

Demelza Life

Spring 2022

- Read Fia's, Louise's and Ethan's stories
- Demelza appoints new CEO
- Festive Wishes Appeal raises over £51,000
- Young fundraiser donates cuddle cot
- Grand-grandfather scoops £25,000 Superdraw win



Demelza
Hospice Care for Children

Welcome

Welcome to your spring 2022 edition of Demelza Life.



I have enjoyed over 22 years' service at Demelza and following a recent external interview process, I am thrilled to announce that the Trustees have asked me to be Demelza's new Chief Executive.

I cannot tell you how excited I am to lead Demelza through the next phase of our development.

Despite the Governments Plan B restrictions and a rising infection rate, #TeamDemelza did not let December and Christmas pass uncelebrated; as if we could!!

An amazing 638 gifts were picked, wrapped and packed over the festive period; 390 of which were delivered to 180 homes across our region by Demelza elves. We were delighted to welcome 56 families to meet Father Christmas at a special grotto at our Kent hospice – complete with a magical festive walk of donated lights and attractions. A further 410 children received a personalised letter from Father Christmas and 332 received a personalised video message.

I am so pleased we were able to do this for families who wanted to participate and shine a light on the festive

season. There was a lot to consider and put in place to keep proceedings COVID-19 safe, but everyone complied brilliantly, were very patient, and we hope families were helped to make special memories together.

A heartfelt thanks to our amazing staff, volunteers, donors and customers. Without your support we couldn't offer the range of services to the babies, children, young people and their families who need them. And a thank you to the families too, without their inspirational accounts of their experiences, there would be less understanding of how we might help in some small way.

Our new strategy starting in April 2022 will focus on the range of services we can offer and to try to make sure we are meeting the needs of more children in our communities, with particular attention on reaching underrepresented groups and those who do not access services at the moment.

I hope you enjoy our news over the next few pages and thank you so much for your continued support.

Lavinia Jarrett, Demelza CEO



• Fia and big sister Flo enjoying time together at Demelza East Sussex

Fia's story

“When our children use the hydro pool at Demelza; they are equal. For Fia, who has numerous medical problems, she can have freedom – she can be just like her big brothers and sister. It does her the world of good and the four children can play together - like all siblings should.

Fia is our youngest child and for the first few years of her life we saw Fia learn to walk and talk; just like we had with our three previous children. But there were some warning signs that something wasn't quite right – Fia vomited constantly and she was slower to reach her milestones. When Fia turned three, our lives changed forever.

An MRI scan revealed massive brain damage and Fia was diagnosed with Alexander disease; a rare neurodegenerative brain disease. Over the years Fia's health has deteriorated – cognitively she is still the same mischievous little girl, but the ability to use her body has changed beyond all recognition.

When Fia started having seizures, Demelza supported Fia to attend a specialist school for children who have complex needs. Fia used to stop breathing up to 15 times a day needing resuscitation, but this improved once she had a pacemaker fitted. It was just awful but again Demelza supported Fia to get her health needs met.

Fia has a great time when Demelza's Community Team in East Sussex take her out and I feel at ease knowing Demelza's Registered Nurses and Health Care Assistants can tend to her very complex care needs. For those hours that she is out enjoying herself, I can do the everyday chores that are just impossible to do when Fia is at home. Fia needs constant supervision to stay safe so to be able to get upstairs and tidy



• Fia's first visit to Demelza, age 4

Turn to page 9 to read about how Demelza has supported Fia's siblings

up is a dream. Fia also loves visiting the care team at Demelza's base in St Leonard's; a safe space where she and her big sister Flo can paint, play with the toys and have a much-needed change of scenery.

The COVID-19 pandemic has been incredibly hard for many families and Demelza stepped in. Having that extra pair of hands to help care for children like Fia or having someone to call on for help, advice and support is invaluable for families like ours. Every little bit helps and we are so very grateful to those who donate to Demelza and make their services possible.”

Lian, mum to Fia

Demelza is coming to Sevenoaks

New charity shop opening in spring.
Staff and volunteers needed!
To apply visit www.demelza.org.uk/work-with-us

Festive Wishes Appeal 2021



Did you know?

Demelza's Christmas Tree-Cycle in January raised a tree-mendous £20,000, with over 1400 trees collected and chipped over three days!



• Demelza's Fall On Me Choir

Thank you to everyone who made a special Christmas donation to help pay for expert care and magical experiences for children over the holidays.

Last year's Festive Wishes Appeal raised over **£51,000** thanks to the generosity of Demelza supporters and kindness shown by volunteers.

Hundreds of children and their siblings were sent a personalised video message from Father Christmas and were invited to a socially-distanced grotto and light trail experience at the hospice in Kent.

