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**BLUE SKYE THINKING COVERAGE** September 2014



## Abingdon's Skye Hall loses his cancer battle



Skye began making loom bands during his hospital stays and came up with the idea to try to make the world's longest one.

**A five-year-old boy from Oxfordshire has lost his battle with cancer.**

Skye Hall, from Abingdon, died just a year after he was diagnosed with an aggressive brain tumour.

He had undertaken a challenge called Loom to the Moon, to create the world's longest loom band, in a bid to raise money for brain tumour research.

He and his parents also set up a charity called Blue Skye Thinking to support the research and treatment of childhood brain tumours.

### 'Inspiration'

Skye began making loom bands during his hospital stays and came up with the idea of trying to make the world's longest one.

However, when he became paralysed from the shoulders down, after undergoing radical surgery, Skye and his family turned to the public to help.

They received support from across Oxfordshire and around the world, as people sent them their loom band creations.

Speaking to the BBC before Skye's death, his father Andrew said: "We want it to be a story of inspiration. Yes, of course, it is incredibly difficult for us.

"But he has inspired us and will continue to do so long after he has gone."

The family said Skye's younger brother Jesse would now try to complete his mission in his memory.



## Abingdon's Skye Hall loses his cancer battle



**A** *five-year-old boy from Oxfordshire has lost his battle with cancer. Skye Hall, from Abingdon, died just a year after he was diagnosed with an aggressive brain tumour. He had undertaken a challenge called Loom to the Moon, to create the...*

[BBC News](#) 2014-09-01

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## Farewell to Abingdon boy Skye Hall, who lived his short life to full



Five-year-old Skye Hall, who died on Friday Picture: OX69322  
Damian Halliwell

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# Oxford Mail

IN the final hours of his life, brave youngster Skye Hall showed incredible strength and told people to remember to make the most of what they have.

The five-year-old from Abingdon died at home on Friday after fighting a brain tumour for a year.

Skye's family appealed to the public through the Oxford Mail last month when they were trying to tick items off his 'bucket list' of things to do before he died.

After their request appeared on the front page, the family were inundated with offers of help.

Last night his mother Sally said: "I waited my whole life for the moment when Skye was born. It is both a responsibility and an honour to care for a child.



- Skye Hall with loom bands



# Oxford Mail cont..

"Every night I used to whisper to Skye: 'Love you to the moon and back,' and in keeping with showing his love but also wanting to get one-upmanship on anyone, he always replied: 'Love you to infinity'.

"On the day he died he asked Jesse, his two-year-old brother, to help him complete his challenge to loom to the moon as he was 'feeling a bit tired today'."



Skye's nursery teacher Buzz McKenzie from Long Furlong Primary School said: "He will live in our hearts forever."

Prime Minister and Witney MP **David Cameron**, who met Skye earlier this year, said: "I was greatly saddened to hear about Skye's death."

Skye died at home after being treated for a brain tumour, but the treatment that helped control the cancer made Skye sicker than ever.

He was diagnosed with a brain tumour in August last year and in May this year the family were told he had radio-chemo neurotoxicity, where healthy cells in his brain and spinal cord had been damaged by the radiation therapy and chemotherapy.

Mrs Hall, 36, said: "Instead of being able to move forward with our plans to say farewell to Skye, everything has been put on hold in order for the correct cause of death to be printed in black and white for all to see.

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#### • Skye with his younger brother Jesse in a clip from the family's video tribute

"It would be selfish and easier for us to agree to his tumour being recorded as his cause of death but this would be untrue as it was the treatment itself which was the cause.

"Skye always wanted games to be played 'correctly' and we owe it to him and future children not to have these statistics skewed as so often happens."

She urged people to donate to the family's charity Blue Skye Thinking, which aims to raise money for alternative treatments for child cancer.

Mrs Hall added: "For now, Jesse seems calm with the fact that Skye is still, but did say: 'Mummy, I don't want to be the big brother now, I want it to be Skye'.

"Skye and I had too little time together but following his own parting words of wisdom to his fans, we did make the most of what we had. I will miss you, my best friend."

Mr Cameron added: "He was an extraordinary little boy who displayed extraordinary bravery and my thoughts are with his family at this devastating time."

