

# FAMILIES FIRST

SPRING/SUMMER 2023

## INSIDE:

- Meet Sophia and Emily - find out how your support is helping
- A week with Family Support Worker Sammii
- How you can get involved



**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

# Dear Supporter

**In this edition we are sharing Emily's story with you and the impact your support has had not only on her but also her parents and siblings, Oliver and Caitlin.**

I am very excited to share that our new teams in Reading and Liverpool are both now fully operational. They each have increasing caseloads and a networking breakfast was held in Liverpool to announce our presence and share our vital work. We plan to follow with something similar in Reading.

The Kentown Children's Palliative Care programme in North West England is also up and running, in collaboration with Together for Short Lives and The Kentown Wizard Foundation. It focuses on bringing together nursing care, social care and information and awareness, so families can easily access all the help and support they need, strengthening co-ordination and avoiding duplication to make life easier for them.

Rob Delaney published 'A Heart that Works', a moving memoir about the death of his son Henry aged two from a brain tumour. Our immense thanks to Rob for helping to shine a light on the most traumatic experience that a parent can go through and the support we provide.

I would also like to express our heartfelt thank you to the I Love Claims community for over a decade of wonderful fundraising, to Michael Josephson MBE for his very generous support and to all our fundraisers, corporate partners, volunteers, and supporters. It is only thanks to your help, dedication and generosity that we can continue supporting seriously ill children and their families.

Look out for us again at CarFest, the family festival created by Chris Evans in Hampshire, this summer, and if you would like to get involved and show your support there are lots of ways to be part of the Rainbow Trust team. See page 10 for more details.

Best wishes



Zillah Bingley, Chief Executive



### Cover photo:

Bea is two, has heart failure and is being kept alive by a mechanical heart until a donor can be found. Bea and her family are supported by Rainbow Trust.



## Magic wand

Taken from wishes by 105 children when asked '**What would you wish for if you had a magic wand**' as part of our annual snapshot audit 8-21 November 2022.

If I had one wish ...

**"Spend time to play with my Family Support Worker every day."**



# THE IMPACT OF YOUR SUPPORT

Families coping with their child's serious diagnosis face many challenges. Rainbow Trust Family Support Workers help them practically and emotionally as they navigate the new world they find themselves in. To us family means everything, so when serious illness affects a child and family life is turned upside down, this tailored, expert and constant support enables families to make the most of their time together.

**6,879**  
sessions of emotional support for sick children and their families



**33,068**  
support sessions provided



**490**  
hours of bereavement support

**1,048**  
hours of neonatal support for families

**271,000**  
miles travelled supporting families including to hospital, for check-ups and treatment



**21**  
family activity or siblings' days out held

**2,579**  
support plans created and reviewed



**1,129**  
sessions of practical support for families



**1,783**  
hours of hospital support for families



Figures from *Our Impact*, covering July 2021 to June 2022. Download a full copy [rainbowtrust.org.uk/our-impact](https://rainbowtrust.org.uk/our-impact)



## HIGHLIGHTS

**1,126**  
families received in-depth support

**5**  
*It's About Time* Family Support Workers recruited

**2**  
new care teams announced in Liverpool and Reading

Expansion of **online** family support service

**£5.3m**  
raised to support families

# SOMETIMES IT'S THE SIMPLE THINGS THAT HELP A FAMILY IN NEED

**Sophia spent nearly six months in hospital after she was diagnosed with a life-threatening condition.**

**Sophia was born in June 2022 and was diagnosed with severe combined immunodeficiency disease (SCID).**

Babies with this condition appear healthy at birth, but are highly susceptible to severe infections as their immune system is compromised and they are unable to fight infection effectively.

An early diagnosis meant that Sophia could be treated immediately so, at seven weeks old, Sophia was admitted to the Great North Children's Hospital in Newcastle.

Sophia had to have chemotherapy before undergoing a bone marrow transplant, which she received from her mum Janine, to introduce normal infection-fighting cells. Following the transplant, Sophia had to stay in hospital for four months to recover and to make sure the treatment had worked.

