

Skeletal Cancer Trust

Magazine

Skeletal Cancer Trust is dedicated to the advancement of bone cancer research, to providing the best possible care and support at each stage of treatment and to improving the quality and dignity of life for all patients. To find out more about this great charity, including how to donate and how to get involved, visit skeletalcancertrust.com. To sign up to receive this magazine via email, click here.

This magazine lands in your inbox at a very strange period in all of our lives, I want to start with a message from our Chairman, Steve Cannon.

AUTUMN 2020

"We are travelling through unprecedented times. No-one has experienced the medical and social disruption that has been caused by Covid-19 both in the UK and worldwide. As Chair of Skeletal Cancer Trust I would like to express on behalf of the Board of Trustees and myself our continued support and thanks for all the medical, nursing and ancillary staff as they face the deluge of problems they encounter. Our support as well particularly for our patients who are so vulnerable, together with their whole families. The national lock down has inevitably resulted in changes in our fundraising but may I thank all those who continue to support us as we look forward to the return of normality. Everyone please stay safe."



As you will no doubt be aware, fundraising is rather difficult at the moment. It was with real sadness that we watched as our fundraising events were cancelled one after another. I want to thank everyone who is still thinking of us and supporting us. Although there are limitations on our 'normal' channels of fundraising there are new and exciting ways of supporting – keep reading to find out more. I also want to take the opportunity to thank Ross Johnson, Scott Watson, Rich Biscoe, Chris Burt,

Chris McDermott, Sam McDermott, Prathna Thakore, Kenny Stuart and Dave Toscano and James Wright who all trained of the London Landmarks Half Marathon – we will run this half marathon, I will make sure of it.



Sarah Wright Head of Fundraising

CAMPAIGN LAUNCH: 'SHARE YOUR FARE'

Make your commute count and share your fare by donating your daily, weekly or monthly commute cost to Skeletal Cancer Trust. Turn your commuting miles into smiles and help to improve the lives of children and young people with bone sarcoma.

www.justgiving.com/campaign/make-your-commute-count



Here's a reminder of where your money is going.

Primary bone cancer (also known as bone sarcoma) is rare, but often affects children and young adults. Most patients require complex and life changing surgery. Some also need chemotherapy and/or radiotherapy. Treatment protocols are extremely arduous

and sadly at present only around 70% of patients survive. Surgery to remove the tumour is essential, many patients face amputation, and almost all are faced with lifelong disability as a result. The RNOH is one of the largest centres in Europe for the surgical treatment of patients with musculoskeletal cancer and has a leading role in treatment, training and research.



Christmas Cards

Our wonderfully talented Jo Buonaguidi has designed and donated the image for our Christmas cards again this year. She works really hard to organise this for us.

The inside has been left blank for your own message

To purchase your cards please email rnoh.sct@nhs.net

Get involved: The 'Bridge'ie' challenge

- the alternative Thames Bridges Trek

As many of you know, one of my favourite events on the SCT fundraising calendar is the Thames Bridges Walk, a 25km walk across 16 of London's iconic Bridges, which usually takes place at the beginning of September. Well, this year I propose we take part in the virtual 'Bridge'ie' challenge.

The details:

The challenge: Walk (or run) 25km over October - include at least one bridge and have a photo taken on it – it's a selfie on a bridge – a 'Bridge'ie' - post this photo to Instagram with the hashtag #onebridgechallenge – don't forget to tag @skeletal cancer trust

The fundraising: set a target of £150 and raise money for SCT

How to get involved: email Sarah at rnoh.sct@nhs.net



ART PRINT IN RETURN FOR YOUR DONATION

"During lockdown Captain Tom Moore raised our spirits and our faith in ourselves that we can all make a difference. I cannot run, I cannot sing, I cannot play a musical instrument sooooo I have painted a picture as a tribute to a massively special man. I believe history will record the 'Walk of Captain Tom.'

"I have a very special leg. As a result of what was then pioneering surgery, back in 1985, instead of having my leg amputated due to a bone tumour, I benefited from a Stanmore prosthesis which replaced most of my left femur and knee joint).

