

Demelza Life

Autumn 2019



- Demelza East Sussex marks 15th Anniversary of Community Team
- Learn how we're working to reduce our environmental impact
- Hear from some of our staff on why they love being part of #TeamDemelza



Demelza
Hospice Care for Children

Welcome

Dear All

15 years of Demelza service to the children and families of East Sussex is another great reason to celebrate 2019. This year I will enjoy my 20th anniversary of working for this wonderful organisation and I am excited for the future.



Through the generosity and hard work of our supporters, volunteers, service users and staff, we continue to develop Demelza services based on family need. The successful Care at Home project in Kent will be rolled out further in the county and in South East London. The successful pilot for Practical

Volunteering Support direct to families in their own homes is also being rolled out to other areas.

We have a sharp focus on the more challenging economic climate around us and will remain financially viable when others around us may not be able to do so. Cost efficiencies and long term funding are an intrinsic part of the thinking as we develop. We continue to be part of the campaigning voice to reach Government's ear that

children's palliative care is a vital service that must receive a fair proportion of the limited public purse. Ensuring we can attract, develop and retain key staff and volunteers in all areas remains key to all our goals. Demelza must continue to keep pace with the increased NHS salary scales to attract the skills and talent our children need and deserve, promoting Demelza as an Employer of Choice.

Our supporters have given us great gifts with which to make these things possible, rest assured that we will continue to deliver the very best value for every £1 you have entrusted to us.