To protect patients, the ward that Sophia was on had very strict infection control policies and one parent had to stay with her twenty-four hours a day. Janine and David, Sophia's dad, took turns to stay with her and only saw each other briefly every day.

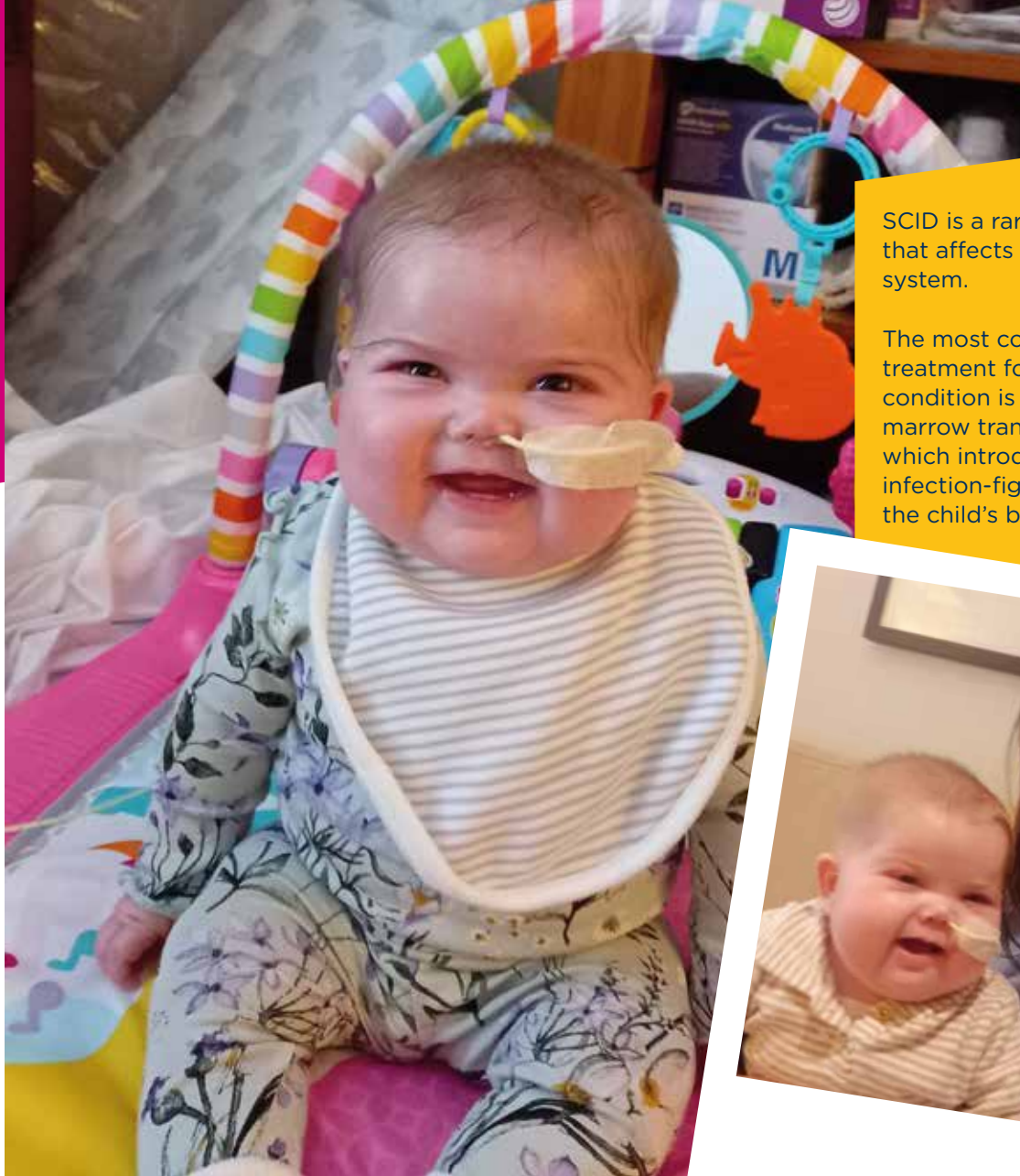
Family Support Worker, Jen, started supporting Sophia and her family in August 2022. As one adult always had to be with Sophia, Jen visited once a week to give Janine and David the chance to be together, spend time away from the hospital and have a break to catch up as a couple.