Magical experiences were also made possible closer to home, with children across Kent, South East London and East Sussex receiving a hand-delivered gift from Demelza's volunteer elves. Mum Carol and son Mark from Maidstone delivered a present to 12-year-old Lucy who has a unique genetic condition and multiple medical issues which means she is non-verbal and uses a wheelchair.

Carol said: "It was such a pleasure to meet Lucy and the excitement on her face when we arrived is a memory we will always treasure."

Lucy and her mum Sam always look forward to music therapy with Demelza and during a group Zoom session at the start of the pandemic, Sam heard a track that would then inspire a very special project.

In the months to follow, Sam and other parents formed a virtual choir to record their own version of Andrea and Matteo Bocelli's 'Fall On Me'.

The heart warming track and video played a leading role in the Festive Wishes Appeal.

Sam, who performs as a soloist, said: "The words resonated so much with me. Having a child with a life-threatening condition, all that means on a day-to-day basis and with the added pressure of shielding from COVID-19, lockdown felt isolating. When we needed help, Demelza staff were there to catch us from falling."

Watch the Demelza Fall On Me Choir at www.demelza.org.uk/fall-on-me



Inspirational Ronnie's mission to help other bereaved families

A seven-year-old fundraiser from North Devon has donated a cuddle cot to Demelza in memory of his baby brother.

Last summer Ronnie Hawkings embarked on a daily five-mile cycling challenge to raise £2,000 to purchase the special cooling pad and memory boxes for causes that help bereaved families.

He was inspired to fundraise following the death of his little brother Vinnie in 2019.

Ronnie's parents, Carly and Ryan, were able to spend five precious days and nights with their child by using a cuddle cot, after he was stillborn at 32 weeks.

After doing his research, Ronnie decided that Demelza should be the recipient of the specialist equipment. Mum Carly, said: "If we hadn't used the cuddle cot, we wouldn't have had those precious days with Vinnie; we wouldn't have had time to say goodbye. We are so proud of Ronnie – the fundraising is all his idea. He wanted everyone to remember his little brother.

"Ronnie researched several organisations and he knew straight away that he wanted Demelza to receive the cuddle cot. It's important to him that he helped other families experiencing loss and grief."

In March, Ronnie is planning on travelling over 200 miles to Demelza's Kent hospice to hand-deliver the cot and three memory boxes.

Senior Healthcare Assistant Louise Cariney, who is a bereavement lead at Demelza, said: "Ronnie's fundraising efforts are nothing short of remarkable and he should be very proud of all he has achieved in Vinnie's memory.

"Thanks to Ronnie, families who have experienced the death of an infant will have the choice to use the cuddle cot if they wish, giving them time to be together to create memories."

Did you know?

A cuddle cot is a cooling mattress that can be placed in a cot or a pram. It allows bereaved parents and family members to stay with or visit a baby before their funeral.

“According to doctors, **there was more chance of us winning the lottery** than having two children with very complex health needs caused by completely different conditions.”



Louise with little brother Ethan

“My daughter Louise was eight when she died at Demelza’s hospice in Kent. Her little brother Ethan was just 18 months, and to our knowledge, would grow up and live a happy and healthy life like all children should.”

In the months leading up to Louise’s death we shared wonderful times together as a family at Demelza. However, in 2013, following months of Louise being in hospital, we returned for what was to be our last precious time together as a family of four. At first, we lapped up the amazing food and relaxed in the knowledge that our little girl was receiving the best possible care. But things soon took a turn for the worse when Louise developed an infection and wasn’t responding to treatment.

From the moment of finding out that Louise had a serious condition when she was just a baby, I knew that when the time came, I wanted her to die at home. But now I’m relieved she was at Demelza.

I remember feeling overwhelmed with sadness and a nurse coming into Louise’s room and opening the curtains – she seemed really chirpy. “We’re going to do some painting”, she said. “No, we’re not!”, I responded bluntly. But within an hour we were laughing together and reminiscing about happy times. Louise’s grandparents were there too. I still have all of those canvases of our hand prints – those wonderful, precious memories – and I’m so grateful that I do.

If we’d been at home, we would have been wallowing in despair; Louise wouldn’t have wanted that. She was at peace with her family around her. If we’d been at home there’s no way I could’ve done things like painting. In that moment, the thought of dipping her little hand into paint would just not have crossed my mind – I would’ve felt guilty for trying to do something fun at our most devastating time. But at Demelza you don’t have to feel guilty for laughing – or crying for that matter. It’s ok to feel every emotion you are feeling.

And it wasn’t just the emotional support that got us through. Demelza helped so much with making arrangements after Louise died; I wouldn’t have known where to start. But our journey with Demelza didn’t end there. The support we’ve received to this day has been incredible and I will forever be grateful.