Thank you all for your support,

Lavinia Jarrett
Deputy CEO

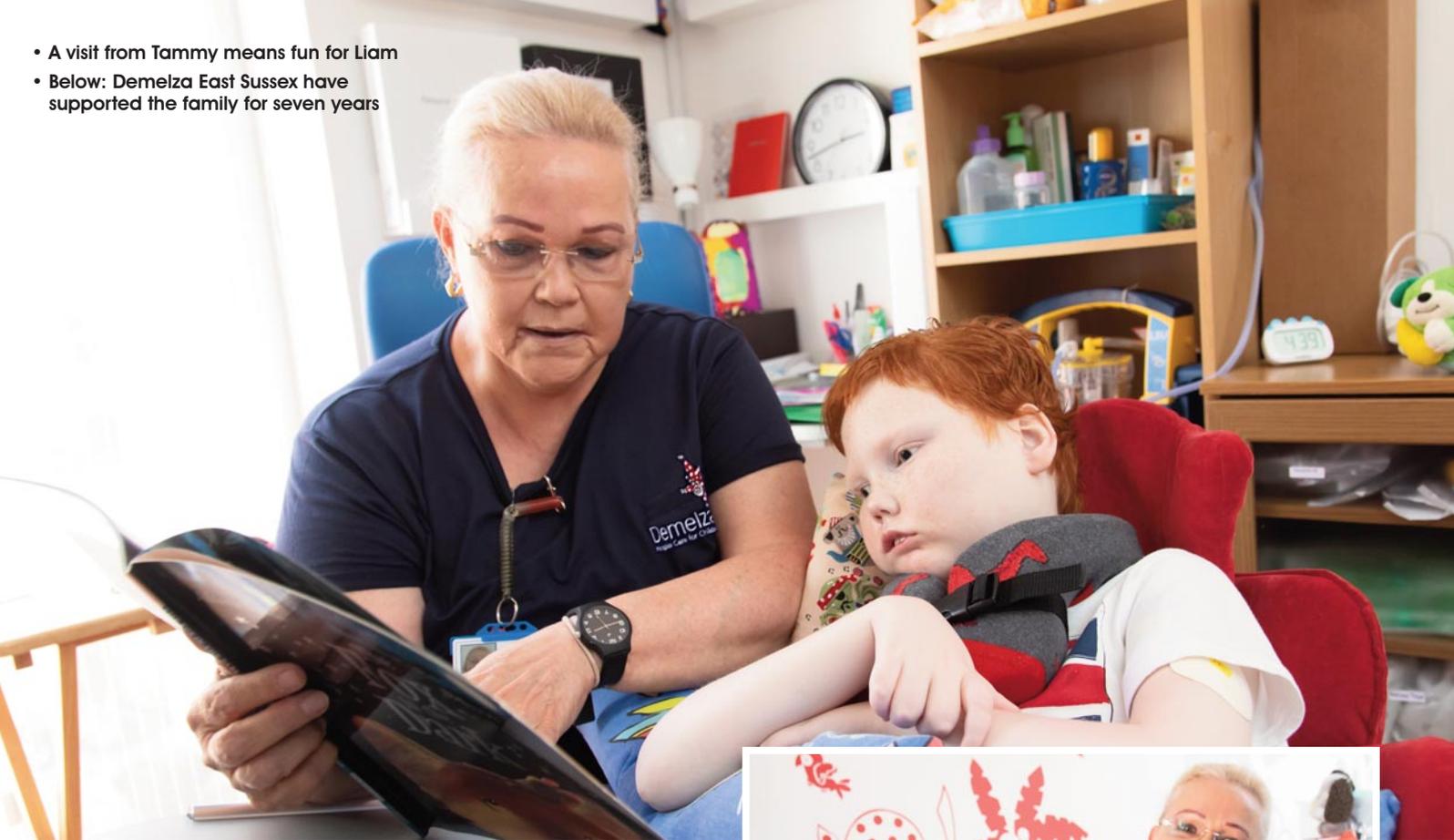
A CELEBRATION OF
CHRISTMAS

Canterbury Cathedral
Monday 16 December
7.30pm

Join us for an evening of joyful celebration. With a beautiful arrangement of carols, readings and musical performances the evening is set to be a truly uplifting occasion.

Tickets from £12. To purchase tickets please visit www.demelza.org.uk/carolconcert
Registered Charity No. 1039651

- A visit from Tammy means fun for Liam
- Below: Demelza East Sussex have supported the family for seven years



Liam's story

Liam was born a healthy baby but at six months old, caught a virus that would change his life completely.

Mum Chrissie, said: "He stopped feeding, had a high temperature and kept screaming, so we took him straight to the local children's hospital." When a consultant noticed something wasn't right, Liam was immediately referred for scans and tests, and was found to have a global loss of white matter in his brain.

Liam, now 10 years old, will never be able to walk, is severely visually impaired and has global developmental delay. Not long after this diagnosis, Liam began experiencing seizures. "It was gutting to find out," said Chrissie. "We didn't know what the future would look like for him, but we knew it was going to be hard."

It was when Liam was almost five years old that it became near impossible for him to swallow or keep down his food and medication, eventually becoming so frail from that he had to be intubated and taken to intensive care. It was at this difficult time that Chrissie first faced the possibility she may lose her son. "It was decided we would try to get him home for end of life care," she recalled.

Liam continues to fight on however, and will soon celebrate turning 11 years old. "His health status changes almost daily," Chrissie told us. "We deal with each day as it arrives. When times have been very dire, knowing we have the support of Angie and the Community Team at Demelza East Sussex has helped us beyond words."

Liam is now medicated and fed intravenously with a regime of 4-6 hourly infusions, meaning he is no longer able to attend



DID YOU KNOW?

All families supported by Demelza Community in East Sussex also have use of our children's hospices; Demelza Kent in Sittingbourne and Demelza South East London in Eltham.

school apart from an occasional visit, so Health Care Assistant Tammy comes to spend quality time with him. "It gives Liam a fun relationship in his life which we really appreciate," said Chrissie. "He enjoys music and sensory play, or getting messy with paint! Tammy knows Liam well enough to understand him and also what it means to get a smile from him, because even that is difficult for him to do now." For Tammy, Liam's delight is the ultimate reward. "I love what I do," she added. "I'm 68 but I'm not ready to retire yet - I'm not going anywhere!"

Richard Jones enchants families at Summer Party



Lance Corporal Richard Jones, the only magician to ever win Britain's Got Talent, popped in to the Metrogas Sports Club in New Eltham on Sunday 30 June to entertain children and families.

Demelza South East London celebrated 10 years of outstanding care in March this year and held a summer party for the children and families who access their services. Families from across the area made the most of the warm weather, enjoying a performance by a Royal Mail choir, and circus entertainers, whilst relaxing in the gardens with tea, cakes and a BBQ. Police horses and a local fire engine also dropped by and Demelza's fantastic team of volunteers ran a tombola, raffle and plant stall.

Richard Jones performed a spectacular routine to an enthusiastic audience, enthralled children and adults alike with his magic tricks. Richard, Ambassador for Together for Short Lives, the UK charity for children's palliative care, said "I've had a lovely afternoon spending time with such a responsive crowd, thank you very much to Demelza for inviting me along."



• Our Parent & Carer Forum at Demelza South East London

Giving families a voice at Parent & Carer Forums

Throughout the year our Family Engagement team run special forums for parents and carers, giving them the opportunity to meet other service users at Demelza to share their thoughts around their child's care and how we can best support the whole family.