Janine and David said:

*During Sophia's treatment, Jen has allowed us the opportunity to spend a few hours together as a couple outside the hospital, whilst she looks after and entertains Sophia. This has provided us with much needed breaks during a difficult time and we know that Sophia is in very safe hands.*

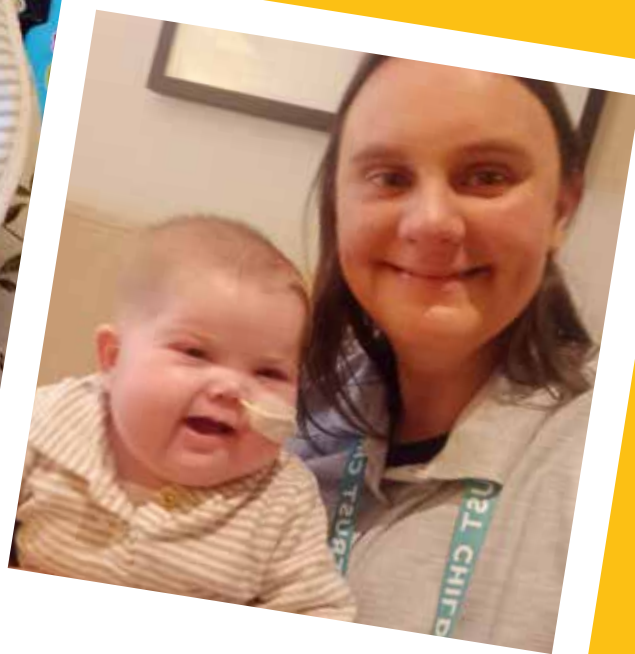






SCID is a rare condition that affects the immune system.

The most common treatment for the condition is a bone marrow transplant, which introduces normal infection-fighting cells into the child's body.



“Jen is amazing and Sophia loves spending time with her.”

Jen helped to look after Sophia, whose favourite things were playing with sensory toys, nursery rhymes and story time. Following medical advice, Jen also did 'tummy time' which was a series of muscle exercises to strengthen Sophia's core and build strength, which will help achieve her baby development milestones of sitting, to eventually crawl, stand and walk.

- ^ Sophia sharing her wonderful smile
- > Sophia with Family Support Worker Jen
- < Sophia in hospital

Following her bone marrow transplant, and once her immunity had reached key levels, Sophia was able to go to a half-way house at the end of November to allow her immune system to continue to rebuild.

Sophia finally went home on 16 December, just in time for her first Christmas at home, where she was able to spend lovely moments with her grandparents, who hadn't seen her since she was two weeks old.

→ £30 will provide one hour of support for children like Sophia and her family. Visit [rainbowtrust.org.uk/donate-magazine](https://rainbowtrust.org.uk/donate-magazine)



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# I TRY TO LIGHTEN THE LOAD FOR THE WHOLE FAMILY

Family Support Worker Michelle talks to us about starting to support Emily's family in June 2022.

**Emily is 12 and has Demyelinating neuropathy, a neurological disorder characterised by progressive weakness, with reduced function of legs and arms.**

Emily also has severe scoliosis, an abnormal curvature of the spine, that is causing her internal organs to be squashed, her ribs are rubbing on her pelvic bone and her lung function is progressively decreasing. Her parents, Ben and Laura, have recently been told her scoliosis cannot be operated on. Emily's condition is so severe that her family has been told she could just stop breathing or, if she catches a cold, she will need to be ventilated and the outcome may not be good for her.

*"Emily lives in constant pain but she never complains. She tries to put a smile on her face and tells everybody she is fine." Mum, Laura*

Ben and Laura also have two other children: Oliver, seven, and Caitlin, three. I help the family in many ways. I pick Oliver up from school so Laura can attend hospital appointments with Emily and Caitlin is now happy to play and have fun with me without mum being around.

