SAW is 2-8 July 2018, look out for updates.
Sarcoma UK’s Support Line

During our Sarcoma Awareness Week in July 2017, we took our Support Line on tour around the UK to meet patients, and find out how we can keep on helping you all in the right way.

We travelled to Belfast, Oswestry, London, Swansea and Newcastle. It was a great chance to meet new faces. But our Support Line is always here for you. No matter where you are.

- Our Support Line is independent and confidential
- We believe no question is a silly question
- We lend a listening ear
- We can point you in the right direction

Call us on 0808 801 0401, either during our opening hours, or leave a message and we will get back to you. If you don’t feel comfortable calling, supportline@sarcoma.org.uk is the email address to message instead. You can ask us anything about sarcoma, whether you’re a patient, partner, carer, colleague, friend or you may have found a lump and are concerned.

If you have any feedback, please let us know too. We want to constantly improve our service to you.

Our general opening hours are:
Monday 10am - 2pm
Tuesday Midday - 4pm
Wednesday 10am - 2pm
Thursday* Midday - 4pm
Friday* 10am - 2pm
*Please note for the first Thursday and Friday of the month our Support Line hours are Thursday 13.30 – 16.30; Friday 9.30 – 14.30. The Support Line will be closed during Christmas: 23 December – 1 January.

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Until this morning, Hannah had never heard the word sarcoma. This morning was when a doctor told her she has sarcoma.

There are so many questions Hannah didn’t have a chance to ask. And she is scared. She needs to talk to somebody who understands sarcoma, now.

Sarcoma UK’s Support Line Team are here for every person affected by sarcoma.

Will you donate £15 a month to give people like Hannah somebody to talk to?

I’d like everyone affected by sarcoma to get the support they need.

To register, please fill out both forms. Form A should be returned directly to your bank (or you may be able to do this online), and Form B to us at: Sarcoma UK, 49-51 East Road, London, N1 6AH. Form B notifies us that you have set up a standing order gift and allows us, if applicable, to claim Gift Aid from your donations.