For many parents this is a chance to talk about what matters most to them, as well as find common ground with other families facing similar situations. At one of our forums, two mothers who happened to sit next to each other soon discovered their children had the same rare condition - it was the first time either of them had met another family who understood exactly what they were going through. As well as friendship and inclusivity, our forums are always brimming with ideas on how to shape our future services.

Eco-friendly, sustainable, zero waste – you can't ignore the huge increase in awareness for living greener lifestyles. More and more of us have been searching for ways to make positive changes at home and so have we! As a charity we always try to make the best possible choices to improve the way our whole organisation operates in an effort to reduce our environmental impact.

It's easy being green

Here's our journey so far...

- ✓ All 27 of our shops are ditching plastic in favour of recyclable paper bags
- ✓ We're working on taking less trips and shorter journeys in our Retail vans to reduce emissions
- ✓ Our food waste is being composted where possible in the garden
- ✓ We're working to swap single-use plastics to more sustainable alternatives
- ✓ Later this year we'll be fitting solar panels at our hospice in Kent
- ✓ We're doing our bit to reduce energy consumption by turning off unnecessary electrical items and replacing equipment with power-saving alternatives
- ✓ Our organisational cardboard goes to our distribution centre in Maidstone to be recycled



Five ways supporting Demelza can help you be more eco-friendly:



1 Carry a reusable shopping bag like this fabulous Demelza tote*



2 Donate your unwanted goods for us to sell or recycle – see a full list at <http://bit.ly/don8goods>



3 Need some new pieces for your Autumn wardrobe? Say no to fast fashion and buy quality pre-loved items in our shops



5 Buy a re-usable coffee cup like our eco-friendly bamboo one*



4 Call our furniture collection line on 01795 503110 to find a new loving home for your old pieces, or buy something else and upcycle it

**available to purchase in Demelza shops*



Psst!

Look out for Dottie's Green Spot coming soon on social media to see what else we're doing to reduce our impact!

East Sussex 15th Anniversary

This summer, our Community Team in East Sussex celebrated providing 15 years of outstanding specialist care to children and their families in the area.



• Connie and Health Care Assistant Chelsea join the party

In 2004, Demelza merged with James House, a charity established in East Sussex by Robin and Mary Gooch following the death of their 11-year-old son James. Demelza has continued to provide therapies, short breaks and end of life care in the comfort and security of a child's own home across the region ever since.

Staff and families marked the occasion with a party at St Elisabeth's Hall in Eastbourne to recognise the huge contributions from the East Sussex community that enable Demelza to provide specialist care services across the county 24 hours a day, 365 days a year, completely free of charge. Businesses from the area donated refreshments and the cake was made by Jenna Heritage from Demelza's care team, which was cut by 15-year-old Connie, who uses Demelza's services.

Demelza's Chief Executive Ryan Campbell said "I am so proud of the work we do at Demelza in supporting children with serious and terminal conditions and their families. A heartfelt congratulations to all of the team across East Sussex

– including the care staff, fundraisers and the volunteers who keep everything running. This incredible team ensures Demelza provides care and support to families when they desperately need it. Here's to another 15 years of outstanding care."

DID YOU KNOW?

