# BLUE SKYE THINKING COVERAGE March 2015





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### **Portsmouth News**

Edward said: "Sally and I have been friends for over 15 years and have even worked together in the past. To know Sally and Andrew and their children is my privilege.

"When Skye was diagnosed there was a sense of disbelief among our group of friends, I suppose in some ways there still is. But running events such as these helps me to remember and honour Skye.

"When I am out training, or during a race itself, it gets tough, my knees are not as strong as they used to be and distance running doesn't come naturally to me, but then you think of Skye, and Jesse, Sally and Andrew and it spurs you on.

"I am running for Blue Skye Thinking so that more money can be raised, as well as awareness, and less children need suffer in the future."

Sally said: "What a challenge Edward has set for himself ... three half marathons over three consecutive Sundays has definitely a feel of March madness about it but if anyone can do it, I know Edward can. Good luck and we'll be there to cheer him on!"

To sponsor Edward go to www.justgiving.com/Edward-Blagrove1/.

### Man to run three half marathons

Local Crime Traffic & Travel Business Campaigns Defence Education

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updated		published	
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Health Politics Regional

A fundraiser is to run three consecutive half marathons this month in aid of a children's charity.

Edward Blagrove, 32, from Oxford, will run the Cambridge half marathon on March 8, followed by the North London half marathon on March 15 and the Reading half marathon on March 22 to raise awareness and money for Blue Skye Thinking.

The charity was set up by Edward's friend Sally Hall and her husband Andrew Hall after their son Skye was diagnosed with medulloblastoma, an aggressive and cancerous brain tumour. Skye died at home aged just five years old last August.



### **Littlehampton Gazette**



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### **Oxfordshire Guardian**



#### Edward's marathon task for Skye's charity

🛗 March 5, 2015 | 🗀 Filed under: Community.Featured Articles.Latest.Slider | 🏖 Posted by: Oxfordshire Guardian

A Radley man is tackling three half marathons over the next three weekends to raise money for Blue Skye Thinking - a charity set up in honour of an Abingdon boy who died last year.

Edward Blagrove, 32, is running the Cambridge half marathon on Sunday, followed by the North London half marathon on March 15 before his final race in Reading on March 22.

He is hoping to raise thousands of pounds for the charity, which was created by his friend Sally Hall and her husband Andrew in July last year after their son Skye was diagnosed with a brain tumour.



Edward Blagrove

Five-year-old Skye died on August 29, and the charity has been campaigning and raising funds for research into brain tumours in children.

"When Skye was diagnosed there was a sense of disbelief among our group of friends," said Edward.

"I suppose in some ways there still is, but running events such as these helps me to remember and honour Skye.

"When I am out training it gets tough, my knees are not as strong as they used to be and distance running doesn't come naturally to me, but then you think of Skye and it spurs you on.

"I am running for Blue Skye Thinking so that more money can be raised, as well as awareness, and so that fewer children need suffer in the future."

Edward also took part in the Oxford half marathon in October last year, where he and three friends raised £400 for the charity.

Skye's mum Sally said: "What a challenge Edward has set for himself.

"Three half marathons over three consecutive Sundays has definitely got a feel of March madness about it.

"But if anyone can do it, I know Edward can.

"Good luck, and we'll be there to cheer him on."

To donate to Edward, go to justgiving.com/edward-blagrove1.



Skye Hall

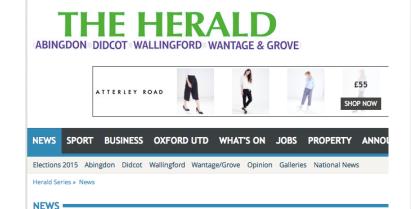


### **BBC Radio Oxford**



Interview with Ed Blagrove on Breakfast Show re his March Marathon challenges





Skye Hall's death sparks demand for research to stop cancer sufferers dying from neurotoxicity from treament





LEADING specialists have joined the parents of Skye Hall to demand research to prevent more deaths after the treatment that killed him was suspended.

