

# Brainbow Annual Report

April 2020-March 2021



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# Introduction 03

September 2020 marked Brainbow's 7th Anniversary since its launch in 2013. 2020/21 has been a year of many challenges following the outbreak of COVID-19 and the huge effects this has had on societies across the world. Within the NHS there have been extraordinary measures taken in order to provide treatment and care for those suffering as a direct result of the pandemic and also in order to keep the wider society as safe and healthy as possible. Brainbow is no exception to this and the team has had to learn to adapt to the ever changing guidelines and restrictions to ensure all children with a brain tumour within the East of England continue to have access to the best support possible to help them reach their full potential. In this annual report we will provide an update on how Brainbow has adapted and how we have been able to review practices in light of the national situation which we hope will benefit families for years to come.

Brainbow was founded by three local charities, Anna's Hope, Camille's Appeal and Tom's Trust and it is to these charities we owe our thanks for the vision and inception of the first specialist rehabilitation service dedicated to children with brain tumours.

Anna's Hope, Joshua Tarrant Trust and Tom's Trust have continued to fund 75% of the Brainbow staffing costs, for which we are sincerely grateful. The generosity and consistent support of these charities has enabled Brainbow, this year, to provide care for over 170 children and their families, not including others who have benefited from the other Brainbow events and activities.

As in previous years we would like to recognise the hard work and dedication of our Brainbow team who through working together with the children and families within the service have been resilient in the face of challenging circumstances in order to best support the many children under the care of the Brainbow service.



