



**Solving**  
*Kids' Cancer*

**Meet Teddy – a cheeky, funny and affectionate little boy. He adores cuddles with his loving parents, playing with friends and is obsessed with horses.**

### **Being diagnosed with neuroblastoma**

When Teddy was just 16 months old he became ill. He stopped crawling and his personality changed from lively and jolly to fearful.

Initially doctors thought it was a virus, but in April 2018 a tumour was found in his stomach and he was diagnosed with stage 4 high-risk neuroblastoma.

**“We were shell-shocked and in total denial. I remember sending a message to work to say I wouldn’t be in the next day but little did I know that I would be giving it up entirely to care for Teddy as he fought for survival. We got in contact with a few other families who were being supported by Solving Kids’ Cancer and they recommended the charity.”**

Jamie and Emma, Teddy’s parents.



Solving Kids’ Cancer are here for parents like Teddy’s throughout their cancer journey. We offer evidence-based and impartial information to help them make choices about their child’s treatment, and support families to access treatment if it is not available on the NHS.

### **Starting treatment immediately**

As well as identifying the mass in Teddy’s stomach, blood tests confirmed that Teddy was also extremely anaemic and needed a blood transfusion straight away.

Brave Teddy went through frontline treatment in the UK and endured a long list of treatments including 37 gruelling rounds of chemotherapy, 14 rounds of radiotherapy and stem cell harvests.

### **Our Family Support Service**

Donna Ludwinski, our Family Support Consultant at Solving Kids’ Cancer, was on hand to support the family throughout Teddy’s treatment.

**“Donna was indispensable. She made our lives less stressful and she was an amazing person to call to answer the endless questions we had.”**

### **Accessing treatment abroad**

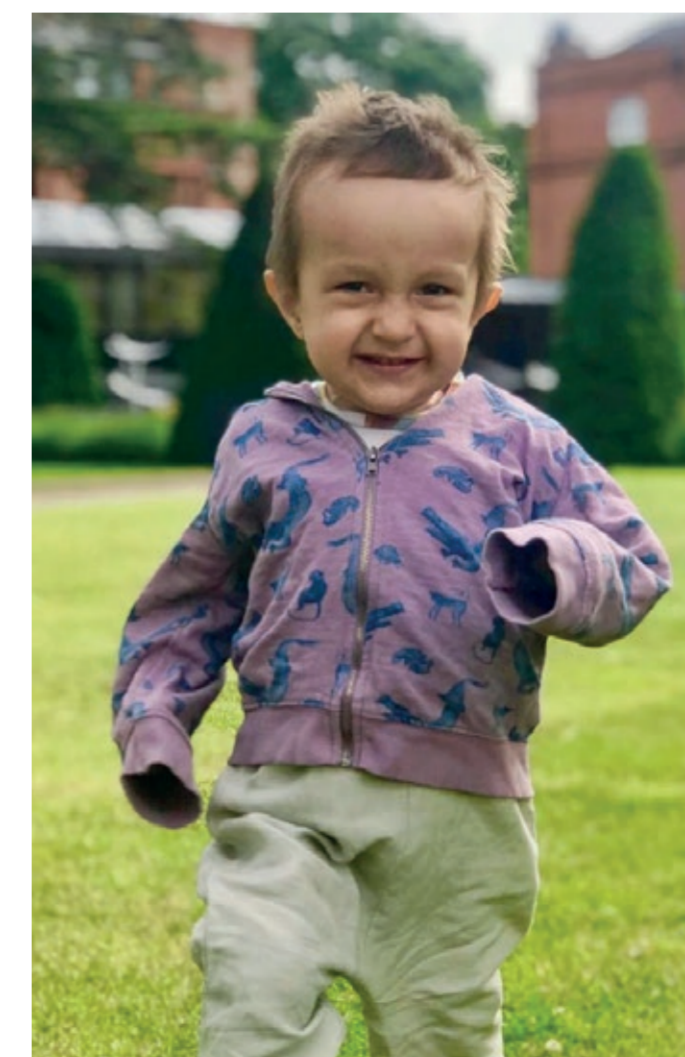
Teddy’s family were supported by Solving Kids’ Cancer to raise almost £300,000 for Teddy’s treatment.