Five-year-old Skye, from Abingdon, died in August after battling a brain tumour for a year, but he passed away from radio-chemo neurotoxicity.

It meant healthy cells in his brain and spinal cord were damaged by a regime of radiation therapy and chemotherapy known as the Milan protocol.

The protocol, which was recommended by the Children's Cancer and Leukaemia Group (CCLG) in 2008, has since been abandoned.

#### Our top stories

New guidance from the CCLG, which works with all children's oncologists in the UK, now encourages doctors to stop the treatment.

Skye's mother, Sally Hall, said: "Initially we were told [Skye's death] was a unique and exceptional unexpected complication."

But it became clear that other children across the country were also suffering from severe neurotoxicity.

Skye's parents have set up the charity Blue Skye Thinking to help research into alternative cancer treatments for children.

Mrs Hall, also mum to three-year-old Jesse, said: "What we have learnt over the past few months is the shocking fact that there is no country-wide formal body in place to gather, monitor and share data for standard guideline treatment as there are with clinical trials.



### The Herald cont..

"Despite the fact we now know other children had been suffering in a similar way and different treatments had been tried, [Skye's doctor] could not easily obtain this information.

"It was a matter of phoning round individual colleagues to ask them directly all the time having to watch Skye deteriorate.

"This is not acceptable. This is extremely dangerous and raises questions over avoidable deaths."

Chair of the neuro-oncology special interests group at CCLG Dr Nicky Thorp said the group had suspended the treatment in May last year, as soon as doctors noticed patients becoming ill.

Dr Thorp said: "We did a national audit of the 80 children in the UK who were treated with the Milan protocol.

"We found there were about 10 per cent with severe neurotoxicity.

"Their symptoms varied, but some had devastating effects, losing their mobility and not being able to swallow."

The consultant clinical oncologist, who works in Liverpool, said: "We definitely agree with Skye's parents.

"What we really want is a national database to collect information in real time."

Oxford West and Abingdon MP Nicola Blackwood called for more standardisation and data collection in the House of Commons last month.

Ms Blackwood said: "The architecture for collecting the information is in place, but the lack of a formal data collection requirement and of a single responsible body can have devastating consequences for families."



#### THE HERAID ABINGDON DIDCOT WALLINGFORD WANTAGE & GROVE



NEWS =

A marathon month ahead for runner's tribute to tragic boy





Ed Blagrove who is running three half marathons in March for his friends Sally and Andrew Hall in memory of Skye. Picture: Lucy Ford

First published Saturday 7 March 2015 in News



by David Rivers, Reporter covering Kidlington. Call me on (01865) 425433 Follow 34 followers

A RADLEY man will take on three half marathons on consecutive weekends in memory of five-year-old Skye Hall.

Ed Blagrove will run the Cambridge half marathon tomorrow, the North London half marathon on March 15 and the Reading half marathon on March 22.

The systems trainer at John Radcliffe Hospital in Headington is attempting to raise £1,000 for Oxfordshire charity Blue Skye Thinking.

### **The Herald**

His motivation stems from a close 15-year friendship with Blue Skye Thinking founders Sally and Andrew Hall from Abingdon.



#### Our top stories

Their son Skye died in last August as a result of his cancer treatment, which resulted in radio- chemo neurotoxicity.

The Oxfordshire charity's goal is to fund the best researchers into alternative cancer treatments for children.



Skye Hall pictured in hospital with his mother Sally.

Ed Blagrove first became friends with Mrs Hall when they started acting together at the Oxford Playhouse and was introduced to her husband and then their son Jesse, now three.

Mr Blagrove said he remembered the pain of seeing his friends lose their child and feeling helpless.



### The Herald cont...

Now the Oxford Operatic director says he wants to do his bit for his "lovely family" by raising money.

The 32-year-old said: "It is difficult to know how to help when someone loses a child but what I can do is put some trainers on and get sweaty by doing my bit.