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**BLUE SKYE THINKING**  
SUPPORTING RESEARCH & TREATMENT OF CHILDHOOD BRAIN TUMOURS

# Oxford Mail cont..

Ms McKenzie added: "He was an exceptional boy who took an interest in everything; he had a unique outlook, a positive attitude and was an inspiration to others.

"Everyone who taught Skye has special memories."

The family released a video of Skye's last message on the day he died, as well as urging people to help his younger brother Jesse.

Jesse, who is filmed speaking and playing next to his sleeping brother, said: "My brother needs my help.

"Help us Loom to the Moon."



- With his family at Oxford United

The family set up the Loom to the Moon appeal last month to try to make the world's longest loom band — where elastic bands are twisted together to form a chain.

It has more than 12,800 likes on Facebook, and the family have already received more than 9.5km of loom bands – more than the height of Mount Everest.

People from as far as Kenya and Australia have been posting loom bands to the charity.

**Oxford United** have also championed Skye's cause, with fans working to add to the chain.

On Saturday, August 23 Skye went onto the pitch at half time during the match against Portsmouth.

Peter Rhoades-Brown, the club's business development manager, said: "It's really sad news, but the club is happy that we have managed to give him a little bit of a lift before he passed away.

"We will continue to loom and help the appeal."

Completed chains should be posted to Blue Skye Thinking, 59 Hendred Way, Abingdon, OX14 2AW.

- To donate text LOOM66 £2 to 70070 or visit [justgiving.com/skye-hall](http://justgiving.com/skye-hall)
- For more information visit [facebook.com/loomtothemoon](http://facebook.com/loomtothemoon)

**2 September 2014**



## Oxfordshire Guardian



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### Tributes paid to 'beautifully brave' Skye

September 4, 2014 | Filed under: Community | Posted by: Oxfordshire Guardian

An Abingdon boy who became renowned for his Loom to the Moon challenge has died.

Skye Hall's family said on their charity website Blue Sky Thinking that the five-year-old passed away peacefully on Friday.

He had been diagnosed with a terminal brain tumour just over a year ago.

In a video posted on the website, Skye says to viewers to "make the most of what you have got".

And his brother Jesse has pledged to carry on Skye's Loom to the Moon challenge, which has seen him work on building a long enough loom band chain to reach the Moon.

Tributes have been left to Skye on the website, with Claire Woods posting: "I hope Jesse achieves the Loom to the Moon challenge on behalf of the beautifully brave Skye."

Alastair Eales wrote: "Skye's goodness shined through and glowed incandescently bright against the horrid disease and subsequent side effects for his treatment.

"Skye's enduring smile and good humour in the face of such adversity is a testament to the wonderful Hall family."



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## Parents of boy who died from effects of cancer treatment call for more funding

Doctors say more research into child cancer needed after death of Skye Hall, who had same kind of brain tumour as Ashya King

Sarah Boseley, Health editor

The Guardian, Thursday 18 September 2014 17.35 BST



Skye Hall with Loom Bands after the launch of fundraising campaign Loom to the Moon. Photograph: Guardian

The parents of a five-year-old boy who recently died after suffering from the same kind of brain tumour as [Ashya King](#) have called for more funding and research into combating childhood cancer.

The death of Skye Hall from the toxic side-effects of radiotherapy and chemotherapy has led NHS doctors to suspend the treatment regime he was on.

Ashya King was the centre of media attention when his parents fled to Spain, fearing the possible damage to their son from conventional radiotherapy in the UK. He is now undergoing radiotherapy using targeted proton beams in Prague – although doctors say that the side effects will be similar with proton beam therapy because so much of the brain and spine have to be irradiated following surgery for this cancer.

Unlike Ashya, Skye's cancer was advanced when it was detected. The best hope of a cure was thought to be the Milan protocol, a [tough treatment regime involving chemotherapy](#), followed by radiotherapy and then further high-dose chemotherapy. His parents have only praise for their son's doctors and say that proton beam radiotherapy would not have helped their child. But, they say, better treatments for [medulloblastoma](#) and other brain tumours in children are badly needed.