**Dr Amos Burke**  
Consultant in Paediatric Oncology,  
Clinical lead for Brainbow



**Amanda Cahn**  
Associate Director of Operations,  
Women's and Children's Service

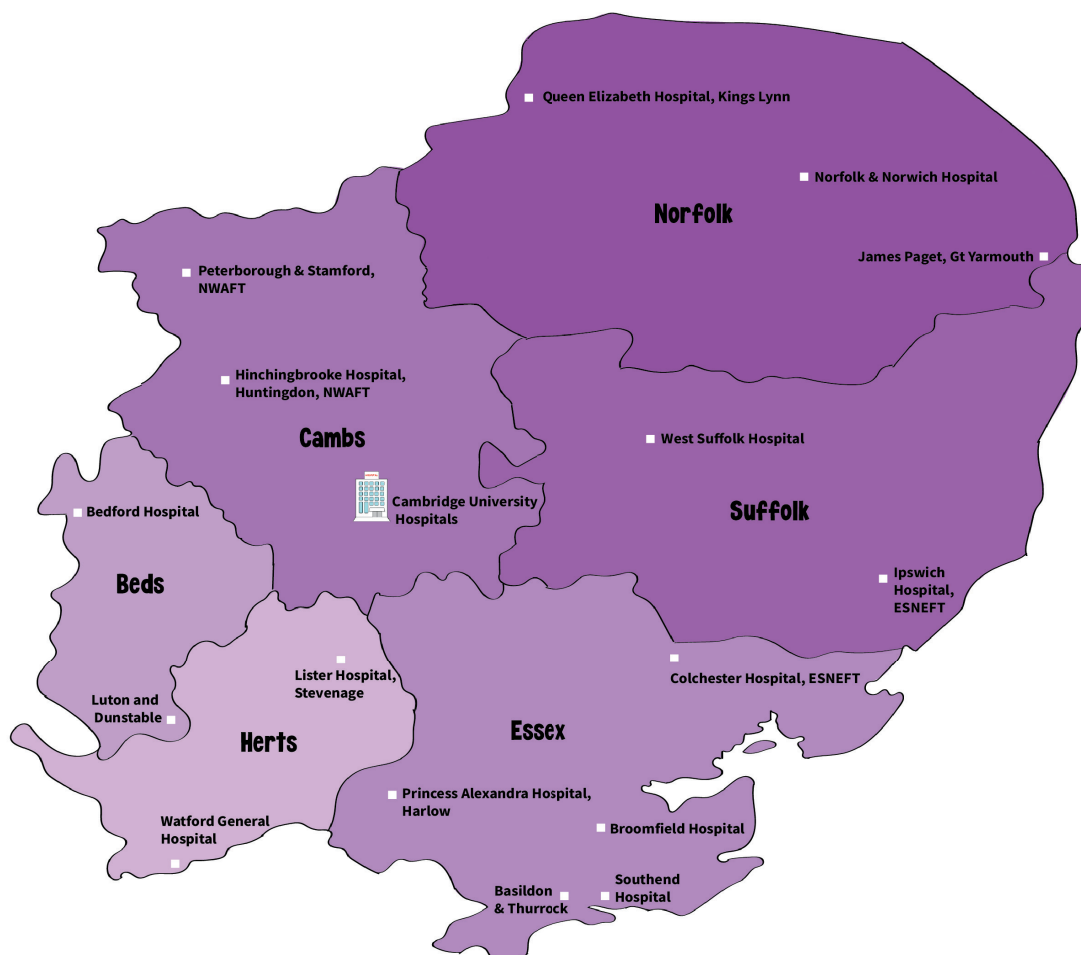


**Laura Howden**  
Joshua Tarrant Trust Brainbow Service  
Delivery Manager

# 04 what is Brainbow?

Brainbow's aim and vision is "to ensure all children with brain tumours reach their full potential". Brainbow provides co-ordinated specialist neuro-rehabilitation assessment and treatment for children and young people with brain tumours. The service is based at Cambridge University Hospitals within the care provided by the Paediatric Haematology, Oncology and Palliative Care Department and treats all children within the region who receive their specialist care at Addenbrooke's.

The region is represented in this map. All children and young people within this area who are diagnosed with a brain tumour will receive their specialist care from the Oncology team at Addenbrooke's in Cambridge with the exception of families in the far south of the region. The hospitals in the south of the region (Watford, Harlow and Chelmsford) share links with Cambridge and London and are able to refer families according to geographic ease whereas Basildon and Southend refer families directly to London. Once a child is under the care of the CUH team they are directly referred to Brainbow for treatment.



Brainbow is able to provide specialist rehabilitation support and continuity of care through the journey of children with brain tumours. When possible Brainbow offers support from diagnosis, during hospital admission and out in the community after discharge. Brainbow's main focus is outpatient support for the children and their families after being discharged from hospital, providing care both within the hospital outpatient facilities and also in the community in patient's homes, schools or nurseries.

The holistic rehabilitation provided by Brainbow includes all aspects of the patient's life and on-going development, such as their physical needs and development, their emotional wellbeing and their education.



# 05 what Brainbow offers

Brainbow currently has 213 young people within the service up to the age of 18. Each and every family within this caseload is able to access Brainbow for support whenever required no matter how old or how long after diagnosis they are. When a young person leaves the care of the Paediatric Haematology, Oncology and Palliative care Service to transition to adult care, Brainbow is involved in the Transition and provides as much signposting and transition support as possible to help the young person navigate this hugely important step.

Over the years since its launch Brainbow has been adapting its service model in order to best provide care for the families it serves. There are a variety of ways in which children periodically access Brainbow support, here is a brief summary regarding the care offered by Brainbow:

1.

Upon Brain Tumour diagnosis the paediatric oncology team refer every patient to Brainbow. At this time whenever possible, the young person and their family will be seen by as many members of the Brainbow team as possible before treatment and then during the family's stay in hospital. This journey is different for every family, therefore the service offered and provided by Brainbow is adapted to best suit the family.

2.

Once a young person is discharged from hospital they are moved onto the 'Brainbow Follow Up Pathway' described over the page.

3.

At any point in a young person's journey following diagnosis that their parent, carer or healthcare provider identifies a need in the young person on the family's life Brainbow is able to receive referrals for support and on a case by case basis will support families as required.

4.

At any point that a Brainbow young person is admitted to hospital for a longer stay, the Brainbow team are made aware of the situation and will provide inpatient support appropriate to the family's needs.

5.

Every young person and their family is invited to Brainbow special events (see page 12 & 13) throughout the year.



# 06 what Brainbow offers continued

Over the years since its launch Brainbow has been adapting its service model in order to best provide care for the young people and families it supports. As rehabilitation of this kind does not have a prescribed patient pathway or specification from the NHS the team have been working on this from the beginning.

There are three main phases of care that the Brainbow pathway identifies:

1. At diagnosis – this is the care we aim to provide families from the point of diagnosis until they reach either phase 2 or 3 below, this usually includes surgery.
2. On treatment – this is the care we aim to provide families whilst the young person is undergoing treatment such as chemotherapy or radiotherapy.
3. Off treatment – this is the care we aim to provide families once the young person has finished their treatment.

## At Diagnosis

The Brainbow service is informed via the medical team in Paediatric Oncology when a new diagnosis has been made, and the young person is referred straight away into the Brainbow service. Once the referral is received by the Brainbow team, the team track the young person's in hospital stay and where possible and appropriate, provide visits to the family on the ward. Ideally Brainbow assess the young person before their surgery in order to obtain a baseline and to get to know the family as early as possible. This is not always possible due to time or due to appropriateness for the family.

After surgery the Brainbow Team work with the staff on the ward to provide any necessary care the young person or their family require, this can include psychological support, movement support, speech and swallowing help or accessing education. The level of support offered is tailored to each family dependant on need.