Oliver is going through a difficult time at school. I have recently trained in drawing and talking therapy and am discussing being able to deliver it weekly in school. This time will encourage Oliver to share his feelings and to explore solutions and ways to manage his emotions.

A few weeks ago we went to the park with my colleague Matt and played football. When we got home Laura said she couldn't believe how much she had got done in the time the children were with us. The following week she sent me a text,



*Caitlin off to the park with Family Support Worker Michelle*

*"Oliver had been lacking confidence in his football but after his time with Matt he played really well for his team and got Parents Man of the Match and Managers Man of the Match. This has really boosted his confidence." Mum, Laura*

I know that for Ben and Laura it is really hard to see Emily in such pain and having to deal with her condition. As a Family Support Worker I try to help in whichever way I can, trying to do what is of most value and assistance to the family so they can share their time together.



*Emily enjoying pottery painting with Michelle*



*“My sister gets very excited when Michelle is coming. She keeps opening the door to see if she can see her car. It makes me happy when Caitlin is happy because she is my best friend.” Emily*



*“ The support my family has received from Rainbow Trust is outstanding.*

*Our Family Support Worker Michelle has gone above and beyond for our family. She has provided us with different things like sibling support, emotional support and help when I have needed to get Emily to appointments.*

*She makes her visits fun and manages to keep a very active three-year-old busy. My youngest daughter, Caitlin, sometimes finds it hard to leave me. Michelle manages to distract her and keep her busy while I'm gone.*

*Michelle picks my son up from school when I need to attend an appointment. All my children love their time with Michelle. She is a fun, caring person and without her support things would be even more difficult than they already are.*

*Michelle is always very easy to talk to and I now feel when things become difficult and I'm feeling alone I can always let my emotions out and talk about my feelings. She will sit and listen and will always have suggestions on how I can manage things.*

*There have been several occasions when I have needed someone to talk to and I have called or messaged Michelle and she is always more than happy to chat.*

*As a parent with a child with a life limiting condition, in the past, I have felt very alone. Since having Michelle's support in place I no longer feel that way.*

*Our family cannot thank Michelle enough for all the support she has provided and continues to provide. Her care is just outstanding.*

*Thank you.*

*Laura*



Sponsor a Family Support Worker like Michelle. Just £5 a month can help more children like Emily and her family.  
[rainbowtrust.org.uk/sponsor-us](https://rainbowtrust.org.uk/sponsor-us)

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# A WEEK IN THE LIFE OF A FAMILY SUPPORT WORKER

Sammii is a Rainbow Trust Family Support Worker in the Reading Care team and shares her typical week with us



## MONDAY

I started my week by confirming appointments with families for the coming week.

I went to the Royal Berkshire Hospital to meet a newly referred family. Their son, Owen, was born prematurely in November 2022 with multicystic dysplastic kidneys. I met his mum, Natalie, and two-year-old sister Esmae. Natalie needs me to play with Esmae on the ward and out in the community so she can spend more time with Owen. She also has two older children: Neve, 13, and Evelyn, nine, that I also spend time with when they are visiting Owen with Natalie on the ward.

Whilst at the hospital, another mum, Ariel, asked to see me to talk about her baby son, Finn, who is two months old. Finn was born prematurely and Ariel has another two boys at home, she doesn't drive and has to get the bus every day to visit Finn. Rainbow Trust will be helping them with transport to hospital and support at home with her other sons.

In the afternoon I went to see a family in Wokingham. Nathan is 14 and is receiving treatment at University College London Hospital everyday for a rare type of cancer, metastatic Ewing sarcoma. Rainbow Trust provides transport for Nathan and his mum to and from hospital. I went to their house to support his siblings Mimi, 16, Jonas, 12 and Annie, 9. I helped Annie with her maths revision, did crafts with her and gave them dinner.

I had a very long journey home that day as the M3 was shut!

## TUESDAY

I went to a house for families with very ill children within Southampton General Hospital to meet a new family. Baby Liam is four months old. He was born with Down's syndrome, a congenital heart defect and a serious lung disorder. Liam has a five-year-old sister, Nicole, who is undergoing tests for ADHD. I will be supporting Nicole by picking her up from school and spending time with her. I will also support Liam in hospital, looking after and playing with him to give Mandy and Michael, his parents, a break and to spend some time with Nicole. I will also be looking for counselling support for Mandy, who is finding things difficult.

