



Skeletal
Cancer
Trust

News

Winter 2019

The 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.org



It has been another great year here at SCT and I decided what better time than now to list some of our incredible achievements, which has included: a name

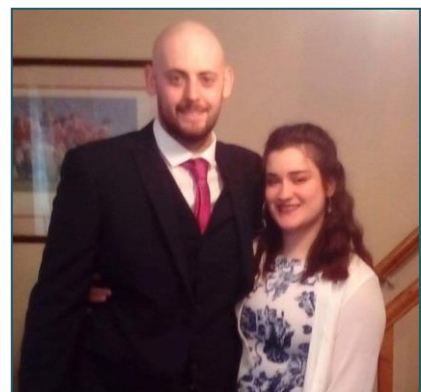
Merry Christmas

change and re-brand; the launch of the 'SCT Hour'; a Halloween fundraiser; 'Merry Christmas Deer' Christmas cards; 10 amazing finishers in the London Landmarks Half Marathon; 36 finishers in the Thames Bridges Walk; Steve Cannon's interview with the BBC; the official opening of the Stanmore Building; donations from Bowls Clubs, Golf Clubs, bake sales and table top sales; the exciting launch of the 'survivorship after

musculoskeletal cancer' project; the appointment of a MSK Pathology Project Manager; continued support for amputees through the 'live life to the full' campaign and yoga, to name a few! I am always amazed at how much this great charity achieves. We have done so much but we must do more. So as we head into 2020 (!!!) we are fuelled with ambition and armed with a 'to do' list. From all of the Trustees here at SCT we wish you a **Merry Christmas and a Happy New Year.**

This edition of the newsletter is dedicated to Tom Carter.

Through the Live Life to the Full campaign Tom was given an upgraded prostheses enabling him to play cricket again which was a massive part of his life. A true inspiration to so many, very much loved and very much missed.



Looking for a New Year's resolution - Pledge a monthly donation

With a regular donation you can help us get a better understanding of sarcoma, how to treat it, how to cure it - how to survive and live a full and long life.

"SCT provided my daughter Shannon with amazing support at a crucial time in her treatment which really made a difference. I thought - how can I ever thank them? Then I heard about the monthly donation scheme and by donating even a small amount I can help others get the valuable support."

Email rnoh.sct@nhs.net for details on how to get started.

Charlie Hewson

"November, 2010... just another day with a busy nine month old. I got him changed. I looked at his left leg, it looked swollen and felt slightly misshapen, however he was still being his happy self and he was ok to stand on it. 'Maybe I should get him checked out at the doctors?' I thought to myself, 'will I just be wasting their time?' My mum and sister are nurses. 'Just take him to A&E in the morning, even to just put your mind at ease.' Thankfully we did take him, X-rays were taken, CT scan done.... 'We are going to transfer you to Great Ormond Street, we fear it may be serious' the doctors said.

"Bone marrow aspirate, MRI scan and finally a biopsy confirmed it was indeed bone cancer, Ewing's Sarcoma to be exact - in his left femur. The soft tissue around the femur, in his bone marrow and it had also metastasised onto his lungs and ribs.

"A rigorous chemotherapy protocol followed, six rounds of chemotherapy administered every three weeks, neutropenia with temperatures, antibiotics in the local hospital - it was relentless.



“‘We need to talk about surgery’ said Dr Michalski, our oncologist. We are going to refer you to see Mr Pollock at the RNOH. That first meeting was a bit of a blur, we were so caught up with the cancer treatment that we hadn’t given the fact he may need surgery any thought.

“Mr Pollock advised - ‘We think Charlie would most benefit from Rotationplasty. It involves removing his femur, moving his tibia up into his hip joint and rotating it 180 degrees’. The shock was immense. Here was my beautiful baby boy who had gone through so much already. What if he might never walk? He is going to look different from everyone else, I can’t make that decision for him. It was an agonising time, this is for the rest of his life.

“With the amazing support from the hospital, they finally made us realise that not only is this surgery going to save his life, it will also give him the best chance of having as normal a life as possible, and how right they were. Six months after surgery, he had his first prosthetic leg fitted. Six months after that, he took his first steps alone and where are we now... he is football mad. He plays for Brighton and Hove Albion amputees, he attends training sessions at the England Football amputee association and he plays mainstream football for his local team and in August he competed in a triathlon. Not bad for a nine year old.

“I will be eternally grateful to everyone involved with not only his care and rehabilitation, but also mine and my husband’s. It has been quite a journey.

“His strength and determination continues to amaze us every day. He is a happy and healthy boy with so much energy and enthusiasm. Nothing stands in his way - he is our inspiration.”



