# Supporting the families of children with cancer SPRING 2021 Issue: 77 Bumper edition! LAST YEAR'S Find out more on pages 4 & 5

To support us or find out more visit: WWW.Candlelighters.org.Uk











# Welcome!



Hi, it's Candlelighters here. You might have wondered why you didn't receive The Candlelighter newsletter from us last year. Don't worry (no one's pinching your post!), we decided during such a challenging year that we needed to focus our time and resources on supporting families and ensuring the charity can continue running, so we didn't print any newsletters in 2020. We're delighted now however, to be able to welcome you to our extra-special Spring 2021 Bumper Edition which is packed full of the many achievements, stories and simply inspirational feats that together we have accomplished over the last year.

#### Pages 4 & 5 Take a look at Last Year's journey!

Pages 6 & 7 Find out about our Day of Memories 2020 the support we receive from the wonderfu

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We hope you enjoy this jam-packed edition. Our first update is from Stephen Redman, who in June last year, stepped down from his role as Chair of Trustees to welcome new Chair, Keith Hardcastle.





I feel so privileged to be able to continue my support of Candlelighters in my new role as Chair, after many years as parent, Trustee and Vice-Chair. Firstly, on behalf of everyone at Candlelighters, I have to express our huge gratitude to Stephen for his passion and commitment during his time as Chair. Not only has he been pivotal in making Candlelighters the charity it is today, he has been so supportive to many within the organisation.

Update from our Chair - Keith Hardcastle

Like most people in these strange times, we have many challenges to face in the coming months, alongside our business-as-usual support for the children and their families, together with strategic adaptation. However, we have a superb board and amazing team at Candlelighters, whose focus and passion for what they do always amazes me. Every penny makes a difference, and the future is bright: we will keep our candle burning for all that need our support.

Our excellent team are agile and flexible, continuing to provide support where it is needed. Don't forget, we are still here for you, please get in touch if you need us.

To our supporters and volunteers too, I'd like to express huge gratitude from us all - we could not do what we do without you. We need your help now more than ever and appreciate everything you do to support us during these difficult times, no matter how large or small.

I hope that one day I am able to meet more of you, but send an interim 'thank you' in anticipation of your continued support. I look forward to the challenges of being Chair and send heartfelt wishes to all families affected by childhood cancer, our thoughts are with you.

## Update from Stephen Redman

As I write this, I am well aware that this is probably my last time writing for this magazine. I have been volunteering with the charity for 22 years, I have been on the board for about 13 years and have been the Chair for six and a half years (my term ended in June).

All charities deserve fresh blood and my first act as Chair was to ensure that we had a policy about who was Chair and how we replaced them. I was re-elected after three years for a second term, but now I have handed on the torch. In the last couple of years, I have been overseeing a programme to make sure that the Trustee board has fresher faces and ensuring that in terms of governance we are ready for the next decade. I will remain on the board until the next AGM but then I will move on.

#### Will I disappear? No way! I will remain available to you and to the charity.

Like most of you, I am committed to Candlelighters because of a personal link that will not go away. My son, Rocky, was treated in 1998/1999 and died of neuroblastoma in 2001. He is still part of our lives every day and I can no more forget Candlelighters than I can forget him.

Our new Chair, Keith Hardcastle, and the other Trustees have a huge task ahead, recovering the charity from COVID, but I am personally confident in him and believe in good years ahead for Candlelighters.

Like me, you can still help the charity with your coffee morning, your sponsored walk, your business support, your bath in pink custard or even a legacy in your will - all of which makes a huge difference and allows us to help families that are facing now, what my family faced two decades ago.

Together we can make the difference - together we can fight children's cancer!

# Update from our CEO, Emily Wragg

I am delighted to welcome you to this edition of our newsletter. I hope, despite the difficulties we have all faced this year, when you read this, it will highlight just how much can be achieved with the support of so many incredible people. COVID-19 has impacted all of our lives, but it has made life for families affected by childhood cancer even harder, which is why our absolute priority has been to ensure that we continue to support families as and when they need us, for as long as they need us.



Like many other charities, the pandemic continues to have a significant impact on our income, with events and some traditional fundraising activities still unable to take place. I am truly amazed by the support we have received so far from everyone helping us to raise money, it's incredibly heartwarming and I cannot thank you enough, you are all so unbelievably inspirational. Without your support and dedication we would not be able to do what we do and every penny raised is helping us to keep our candle burning.

I also feel incredibly proud to be working alongside so many wonderful colleagues from Candlelighters, the NHS, Leeds City Council, Leeds and York Universities, other charities, and organisations who work tirelessly to support children affected by childhood cancer across Yorkshire. I would also like to thank Stephen for his amazing leadership over the years, who we know will always be a part of our Candlelighters family, and to Keith, who is already doing an amazing job in his role as Chair.



# Last Year's Journey!

Alongside people all across the country, we were sent to work from home in March 2020, due to the COVID-19 pandemic. Most things we had planned for the year were cancelled overnight. We knew we had to keep raising funds and supporting families, although we weren't entirely sure what either of these things might now look like. Immediately the team and our amazing supporters rose to the challenge and here's what we did...



We raised over £4,800 for our first ever VIRTUAL fundraising event, including live party games, a quiz and a DJ set!

### Day Of Memories

Restrictions meant that our annual event had to go ahead a little differently. We decided to mark the occasion in a special, virtual way, for families to come together and remember the children they have lost to cancer.







Our annual Christmas raffle went digital too! We raised £4,153 and to top it off, the first place prize was won by a family on treatment which was a lovely Christmas present for them.

### We're still here for you"

Lockdown didn't stop us from being there for our families, we quickly adapted our services so we could continue delivering them virtually.



Our team and supporters took on the virtual challenge from London Marathon organisers, raising £21,390!

challenge

We celebrated CCAM with a Big Golden Quiz, Golden Hour, and by sharing family stories.

We raised £645 throughout **CCAM through Facebook alone!** 





We spent lots of time

preparing to open The

Square, making it COVID-

secure for families. Then,

Leeds, we decided to not

due to rising cases in

re-open as planned. It proved to be the right

decision as soon after. Leeds was placed into a local lockdown.





#### Christmas Stars

Our final fundraising campaign of 2020, asking supporters to light up a virtual star for someone who has brought light to their life. We saw some truly beautiful messages for a whole variety of reasons.

There were 99 stars in total, raising £4,529.