“When I was pregnant with Ethan I naturally felt anxious but doctors had no reason to believe that he would have the same condition as his big sister. But, after being born prematurely at 35 weeks, Ethan underwent major surgery to fix a faulty valve in his heart. It was a traumatic time and my own heart was split in two knowing my little girl was at home needing 24-hour care.”

After Louise died, our concerns about Ethan began to heighten. Just before he turned two, he stopped in the middle of the room, his eyes rolled up and he dropped to the floor. After being diagnosed with epilepsy we sadly saw a rapid decline in him.

There is a never-ending list to his problems – a decline in muscle tone, heart, mobility and eye defects to name but a few. I sometimes compare our lives to a game of ‘Whac-A-Mole’, you think you have everything under control and then something else comes up. When we were referred to Demelza, I remember thinking: ‘Thank goodness’.

Finally, we were getting some help. I was exhausted, Ethan was exhausted. I felt overwhelmed with relief but I also felt

really sad – ‘How are we here again?’ All of my hopes and dreams for my son felt dashed.

When COVID-19 struck we were advised to shield at home and it was very intense. As things started to open up we were finally able to welcome the Demelza East Sussex Community Team to our home for visits.

Going from lockdown to strangers coming in took some adjusting but everyone was so patient and understanding; they wanted to help. Within a few months, we’d built great relationships with the nurses and health care assistants, and for the first time ever, Ethan was given the opportunity to be taken out and have independence away from his parents.

There was one visit when Ethan was poorly and just wanted his mummy, so the Demelza health care assistant sat down with his younger sister Isabella and read her school book with her. I’ll never forget what that meant to me as a mum who felt incredibly torn- that kind gesture meant that she wasn’t pushed to one side. Her needs were not neglected which can sometimes so easily happen to siblings of children with a serious or terminal condition.

The future is very uncertain for Ethan but with the help and support of Demelza we can focus on making life as great as possible for him. Demelza will always hold a special place in my heart.”

Harriet, mum to Louise, Ethan and Isabella

Harriet, James, Ethan & Isabella



Ethan enjoying a care at home visit

Great-grandfather pockets £25,000 Demelza Superdraw jackpot



Great-grandfather Alan was able to give his family a Christmas to remember thanks to a lucky Demelza Lottery windfall. The 73-year-old from Hastings pocketed the whopping £25,000 prize in December – our last Superdraw jackpot win of 2021.

"I received the call two weeks before Christmas and I was in total disbelief," says Alan. "I then felt guilty – my motivation to play the Lottery was always to help Demelza; not to necessarily win."

The retired father-of-three signed up to become a member of the Lotto in 2014 after speaking to a Demelza Lottery Canvasser in his local supermarket. In 2017 he upgraded his membership to include the Demelza Superdraw, which offers a chance of winning up to £25,000 for an additional £1 a week.

Alan's festive win meant his family could end the year on a high after he gifted some of the prize money to his

children and sister. The great-grandfather has also made a donation to Demelza from his winnings which will go towards vital care for children with serious and terminal conditions and their loved ones.

Alan added: "My son joked that I would end up in debt after giving all the money away. But it's important to me that my family can enjoy the win too. After a difficult few years this Demelza Lottery win really gave us all a big lift and it also means that my wife Debbie will be able to take early retirement in the spring.

"You can't help but want to support Demelza. When you read about some of the children and families it's nice to know that you have done your little bit to help."

Did you know?

From just £1 a week, you could win the Demelza Lottery at the same time as you help children with serious or terminal conditions. For just the price of a newspaper or a pint of milk, you can raise vital funds to help Demelza support children in our care.

For more information please visit www.demelza.org.uk/lottery



Fun times for siblings supported by Demelza

Brothers and sisters jumped at the chance for a fun-filled day out with Demelza at Gravity last year.

The group, who all have a sibling supported by Demelza, spent the day bouncing with new found friends at the trampoline park in Bluewater Shopping Centre – all before tucking into hot dogs and chips.

Lila Dowie, Demelza's Head of Corporate Partnerships and Trusts, said: "We'd like to say a huge thanks to Gravity, as one of Demelza's valued corporate partners, for giving the children the opportunity to bounce, bond and blow off steam with friends old and new."

In November another group of 12 siblings enjoyed a fun-packed activity day at our hospice in Kent, complete with music sessions, parachute games, football and baking.

Card tricks, a quiz and delicious pizza and ice cream finished off the afternoon, before settling down for a movie, popcorn and goodie bags in the cinema room.

As this edition of Demelza Life goes to print, another group of children will be enjoying another session at Gravity during the February half term.

How your donation helps the brothers and sisters of children like Fia

"Fia's deterioration hasn't just changed her life; it affects the wider family too. I had to give up my job to become Fia's full-time carer and since the pandemic struck, I've been home schooling Fia's siblings as we continue to shield at home until things settle. During the first lockdown Fia's brothers Fraser and Freddie enjoyed online sibling support groups where they did quizzes and played games with other children.