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This treatment lead to an ongoing relationship with this type of orthopaedic surgery for over 35 years and still going. It has been a privilege to be involved with this charity.

"I painted this picture of Captain Tom Moore as a result of the happiness he spread during these difficult and sad times. His spirit is infectious and the picture reflects how my heart felt when I painted it." – Jo Buonaguidi

We also have the Captain Tom prints available as postcards.

You can purchase a signed 30 x 37cm signed print for £50 or an A4 size print for £26 here's how:

Step 1: Go to https://www.justgiving.com/fundraising/jo-buonaguidi-captaintomprint and donate £26 or £50 (depending on the size you would like to purchase).

Step 2: email your order, including your name and address to rnoh.sct@nhs.net or to Jo@JoBuonaguidi.com

Step 3: receive your print (please note: this may take up to a week)

One Autumn Day

One of our many talented supporters is Fred Scott. Not only is Fred a fantastic musician and composer he also wrote and published a book about his experience of surviving cancer. 'Fred's physical and psychological battles are both encouraging and inspirational. His heart-warming story will certainly offer consolation and reassurance to those living with the reality of cancer.'

Fred and his daughter Lily (also a musician) were recently guests on the 'as it comes' podcast which you can listen to here:

asitcomespod.podbean.com/e/episode-26-fred-and-lily-scott-the-gig-goes-on

You can find out more about Fred's book, One Autumn Day, here: www.oneautumnday.co.uk



Henry's Duke of Edinburgh fundraising activities

"Ellis was diagnosed with Osteosarcoma at 12 years old. Osteosarcoma is the most common form of bone cancer. A month after Ellis's 16th birthday she lost her battle. My brother Sonny and I were only young at Ellis' 16th birthday party in the garden but I remember that it was fantastic afternoon, we wore matching shirts, which were covered in chocolate from the chocolate fountain.

"SCT is the charity supported by the Ellis Harriet Clark Foundation and my whole family so I asked if I could tailor my Duke of Edinburgh activities to raise money support other children with bone cancer whilst also raising awareness.

"My Duke of Edinburgh fund-raising activities so far have been the sale of Christmas cards.

Every weekend in December, I went to my Dad's shop to sell the cards.

"I also arranged for a local Hotel to donate the profits of their burger for a week to the charity.

My others plans are:

- Movie night at home with my family ticket entry
- · Zoom 'Elberts' Party DJing donate to join
- Bake sale
- Guess the number of sweets in a jar
- Car wash
- A FIFA 20 Pay-to-play tournament, a winner from each division goes through to the final play-offs.
- Henry Shipton



The 'Burpee Challenge'

Virtual and innovative fundraising is the order of 2020 and this challenge was certainly innovative. Orthopaedic Oncology Physiotherapist at the RNOH, Abby McCarthy, and a team of

enthusiastic (and clearly very strong) physios took part and completed the 5300 Burpee Challenge. Collectively they smashed their £500 target. A huge thank you from me and the Board of Trustees.

Pledge a monthly donation

As previously mentioned, we are really missing the donations that we normally receive through the fundraising activities that so many of you take part in. If you would like to support children, young people and adults with sarcoma you can pledge a monthly donation of whatever you can afford, every little bit helps. Here's how: simply click here and then set up a standing order with your bank.

Here's why Debbie supports us with a monthly donation

"After the absolute heartache that followed Becky's diagnosis of an Osteosarcoma in 2004 we have been so lucky to have so many highlights and positive occasions – all of her birthdays, Christmases, gaining her A-levels, a place at university and her Graduation Day (where her Dad and I unashamedly cried tears of utter joy throughout the entire service as we had never imagined we would celebrate such an amazing day). YOUR DONATION TO SCT will ensure more families get to experience amazing days like these and gradually replace the memories of the awful ones that

came through the period of diagnosis and recovery. Although they never leave, they gradually fade and your life is filled again with happy occasions and laughter.

"So please give up the price of one coffee a month, or one lunch or dinner out and put a smile on someone's face, it's a much better feeling than any amount of caffeine or a full tummy can give you. We are now 15 years on and still donate to SCT and The Marsden because simply without theirnsupport Becky would not have had such great odds in her favour and therefore her character limited. Life really is so so precious.