Once a family's main needs and areas for support are identified, Brainbow assign a keyworker. A keyworker is a member of the Brainbow team who is the point of contact for the family. The keyworker liaises with the multidisciplinary team (MDT) in order to ensure the care provided by Brainbow throughout the young person's entire journey is responsive to their needs.

## On treatment

Once a young person moves onto treatment, Brainbow take a back seat in the family's journey unless it is clinically indicated that immediate care is required. Whilst on treatment the Brainbow keyworker regularly checks in with the family to ensure any needs are picked up and support is provided. Again, Brainbow will flex to the needs of each family in order to provide appropriate family centred care.

## Off treatment

When a young person comes off of treatment Brainbow follows the following pathway for everyone. As well as this pathway, every family has open access to request Brainbow input and also the medical team looking after the child is also able to refer a family into Brainbow for additional support at any time.

By focusing the below pathway around a child or young person's key transition points, Brainbow is able to provide supportive evidence for any EHCP applications (education and healthcare plan) and the specialist teacher is able to guide parents and schools through this process as necessary.

# 07 what Brainbow offers continued

The **Key Worker** contacts the family for a

## Telephone Triage call

These calls are made 6 months after the end of treatment and at each transition point (EYFS to KS1, KS1 to KS2, KS2 to KS3, KS3 to higher education or transition to adult services).

The telephone triage calls can take between 1 - 3 hours to complete, depending on the level of need for the child or young person and in response to the parent's need to talk/access support.

**Key Worker** feeds back Telephone triage call to weekly

## Caseload Meeting

The needs of the child or young person identified are discussed with the entire team and decisions are made as to which disciplines need to carry out further assessments.

**The Administrative Assistant** co-ordinates the dates and venues for the assessments and confirms the appointment(s) with the family.

Each **discipline** carries out the appropriate

## Assessment

The specialist education support may contact the child or young person's school at this stage to gather information about progress and attainment and any difficulties the child or young person or school is experiencing in education provision.

**Physiotherapy, Occupational Therapy and Speech and Language Therapy** score and evaluate their assessments to determine what further support and advice is needed.

Neuropsychological assessments are provided by **Clinical Psychology** to every child or young person at these transition points.

**Care providers** may make a referral to local services, may arrange to deliver a block of therapy themselves, or provide a plan (e.g. exercise plan, which the family/school can deliver) depending on the need.

The **Brainbow Team** organises a

## Formulation Meeting

to discuss each **discipline's** findings and the implications for the child or young person's health and education. Key points and recommendations are agreed for the

A meeting with family/school is arranged to share the key points of the MDT report and draw up goals to be worked on by all those involved. Review dates are identified alongside who is responsible for reviewing the goals.

The **Keyworker** compiles the MDT report and the **Administrative Assistant** sends out the completed report to family and school.

## Feedback Meeting





Colorful  
Puzzle 3D  
4 Paragraph  
3D PUZZLE  
BUILDING & COLORING





# 09 Funding

Brainbow was founded by three East of England based charities, Anna's Hope, Camille's Appeal and Tom's Trust, and was funded by these charities for a number of years. After Camille's Appeal sadly closed in 2016 the charity kindly provided funding for an additional 2 years. In 2018 Brainbow welcomed Joshua Tarrant Trust, who kindly funded the remaining posts from April 2018.

In 2017/18 CUH committed that in the following financial year, CUH would begin funding part of the service in order to show the Trust's support of the service and to begin the transition away from charity funding to NHS funding. The following table illustrates the Charity and NHS funding transition plan. Anna's Hope, Joshua Tarrant Trust and Tom's Trust have all committed to provide funding until April 2023 in line with the below.

| Year    | % Charity Funding | % NHS Funding |
|---------|-------------------|---------------|
| 2017/18 | 97.5%             | 2.5%          |
| 2018/19 | 95%               | 5%            |
| 2019/20 | 92.5%             | 7.5%          |
| 2020/21 | 75%               | 25%           |
| 2021/22 | 62.5%             | 37.5%         |
| 2022/23 | 50%               | 50%           |
| 2023/24 | 0%                | 100%          |

During 2019/20 the following funding was received from Anna's Hope, Joshua Tarrant Trust and Tom's Trust.



£163,789  
Anna's Hope



£45,287  
Joshua Tarrant Trust



£96,686  
Tom's Trust

During 2020/21, CUH funded £101,920 of Brainbow's staffing costs.

## Staffing

There have been 4 key changes in personnel during 2020/21, detailed below.

