



# BLUE SKYE THINKING

SUPPORTING RESEARCH & TREATMENT OF CHILDHOOD BRAIN TUMOURS

## Trustees' Annual Report

***Blue Skye Thinking***

**From 1 April 2019 to 31 March 2020**

**Registered Charity Number 1158021**

**Principle Address:**

66 Five Mile Drive  
Oxford  
Oxfordshire  
OX2 8HW

**Names of Trustees:**

Mr Andrew S Hall  
Mrs Sally G Hall  
Mrs Victoria E B Marcham  
Mrs L Ruggles

**Website:**

[www.blueskyethinking.org](http://www.blueskyethinking.org)

**Contact Email:**

[contact@blueskyethinking.org](mailto:contact@blueskyethinking.org)

**Contact Telephone:**

01242 262731

**Bankers:**

Royal Bank of Scotland  
32 St Giles'  
Oxford  
OX1 3ND  
Account No: 11002339  
Sort Code: 16-10-15

## **Introduction to *Blue Skye Thinking***

In August 2013, Skye Hall, aged 4, was diagnosed with a brain tumour, which had metastasised to various parts of his brain and spinal cord, despite showing very few symptoms over a period of just 4 weeks. Just 12 months later Skye died as a direct result of the side effects of the treatment, which included surgery to remove the bulk of the tumour, an 11 week course of Chemotherapy, 5 weeks of Radiotherapy, followed by high dose Chemotherapy. The disease was stable, but the rigorous treatment protocols which he was subjected to, led to his paralysis and subsequent death.

In response to this, Skye's parents, Sally and Andrew Hall, set up Blue Skye Thinking in order to accelerate research into the Research and Treatment of Childhood Brain Tumours, so that all children diagnosed would have a better chance of survival and a better quality of life post treatment. Blue Skye Thinking is a registered charity with the Charity Commission and as a Charitable Trust with the HMRC, and is governed by the Trust Deed dated 24 July 2014.

## **Aims and Objectives**

To help promote research into the causes, cures and prevention of childhood brain tumours and to disseminate the useful results of such research for the benefit of the public.

The relief of children who are suffering from a brain tumour by the provision of grants and financial assistance to provide equipment and apparatus to hospital wards, and support people suffering from brain tumours, their families and carers.

Raising awareness of brain cancer as the number one cancer killer amongst children and teenagers.

## **Trustees**

There must be at least three [3] trustees. Apart from the first trustees, every trustee must be appointed [for a minimum term of two years] by a resolution of the trustees passed at a special meeting called under clause 15 of the Deed.

In selecting individuals for appointment as trustees, the trustees must have regard to the skills, knowledge and experience needed for the effective administration of the charity. The trustees must keep a record of the name and address and the dates of appointment, re-appointment and retirement of each trustee. The trustees must make available to each new trustee, on his or her first appointment:

- (a) a copy of this deed and any amendments made to it;
- (b) a copy of the charity's latest report and statement of accounts.

## Achievements and Performance

### **Committee Member for Stratified Medicine Paediatrics: Genomic Characterisation of Relapsed Paediatric Cancers for Diagnostics**

We were delighted that Trustee, Sally Hall was invited to be a member of the steering group for SMPaeds in January 2020, with the primary objective to establish rapid-turnaround, multi-mic profiling of paediatric and young-adult patients with relapsed/refractory solid tumours, suitable to confirm the presence of molecular alterations and provide information about individual targeted therapy options.

The Charity continues to work with these three core principles:

#### **PROGRESSING world-class research into childhood brain tumours to improve survival rates.**

Brain tumours are the No. 1 cancer killer in children, teenagers and young adults yet currently receive less than 2% of national funding including from large cancer charities. Cure rates have not improved in 40 years and current treatments can have devastating side effects.

The Charity now has the funds in place to fund another research project, but the onset of the global pandemic halted the placement of funds. The Newcastle Research Team are eager to progress various areas of research, but specific funding dried up on the back of the pandemic and discussions needed to take place about funding alternative projects. The advantage of receiving money from charities like Blue Skye Thinking is that it gives the Research Teams greater flexibility to follow research pathways which they see as relevant rather than having to adjust their projects in order to fit specific criteria of the larger funding organisations. We are looking forward to funding the next project in the coming months.

### **Effect of Covid-19 on the Specialist Paediatric Brain Tumour Research Community**

Big, collaborative projects that have taken years to implement are facing long periods of inactivity as funding from big charities is put on hold. There is also a significant threat of losing specialists in the field such as our passionate PHD researcher who will be forced to seek work elsewhere.

### **Effect of Covid-19 on Brain Tumour Policy within NHS**

Understandably, people we have been working closely with to improve policies relating to brain tumours within Government such as Professor Chris Whitty, Chief Medical Advisor to the UK Government, have been forced to turn their full attentions elsewhere to deal with the deadly pandemic. Another set back for our community committed to fighting the number one cancer killer in children.

#### **CAMPAIGNING for better data collection to stop preventable deaths.**

Treatment outcomes and dangerous side effects are not being reported in real time, which has lead to the unnecessary deaths of children like Skye and others.