A Demelza volunteer also spent time listening to Flo reading online and supporting her education which gave her some much needed 1:1 time as it was no longer possible for Flo to keep her school placement. Flo, who was just eight at the time of the first lockdown, flourished with this support - which was a much needed and valued opportunity during a very uncertain and worrying time."

Lian, mum to Fia, Fraser, Freddie and Flo



Challenges and Events

"We all know that helping others feels nice. By taking part in a Demelza event you can feel happy in the knowledge that the money you raise will fund specialist care for children and support for their families. Partaking in an event allows you to meet and connect with other like-minded people and to be a part of **#TeamDemelza**. For further information on any of the events listed please visit www.demelza.org.uk/events or call 0300 365 3653*"

Kat Cordrey, Head of Community and Events

*(calls are charged at a standard network rate).



TCS London Marathon

Sunday 2 October

Join Team Demelza in 2022 for a chance to participate in the greatest marathon in the world. Run past iconic locations of London.

Do you have your own place in the marathon? Then why not join **#TeamDemelza** and support your local children's hospice.

www.demelza.org.uk/londonmarathon



Easter Egg Hunt

Friday 15 April, Doddington Place Gardens, Faversham

The annual Easter Egg Hunt is returning to a new location! Join us this Good Friday to help Cotton Tail find his friends in the grounds of Doddington Place Gardens. Every child taking part will receive an Easter treat! Tickets are now on sale, but there is limited availability so make sure you book early to avoid disappointment!

£5 per child, £1 per adult
www.demelza.org.uk/easter



Royal Parks

Sunday 9 October

Take part in the iconic Royal Parks Half Marathon this October. The stunning 13.1 mile route takes in the capital's world-famous landmarks on closed roads, and four of London's eight Royal Parks – Hyde Park, The Green Park, St James's Park and Kensington Gardens.

Registration £35, minimum sponsorship £350
www.demelza.org.uk/royalparcs



Little Warrior

Sunday 12 June, Dunorlan Park, Royal Tunbridge Wells

This family fun run will see you and your fellow warriors take on our experience zones so that you can **#UnleashTheWarriorWithin**. Whether you're a little or a big warrior we're sure you will love it. Our zones will include: hydrotherapy, music, sensory, art and memory.

£18 adult, £12 child, minimum £20 sponsorship per person
www.demelza.org.uk/little-warrior



Bubble Rush

Sunday 22 May, Betteshanger Park, Deal

Sunday 26 June, Avery Hill Park, Eltham

Sunday 10 July, Mote Park, Maidstone

Bubble Rush is a frothy fun run like no other! Walk, run or toddle your way through thousands of different coloured bubbles, whilst raising funds for your local children's hospice.

Adults from £12.50, child (under 16s) from £10, under 3s £3

www.demelza.org.uk/bubblerrush



Mount Kilimanjaro

Starting Thursday 22 September

Have you got what it takes to conquer the highest free-standing mountain in the world? Join **#TeamDemelza** for an experience of a lifetime and experience the stunning scenery of Africa from the world's best vantage point.

10-day adventure
Registration fee £195, minimum sponsorship £4,700
www.demelza.org.uk/mount-kilimanjaro



Queen's Platinum Jubilee

Friday 3 June

Help fund Demelza care on the extra Bank Holiday to mark Her Majesty The Queen's Platinum Jubilee. Head over to Demelza's website and download our special Platinum Jubilee fundraising pack for fun and inspiring ways to fundraise!

www.demelza.org.uk/queens-jubilee



Millwall Stadium Stair Climb

Sunday 25 September

Let's go round The Den! Do you dare climb the stairs to fund children's hospice care? Join us for our brand-new event at Millwall football stadium. Step up to the challenge and climb your way up and down all 1,868 steps in The Den!

Registration fee £35, minimum sponsorship £250
To apply visit www.demelza.org.uk/stairclimb



Shorts 4 Short Lives

Friday 24 July

Have you got a crazy pair of shorts hidden in your drawer or a pair you can never find the right occasion to wear? Here's the perfect opportunity! Join us on Friday 24 June, pull on those shorts, donate and show your support for those we care for in your local community.

To apply visit www.demelza.org.uk/shorts4shortlives



Pay for a day is an opportunity for you to make a real difference.

A difference to the lives of hundreds of children with serious or terminal conditions and their loved ones across Kent, East Sussex and South East London.

Could you pay for a day? By paying for a day of care you are helping us to provide clinical and emotional support to some of the most vulnerable families within our communities.

To find out more visit
[www.demelza.org.uk/
payforaday](http://www.demelza.org.uk/payforaday)



Demelza
Hospice Care for Children

PAY FOR A DAY

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www.demelza.org.uk

Registered Charity Number: 1039651

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