### Anna's Hope Specialist Paediatric Physiotherapist

We sadly said farewell to Kylie Langridge, our Physiotherapist as she went on to pursue other ventures in Paediatric Neuro Rehabilitation elsewhere. We wish Kylie all the best in the future and thank her for the support and hard work she provided to Brainbow in this past year. We have successfully recruited to the vacancy, and are looking forward to welcoming our new physiotherapist to Brainbow in summer 2021.

### Anna's Hope Specialist Paediatric Occupational Therapist

Katie Williams came back from maternity leave in summer 2020, to work 3 days a week. Karen De Villiers who had been covering Katie's maternity leave was successful in her application to fill the remaining 2 days a week on Katie's return. Katie and Karen work together to provide the occupational therapy for all the children in Brainbow.

# 10 Staffing Continued



## Anna's Hope Specialist Speech and Language Therapist

Lizzie Berry is currently on maternity leave and is due to return in early 2022. We welcomed Lydia Humphreys to the team in February 2021 for 1 year to cover Lizzie's absence. Lydia has come from a local special needs school which has meant she has brought with her a fresh perspective and valuable experience. Lydia has picked up Lizzie's very busy workload and has done a great job at getting up to speed.

## Tom's Trust Clinical Psychologist

Dr Sarah-Jane Archibald, the Tom's Trust Clinical Psychologist, returned from maternity leave in Autumn 2021. Dr Victoria Matthews joined the team in October 2019 for 1 year to cover Sarah-Jane's absence. Vicky was a great asset to the team and we were sad to say goodbye to her in November 2020 although very happy to welcome Sarah-Jane back.

| Post  | Banding | WTE                            | Comments  |
|---|---------|--------------------------------|---|
| Anna's Hope Specialist Paediatric Physiotherapist               | Band 7  | 1.0<br>(37.5 hours per week)   |   |
| Anna's Hope Advanced Specialist Speech and Language Therapist   | Band 7  | 1.0<br>(37.5 hours per week)   |   |
| Anna's Hope Speech and Language Therapy Assistant               | Band 4  | 0.6<br>(22.5 hours per week)   |   |
| Anna's Hope Highly Specialist Paediatric Occupational Therapist | Band 7  | 1.0<br>(37.5 hours per week)   | Post reduced to 0.5 WTE until June 2020   |
| Joshua Tarrant Trust Specialist Teacher                         | UPS1    | 0.48<br>(18 hours per week)    |   |
| Joshua Tarrant Trust Service Delivery Manager                   | Band 7  | 0.4/0.2<br>(15 hours per week) | This post was 0.4 WTE until July 2020, when Laura Howden returned from maternity leave, the hours were reduced to 0.2 WTE |
| Joshua Tarrant Trust Administrative Assistant                   | Band 3  | 0.67<br>(25 hours per week)    |   |
| Tom's Trust Specialist Clinical Psychologist                    | Band 8b | 0.4<br>(15 hours per week)     |   |
| Tom's Trust Clinical Psychologist                               | Band 8a | 0.5<br>(18.75 hours per week)  | When Sarah-Jane returned from maternity leave, this post was reduced to 0.4 (15 hours per week)                           |
| Tom's Trust Assistant Clinical Psychologist                     | Band 5  | 1.0<br>(37.5 hours per week)   |   |

# Case Study - Catherine

## Background

Catherine was 15 when she was diagnosed with a brain tumour. She was in her last year of secondary school so was preparing to sit her GCSE's. She had been experiencing difficulties for a while including headaches.

Catherine required extensive surgery to remove the tumour.

## Brainbow Input

Following surgery, she had significant left sided hemiparesis. This made life very difficult for her and she was unable to walk independently or carry out daily living tasks. Whilst an inpatient at Addenbrookes Hospital, Catherine needed daily physiotherapy from the Anna's Hope physiotherapist and ongoing support from the Anna's Hope Occupational therapist and Anna's Hope speech and language therapist to help her begin her rehabilitation and regain some use of her left side. Catherine worked very hard and pushed herself to make the best progress she could even though it was exceptionally challenging. She also had support from the Tom's Trust Clinical Psychologist to help deal with the emotional impact of her neurological difficulties and the longer-term consequences including fears around living with her scar, seeing friends again and going back to school and losing some independence. Catherine had a baseline cognitive assessment prior to surgery, undertaken by the Tom's Trust Assistant clinical psychologist. Catherine was eventually discharged to Tadworth for ongoing inpatient rehabilitation.

Catherine made very good progress. Once home Catherine still needed intensive local physiotherapy and occupational therapy support. Catherine continued to receive support from the Tom's Trust clinical psychologist to help with the ongoing life adjustments and processing what had happened. Catherine was also very motivated and focused to help herself reach her full potential.