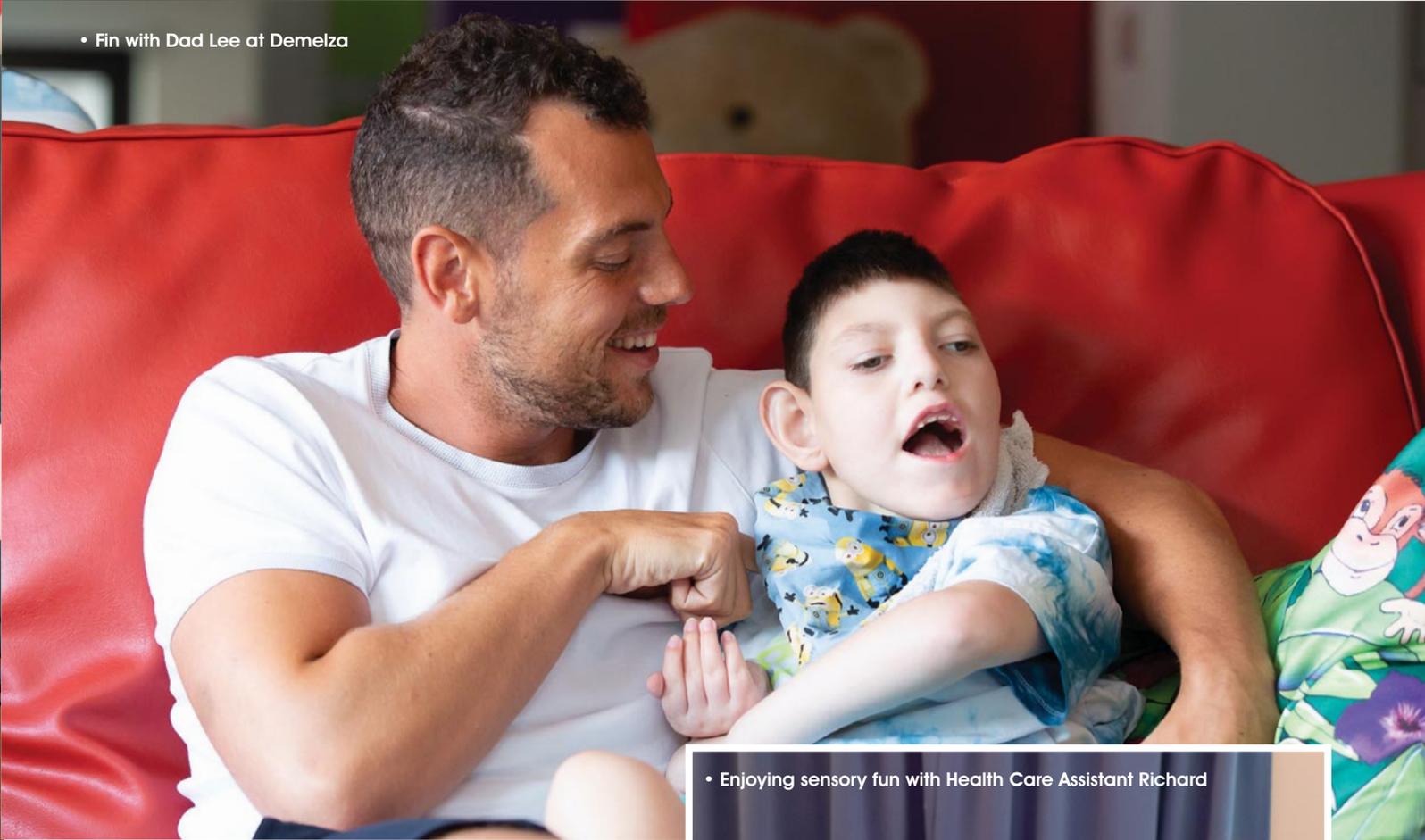
Demelza cared for more than **80 families** in East Sussex last year, a quarter of which were newly referred to our services.



Finley's summer holiday

Eight-year-old Finley first came to Demelza Kent when he was one, and now returns every year for short breaks. Dad Lee, said: "We'll go away with the rest of the family for our holiday, and he comes here for his. It's too much of a worry to take him abroad with his health."

• Fin with Dad Lee at Demelza



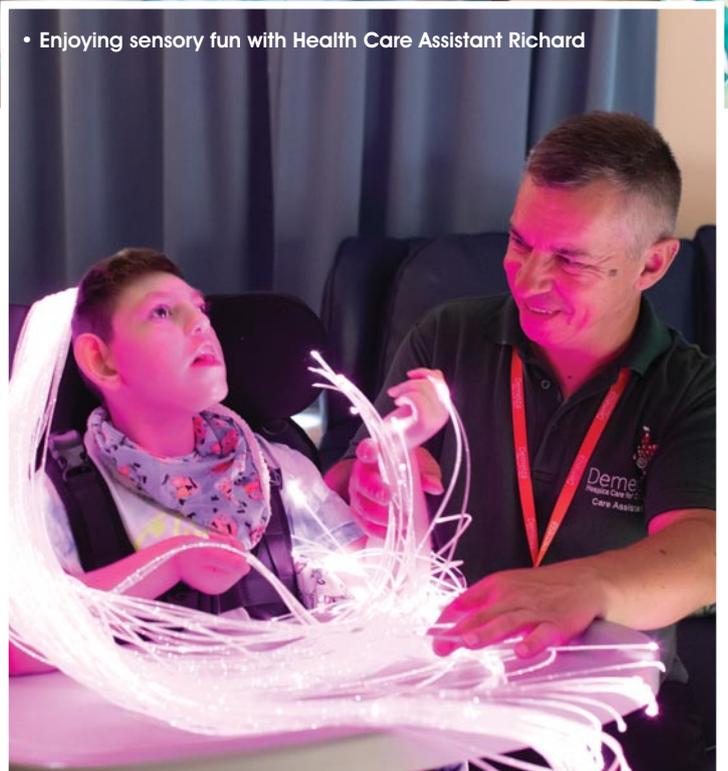
Fin, who cannot speak and is registered blind, also has cerebral palsy and up to 30 epileptic seizures a day. "We don't get any other help and we need a break from being Fin's carer," explains Lee. "It's a full-time job and now he's older, it's getting even harder to lift him. We know Fin is in good hands at Demelza."