Skye's cancer, discovered just before he was due to start school in August last year because he was vomiting every day, was metastatic – it had spread within the brain and spine. He had brain surgery at the [John Radcliffe hospital in Oxford](#) within days to remove as much of the tumour as possible, before starting on months of chemotherapy and radiotherapy to kill remaining cancer cells.

Sally and her husband Andrew were told what complications to expect at every stage, she said. "My husband struggled with having to sign the consent form every time but what choice does one have when you are trying to tackle a disease which left untreated would kill them," she said.

At the end of the course of radiotherapy, Skye was very bright, walking and said to be in "good health". But he was then put on a further chemotherapy course with a drug called Thiotepa in accordance with the Milan protocol – a regime that had been reported to have good results in Italy. Doctors in the UK and internationally who specialise in the treatment of children with cancer talk all the time, because the cases are relatively rare. It was thought within that community that the protocol offered the best option for a child in Skye's position. He had a one-hour infusion of the drug for three days.

"On 1 April Skye's MRI scan gave us much awaited good results that Skye's tumour was significantly reduced and all that was potentially left was scar tissue," said his mother. "He was discharged but was unable to walk. At that stage it was attributed to muscular wastage from being bed bound for so long."





# The Guardian cont..

But Skye was suffering from the effects of his aggressive treatment, which had caused nerves in the brain and spine to die. He became paralysed from the neck down. His doctors told the family he was a victim of radio/chemotherapy neurotoxicity. "Due to it being acute rather than chronic over a very long period of time it is widely agreed that is was certainly treatment related, most likely due to a combination of hyperfractionated [twice daily] radiotherapy closely followed by high dose Thiotepa," Sally said.

She said she does not blame anyone. "For us, facing his initial diagnosis, once the shock had worn off, we were full of hope, the doctors had a 'plan', it was going to be a long, hard journey but we had hope.

"Strangely I have never felt angry at the fact that Skye developed the disease in the first place or that the treatment was his cause of death. I believe this can be attributed to keeping an open line of communication with our incredible consultant Dr Sheila Lane.

"She has always been honest, willing to explore any ideas we researched and presented to her and was always happy to help us gain second opinions both within the UK and internationally, which we did often. I cannot stress enough the need to develop trust between doctor and patient. She always put Skye at ease too, which was incredibly important to us," she said.

"The NHS have so much bad press but our experience has shown the NHS to have a wealth of dedicated, professional and caring people who go beyond their duties to help the patients entrusted to their care."

Skye's parents embarked, with the doctors, on a desperate hunt for any treatment that could save his life, but those drugs that were tried failed to help him. He became progressively weaker and died on 29 August, from the toxic effects of his treatment.

Sally Hall described Skye as "an extraordinary little boy" who, young as he was, helped publicise the need for more funds for cancer research. He started a [Facebook campaign](#) asking people to help him make the biggest Loom Band in the world, which would reach to the moon.

"He was a beautiful, witty, and engaging boy who loved magic, telling jokes and giving to others," she said. "Some people who didn't know Skye have said at least he is not in pain and is at peace now but let me tell you, he chose life every day during his illness, regardless of pain, regardless of being paralysed. He had his mind and his mouth which he used to inspire people with his wise words.

"His video to his 'fans' during his last hours where he said 'make the most of what you've got' is what I am trying to do every hour but it is hard doing it alone. I miss him dreadfully."

She and her husband started a charity, [Blue Sky Thinking](#), to advocate better treatment. Doctors agree that research into childhood cancers like Skye's and Ashya King's is underfunded because of the relatively small numbers of cases compared to adult cancers – there are fewer than 100 medulloblastoma cases a year in the UK.

Sheila Lane, Skye's consultant at the John Radcliffe hospital, said: "What is clearly evident is that there is a desperate need for better and indeed new treatments for childhood brain tumours. The treatment protocols worldwide are not curing enough patients and those that are cured are displaying significant problems in later years."

Simon Bailey, professor of paediatric neuro-oncology at the Royal Victoria Infirmary in Newcastle, said: "To make real progress in treatment there needs to be urgent, significant funding.

"In recent years we have been concentrating on not only trying to cure children with medulloblastoma, but trying to identify biological markers that can guide us to reduce treatment in those that do not need the same intensity of treatment. We are very concerned about the consequences of cure in the long term, as this has a profound effect on the future of children, young people and their families."