The Tom's Trust clinical psychologist ensured that the college followed the guidelines recommended by the various cognitive assessments conducted and that the necessary support was in school. Psychological Support has continued along with strategies

## Impact

Catherine has made an astonishing recovery, thanks to her determination, courage and strength of character.

Catherine is now sitting her A levels and plans to go to university. She has also passed her driving test. This is a remarkable achievement. Catherine is an inspirational individual.





# 13 The impact of the Pandemic

The effects of the COVID-19 pandemic began impacting the NHS at the end of March 2020 and to date continue to affect NHS services. Financial year 2020/21 has been an incredibly challenging and difficult year for all services at Cambridge University Hospitals, including Brainbow.

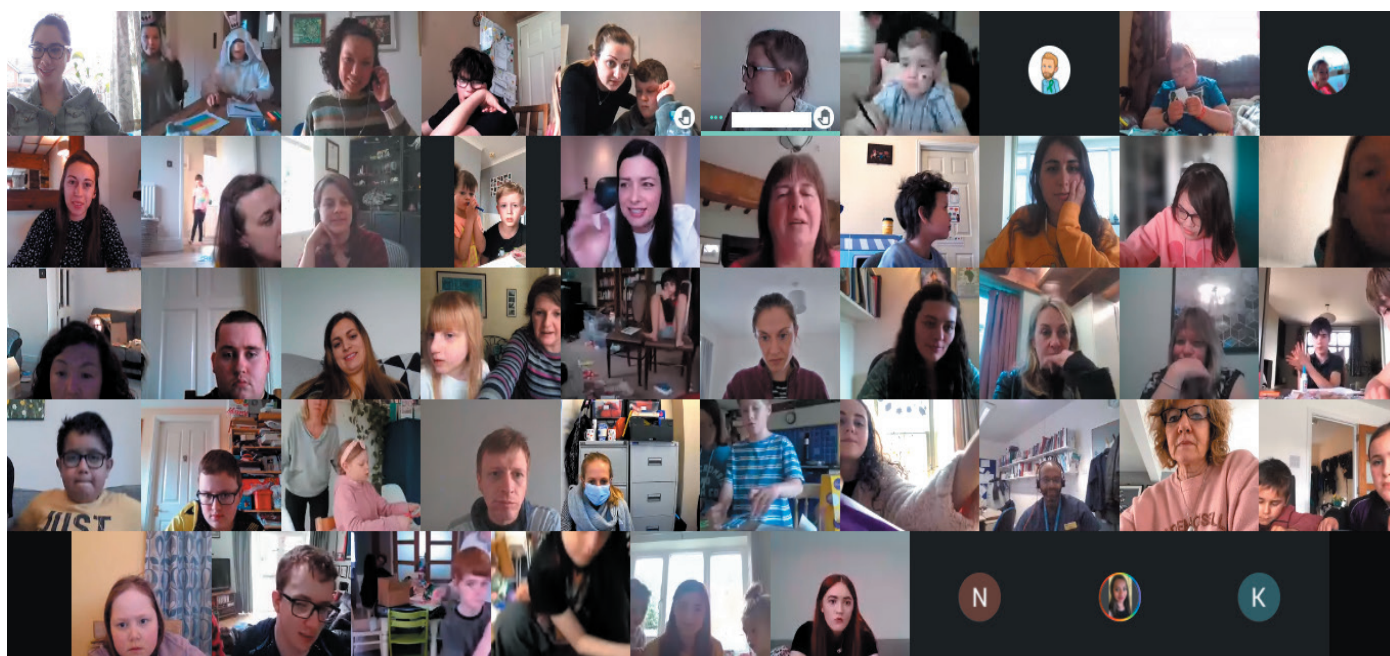
At around the time the first lockdown started at the end of March 2020, CUH cancelled all face to face outpatient activity and planned surgery apart from the cases and situations when delay of treatment was considered a higher risk to the patient than potential COVID-19 exposure. Cancer services continued throughout the hospital, although new safety measures and protocols were quickly put in place to ensure children and adults in these areas were kept as safe as possible. Brainbow appointments were agreed to be non-urgent and therefore all Brainbow essential appointments were cancelled and with the rest of the NHS, due to lack of knowledge regarding the virus, there were no plans for re-starting face to face contact.

All services quickly had to adapt ways of working and think outside the box to keep patients healthy and safe at home. Brainbow moved many appointments to telephone calls and ensured all families knew how to get in touch with the team should they have any concerns.