Thanks to donations, Teddy’s family flew to Barcelona in January 2019 to start immunotherapy at Hospital Sant Joan de Deu, to clear any last remaining neuroblastoma cells in his body. His end of treatment scans showed the fantastic news that Teddy has no evidence of disease!

However, high-risk neuroblastoma has an extremely high relapse rate meaning that even after treatment the cancer could come back. Teddy’s family fundraised to be able to access a vaccine in New York at Memorial-Sloan Kettering Cancer Centre that they hope will reduce the chances of his cancer coming back and treatment started in June 2019.

Teddy has just completed his penultimate trip to New York for the vaccine. However, he still must go through another year of scans to check the cancer has not returned.

**Teddy is now 3 years old, thriving at nursery and has just become a big brother!**



Solving Kids’ Cancer is fighting for a future where no child dies of neuroblastoma or suffers due to its treatment. We do this in four ways: family support; access to treatment; funding innovative clinical research; and campaigning for the best treatment here in the UK. Your support will allow us to continue supporting the lives of children like Teddy.



Kira's been fighting neuroblastoma since she was 11 years old. She's now 16 and has faced four gruelling rounds of treatment while trying to get rid of her disease.

### Treatment in New York

Thanks to the huge fundraising efforts and public generosity in response to their urgent appeal, Kira's family raised more than the £340,000 needed for her life-saving surgery in 2018.

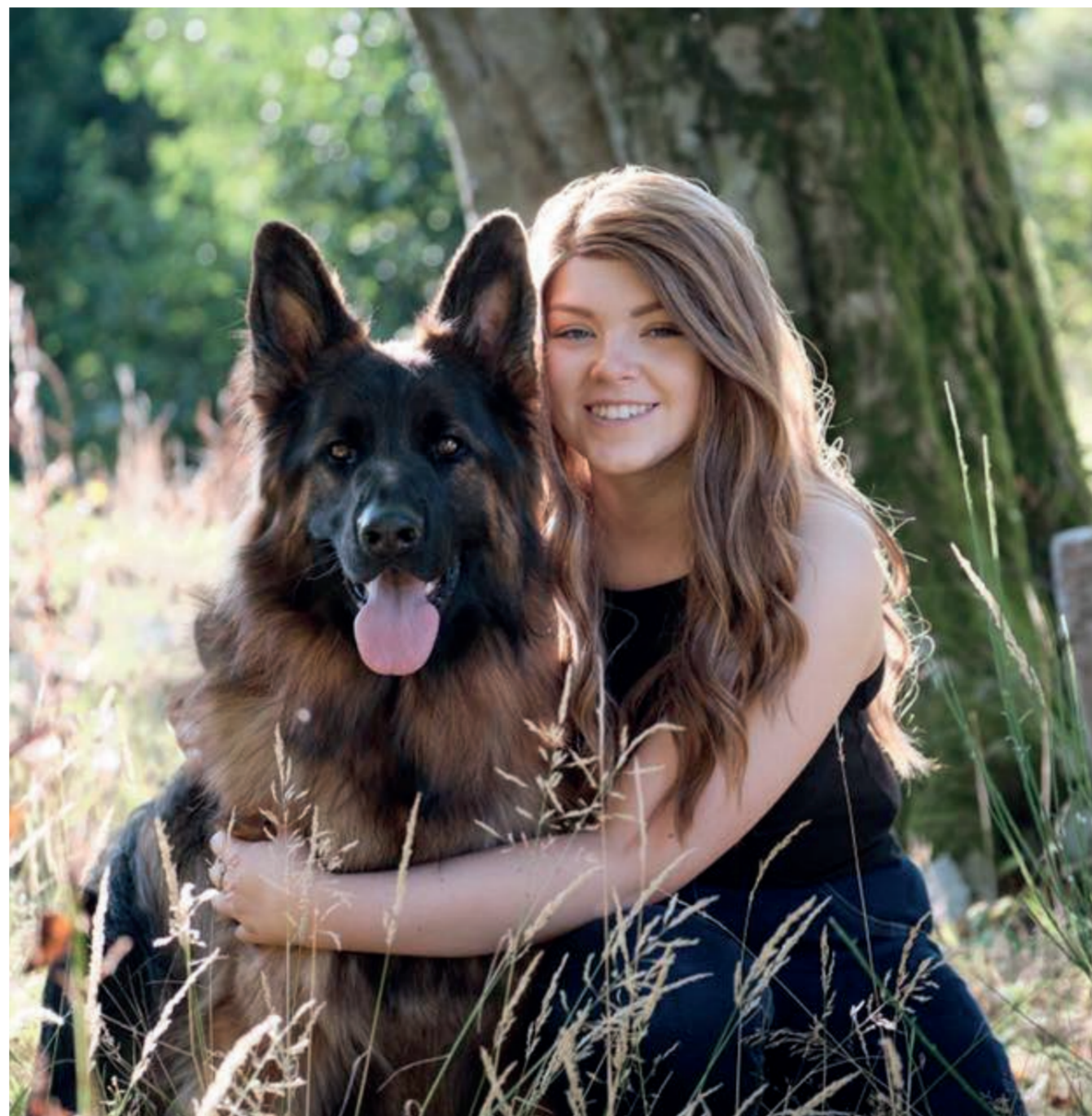
The operation at the Memorial Sloan Kettering Cancer Centre was a success.