## Christmas on the Wards

**444444** 

We made Christmas as special as it could be for families staying at the hospital: from gifts and treats, virtual Santa visits, Christmas dinner for parents to our very own Candlelighters Elf. It was truly magical!



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Through the pandemic, Trusts and Foundations stepped up to support charities like ours, affected by huge income losses. We received funding from over 30 Trusts and Foundations, providing emergency support, funding specific projects and roles, and covering core costs. We're incredibly grateful to these organisations, including The Julia and Hans Rausing Charitable Trust, who supported over 300 UK Charities, including Candlelighters, through their Charity Survival Fund. It has made an unbelievable difference. If you know a charitable Trust or Foundation who would consider an application from Candlelighters in 2021, please email Roz. Walton e candlelighters.org.uk.

At first our team were

unable to work on the

hospital wards so, we

We also made an

came to families virtually:

interactive goody bag for

newly diagnosed families,

demonstrating the work

that we do through

a variety of treats and treasures!

Watch here..

We released our film appealing for support in such difficult times. It got 18.5k views!



## TEAM 500!

We created Team 500 as an easy way for businesses to support families through the pandemic, by donating £500 or more.

30 amazing members joined, raising £110,995!



A iam-packed virtual event diary for families throughout the school holidays, including a mini-vacation to Island Zoom-tugal, a time for families to catch up with each other and have some fun.



**44** 



- Over the year we have offered **\*** 42 Virtual Family Groups
- ★ 7 Support Groups at The Square for bereaved families
- ★ 37 Virtual Events and **Group Activities such as** our Virtual Beach Party and Summer Disco

#### From April-December we provided

- ★ 327 Individual Wellbeing Sessions
- ★ 114 Individual Adult Talking Therapy Sessions
- **116 1:1 Young Person's Support Sessions**

### Over the year we have delivered

We continued funding roles across the

Trust, adapting support for NHS staff,

key workers, and outreach teams. We

sessions for hospital staff, tea, coffee

and biscuits, plus so much more!

provided Talking Therapy and Wellbeing

★ 238 1:1 Virtual **Craft Sessions** 

Working from home, our team embraced new ways to keep in touch and keep the charity running, including tools like Zoom and Slack!



Pink It Up!

A month of virtual activities,

raising £2,881.

The Great British Bake

Candlelia

We even got stars of

Off to judge our Big

Pink Bake Off!



It meant more than ever to hear your fundraising stories and how you continued to support Candlelighters in a variety of ways. To this day, we've been sharing these stories on our social media with the hashtag **#SupporterSunday!** 

To the best of our abilities, we continued providing memory-making activities for children receiving end of life care, ensuring these families could still create special memories together

We'd like to say an enormous thank you to our wonderful volunteers for your patience and continued support throughout 2020. Government guidance won't allow us to welcome you back just yet, but we've been thinking lots about how we can involve you safely (and potentially virtually!). In the meantime, please keep in touch with us and continue to support our campaigns, we'll be in touch as soon as we can.

All in all, 2020 was filled with challenges but we're so proud of what we achieved! Despite the challenges we faced, we continued to raise funds and support families, and we're so glad you came on the journey with us.





In 2020, we were vitally supported by numerous Trusts and Foundations. Ian Pruchniewicz, Chairman of Trustees of The Susie P Charitable Foundation, a generous supporter of Candlelighters for several years, tells us more...

### Why was the Foundation set up?

In 2006, when my late wife, Susan, was undergoing chemotherapy for metastatic liver cancer, she spent many days in the oncology department of the Leeds Teaching Hospitals. At that time, she saw children also being treated for a variety of life-threatening cancers. She went through her own treatment with strength and dignity, but would often be upset by seeing the children there too. She would say, 'I have had a good, fortunate life with a loving family, but these children are only just starting their lives and need all the support that they can possibly get'.

She sadly lost her battle with cancer in May 2007. As part of her legacy, in agreement with our three sons, we decided to dedicate some of the assets held in Susie's name to a charitable trust with a very specific aim: to improve the lives of children suffering from cancer in the West Yorkshire area.

#### How did you support Candlelighters in 2020?

After discussing with Candlelighters, the Trustees agreed to support a shortfall in two areas. The first was the ongoing need for professional support for families with children undergoing treatment, facing exceptionally difficult circumstances due to COVID-19. The second was the need to provide small grants to families experiencing financial hardship, to give their children a 'normal' Christmas during a very challenging year.

We are so grateful to The Susie P Charitable Foundation, and all of our Trust and Foundation partners for enabling Candlelighters to continue delivering vital support to families.





"Sometimes memories sneak out of your eyes and roll down your cheeks." At Candlelighters, we understand how important Day of Memories is - each year, families and teams from the hospital, community and Candlelighters come together to remember the children who have sadly passed away from childhood cancer. Due to the restrictions last year, our annual event had to go ahead a little differently and so, we decided to mark the occasion in a special, virtual way.

We all gathered digitally to watch a video dedicated to the children who have sadly lost their lives to cancer. This very special video included readings of poems, songs and stories, delivered by members of the hospital staff and outreach teams. Meeting virtually gave an opportunity for families and staff to chat to one another, and reflect on fond memories.

As a final act of remembrance, two trees are to be planted to commemorate this special day: a lovely cherry tree at Shibden Park, Halifax, and a beautiful beech tree at Rowntree Park, York. More details of these will be sent to our families shortly.

I cannot thank Candlelighters enough for your continued support throughout this very different year. Once again, you have gone above and beyond to get everything just right. Both my mum and I thought the memory day was just perfect. It was just enough and you still managed to cover everything, even down to the activities. I am so grateful to you all for making this day possible, thank you all so much, you are all amazing people.

Bereaved Mum

## DONATIONS IN MEMORY

Donations in Memory are very precious to us. Whoever your donation remembers, we thank you for your very special way of showing your support DONATIONS FROM 1ST JULY 2019 - 30TH NOVEMBER 2020.