Fin gets to enjoy his favourite pastime while on holiday at Demelza – swimming in the hydrotherapy pool, which would not be possible for him to do with his family anywhere else. "I don't know what we would do without Demelza. It's so good for Fin to get out the house and have a change of scenery."

"We know Fin is in good hands at Demelza"

Lee, Dad to Finley

• Enjoying sensory fun with Health Care Assistant Richard



Care in the **comfort of home**

Demelza's Community Team offers a hospice at home service for families across East Sussex. Just like our hospices in Kent and South East London, this encompasses therapies and practical short breaks as well as end of life care.



• One of our Bereavement Suites at Demelza South East London



Bereavement Suite APPEAL

This year we launched a special campaign to raise the funds we needed to refurbish our Bereavement Suites at Demelza South East London, providing a supportive and tranquil place for families to grieve and say goodbye after the death of their child.

We are delighted to have raised over £25,000 - thank you to everyone who donated to or shared the appeal on social media and supported us in reaching this incredible amount. We are very grateful to you for recognising the importance of this special service and what it means to those families who have been comforted by it, or may need it in future.

The refurbishment work is planned to take place at the end of October providing the suites are not in use. Follow us on Facebook to see updates on the finished rooms later this year.

Our committed team of Community Children's Palliative Care Nurses, Health Care Assistants and Family Support Workers recognise that looking after children with terminal conditions in the comfort of their own home brings its own unique challenges.

Palliative Care Nurse Advisor Jane Streeter explains: "When a family comes into a hospice or hospital they fit into that environment. Our job is to fit into the family's environment; the complete opposite. How we manage these dynamics is crucial." Jane describes the team's role as conductors of an orchestra – the players being other professionals from multi-disciplinary teams who are involved in the child/young person's care provision.

"Parents are frequently faced with complex care regimes, the enormity of which can sometimes be unachievable alongside everyday life. We support the family to prioritise and liaise with professionals to ensure achievable goals and plans of care are in place. As the children get older we involve them as far as they are able to consider and make decisions for themselves. This is hugely important when preparing for adulthood and making informed choices.

The team are on hand at the times when life is at its most chaotic for any family, but especially for those with a seriously ill child. They help with administering often complex medication and care, offer a listening ear to concerned parents and siblings dealing with difficult emotions while, above all, being there for the young person themselves. That might involve a trip out to the park, creative activities – all the small things that add up to precious memories – or, if they are very unwell, simply keeping them company and freeing up time for their parents is hugely needed and appreciated.

"Our families haven't chosen this journey and we can't change it, but we can help to prepare them for any future eventuality by sowing seeds for thought and laying down potential stepping stones to ease that journey, in the hope they can live as normal a life as possible. I often find myself asking 'what is normal?'"



• Jane has been part of the East Sussex Community Team since 2000, before the service merged with Demelza

We #TeamDemelza!

Get to know some of the friendly faces working to make lives better for children and families here at Demelza.



Sian, Pharmacist

"I'm originally from Wales, and I fit the stereotype as I love rugby and singing! I have spent most of my working life at Guy's and St Thomas' NHS Foundation Trust. Having specialised in paediatrics in 2009, I've spent the majority of that time, 10 happy years, at the Evelina London Children's Hospital.

I became aware of Demelza through my involvement with these patients. The palliative care team at the Evelina has expanded over the last 7 years and the number of prescriptions I have dealt with for children going home or to a hospice for end of life

care has consequently increased. I completed the prescribing course at King's College University a few years ago, which taught me the importance of identifying adverse effects and de-prescribing medication, in addition to the skills and knowledge I need to prescribe medicines.

I am passionate about getting things right and optimising pharmaceutical care for the children at Demelza, who are often on a complex cocktail of medication to manage their symptoms."