"When Skye was diagnosed there was a sense of disbelief among our friends, I suppose in some ways there still is.

"But running events such as these helps me to remember and honour Skye.

"You can't put in to words what it is like to see your friends suffer in that way because it is impossible to know what to do.

"I have known Sally for 15 years because we used to act together at the Playhouse and did the South Pacific musical.

"I got to be friends with Andrew through her and we have become greats friends, we also share a big passion for rugby.

"I am running for Blue Skye Thinking so that more money can be raised, as well as awareness, and less children need suffer in the future.

"When I am out training, or during a race itself, it gets tough, my knees are not as strong as they used to be and distance running doesn't come naturally to me, but then you think of Skye, and Jesse, Sally and Andrew and it spurs you on."

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"Three half marathons over three consecutive Sundays has definitely a feel of March madness about it but if anyone can do it, I know Edward can.

"Good luck and we'll be there to cheer him on."

• To support Mr Blagrove visit justgiving.com/Edward- Blagrove1/









# We'll loom to the moon FOR OUR LITTLE BOY

Sally Hall, 36, is determined to help three-year-old son Jesse fulfil the wish her eldest son Skye made before he died of a brain tumour aged only five

so young why his treatment was making

him feel worse, not better and as he slept,

We were in hospital for months but it's a

mother's job to turn the worst days into the

his little hand would stretch out from

under the covers, looking for comfort.

for Skye's sake.

I never left his side

kye has a fantastic imagination and makes the most of every opportunity. It has been a delight have him in nursery. His unique personality has left a mark and his absence will leave a hole. we found ourselves at the hospital.

When I first read this report from my son Skye's preschool teacher as he left to go to school, my heart swelled with pride. Any mum loves to hear such lovely words about her children and, in just a few short sentences, she'd summed up my blondehaired, blue-eyed boy perfectly.

Now, I can't think of her words without being ripped apart with grief. Because, after being diagnosed with a brain tumour at four years old, Skye passed away. Just like his teacher said, his absence has left a hole in my heart that can never be filled.

With my husband Andrew and my two sons, Skye and Jesse, our family was always close but when Andrew, 43, took a

sabbatical from his job as a teacher and we travelled around South Africa, Australia best, so we'd spend hours making badges or cards. and New Zealand, we bonded in a way I'd But his highlight was always visits from never thought possible. Cramped together in a camper van for four months, it was the Jesse, now three. He worshipped his big brother and would do anything to make happiest time of our lives. him smile. Together, they'd play magic

36 reveal co.uk

Which makes it seem even crueller tricks on the nurses, giggling hilariously that it was just after we returned to our home in Abingdon, Oxfordshire, that Skve between themselves. After his high-dose chemotherapy, became ill. In July 2013, when he started

Skye and I were on an isolation ward for vomiting every morning, I assumed he had a stomach bug. But when it didn't clear up, eight weeks. Even then, Jesse would play charades with us through the window or hold up pictures for Skye to see.

Hearing that your four-year-old has a brain tumour is news you wouldn't wish on Finally, in April 2014, we got good news. The tumour had gone. Watching him come your worst enemy. But I had to be strong home, sleep in his own bed and even go to school part-time. I relaxed for the first First, he underwent an eight-hour brain time in months. It was like being able to operation, then aggressive chemotherapy breathe again. and radiotherapy. It was impossible to explain to someone

Sadly, our happiness was short-lived. In a month, doctors discovered his treatment affected his brain and spine. "He's so weak, I'm surprised he's conscious," the doctor told us. "We don't know what will happen but we suspect he won't recover." The news hit me like a blow to the stomach and the shock sent me into

denial. So while I spent my days ensuring Skye was having as much fun as possible, I spent my nights on the computer, desperately searching for solutions

In hospital, he spent hours in an oxygen tank, wearing a special helmet. "You look like you're going to the moon," I joked.