### A - G

Abigail Rose Haley £32.50, Adam £18.75, Adam Saeed £93.75, Aisha Coggan £599.17, Alan Robert B £56.25, Alex Marsh £89.56, Alex Read £2.37,
Ali Khan £2,094.84, All the children that have sadly lost their fight £50.00, Amanda Botham £20.00, Andrew (Chalky) £720.66,
Arthur Ray Lyall's Brother & Barrie £250.00, Audrey & Eric Doyle £35.00, Audrey Doyle £35.00, Auntie Linda £25.00, Barbara Ann Lowe £176.20, Barrie £812.50,
Belle & Neve Boitelle £1,689.94, Belle Ellis £749.02, Ben Lilley and Benita Duthoit £50.00, Benjamin Ramsay £15.00, Beryl Hebron £99.00,
Bethany Fitzpatrick £125.00, Billy Pilotille £163.35, Blake Holdsworth £55.00, Bradley MacDonald £2,647.39, Bradley Stevens £12.50, Brenda Tinker £613.00,
Brendan Myers £740.13, Brian £20.00, Calvin Marshall-Patel £3.56, Carrie Langford £465.00, Catherine & Corrie £25.00, Ceri Anderson £1,166.87,
Ceri Hill £25.00, Chris & Kev £506.25, Chris Ronald Weaver £12.50, Christian Milner £3,429.20, Christine Robertshaw £250.00,
Christopher & Chloe Smith £297.43, Christopher Chapman £422.74, Clifford Hardcastle £300.10, Colin David Arc £1,220.00, Collette Rhodes £1,164.44,
Connor Lancaster £33.44, Cristiano Sousa £120.05, Dangerous Dave £25.00, Daniel Bland £10.00, Daniel Jackson £782.13, Daniel Stamp £125.00,
Danielle Wade £25.00, David Barker £118.75, David Coopland £11,668, David Durkin £115.00, David Hood £1,396.89, Don £37.50, Don Cunningham £50.00,
Dorothy Busby £350.00, Earmon Crossley £21.00, Eileen White £473.78, Eirik Kjellstad £112.50, Elaine Patchett £95.00, Elizabeth (Liz) Clements £1,228.75,
Ella Crann £909.19, Ellis Price £202.50, Elsa McGee £95.00, Elsie Ward £260.00, Emilie Robinson £103.76, Enzo £125.00, Father of Raymond Hartley £10.00,
Finlay Nuttall £312.50, Finley Bailey £1,129.04, Freddie Thompson £1,072.67, Freya Lewis £15,098.44, George Harker £31.25, Gerald G Scott £100.00,
Gordon Hurren £201.25, Grace Wheeldon £15,980.78, Graham & Vera Elliott £62.50, Gran Thomas £6.25, Greg Vinnicombe £1,234.33, Guy Metcalfe £15,315.08,

### H-K

Hannah Collins £1,375.00, Harold Fox £78.55, Harri £400.00, Harrison Torr £452.10, Harry Buckley £544.35, Harry Coates £360.00, Harry Cook £267.19, Harry Flatt £1,612.09, Harry Taylor-Robinson £755.75, Harvey Kendrew £88.17, Harvey Pettit £125.00, Hayley Blogg £25.00, Hazel £25.00, Heather Hilliard £896.00, Helen Long £72.50, Helen Megginson £405.00, Henry Harner £913.95, Holly Price £788.00, Hope Rooms £419.38, Hughie £yles £540.00, Ian Michael Appleby £456.30, Ian Smith £1,060.15, Isabelle Ellis £160.00, Isobel Crawshaw £150.00, Jack Gales £475.00, Jaiden Worrall £4,009.27, Jake Knowles £50.00, James £9.61, James Brook £4,189.72, James Martin £197.94, Jane Eyre £200.00, Jane Gilbert £4,602.23, Janet & Thomas £6.25, Janet Wood £341.56, Jean Carter £35.00, Jean Cleminson £12.50, Jean Mee £275.00, Jeanne Roberts £75.00, Jennie Hockin £31.25, Jessica Weaver £10,454.66, Jo Wood £62.50, Joan Badrick £85.00, Joan Mary Dalrymple £18.00, Joan Walsh £537.50, Joe Stewart £1,546.25, John & Anne Rogers £300.00, John & Vera Elliott £1,250.00, John Elliott £24.00, Joseph Mayman £2,203.97, Joseph McDermott £462.50, Joseph Stewart £295.00, Joshua Kinnear £2,472.59, Judith Sykioti £25.00 Julie Andrew £25.00, Julie Beaumont £91.18, Justin McKeown £31.25, Kathleen Adcock £525.00, Kathleen Lucas £191.50, Kathryn Hopwood £87.50, Katie Atkinson £50.00, Katie Raw £107.50, Kayleigh Logg £92.05, Kenneth Gallimore £190.00, Kev Hirst £88.78, Kevin & Andy £250.00, Kevin Adcock £807.57, Kevin Hirst £145.36, Kieran Duffy £972.81,

#### 1-0

Late Wife of Geoffrey Sutcliffe £1,000.00, Laura Hart £5,146.94, Lauren Kisby £2,566.49, Lauren Young £749.97, Leanne Holt £36.25, Lionel Moon £100.00, Lucy Moore £163.75, Maci Craddock £9,710.69, Marianne Shackleton £140.82, Marion Wear £96.10, Marjorie Berry £243.00, Mark Ashley £20.00, Mark Butterfield £155.00, Mary Carter £122.00, Matthew Adcock £2,475.14, Matthew Wrigglesworth £575.59, Maureen Allison £250.00, Maureen Hewitt £40.00, Maurice Tettey £307.80, Megan Bell-Walker £267.05, Megan Pratt £433.39, Melanie Laffey £3,883.28, Melinda Greaves £395.20, Michael Deakin £30.00, Michael Norfolk £764.22, Michelle Karen Smith £58.14, Michelle Lord £425.00, Mick Walker £1,893.39, Millicent Smith £138.95, Molly Clark £61.77, Molly Kathleen Clark £250.00, Mother of Alison Stewart £270.00, Mr David Lightfoot MBE £902.00, Mr Fitzgerald £380.00, Mr Fitton £163.33, Mr Keith Hardbottle £137.86, Mrs Hilda Mary Wood £101.48, Mrs Pat Coopland £25.00, Musadique Ahmed £476.00, Nannie Ida & Abigail £20.00, Nicholas Throssel & Daniel Poskill £50.00, Nick Gill £50.00, Nicola Aisthorpe £554.64, Nicole Stevens £52.45, Nioni Grant £353.60, Noel Fawcus £380.00, Nola Shipley £118.75, Norah Cartile £170.00, Noreen (Nanny) Craddock £31.25, Olive Hewson £10.00, Oliver Field £39.46, Olivia Arnold £503.86, Patricia Ann Coopland £30.00, Patricia Sutcliffe £50.00, Peter Bray £50.00, Peter Shepherd £12.50, Poppy Scaife £30.00, Qasim Warsi £50.00,