### Receiving devastating news

By August 2018 an MRI scan showed neuroblastoma in the pancreatic area and it was decided that Proton Beam Therapy in New Jersey would be Kira's best treatment option.

Sadly, Kira's cancer continued to grow during Proton Beam Therapy and scans in January 2019 showed new spots of disease in her abdomen. Her family were given the devastating news that Kira's disease is incurable.

# Kira's neuroblastoma story



"For the past four and a half years I've been attached to walls, attached to drip stands, had wires hanging out of me everywhere. I've been so ill to the point where I can't walk, vomiting everywhere, being infused with chemo for over 48 hours to then be basically in hospital for months on end. It's just absolute hell on earth. To then being able to go on this [Lorlatinib] and for being able to live a normal teenage life – it's just so amazing, and this is why we need more of this and not chemotherapy." Kira

### Our commitment to research

Solving Kids' Cancer funds innovative clinical research to fight for a future where no child dies of neuroblastoma or suffers due to its treatment. But this will not happen without actively initiating clinical research, like our funding of trials such as Lorlatinib.

We are driving forward the development of more improved treatment options in the UK which are less toxic to children fighting neuroblastoma now.

We are determined to advance science and find a cure for future generations.

### Renewed hope

Kira has since been granted compassionate use of the third-generation ALK inhibitor drug Lorlatinib, part-funded by Solving Kids' Cancer. So far, the Lorlatinib has been effective and latest scans have even shown a decrease in her disease!

Relapsed neuroblastoma is a hugely challenging cancer to treat with children facing painful, invasive and gruelling treatments. In contrast, daily tablet treatments like Lorlatinib are minimal toxicity. This means children and young people like Kira are free to live their lives away from hospitals.

Your support allows Solving Kids' Cancer to continue to fund innovative clinical research and fight for a future where no child dies of neuroblastoma, or suffers due to its treatment.



Our special thanks to Oscar and his parents Leona and Stephen and all of the Oscar Knox Fund's donors and fundraisers for helping to bring this clinical trial to fruition, continuing Oscar's legacy.