Later in the spring, CUH launched Attend Anywhere which is a secure platform for video consultations. This enabled Brainbow to begin seeing children for blocks of therapy in a virtual setting. Many of the therapists would travel to patient homes or schools for assessments or therapy blocks as these often work best when a child or young person is in a familiar and comfortable environment, however this travel could now be avoided which freed up a lot of therapy time. Therapists were able to see more patients, more often and for longer sessions which greatly benefitted many families. This is clearly reflected in the activity data in the later pages of this report which show a very small dip in activity between 2020/21 and 2019/20, even though the team had a large gap in time when both virtual and face to face appointments were unavailable and have had a significantly reduced capacity to see young people and families face to face since.

Feedback from families regarding virtual appointments has been overwhelmingly positive, many expressing that they appreciated not having to travel and enjoyed being able to remain in a familiar environment at home rather than being in the hospital which for many young people and their families can induce anxiety. The service will continue to use this virtual platform for appointments even after face to face appointments return to pre-COVID levels.

There remain a number of assessments (physical and neuropsychological) and treatment blocks which cannot be done virtually, and some families prefer to meet face to face. As a result, the Brainbow waiting list grew over the months following March. During the year there have been pockets of time where restrictions nationally and locally at CUH enabled the Brainbow team to see the more urgent cases on the waiting list and the team continues to prioritise the waiting list on a regular basis to ensure families are being seen in as timely a manner as possible.



# 14 Brainbow Family Events

Since 2017 Brainbow has aimed to provide 3 family events each year as part of the wider rehabilitation opportunities provided to the children, young people and families involved. The events are organised with the help of PwC (Pricewaterhouse Coopers), and aim to provide a safe space away from the hospital for Brainbow families to meet each other and enjoy a variety of activities together. 2020 was a very different year for this too. Unfortunately the 2020 Easter Event was cancelled and the summer Funlympics was also unable to go ahead due to social distancing requirements. However, in the new world of virtual meet ups, Brainbow decided to embrace technology and have a go at hosting a virtual event for Christmas.

## 2020 Christmas Event

The Cambridge PwC office worked together with the Brainbow team in order to facilitate the first ever virtual event. The Brainbow events are usually characterised by plenty of crafts and group games, so the planning group worked through ideas to bring this to life in a virtual setting. The charitable account Brainbow has access to, held by Addenbrookes Charitable Trust, was able to fund the purchase of incredible gift boxes for all who signed up. These gift boxes included craft packs, craft accessories, treats, reindeer food, elf hats for all and many other exciting surprises! These gift boxes were then couriered out to people's homes by Grabbit and Run in advance of the event so everyone had access to the same supplies and were able to join in with group activities from all over the region. In each gift box was a personal gift for each Brainbow child or young person, from the Cambridge PwC office. We would like to again express our appreciation to the PwC team who devoted a lot of time, energy and resource into the event, their generosity to Brainbow is truly valued by the Brainbow team but also the families who join in.

All who joined in with the event were invited to share some photos and videos of what they got up to so we could create a video to keep as a keepsake of the fun that was had. Ophelia Weston, Communication and Commercial Support Administrator, very kindly pulled everything together into a fantastic video for all to enjoy. The video can be seen at this link: [https://drive.google.com/file/d/1qhb4\\_DUHiXwX9nTOmiOnKthCh2A0qCUS/view?usp=sharing](https://drive.google.com/file/d/1qhb4_DUHiXwX9nTOmiOnKthCh2A0qCUS/view?usp=sharing) or by scanning the below QR code.

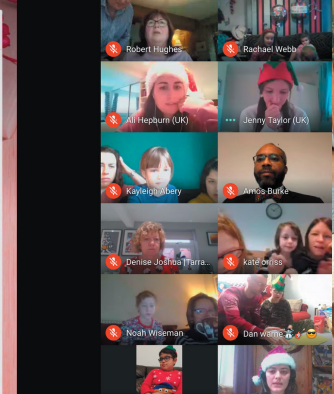
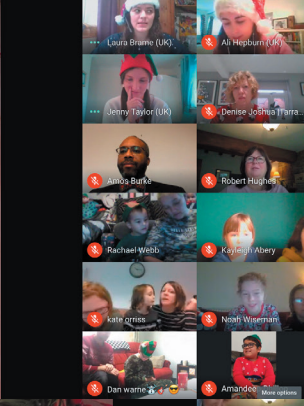
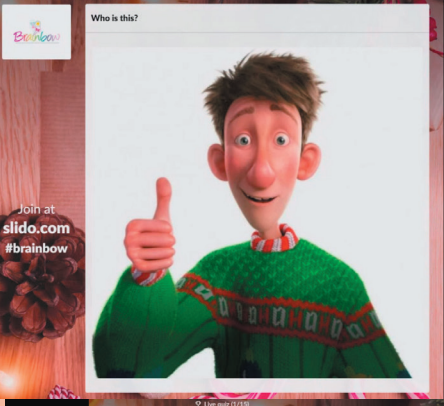


Overall the event was a huge success with over 25 families in attendance on the day with an additional 30 families receiving a gift box to enjoy at a different time due to other commitments and circumstances meaning they were unavailable on the day. Feedback from families was overwhelmingly positive and as such planning for a Virtual Easter Event in 2021 started shortly after the Christmas break!