### R = 7

Rebecca Roberts £10.00, Rebecca Varney £2.37, Regine Allan £20.00, Renee Payne £178.00, Rueben Walder £13,632.67, Richard Cogley £92.14,
Richard Hall £107.12, Rob Brown £74.89, Robert Blundell £129.00, Robert Naylor £625.00, Rory James Welsh £3,287.90, Rosemary Gail Ackroyd £236.16,
Roy Bedford £213.75, Sadie Clifford £777.50, Sarah Bainbridge £2,666.45, Shaun Clapham £1,866.21, Shaun Markey £77.80, Sheila Arkell £100.30,
Sheila Thornton £177.00, Shirley Stoddart £30.00, Sienna Shield £7,116.40, Skye Sutcliffe £3,670.99, Sophie Drake £25.00, Stephen Griffin £93.75,
Stephen Rollinson £120.00, Stephen William Brady £3.00, Stuart Whittaker £30.00, Summer Rose Thompson £4,393.12, Sylvia Dawson £1,440.25,
Taylor Sheldrake £11,990.10, Ted Semain £100.00, Thomas Cammack £524.68, Thomas Hudson £12,471.13, Tim Slater £156.25, Timothy Cawley £94.52,
Timothy Wray £157.50, Tom & Emily Smith £10.00, Tony Rich £100.00, Tracey Clark £152.94, Trevor Leach £394.20, Vera Elliott £459.75, Vicki Lynas £946.25,
Victoria Joy Leed £34.00, William Watson £50.00, Young Cousin of Ruwena Khan £875.00, Zack Barrett £6,044.54, Zoe Kilby £307.11

Looking for donations from December 2020? At the time of writing this newsletter, the donation figures for December were still being calculated so we were unable to include them. Rest assured they will be in our next newsletter in Autumn 2021.



# Every Step of the Way ...

# Rhian's Story ...

Hi everyone. We are Julie and Andy, parents to Rhian and Keeley.

Rhian was diagnosed with acute lymphoblastic leukaemia (ALL) shortly after her fifth birthday in 2015. She completed her treatment in August 2017 and was clear of cancer for 20 months. She sadly relapsed in April 2019 and then during her treatment for this relapse, she relapsed again in June 2020, which resulted in Rhian needing a bone marrow transplant. Luckily Keeley, her twin sister, was a 100% match.

In July 2020, Keeley donated her bone marrow, which was then transfused into Rhian. The transplant went well and we were sent home from hospital later that November, with quite a few trips back and forth towards the end of last year. On the 22nd of December, we were back in hospital overnight for a TNP (IV nutrition – you get to know all the terminology) as Rhian wasn't eating so well. Luckily, we were able to spend Christmas Eve and Christmas Day at home, as well as New Year's Eve and New Year's Day. We were able to go home on day leave, just needing to go back to hospital in the evening and overnight.

Candlelighters, the Play Team and all the staff made it very special for us over Christmas, with all the treats, presents and messages we received. We were discharged on 7th January 2021 and have been home ever since. Rhian's appetite is improving and she is starting to feel much better and getting stronger every day.

During all of Rhian's treatment, Candlelighters have been there every step of the way.

Candlelighters puts smiles on our children's faces during very difficult times. Some of the things Candlelighters has supported us with are:

- Being there on the ward and bringing us anything we need (especially Elaine with her warm breakfasts and lemon slushies!)
- Sitting with Rhian so I could get a shower or nip out for supplies.
- ★ Shaving Rhian's hair when it first started falling out.
- Center Parcs holidays, to escape for a few days from treatment and hospital.
- ★ A Sibling Residential to support Keeley, and offering much-needed haircuts for me when I've been on the ward for long periods of time



Christmas parties

ddy Bears' Picnic Hallowee

A Mad Scientist eve

An Under the Sea eve

A movie afterno

A Christmas Eve themed even

All these things take our minds off treatment for a bit and make the girls really happy!

All of the Candlelighters staff are really friendly and always have time to have a chat and ask if there is anything we need.

Julie & Andy x

It is crucial that we can give families like Rhian's the support they deserve, providing emotional, practical and financial support.

We can only do this with your help. If you can, please help us to support families by making a donation on our website www.candlelighters.org.uk



## Meet our Candlelighters Teams

Teams are special fundraising groups made up of family, friends and local communities all with a common goal: to raise funds and support our families.

### TEAM BRAMHOPE



Tariq Qadeer, owner of Bramhope Village Newsagents, formed Team Bramhope by encouraging local customers and friends to come together for charity. The team have raised lots from their various fundraising events, including their yearly Three Peaks walk, 10-mile run and other physical challenges. They have done an incredible job of raising awareness for Candlelighters in North Leeds and have brought members of the community together in a positive way.

## TEAM EMILY



Emily was diagnosed with infant acute lymphoblastic leukaemia at the age of nine months old in 2018. The team's fundraising began in 2019 with her Dad completing the Yorkshire Three Peaks twice in one day! Emily's brother, Oliver, organised a non-uniform day at his school and asked for donations instead of presents on his sixth birthday. Tanya, Emily's mum, arranged other fundraising activities, including a bag pack and a skydive! Sadly, Emily relapsed in April 2020, however, Team Emily have continued to raise vital funds and awareness for Candlelighters.



#### TEAM FILIOT



Eight year old Elliot's fundraising started in January 2019, when he decided he wanted to raise money to help poorly children and their families. Since then, alongside family and friends, Elliot has taken on the Yorkshire Three Peaks, a 50-mile trek, half marathons, and other inspirational challenges for Candlelighters! Elliot's four year old brother, Joseph, has been known to join in too, summiting Blencathra. We're told the team have even bigger plans for 2021!



#### TEAM RUEBE



Team Rueben's journey began in May 2019 when ten year old Rueben Walder was diagnosed with a rare, high graded brain turnour. Very sadly, a year to the date of his diagnosis, Rueben passed away. Rueben wanted to give back and help others; fundraising for another local charity from the onset of his diagnosis. Following his example, Rueben's step-mum, Liz, organised a 'Warrior Mums' walk in their local community, raising funds for Candlelighters. During the COVID-19 pandemic, Liz, Rueben's Dad, Steve, and Rueben's brothers, Otis (then nine) and Sidney (then eight), walked coast to coast (196 miles) from St Bees to Robin Hood's Bay, Rueben's favourite place, in his memory.