Halloween Party in memory of Adam Thomas

Great fun was had by all on the 2nd November this Year as family and friends gathered to celebrate a year of fundraising in memory of Adam Thomas.

Adam lost his life to Osteosarcoma at the age of eight and would have been 30 on the 31st Oct 2018. Family and friends decided to take part in a year of Fundraising for SCT in his honour culminating in a Halloween party.

There were various fundraising activities on the night including a cake sale, a book sale, face painting and balloon making. The children were entertained by well-known magician 'Mr Tiz' and the adults danced the night away to the tunes of local band 'The Purple Sound'.

The highlight of the evening, which was a complete surprise to the family (even to James' parents) and friends, was when Adam's brother James and his friends John Smith, Brett Shiels & Harry Whitbread re-formed their boy band for one night only

and performed a Back Street Boys 'tribute' medley. James, John, Brett & Harry attended a local performing arts school until they were 14 and had not performed together for 15 years! Needless to say, they brought the house down!

Along with a top prize raffle and Halloween fancy dress competitions for young and old, the evening was a sparkling success and £1,700 was raised for SCT on the night.



SCT Hour

All SCT Hour podcasts are available on our website.

More to follow in the New Year – including Tina Thomas, Andy Roast, Rob Pollock and many more.

www.scatbonecancertrust.com/sct-hour

The SCT Hour is a sixty minute show on all things related to Sarcoma at the RNOH, hosted by Sarah Wright, Head of Fundraising at the Skeletal Cancer Trust.

Including interviews with fundraisers and supporters, as well as physiotherapists and surgeons who work at the RNOH. We will also feature highlights from some of our fundraising events.



SCT Project – Maffucci and Olliers Research Nurse

The 7th Maffucci and Olliers Association conference was held on the 5th October in Wembley, London and was a huge success. The attendees have increased year on year, which shows the need for a support network for patients. The conference covered a range of topics including talks from Consultant Histopathologist Professor Adrienne Flanagan OBE, Consultant Orthopaedic surgeon Professor Robert Ashford, Consultant Neurosurgeon Mr John Gooden, Occupational therapist Lisa Heywood and Association founder Charlotte Anwyll.

This year we were able to introduce a new role; the Maffucci and Olliers Association Research Nurse Millicent Lipshaw, funded by The Red Robin Trust, the Royal National Orthopaedic Hospital Trust and the Skeletal Cancer Trust. Without the support this venture wouldn't be possible. This is a brand new role and has been designed to help facilitate Clinical Guidelines, undertake research, meet with patients and families and to help support patients with these conditions.

“I have been spending time with families and healthcare professionals to understand the difficulties faced from both sides. I have seen some of the challenges patients have faced; from their journey to a definitive diagnosis, to feeling understood and supported by healthcare professionals along the way.

We are working to provide more recognition and national guidelines so that families all over the UK will receive the same standards of care.

It is an exciting project to be part of and I am really proud to be an advocate for patients and families who are living with these rare conditions.”

- Millicent Lipshaw



Thames Bridges Trek 2020

Join the SCT Team on Saturday 12th September

Sign up here:

skeletalcanertrust.org/thames



Eileen Stoner and supporters

“Our SCT stall at Stanhope Agricultural Show was a great success. I was donated bags of excellent small toys for the children's Lucky Dip and we also ran a Tombola. My son David helped on the and was amazed at the number of people supporting us ! The stall raised £300.

I have another donation of £30 to add, raised on the counter of our local Chatterbox Cafe in the next village, St Johns Chapel: they are selling books for me written by friend Peter Thompson whom I met when I was volunteer Secretary and he was volunteer Chairman of Stanhope Open Air Swimming Pool (a charity). He retired wrote a book, and has donated the remaining copies for me to sell for SCT. The book is 'Monnet, a Good Impression'- amusing and interesting account of his DIY renovation of a derelict

ancient farmhouse in France 'with the help of friends'.”

Eileen has supported SCT for the last 10 years after her Grandson Thomas (son of David mentioned above) was so successfully treated by Mr. Pollock a decade ago. To date, Eileen has raised almost £8,300!

“So many folk have helped me over the years - a local choir held a concert and donated their takings of £115; Stanhope Travel agent Jon and his father ran in the Great North Run and was sponsored for £1,000!; a local lady knits beautiful items for me; Bruce's Dad buys the lollies and paper bags for my Lucky Dips; a bag of toys was left in our porch on Friday ... and so it goes on! The support is wonderful. This has become my occupation and hobby.”

Thank you

To everyone who has bought Christmas cards and has supported us throughout the year.

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Skeletal Cancer Trust

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