# 15 Brainbow Family Events Continued





# 16 case study - Abigail

## Background

Abigail was diagnosed with a Brain Tumour in 2012. She was treated with surgery and chemotherapy. The consequences of this treatment have become more apparent as Abigail has progressed throughout her school years.

## Brainbow Input

Abigail was seen for an introductory assessment with the Brainbow Service in 2014. Abigail was assessed by the Tom's Trust Clinical Psychologist and Anna's Hope Speech and Language Therapist. There were concerns noted about certain aspects of her cognitive development and her language skills were noted to be a little immature but she was making steady progress. Abigail continued to be reviewed by the Brainbow team and recommendations were given to continue to support her language development. Abigail was assessed by the Tom's Trust Clinical Psychologist again in 2017 and 2018 due to concerns about progress in school, particularly with numeracy skills, writing and concentration. It was recommended by the Tom's Trust Clinical Psychologist that an education and health care plan (EHCP) be implemented to ensure that Abigail can receive the support she needs to make the most progress she can. Recommendations were also given to school and family to help support Abigail at home and in school.

Abigail was assessed by the Tom's Trust Clinical Psychologist and Anna's Hope Speech and Language therapist and assistant in 2019 in order to review progress and offer advice to school. The Joshua Tarrant Trust Specialist Teacher observed Abigail in a range of class lessons and provided advice for the teacher and TA, ahead of the EHCP annual review meeting. The Anna's Hope Speech and Language Therapy Assistant, Tom's Trust Clinical Psychologist and the Joshua Tarrant Trust Specialist Teacher attended Abigail's EHCP annual review meeting at school in order to feedback the outcomes from assessment.

Following on from assessment:

- A Speech and Language Programme was recommended and modelled in school to Abigail's then Teaching Assistant.
- Some recommendations were given from psychology around developing a structured routine and supporting her with sleep difficulties.
- Training on the Precision Teaching Method was provided by the Joshua Tarrant Trust Specialist Teacher to help Abigail progress with her reading and numeracy skills.

In summer 2020 Abigail started a block of twice weekly online speech and language sessions, conducted by the Anna's Hope Speech and Language therapist and assistant working on developing Abigail's conversational skills, abilities to manage social situations and problem solving skills. These helped her to develop confidence when interacting with others. A social story was written by the Anna's Hope speech and language therapist supporting Abigail with friendships and how to manage emotions. A recent memory assessment was requested because the school she attends had raised some concerns about Abigail's ability to retain information in the classroom setting. Abigail has also recently had an updated (2021) Speech and Language Therapy review assessment to look at her full language profile. Following on from this the Tom's Trust clinical psychologist and Anna's Hope speech and language therapist are going to meet with school and parents to discuss assessments results and provide recommendations on how best to support Abigail.

## Impact

During the lockdown speech and language therapy were able to provide twice weekly therapy sessions virtually. This regular input had a positive impact on social skills to help prepare her for her independence as she moves through her education. Abigail has been able to access bespoke learning and resources through the training and recommendations given by the Joshua Tarrant Trust Specialist Teacher, Anna's Hope Speech and Language Therapist and Tom's Trust Clinical Psychologist. This has supported her learning and development to help her reach her full potential. Abigail's family have been given advice and strategies on how they can best support her in the home.





# 18 Brainbow Data

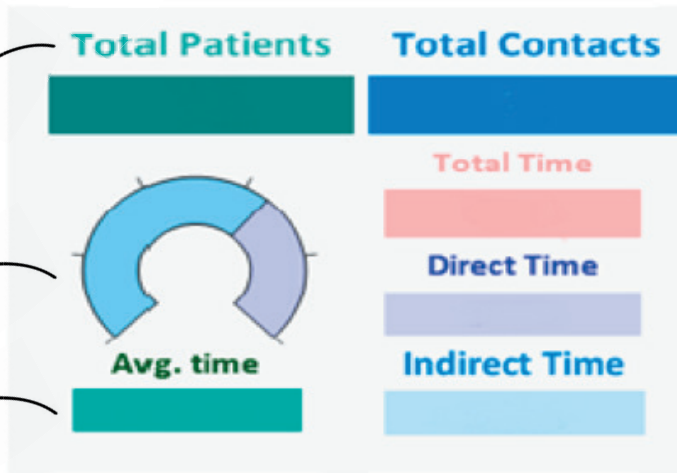
Since 2013, Brainbow has now touched the lives of over 330 children who have had a brain tumour. Within 2020/21 Brainbow provided direct care to 177 children and their families, each child having individual care tailored to their journey and needs. The diagrams below show the recorded activity for each discipline. The wheels show the amount of documented time the Brainbow team have spent working on a patient case. Any time spent working on patient cases outside of Epic (such as report writing) is not included in these figures.