## TEAN





### TEAM GEOR



Mark and Helen Gallimore founded a team after their son, George, was diagnosed with leukaemia in 2013. From diagnosis and throughout his illness, Candlelighters supported George and his family. Every year, Team George take on various physical challenges, including summit climbs and long-distance hikes. In 2020 they arranged virtual events, including a coast to coast walk and joined 'The 2.6 Challenge'! Mark recently set a personal goal, to complete 2000 miles of races or walks for Candlelighters to mark two years of George being in remission.

COULD YOU BE A TEAM? Becoming a Team is a special way to support
Candlelighters. You will join a community of people who share the same vision a
you; to bring light and hope to families affected by childhood cancer in Yorkshire
It's also a great way to recognise and encapsulate fundraising efforts of families,
friends and local communities, who often come together to fundraise.



If you are interested in setting up a Team in your local community or would like a copy of our Teams Fundraising Pack, we'd love to hear from you. Please email us at info@candlelighters.org.uk or call 0113 3229283



## Roles & Radiographers!

Hi! We're Amy and Enily and we're the Paediatric Radiotherapy Specialist Practitioners based at St Vames's University Hospital, in Leeds.

Radiotherapy is a commonly used cancer treatment where radiation is used to treat cancer cells. Radiotherapy can be used on its own, or in conjunction with other cancer treatments, such as chemotherapy. Depending on the patient and their diagnosis, radiotherapy can be used to try to cure the cancer or to manage symptoms.

We are a key point of contact for patients and their families, for whom radiotherapy is part of the patient's treatment plan. Due to the special machines we use, the radiotherapy department is in a different hospital to that which patients and families will often be used to and this change can make some patients feel anxious. We meet patients and families when they are first referred for radiotherapy to discuss the processes involved, such as planning techniques and treatment delivery. Talking through the process helps patients and families to feel more comfortable in a new setting and ensures they are fully aware of how the treatment will take place.

When young people attend radiotherapy appointments, whether for preparation sessions, planning scans or treatment itself, we're there to answer any questions and provide support. This might be moral support and encouragement for patients, providing information to parents, occupying families in the waiting room or making children comfortable through play.

With lots of different professionals involved in the cancer treatment of young people, it's really important this pathway is as smooth and efficient as possible and everyone is aware of a particular child's care plan. A vast majority of our role takes place 'behind the scenes', coordinating the patient's journey through the radiotherapy department and liaising with the wider team over at Leeds General Infirmary. We also work closely alongside the wider radiotherapy team, such as our fellow therapeutic radiographers, technicians, and physicians, to plan and deliver radiotherapy treatment. Our role as specialists is to provide expertise to educate, train and support the wider team in caring most appropriately for young cancer patients.



Isla loved visiting St James's every day for her treatment and really enjoyed having fun with all the team. Each visit she did different crafts - her favourite was some glittery fairy wings! It made this part of her treatment much easier for me and Matt (Isla's Daddy), knowing how comfortable Isla was and how she loved dancing and being silly with the whole team. They really made each day fun for Isla.

One of the things we enjoy doing is celebrating with our patients at the end of their treatment. Unfortunately, the pandemic has meant that children have been unable to celebrate as usual and many children have rung the end-oftreatment bell with only one loved one present. When children come back for their follow-up a week later, they've been able to bring in someone different, so we've set the bell up again for them to ring. This has meant during a very difficult and abnormal time, families have still been able to somewhat share this important moment together.

Funding from Candlelighters is vital in ensuring this role can be filled full-time; meaning patients and their families are supported throughout their whole radiotherapy journey.

DID YOU KNOW? WE ALSO FUND...

It's thanks to your donations that we're able to fund crucial hospital roles to help patients and families on their journey. You can help to directly support families by donating on our website www.candlelighters.org.uk



Club Candlelighters is a brand new way for donors to make impactful contributions to our charity's mission, over a sustained period of time. Going forwards, Club Candlelighters will play a significant role in protecting, improving and expanding our services, as well as in our ambition to invest further into research to improve the lives and outcomes of children with cancer - not just in Yorkshire but across the world.

Members of Club Candlelighters will take on the roles of Guardians, Rockets and Transformers representing varying contributions to the charity over a period of three years - donating £5,000, £10,000, or £25,000 per year.

We would like to send a huge thank you to the very first members of Club Candlelighters!



The pure technology group are our first Transformers, committing to donate at least £25,000 each year over the next three years, helping us expand our services and transform the charity.



Guardians, committing to donate at least £5,000 each year over the next three years,

We're looking forward to working with the pure technology group and Newlay Readymix Limited over the next few years and welcoming more members to the club to help enhance our services for families and improve childhood cancer outcomes



To learn more about Club Candlelighters, visit www.candlelighters.org.uk/club-candlelighters

# Vensen's Story...



We are mum
Beverley, dad
Jason, big brother
Ethan and Jensen
from Huddersfield.
Jensen, now six,
is a fun-loving,
adventurous little
boy who always
keeps us on
our toes.









Jensen was diagnosed with B-cell non-Hodgkin lymphoma in September 2018. We had been worried about his health for a while, going back and forth to the doctors, with everything coming to a head when fluid started leaking from his bowel into his body. We were rushed straight to the HDU (High Dependency Unit) at the LGI where we received his diagnosis. Jensen's treatment plan was short but intensive, seeing us spend almost all of his treatment in hospital on ward L31. He was very sick when we were first admitted to the hospital and the first rounds of chemotherapy hit him hard. He was so, so poorly - more than we could have ever imagined. However, with each round of chemo and surgery in between, he was getting stronger and we could slowly see our little boy returning.

Our first contact with Candlelighters was on L31. This is where we were introduced to Elaine, our 'fairy godmother'. Even though Jensen was refusing to eat, she would come to see us every morning to check if we needed anything. Elaine asked Jensen if he would like some 'rocket toast'; this caught his attention and from that moment on became his staple diet - he loved it.

Candlelighters have supported us all through our cancer journey, from diagnosis till now. Ethan has always attended the Sibling Groups at The Square and even the residential in 2019 which did wonders for his confidence. Jensen however, had only just been to his first Patient Group in March, days before lockdown. We were so grateful that Candlelighters adapted their services to continue supporting the children virtually. One of the first things the boys took part in was a one-to-one craft session, where they made 'Gribbits' - a fun frog game. It kept Jensen focused the whole time (which is unusual for him!) so we knew he really enjoyed it.