At the time. Skye was making loom band bracelets. "Let's loom to the moon, Mummy," he said excitedly.

Seeing his face light up. I agreed to help him make the world's longest loom band to raise money for the charity we'd set up, Blue Skye Thinking, to fund research and treatment for children like Skye. But my bright, bubbly boy was deteriorating quickly. A few days later, he

lost the use of his hands. But by that point, the word had got out. Friends, family and even strangers started sending us their loom bands. As each parcel arrived, Skye and in turn Jesse were thrilled As Skye became weaker, Jesse grew

more protective, rarely leaving his big brother's side. On 29 August 2014, Skye turned to Jesse.

"I need you to help me loom to the moon," he said. "I'm tired today." I swallowed hard, fighting the rising panic inside me. But when Skve insisted

he give Jesse his birthday present - a pink guitar that day, even though it was a month early. I didn't stop him. As Skye's eyes closed, Jesse sang and played to him. "I love you to the moon and back," I whispered to my oldest son. And he

replied as he always did. "I love you to infinity." With those words, Skye slipped away. He was five years old. The days since his death have brought unimaginable pain. Some days I can't stop crying and others I don't want to wake up.

I only make it through by focusing on fulfilling Skye's wish. So far, the loom bands have reached 28,000 metres, so we're

outside the Earth's atmosphere. We've even got celebrities such as Denise van Outen and dancer Danielle Peazer helping us. Jesse talks about his brother every day



Reveal real lives

and says he is in charge of the loom bands. Every time more come, he looks up to the sky and says: "We're getting closer."

Although he's still so young, our loss has made Jesse old beyond his years. He's already decided he wants to be a doctor to stop his friends from dying. He has the same caring attitude as his older brother. Through Jesse and through the charity, Skye will never be forgotten.'

Rachel Mostyn, Sarah Whiteley For more information on loom to the moon, visit blueskyethinking.org

reveal.co.uk 37



### **Dorking and Leatherhead Advertsier**



#### Leatherhead restaurant foots the bill for teacher's marathon challenge

By Dorking Advertiser | Posted: March 16, 2015

By Alexander Robertson alexander.robertson@essnmedia.c o.uk



GRATUITY: Nick Smith, left, with Cafe Rialto's Susan Leveritt and Luis Simoes CRDC20150227C-001\_C Photo by David Cook

A RESTAURANT in Leatherhead is doing its bit to help raise cash towards finding a cure for cancer by offering a portion of its food bills to charity.

The Rialto Lounge is offering 20 per cent off for customers to help St John's School teacher Nick Smith as he prepares to take on an ultramarathon in Capetown, South Africa.

Mr Smith, 46, will take part in the 35-mile Two Oceans challenge on April 4, which he is running to raise funds for Blue Skye Thinking, a children's cancer charity.

Susan Leveritt, who works part-time for the High Street-based Rialto Lounge, said the restaurant was delighted to support Mr Smith's efforts.

"Kiri, who owns the restaurant, read about Nick's story in the Advertiser and was happy to get involved," she said. "The idea is to donate 20 per cent of the revenue from these meals, from now until when the big race will be run in April.

"Of course Kiri hopes that the restaurant will establish contact with more people, but can't think of a better way to do it than helping out with Nick's brave effort."

Blue Skye Thinking was founded by Mr Smith's former colleague, Andrew Hall, and his wife Sally in response to the death of their five-year-old son Skye last August from an aggressive and cancerous medulloblastoma brain tumour.

It aims to raise money to enable the world's best researchers to improve the survival chances and post-treatment quality of life of the 350 UK children diagnosed with brain tumours each year.

Mr Smith, director of music at St John's School, said: "Having three children myself, I felt I needed to show my support and chose the Two Oceans challenge as a way of doing just that.

"I haven't set a limit as I want to raise as much as possible, but it would be great to raise  $\pm 1,000$ ."