Later that afternoon I went to Farnborough to meet one of our volunteers, Annabel. We went to visit Niran at his grandparents' house and spent time with him playing and designing an escape plan just like 'Home Alone'. Niran is 10; his sister Norah is five, has metastatic neuroblastoma cancer and is being treated at the Royal Marsden in London. Norah has been with her mum, Manju, in hospital for six weeks and Annabel will be supporting Niram.

## WEDNESDAY

As Norah was very sick and had a temperature during the weekend I contacted Manju to see how she was doing. She hadn't slept more than two hours a night for 10 days as she feels unable to go to the respite accommodation to sleep because she is scared of leaving Norah. Manju needed support and somebody to talk to so I encouraged her to talk to me.



I then spoke to Justin's mum, Emily. Justin was born at 30 weeks, and had congenital myotonic dystrophy, meningitis and epilepsy. Justin was very unwell and life support was turned off last week, he was just three months old. I will provide phone support to Emily and she may need face to face bereavement support after the funeral. We will always wait for parents and families to tell us how they want us to support them going forward.

In the afternoon I drove to Reading to meet Alicja's family. Alicja is seven and recently rang the bell to acknowledge the end of her treatment for cancer. She had acute myeloid leukemia, a cancer of the blood and bone marrow and still has a tracheostomy and a nasal feeding tube.

I met Kasper, Alicja's 10-year-old brother, for the first time. Anna, their mum, feels that Kasper is angry with her for being in hospital so long with Alicja, and leaving him. I will have one-to-ones with Kasper to play and talk to get him to open up.

#### THURSDAY

I joined our Reading Care team meeting on a call with a young carers charity providing short weekend breaks to 5-12 year old siblings to see if we can refer some of the children we support to them.

Following the meeting I met Hannah's family. Hannah is five and has Lennox-Gastaut syndrome, a severe form of epilepsy, and multiple learning disabilities. She has two siblings, Nathan, seven, and Lauren, two, who I support and I attend hospital appointments with mum to support her too.

#### FRIDAY

I joined the Southampton Care team meeting to gather more information about our planned mental health internal training. I caught up on my administration by updating all my family case notes, care plans and support activities on our database system.

It was quite a busy week. Referrals to the Reading Care team are increasing and our caseload is growing which shows how much our support is needed in the area.

The job of a Family Support Worker is very rewarding. Families trust us to support them with the difficulties and challenges encompassed with having a seriously ill child, I feel this is such a privilege. When I go home I enjoy walks and cuddles with my six month old puppy Frank.



Sammii with her puppy, Frank.

## Leaving a gift in your Will is a wonderful thing

**Last year 13 Family Support Workers, like Sammii, were funded by legacy gifts, allowing 327 families like Erin's receive support for one year.**

For over 35 years Rainbow Trust's vision has been to help every family who has a child with a life-threatening or terminal illness to be able to offer families the help of a Family Support Worker. A gift in your Will would enable that, for as long as they need us.

Take advantage of our free Will-writing service, visit [rainbowtrust.org.uk/legacy](https://rainbowtrust.org.uk/legacy)

No matter how big or small, a gift in your Will is a wonderful act of kindness that will give families the support they need.

**Download your gift in wills guide here.**



Erin died aged nine in December 2022. Thanks to gifts in Wills Erin was supported since she was 15 months old by Family Support Worker Sarah, who is now giving bereavement support to her mum, Helen, and her grandad.

# To all of our amazing supporters and fundraisers thank you!



A team of eager and determined managers at **Samsic UK** took on the challenge of climbing 4,411 feet to the summit of Ben Nevis and the team raised an incredible £3,099.



**Gabriele** climbed Mount Kilimanjaro raising £2,830. She said: *"Kilimanjaro was one of the most challenging weeks I've experienced, but I wasn't going to let anything stand in the way of reaching the summit!"*



**Sportfit Support Services** completed their South Coast stroll, raising £2,050 – enough to provide 78 hours of practical and emotional support for families with a seriously ill child.