When lockdown first happened, both boys seemed to adapt well to the new routine and homeschooling but as time went on, they found it increasingly difficult, especially Jensen. The group Zoom calls provided by Candlelighters gave both boys a chance to interact with other children and have a bit of fun, including a bit of dressing-up and decorating for the virtual Halloween party!

When we got the all-clear in March 2019, we had made it our mission to give Jensen the best year ever, which included lots of travel and adventures. 2020 made us slow down and appreciate the places close by and the fun family times and memories we can make at home.

Now, we're looking forwards to supporting Candlelighters in any way we can at future events. Our hope is that by the end of this year, things will be better for all and (once it's safe to do so) The Square can re-open and Candlelighters can resume supporting families in person, with a place for parents to visit away from the ward, as well as their virtual support.

Family Support Update:

Despite all the challenges the past year has brodge.

e have pulled together for one reason... our families.



New Projects!

Like many charities across the UK, if

someone would have told us just how

much we'd have to adapt and change our

current service delivery, we might have

thought they were making it up! However,

fast forward to nearly a year ahead, and we

are still here for our families, supporting

them throughout the pandemic, with new

Regardless of the challenges we've faced

over the past year, we have achieved

a lot, a lot sooner than we could have

restructured the way our team will

work moving into the future.

And even more exciting, we've completely

ever imagined.

and exciting projects on the way!

## A Poem...

From Halloween Zoom-bie Parties to a Candlelighters Camp & Crafts, To a Teddy Bears Picnic or a Games Night just for Dads!

We've held Grandparents Tea Parties, Talking Therapies and more, And not to mention our very own family Disco with a virtual dance floor!

No matter where our families are we've provided something for them, Even a virtual cuppa', or a craft session for young Ben.

We've talked planets, told stories of science and Egyptians, Sang to Rudolph and Santa, despite the restrictions.

Our family support centre, don't worry, it's not bare! We've managed to keep it running and provide a room or two there.

We've continued our services, though virtual they may be, Yet we've planted trees to cherish, a beautiful memoru.

Our work is so, so crucial it reminds us every day, Everyone is on their journey, and we're here to guide their way.

With love, The Family Support Team x



# Community Support Workers

Working across Yorkshire to provide support to families closer to home. Responsible for being a key contact to our families while liaising with professionals, charities and services in the area.

### Family Support Workers

Providing practical support to all families whether that be helping them to access our services or just being a friendly familiar face to talk to. Working at Leeds Children's Hospital and at The Square, our family support centre.



# Jorkshire Hall I I

We also have team members who work behind the scenes on our strategic side of things, marketing and admin. This new way of working is still a work in progress as we continue to navigate our way through and adhere to government and hospital guidelines.

Sign up to our regular Family Support e-bulletins! See our Going Digital update on Page 18.

Share your story

you would like to share your story or have an idea for a marketing piece or us, please let us know. Email us at: marketing@candlelighters.org.uk



Beverley, Jason, Ethan and Jensen x

# Talking Brain Cancer Research







Candlelighters has funded research into the understanding and treatment of childhood cancers for 30 years. Academic neurosurgeon, Ryan Mathew, has been supported by Candlelighters since 2018, as part of a four year funding programme to enhance brain tumour research.



Children and families worldwide are devastated daily by brain tumour diagnoses. In children, brain tumours remain the most common type of solid organ cancer and the leading cause of death. Despite advances in treatments, outcomes for the most malignant types of childhood brain tumours remain very poor and far worse than other types of childhood cancer.

As an Associate Professor at the University of Leeds and Honorary Consultant Neurosurgeon at Leeds Teaching Hospitals, Ryan is the first and only academic neurosurgeon at Leeds' Hospitals: a role made possible through funding from Candlelighters and Yorkshire's Brain Tumour Charity. He splits his time 50/50 between his clinical work treating patients with brain tumours, and co-leading the research 'Stem Cells and Brain Tumour' laboratory group, with Dr Heiko Wurdak, with an additional group analysing surgical and immersive technologies.

Ryan is passionate about researching brain tumours. He tells us, "The treatments we have for brain tumours are wholly inadequate. Having become a doctor to cure people - not just make them a little bit better, I decided there must be more we could do". Ryan and his colleagues at the laboratory strive to improve understanding of brain tumours and cancers, to work towards better treatments and cures.

The team at Leeds are using incredible techniques to study brain cancers, such as engineering 'mini-brains' (pea-sized 3D tissue cultures grown from stem cells), which recreate features of early developing brains. Ryan and the team can then study the effects of tumours in the 'mini-brains' and understand how stem-cells develop cancerous properties. Ryan tells us, "It's miniaturising the whole concept, and that gives us a model of a tumour growing in a healthy brain which means we can study that interaction. When we can understand that, and the vulnerabilities of the cancer cells, then we can target them". A new member joined the team in January to look specifically at paediatric tissue.

Ryan and the team are also investigating how to treat leftover cancerous cells following surgery with a range of techniques. "Targeting the leftover cells is challenging because they are hard to see and are intermingled with normal brain cells, but it is essential to get rid of them as they are responsible for the tumour re-growing", Ryan says. One of these techniques is that of targeted drug delivery, based on the theory that, "As surgeons, when we operate to get to the tumour, we're right there in the cavity where the leftover cells are. Could we deliver something at the time of surgery that attacks those leftover cells then and there itself?" The team are also looking into other targeted treatments such as the use of precision lasers and nanoparticles.

It is completely crucial that research like Ryan's is undertaken in the field of brain cancer. Ryan says, "Brain tumours have not kept pace with developments and advancements that have been seen for many other cancers. To me, that is unacceptable. It cannot become the forgotten disease amongst all of the other cancers that exist. Research is so important because it's the only hope of making a difference and having an impact on this disease, both now and in the long term."