To support Mr Smith's challenge, visit www.justgiving.com/schmidtnicky



#### Skye is an inspiration to help children read



Skye with some loom bands

CHILDREN at Skye Hall's school will remember the five-year-old every time they have storytime in a special reading corner set up in his honour.

The Abingdon youngster, who died in August after battling a brain tumour for a year, was a pupil at Rush Common School.

His parents, Andrew and Sally, and three-year-old brother Jesse opened Skye's Reading Corner in the school library earlier this month.

Mrs Hall, 36, said: "Andrew, Jesse and I wanted to thank the school so very much for their most touching thought to create Skye's reading corner.

"The new library the school has created, with all its secret cosy corners is a fantastic haven for book lovers. They have created a magical place to encourage and inspire children of all ages, even those who are not old enough to attend school yet – I could hardly drag Jesse away."

As well as cutting the ribbon, the family brought Skye's favourite book – Invisible String, which imagines love as an invisible string between parents and children – for the collection.

### **Oxford** Mail

Skye joined the school in 2013, but because of his illness his health quickly deteriorated, leaving him in a wheelchair and needing constant care.

Mrs Hall said: "Although Skye was only able to attend school for such a short time, he really made the most of his time there.

"Although he was restricted physically, in true Skye style, he used his engaging personality and wit to make lots of friends.

It was so lovely to see his classmates, hear their comments about Skye and see how much they are flourishing at Rush Common.

"We wish them every success throughout their school career."

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Headteacher Laura Youngman said: "As Skye was passionate about books and reading, it was decided that the creation of Skye's reading corner was a fitting tribute to remember him and to encourage other pupils to enjoy and share some of Skye's favourite stories in a bright corner of the library. Skye lives on in our hearts and continues to make a positive and lasting impact at Rush Common School."

Children at the school have also been taking part in the Loom to the Moon campaign, which raises money for the charity Blue Skye Thinking, set up in Skye's memory.

They hope to make the world's longest loom band, with supporters already making more than 25km and raising more than £95,000 for research into new cancer treatments for children.

 Visit facebook.com/loomtothe moon or blueskyethinking.org



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### **Oxford Herald Series**

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### **South West Londoner**

## SWLondoner



#### Fulham man to run half marathon with former rugby teammates to raise childhood cancer charity funds



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A Fulham man is joining his old school rugby teammates this weekend to raise £10,000 in memory of their former coach's five-year-old son who died from a brain tumour.

Will Clegg, 26, originally from Oxfordshire, will be joined by a group of 25 'Old Abingdonians' as they attempt the Reading Half Marathon in aid of Blue Skye Thinking on March 22.

The charity was founded by Sally and Andrew Hall (pictured above), both from Oxford, last year in response to their four-year-old son Skye being diagnosed with a medulloblastoma, an aggressive and cancerous brain tumor.

Sadly Skye died peacefully at home on August 29 last year.

Will said: "Out of the blue one day I got a message from my old friend and ex team mate, Francis Gater, about the tragedy that had befallen the Hall family and his plan to launch a mission for us to raise a significant sum of money to support their charity.

"Andrew was my Under 16 rugby coach as well as acting, most likely unbeknown to him, as a mentor to me at school.

"He was a really great man at school, someone who I respected and looked up too. If it wasn't for him I would have thrown in the towel on my rugby career at school but instead, during the year he coached me, I went on to represent the Schools 1<sup>st</sup> XV in a Cup Match and eventually Captain of the team in my most senior year.



### **South West Londoner**

"Taking part in this race was the least I could do to raise awareness and money for such a worth charity and support Andrew and his family in this way."

Blue Skye Thinking's goal is to fund some of the world's best researchers so that all children diagnosed with brain tumours will have a better chance of survival and a better quality of life post-treatment.

More than 350 children a year in the UK are diagnosed with a brain tumour but less than 1% cent of cancer funding goes towards research in this area.

All the money raised will go into much-needed research into new treatments for childhood cancer.