Wendy, Chef

"I've always had a passion for cooking, but this is by far the most rewarding job I've ever had. I love making mealtimes special for our families and cooking up their favourites. My signature cake is Chocolate and Banana and always goes down a treat!"

**Like to whip up some magic in the kitchen?
Bring your skills to #TeamDemelza!**



Paul, Lottery Team

"I love travelling around meeting all sorts of interesting people. It's such a great feeling knowing that every new person I sign up to play Demelza's Lottery or Superdraw will help children and families that little bit more."

We're looking for dynamic, friendly people to join our Lottery Team as Sales Canvassers. Does that sound like you?



See our vacancies and apply today at www.demelza.org.uk/work-with-us

Challenges and Events

Pumpkin Hunt

24, 25 & 31 October

A ghoulish adventure hunting pumpkins in return for treats in a town near you. Entry £5 per child, adults go free.

Find your local haunt and book tickets at www.demelza.org.uk/pumpkin-hunt



London Landmarks Half Marathon

29 March 2020

From cultural landmarks and heritage to the city's quirky and hidden secrets, runners get to explore the capital on a route like no other!

£35 registration fee, £350 minimum sponsorship.
www.demelza.org.uk/londonlandmarks



Brighton Marathon

19 April 2020

In what is now the second largest marathon in the UK, the Brighton Marathon is a 'must-do' for any runner.

£30 registration fee, £500 minimum sponsorship.
www.demelza.org.uk/brightonmarathon



Prudential RideLondon – Surrey

16 August 2020

Celebrating the legacy for cycling created by the London 2012 Olympic and Paralympic Games, Prudential RideLondon-Surrey 100 starts in Queen Elizabeth Olympic Park. Choose from 46 or 100 mile routes.

Registration from £25. For more details visit www.demelza.org.uk/cyclefordemelza



Kilimanjaro Trek

5 – 14 February 2021

Join #TeamDemelza for the experience of a lifetime and see the stunning scenery of Africa from the world's best vantage point.

Registration from £195, £3,328 minimum sponsorship.
www.demelza.org.uk/mount-kilimanjaro



Fundraising highlights

Brilliant bankers and a famous photographer are just a couple of exciting projects our Fundraising Team have been working hard on.

Royal Bank of Canada's Trade for the Kids

Staff and families had an incredibly successful day in June at RBC Capital Markets for Trade for the Kids!

Demelza were thrilled to have been chosen as one of the children's charities for the annual event and our families have had a fantastic time joining Royal Bank of Canada on the trade floor. Children, young people and parents had a great time taking calls and were evidently pretty good at it as over £127,000 was raised for Demelza on the day!

Lawrence, whose son Joshua attended Demelza's hospice in Eltham, said: "I was delighted and honoured

to be given the chance to represent Demelza Hospice Care for Children at the Royal Bank of Canada's Trade for the Kids event – it was a fantastic day. A huge thanks must be given to RBC for their support. This will make an enormous impact on children and families going through the toughest times. Thank you so much".

Dave Thomas, CEO of RBC Europe Ltd said: "RBC Trade for the Kids is a global day of celebration that everyone here in London looks forward to. We are grateful to continue working with great charities such as Demelza on truly worthwhile causes and would like to thank all our employees and clients for their fantastic support."



• Lawrence tells his story at the Trade for Kids event

Demelza Kids by Juergen Teller

Last year, we invited internationally acclaimed photographer Juergen Teller to our hospices to capture images of life at a children's hospice. In April of this year, Juergen launched the series, titled 'Demelza Kids', at an exhibition in Bonham's of Bond Street. 26 children were featured and several of the families made their way to London for a special viewing.

A special VIP opening also attracted stars like fashion designer Vivienne Westwood, Olympic Gold medallist ice skater and Demelza Vice President Robin Cousins MBE, and Texas singer Sharleen Spiteri. Mr Teller also gifted an exclusive portrait of Kate Moss that was later auctioned at Bonham's to raise £10,000 for the charity.

Photos:

- Top: Demelza Chief Executive Ryan Campbell MBE speaks at the VIP launch
- Left: Ryan with photographer Juergen Teller
- Right: Harry with Mum, Shona, next to his Demelza Kids portrait





Demelza

Hospice Care for Children

"I am very lucky to be able to work at Demelza and help to create precious memories, especially when time is short."

Melissa, Palliative Care Nurse at Demelza South East London

Join our care team and be part of something amazing. See available roles at www.demelza.org.uk/work-with-us



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