We couldn't possibly fit everything that Ryan and the team are working on in this article, so you can find out more by visiting our website, here...

www.candlelighters.org.uk/ talking-brain-tumour-research-with-ryan-mathew

Brain tumours account for 1 in 3



Candlelighters has a mission to bring hope to families by investing in vital research, education and training r aim is to improve the outcomes and lives of children and their families affected by childhood cancer. In the



# \* Leaving a Legacy



Legacy giving is a profound, yet often-overlooked

## What is It?

Legacy giving is a means of donating money to charity, by leaving a gift in your will. After taking care of friends and family, some might like to make a final donation to a charity to which they have a personal connection or affiliation, or one which supports a cause they found important during their life - leaving a lasting 'legacy'. Research finds however, that lots of people are unaware of legacy giving and its benefits to charities.

## Why is it Important?

Every year, for over 40 years, Candlelighters supports hundreds of families across Yorkshire. Legacy donors have a special lasting impact, helping to secure support and improve outcomes for future generations of children with cancer. As a charity, we not only provide emotional, practical and financial support to families, but we invest in research into childhood cancers, in order to find more effective treatments and cures. By leaving a gift in your will to Candlelighters, we can continue to invest in research and support children and families affected by childhood cancer, from diagnosis to recovery and beyond. It's through the generosity of people leaving gifts in wills that we can ensure that children with cancer receive the best quality of care and their families are supported.

## Common Misconceptions about Legacy Giving

You must leave a minimum amount. There is no minimum amount you have to leave as a gift within your will. All donations are gratefully received and play a crucial part in helping to support families of the future. You can even specify to donate what's left after all other gifts have been given out.

Writing a will is time-consuming, complicated and **expensive.** There's lots of guidance available to help when creating a will and you can always create a basic one, to be revisited later and add more detail. Many charities also have 'Free Will Months', working with solicitors to provide their services for free - keep an eye out for Candlelighters' Free Will Month later this year.

You'll be taxed on your donation. Unlike other gifts left in your will, legacy donations to charities are exempt from inheritance tax. You can also reduce the amount of inheritance tax you might pay on the rest of your estate if you decide to gift over 10% of the net amount to charity.





please email tom.robertshaw@candlelighters.org.uk

## Our Amazing Supporter Stories!

Despite everything that happened in 2020, we were blown away by the generosity of people and their incredible fundraising feats. Determined not to let restrictions stand in the way of helping families, our supporters instead focused on what they were able to do and what followed were some unique and admirable fundraising stories.



#### Ted's 'Move it May' Challenge

Throughout the entirety of May, lovely Ted took on an array of physical challenges dubbed 'Move it May'. In 2019, Ted was very poorly with Burkitt lymphoma, spending nearly six months in hospital. Ted's mum said, 'Candlelighters were such a help: funding extra staff on the ward, having the team there on the ward to help us as a family cope, providing support for our extended family. It is an amazing charity. In Ted's words, he wanted to 'help the ladies in pink help other children be happy and better!'. Ted absolutely did that, raising nearly £4,000!

Because of Blake' Christmas Baubles

After Blake Holdsworth sadly passed away aged seven following a diagnosis of hemophagocytic lymphohisticcytosis, his family decided to set up 'Because of Blake', a Facebook page used to honour his memory and promote fundraising campaigns. Each year on Blake's anniversary, his family do something special to keep his memory alive. In 2020, they decided to raise funds for Candlelighters by decorating and selling some truly beautiful Christmas baubles. Some of these

baubles were Christmas themed and some inspired by Blake's interests, likes and memories. There was huge demand for the baubles and Blake's family completely sold out of their creations, raising a wonderful £700.



#### Shaukat's Ramadan Fundraiser

Shaukat Patel kindly supports Candlelighters with donations on a regular basis. During Ramadan in 2020 he set up a fundraising page to encourage his community to donate too, as part of the focus on charitable giving at this time, known as Zakat and Sadaqah. His generous friends and family donated over £600 to Candlelighters during the month of Ramadan - for which we are so grateful.

#### Dr Hadeel Hassan's Marathon

Working as a paediatric haematology and oncology doctor on Wards 31-33 at Leeds Children's Hospital throughout the pandemic, Dr Hadeel Hassan was already an inspirational figure in our books. So during October, when she decided to run a virtual half-marathon to raise funds for Candlelighters, we were in awe! Not only this, she completed the race in between her Saturday and Sunday shifts at the hospital and raised just over £370. Hadeel said 'It was cold, dark, and my legs were tired after my day at work but I did it in 2 hours 10 minutes.

Definitely one of my hardest races but also one I'm most proud about.'



#### Joe Bothamley's 'Secret of Hartwith Hill' Book

We were touched to hear of Joe's unique fundraising story last year, raising £2,200 from sales of a children's book he wrote during lockdown - 'The Secret of Hartwith Hill'.

Joe was inspired to write the book after his Dad was diagnosed with cancer towards the end of 2019. Joe said, 'I wanted the book to raise money for a cancer charity after everything my Dad had been through and how incredible the people caring for him had been. With the book being for

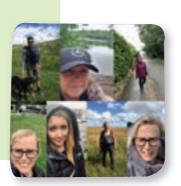


children and seeing the incredible work that Candlelighters do to help the families of children with cancer, it was a charity that I wanted to support with all my might.'



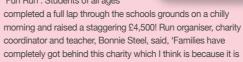
#### Shoosmiths Virtual Race Across Americ

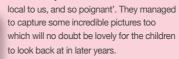
The Leeds Shoosmiths office have been supporting Candlelighters since early 2019 and have taken on numerous challenges in this time, raising over £17,000 to support families. Determined to continue their efforts through the pandemic, the team devised a 'Virtual Race across America' - competing against each other to walk 2,539 miles from one end of 'America' to another. The challenge took eight weeks and a total of 26.6 million steps were recorded! The office raised a wonderful £2,000 for their efforts.



#### Pocklington Prep's Fun Run

After selecting Candlelighters as their 'Charity of the Year', Pocklington Prep School in East Yorkshire kicked off their fundraising with a fabulous 'Fun Run'. Students of all ages







After Naomi's son, Eli, was diagnosed with acute lymphoblastic leukaemia in 2019, she decided to brave a drastic hair cut – raising over £1,600. Naomi shared that 'Since Eli's diagnosis, I struggled to adjust to our new life and I hadn't really wanted to accept it or acknowledge anything to do with childhood cancer. But after a year, I found the strength and courage to share our story and raise awareness, not only for

childhood cancer but also for a fantastic charity who support us on so many different levels.' All of the team here have huge admiration for both Naomi and Eli for sharing their story and selflessly fundraising to help other families too.