## **PROVIDING wellbeing projects for families in hospital.**

We believe the mental wellbeing of children affected by cancer is every bit as important as the medical treatment they receive.

The Trustees are extremely grateful once again to the healthy band of volunteers who have supported Blue Skye Thinking tirelessly throughout the year, without whom, the same level of success would certainly not have been achieved.

## **Fundraising**

The majority of funds have been raised through Donations and individuals raising money through Sponsorship through participation in organised events and received by the Charity from:

- Online donations via the Blue Skye Thinking website, JustGiving and VirginMoneyGiving sites.
- Direct donations from individuals by post in the form of cheques or by bank transfer.
- Donations from organisations or companies, and
- Other Organised Events

## **Events**

### **Chandlings Prep School Summer Ball**

The Charity were delighted to be selected as the Chandlings Manor Charity of the Year which coincided with their 25<sup>th</sup> Anniversary Celebrations. It was a fabulous evening with a Charity Auction hosted by TV personality Charlie Ross. Sally had the opportunity to speak about the Charity and the work that was being undertaken at the time. Nearly £20,000 was raised at the event, which was more than we could ever have expected.



## Thames Paddle Board

On the 4<sup>th</sup> July, two supporters set out from the source of the Thames, and ran to Lechlade from where they picked up their paddle boards and continued to Henley-on-Thames spending 4 exhausting days on the river. Andrew joined them for two days on the stretch from Lechlade to Benson and was full of praise for the efforts. They raised over £2000 in this herculean effort.



## Truck Festival

This particular Festival has become an annual highlight in Oxfordshire, which not only raises a significant amount of money, but it gives the Charity an opportunity to connect with volunteers and supporters in this family friendly event. The Festival in July 2019 saw the Charity's best ever year in terms of profits and sales, and despite increased stock on previous years, we once again sold out of all products by Sunday morning. The candy floss also became a focal point for families with young children. We can't thank our volunteers enough for their tireless efforts over this 4-day period.





## Reserves

A policy decision was taken by the Trustees, that before embarking on the sponsorship of any research projects, the Charity would ensure that the full sum of money was in place prior to commencement, to ensure that should the financial or political climate change, that sufficient funds were available to ensure that any project would run its full course. Hence, the Charity would always operate with reserves in the bank.

## Declaration

The Trustees declare that they have approved the trustees' report above.

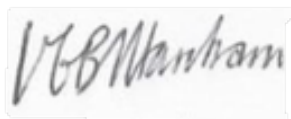
Signed:



Signed:



Signed:



Signed:




Date:

28 January 2021

# Independent examiner's report on the accounts



<b>Report to the trustees/ members of</b>	<small>Charity name</small> <b>BLUE SKYE THINKING</b>		
<b>On accounts for the year ended</b>	<b>31 March 2020</b>	<b>Charity no (if any)</b>	<b>1158021</b>
<b>Set out on pages</b>	<b>4-5</b>		
<b>Respective responsibilities of trustees and examiner</b>	<p>The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.</p> <p>It is my responsibility to:</p> <ul style="list-style-type: none"> <li>• examine the accounts under section 145 of the Charities Act,</li> <li>• to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and</li> <li>• to state whether particular matters have come to my attention.</li> </ul>		
<b>Basis of independent examiner's statement</b>	<p>My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.</p>		
<b>Independent examiner's statement</b>	<p>In connection with my examination, no matter has come to my attention (other than that disclosed below *)</p> <p>1. which gives me reasonable cause to believe that in, any material respect, the requirements:</p> <ul style="list-style-type: none"> <li>• to keep accounting records in accordance with section 130 of the Charities Act; and</li> <li>• to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or</li> </ul> <p>110853396. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.</p> <p><i>* Please delete the words in the brackets if they do not apply.</i></p>		
<b>Signed:</b>		<b>Date:</b>	<b>26 January 21</b>
<b>Name:</b>	<b>CLARE BUTCHER</b>		

Relevant professional  
qualification(s) or body (if  
any):

AAT

Address:

6 PRIMROSE AVENUE

WANTAGE

OXON OX12 7FU

Only complete if the examiner needs to highlight material problems.



Give here brief details  
of any items that the  
examiner wishes to  
disclose.

N/A



	1-Apr-19	Current	
Capital & Reserves (Net Worth)	<b>£312,992</b>	<b>£344,247</b>	<b>£0.00</b>
Previous Donations less Expenses	£298,209	£312,992	
2018-2019 Donations less Expenses	£14,783		
Current Year Donations less Expenses		£31,255	
Current Liabilities	<b>£0</b>	<b>£0</b>	
	£0		
<b>Total Liabilities</b>	<b>£312,992</b>	<b>£344,247</b>	
Fixed Assets	<b>£908</b>	<b>£304</b>	
Computer Equipment	£328	£14	
Freezers	£0	£0	
Candy Floss Machine	£470	£235	
Candy Cart	£110	£55	
Current Assets	<b>£312,084</b>	<b>£343,943</b>	
A&L Current Account	£51,295	£53,154	
Savings Account	£260,789	£290,789	
<b>Total Assets</b>	<b>£312,992</b>	<b>£344,247</b>	
	£0	£0.00	

approved

 26 Jan 2021  
 CLARE BUTCHER