"Never ever think you cannot make a different as every single donation is required and desperately needed. Far too many lives are affected by this horrendous disease and we must all work together to fight it. The facts are that the research works... my daughter is proof."

— Debbie McDonnell

Improving Quality of Life after Sarcoma

The impact of cancer doesn't stop when treatment finishes. After treatment patients may be less active, have muscle weakness, be at risk of falling or bed bound or struggle with everyday tasks, all of which significantly affect physical, psychological and social health, quality of life (QoL) and life expectancy. This has a significant impact on patients and their families. Some patients with tumours of the sacrum can lose bowel or bladder function.

As survival rates for bone cancers have slowly increased, the number of survivors has grown. It is therefore increasingly important to understand their lived experience and develop solutions and services to help them get on with their lives. This includes evidence based follow up services, which go beyond the present technical emphasis on tumour recurrence and deal with the social and psychological impact of bone cancer and how best to return people to normal life. Such services should also minimize expense, time, family and work disruption. We need support to develop the evidence for these services.

— Craig Gerrand and Sherron Fertado



The Skeletal Cancer Trust is driven to support patients through their journey of care and to develop high quality research to support people's treatment and reduce impact of cancer and its treatment.



The SCT Hour

If you haven't listened to the most recent interviews then please click here to hear from Tina Thomas who is just so strong, inspiring and courageous. For Tina and her family, fundraising for SCT has been a chance to channel their grief into something positive.

You can also listen to Jo Buonaguidi, Billie Clark, James Wilson, Abby McCarthy and Hannah Hughes.

And finally...

I am sure that many of you were involved in initiatives in your local areas during the initial lockdown period. This might have been helping neighbours with shopping, joining your volunteer 'hub', clapping for our amazing NHS, carers, and key workers and much more. In my local area in Eltham, Greenwich I was a small part of something amazing, a group of local ladies, driven by the Chislehurst and Sidcup teachers and Parent's Association started sewing scrubs, sewing masks and making face shields and other PPE. One Sunday afternoon it was all hands on the deck around our kitchen table washing and constructing the face shields. Two of the incredible sewers made these beautiful bears and donated them to the RNOH Children's ward. Some of the children that are treated there are with us for many months, some are often understandably very anxious about the operations and treatment that they are undertaking. So a huge thank you to Angela Morton and Susan Roberts.



Notice board

Huge BIG congratulations to Lizzy and Jasper Keech on the birth of their beautiful little boy Alfie he is absolutely beautiful – from Craig, Nicki and the rest of the Stanmore team.

BIG huge amounts of LOVE and best wishes to Fran who is recovering after her operation at RNOH, you are such an inspiration and your positivity is incredible.

Thank you

Jo Buonaguidi, Henry Shipton and his Mum Wendy, Sainsbury's Canterbury, Joe Fraire, Abby McCarthy, Fiona Matthews, Kate Scanlan, Roisin Delaney, Sarah Bitar, Isobel MacCallum, Laura Mitham, Neena Mistry, Olivia, Shea Byrne, Marion Davies, Elaine Liffchak, Debbie McDonnell, Sue Doherty, Janet Bridge at Country Way, Angela Morton, Susan Roberts, Jed Backhouse, Tom Carson, Graham at Kingsmead Cards IoW and Joe at Fine Art Solutions in Chessington.

COMING SOON - for all of our cyclist supporters, we will soon have exciting news to share with you...

Virtual fundraising ideas

Run a Virtual exercise class

Organise an arts and craft session

Pay to play virtual bingo

Pay to participate virtual coffee morning / dinner party

Run a photography competition

Are you musically gifted? Organise a virtual concert and charge an 'entry' fee

Have you had your running, cycling, walking event cancelled? Why not set up a socially distanced event of your own? No more than six people

If you have any virtual fundraising ideas, please do get in touch and I will be happy to help you organise them.

To sign up to receive this magazine via email, please click here. See the latest news, events and research at skeletalcancertrust.org

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