Naomi Lashington



#### Ayaan's Friends and Family's Donation



After hearing of his diagnosis of acute lymphoblastic leukaemia, Ayaan's family and friends kindly clubbed together to make a donation of £400 to Candlelighters which he and his sister dropped off at a visit to the clinic at Leeds Children's Hospital. This was such a thoughtful gesture, appreciated by all of our team.

## Gary, Miles, Andy and Derek's Ultimate Highland Cycling Challer







#### Susan's 70 miles for her 70th Birthday

With the pandemic leaving Susan unable to mark her 70th birthday with a party, she brilliantly decided take on an epic 70-mile journey in seven days instead, walking on The Yorkshire Wolds Way and raising funds for Candlelighters in the process. Susan said, 'I first came to hear of Candlelighters when one of my grandsons lost his best friend to leukaemia at just seven years old. It was a very sad time for everyone but I know the family were helped so much by the charity. Just a few years ago, my daughter had a neighbour whose baby daughter also was diagnosed with cancer. Candlelighters

helped the family so much, and the baby is

now a very healthy little girl.' In total, Susan



#### Finlay's Marathon in a Month

Following his diagnosis of acute lymphoblastic leukaemia back in August 2020, then 14-year-old Finlay set himself a remarkable challenge: to walk 26 miles (the distance of a marathon!) over a month. After his diagnosis, his chemotherapy and steroid treatments started immediately, with gruelling effects. As soon as he began a milder course of treatment and regained some of his strength, he decided to take on this amazing challenge, raising funds for Candlelighters and awareness of childhood leukaemia. Superstar Finlay raised over £10,000 and even gained local news stations' interest, appearing on television!







raised over £600!

WE'LL KEEP YOU POSTED ON ANY CHANGES TO ORGANISED CHALLENGE EVENTS VIA SOCIAL MEDIA!

We want to give our heartfelt thanks to every single person who fundraised or donated to Candlelighters last year.

Without you, our support for families would not be possible, and whether it's £1 or £1,000, you all play a crucial role in helping us do what we do. Both our charity and our families will likely feel the effects of the pandemic for years to come, but thanks to your donations, we can ensure we'll be there for the road ahead.

If you'd like to make a donation to Candlelighters, visit our website www.candlelighters.org.uk or if you'd like support with your fundraising, drop us an email at info@candlelighters.org.uk





The last year has seen us adapt and evolve in so It has been critical that our support for families has never wavered despite the many challenges for us all over the last year, and we're proud of the ways in which we've responded, quickly adapting our services

ing to be the best that we can for the

With this in mind, read below for our next small evolution - our Candlelighters digital newsletter.

# Evolving & Adapting



The team have made lots of video calls this year, in order to keep in touch with supporters, families, and each other!



# WE'RE GOING





After over 30 years of producing the Candlelighters newsletter, we're introducing a digital version too. We recognise that many of you may want to read our newsletter online, to be able to easily share it with friends and family, or to help protect the environment.

You can access the digital version of this newsletter on our website at...

e-bulletins too if you're a family member and don't already receive them.

Playing our part in looking after the environment is really important to us and is one of the key reasons we have decided to make this change. Going digital will also save crucial funds, meaning we can spend even more on supporting families across Yorkshire. Did you know, the cost of printing and mailing our newsletter is equivalent to funding all of our children's Talking Therapies for almost a year!

If you would like to receive the Candlelighters newsletter by email, either instead of, or as well as the physical version, just let us know by filling in your details at...



www.surveymonkey.co.uk/r/candlelighters\_going\_di













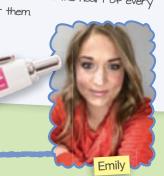
Over a year ago, when we entered 2020, we were excited for the future and keen to work on lots of new projects. Our Board of Trustees had just recently sat down and devised a five-yearplan with objectives which would help us to support more families, utilise technology and invest further in research, to name a few. Little did we know, the year to come was going to turn these plans on their head.

What followed was a year unlike any other, and challenges of the likes we'd never seen. Through it all, everyone involved in the Candlelighters family pulled together to continue raising funds and supporting families. I am so proud of everyone involved and I hope that after reading this edition of our newsletter, you are too.

Sincerely, I'd like to thank everyone who donated, fundraised or otherwise supported us in the last year - you are truly appreciated by everyone at Candlelighters.

Looking to the future, our strategy is changing and evolving and you'll hear more about this soon. Where, how and when we work may change, but what will never change is why we do what we do. We will always put children and families at the heart of every decision - everything we do is for them

Thank you, Emily X





Thank you for taking the time to catch up with all things Candlelighters



Take a donation online: www.candlelighters.org.uk

Send a cheque to: Candlelighters, 8 Woodhouse Square, Leeds, LS3 IAD

take a donation over the phone: 0113 322 9283

Make a regular donation here: www.candlelighters.org.uk/givearegulargift

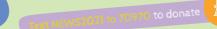


Other really helpful ways you can support us are by following us on our social media, liking and sharing our posts, or simply spreading the word about the work we do to friends and family.

If you'd like to make a small donation to cover the costs









This last year has been a challenging time for many. However, as always, we're blown away by the generosity across the region and the amazing efforts of so many of you who have helped keep our candle burning when families have needed us most. We are so, so grateful for your support. It means the world to us to be able to support families through their whole journey, no matter where, virtually or physically.

Here at Candlelighters we are one big family. And like any family, we look after each other. Anyone touched by childhood cancer, no matter how long ago, is considered a member. Our job? To bring this family together and make sure each person can get the support they need.

To show just how much your support counts, we've pulled together a mixture of quotes and feedback from our families!





The support Candlelighters gives is second to none and is a fine example of what other charities should follow. What is really great though, is you get to meet other parents and children who have gone through the same and fully understand your pain, something that other people just will never get. The best of all is, we all have an extended family of great people who can laugh together about the rubbish and rough times. Love you guys XX





They picked us up when we didn't have the strength to.



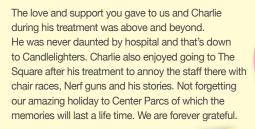


We love Candlelighters! You sent me a Christmas card just after my son's chemo ended, I felt like I was alone until that moment! Always in our hearts and perfectly named, lighting up our lives in difficult times. Blessings for all your wonderful team.

Mum



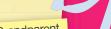
Bereaved Mum







Thank you for thinking





Grandparent



A HUGE thank you to YOU!

We couldn't have done it without your incredible support.