**Chessington Garden Centre's Christmas Wonderland** donations from the public raised an amazing £9,698.



**Kington Langley Scarecrow Festival**, who chose us as their charity of the year, presented the Rainbow Trust team with a £4,000 donation.

## JOIN TEAM RAINBOW TRUST

Show your support and join us, or create your own event or challenge in your community or at work.

### Ride London-Essex 100



Sunday 28 May 2023  
Enjoy cycling through the closed roads of London and Essex.

### Great North Run

Sunday 10 September 2023  
Run this special half marathon from Newcastle to South Shields.

### Royal Parks Half Marathon

Sunday 8 October 2023  
Run past London's landmarks and through four Royal Parks.

### London Marathon 2024

April 2024  
Sign up now and secure your place in the greatest marathon on earth.

### Rainbow Day

Hold a Rainbow Day in your school or company! Departments, teams, groups or classes choose a different colour to wear for the day and each person donates £2.  
[rainbowtrust.org.uk/rainbowday](http://rainbowtrust.org.uk/rainbowday)

**Do something amazing today, sign up online at**

[rainbowtrust.org.uk/events](http://rainbowtrust.org.uk/events)

## Thinking of volunteering?

Giving your time means helping to support seriously ill children and their families when they need it most.

We have roles to suit everyone whatever time you have to give.

The kindness and support of our volunteers is helping to make a real difference. Find out more and get in touch at

[rainbowtrust.org.uk/volunteer](http://rainbowtrust.org.uk/volunteer)



## Thank you to all October 2022 London Marathon runners



**Team Marathon4Martha** (Paul, Emily -pictured- and Zoe) raised an amazing £12,625. Emily is mum to Martha, four, who was diagnosed with leukaemia, supported by Rainbow Trust.



**Team Taylor Hughes** (Paul, Guy, Ed, Dan and Tom) ran in memory of Charlotte, raising an amazing £19,664. Charlotte died of brain cancer at five months old. The family is supported by Rainbow Trust.



**Big Foot Events** visited Freeman's Hospital in Newcastle with a special dinosaur surprise for Bea, who was diagnosed with heart failure in May 2022 and is kept alive by a mechanical heart until a donor can be found.



**Sheridan Lifts** took on Sheridan Group in a brilliant charity football match and the team raised an amazing £1,310.



### Join the #GreatRainbowBake

Sign up and help families who need support now.

Find out more and get your free fundraising pack at

**[rainbowtrust.org.uk/bake](https://rainbowtrust.org.uk/bake)**

**Bake, Eat, Donate ... Repeat !**



# YOUR SUPPORT REALLY MATTERS

How your support is helping to change lives now

Playing, art and crafts, reading stories and days out give the children we support a safe haven and a place to understand and communicate how they feel. It provides some normality, improves their wellbeing and provides parents with some respite.

These lovely smiles and wonderful moments are only possible thanks to your generosity and support, thank you.



↑ Owen had fun with Family Support Worker Shelly at National Trust's Ormesby Hall Park. Owen's brother Erhun has complex health needs so Shelly provides support to the family.



↑ Jayden had lots of fun at soft play with Family Support Worker Sammi, giving him a chance to explore while mum looked after his brother, James, who has a serious skin condition.



↑ 50 families supported by Rainbow Trust had a wonderful day out at Whipsnade Zoo. The special day was donated and organised by TLC Marketing. The day included around 30 volunteers from the company, lunch and activities as well as transport for all the families.



↑ Gene, 13 years old, created a beautiful masterpiece with Family Support Manager Charlotte. Gene has kidney failure and wanted to paint the heart to show how Rainbow Trust has healed his family.



↑ Seven-year-old Molly enjoyed an art and crafts session with Family Support Worker Wendy. Molly's sister, Lucy, has cancer and Molly finds her sessions with Wendy help her anxiety when Lucy is in hospital having treatment.



↑ Eight-year-old Nour had a brilliant time having some fun with Family Support Worker Monica. Nour has been in hospital for the last eight months waiting for a heart transplant.

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## STAY IN TOUCH

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