Andrew Hall, Director of Sport & P.E. at Abingdon School, founder of Blue Skye Thinking and dad to Skye will be joining them in the race.

He said: "I hadn't seen Francis for nearly five years when I bumped into him at the Blenheim half marathon last year.

"A few weeks later he got in touch with me with his idea of all the old boys I used to coach, running the race for Skye.

"I was so moved when he told me what a fantastic response he'd received from everyone, including Will, that I had no option but to join them.

"As a rugby coach, you build up such a strong bond with your players, you see the team four or five times a week, and in particular this team, as it was the first one I coached during my first term at the school.

"I haven't seen some of these boys, now men, since they left school so it will be great to see them all together again and I know they will do me proud on race day."

To support the Will and the 'Old Abingdonians' visit <u>http://www.justgiving.com/Old-Abingdonians-run4skye</u>







Interview with Ed Blagrove on Breakfast Show re completing his March Marathon challenges

#### 



### **Oxford Herald**

#### NEWS I

#### School's big-race effort helps Skye's dad boost special fund



8+ P

Andrew Hall, centre, with colleagues, pupils and former pupils at Abingdon School who took part in the Reading Half Marathon. Picture: Damian Halliwell Buy this photo

NEARLY 50 Abingdon School teachers and pupils - past and present - ran the Reading Half Marathon on Sunday to support the family of Skye Hall.

The group got behind the cause when the five-year-old son of the school's director of sport Andrew Hall died in August as a result of his cancer treatment.

Organiser Francis Gater, who was one of Mr Hall's first pupils at the school, rallied Old Abingdonians and present staff to take part.

He said: "We were the first rugby team he coached in 2003, when we were about 16.

Casala

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#### Our top stories

"He is a great coach - very disciplined and absolutely got the best out of us. I was so sorry for him and so moved by the story."

Mr Gater got the idea of a group run when he bumped into Mr Hall at the finish line of the Blenheim Half Marathon in October.



GUUXI

Members of the group, including Francis Gater, sixth from right, who completed the Reading Half Marathon.

The Besselsleigh resident said: "I contacted everyone in the old rugby team and got an amazing response straight away. One guy flew back from Australia just to do the race.

"Pretty quickly other people from other year groups at the school and teachers wanted to get involved. It's absolutely snowballed.

"That team support that you have at school, is bred within you and given to you by the teachers like Andrew, it stays with you for the rest of your life."

Now training to be a surveyor, Mr Gater said: "Andrew touches the lives of so many people, it's so close to home. When you put something like this in front of people - an event they can really get behind - they really jump on it.

"Running 13 miles is nothing compared to what Andrew and his family have gone through. It went really well, it was a great success.

I was aiming for 1.40 and I did it in 1.41. I was shattered by the end so I'm still pretty pleased."

The group has already raised £15,000 and hopes to hit £20,000 for Blue Skye Thinking, the charity Mr Hall, his wife Sally and their three-year-old son Jesse have set to fund research into alternative cancer treatments for children.





### **Oxford Herald**



*Skye Hall and his mum Sally.* 

If they reach their goal, the charity will have raised £120,000 – enough to pay for its own full-time researcher.

Mr Hall, 42, who also took part, said: "I was so moved when Francis told me what a fantastic response he'd received from everyone, especially those who are travelling across the world to be part of this, that I had no option but to join them.

"As a rugby coach, you build up such a strong bond with your players, as you see the team four or five times a week, and in particular this team, as it was the first one I coached during my first term at the school.

"I haven't seen some of these guys since they left school, so it was great to see them all together again and they did me proud."

Mrs Hall, 36, said: "Having grown up on the school site, Skye was very much part of the boarding school community and was always wanting to join in with the 'bigger boys'.

"He used to often support them at weekend sporting fixtures, which is why it is such an honour that so many of the current and ex-pupils are now supporting Skye's cause."

To donate, visit justgiving.com/old-abingdonians-run4skye and for more on Blue Skye Thinking visit blueskyethinking.org.