## Disipline ← Contact Type

This is the number of individual patients seen by the discipline in the year

This visually shows the split of direct and indirect patient contact

This shows the average time taken for a patient contact



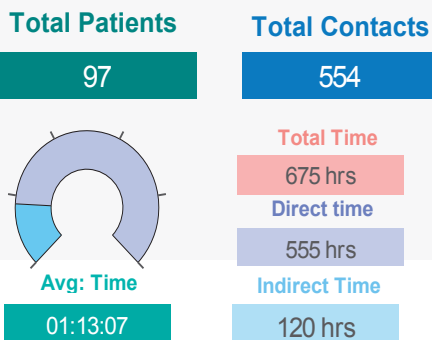
This shows number of individual contacts a member of the team has spent time on a single patient's case, this can be direct (i.e. appointment) or indirect (i.e. writing a report)

This shows the total time (in hours) the discipline has spent on the indirect patient contacts

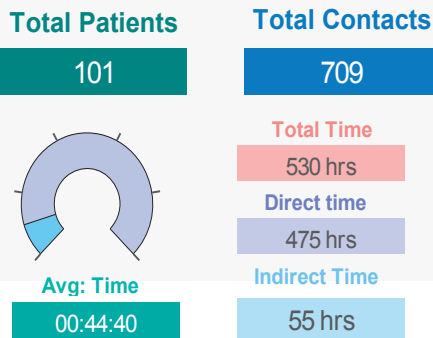
This shows the total time (in hours) the discipline has spent on the direct patient contacts

This shows the total time (in hours) the discipline has spent on the contacts shown above

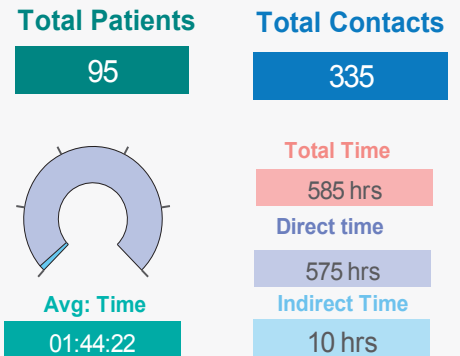
### SLT Contact



### PT Contact



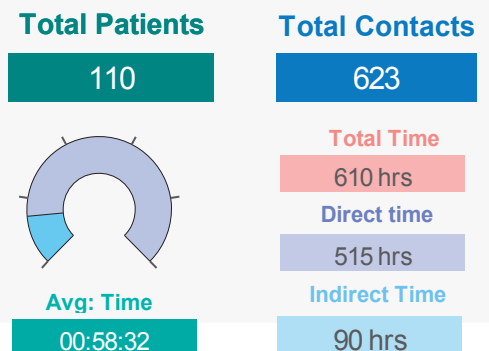
### CP Contact



## Inpatient contact

When at diagnosis patients are admitted for surgery and then during their further treatment admissions, where possible and appropriate, members of the Brainbow service see patients in ward areas. These contacts include Brainbow attending the bedside to introduce themselves and the service, completing pre-operative baseline assessments, providing post-surgery support and rehabilitation and providing emotional and psychological support for the children and their families. During 2020/21 there is record of the team completing just over 100 inpatient contacts with 48 patients and their families totalling over 300 hours. This care is additional to the care provided by the other members of the Paediatric Oncology, Haematology and Palliative Care team on the ward.

### OT Contact



# 19 Brainbow Data continued

## Outpatient Appointments

During 2020/21 the outpatient support delivered by Brainbow mainly consists of three main contact types:

1. Outpatient appointments carried out at Addenbrooke's site
2. Outpatient appointments carried out as a video call (NEW)
3. Telephone appointments with the Brainbow families

As a result of the pandemic, home visits have not been available, except in extraordinary circumstances.

In total Epic has recorded 812 Brainbow appointments between April 2020 and March 2021, 49% were face to face, 36% were video appointments and 15% were telephone appointments. As in previous years a large proportion were attended by multiple members of the multidisciplinary team. The breakdown is shown below:

### Outpatient appointments broken down by clinician combinations

| Anna's Hope            |                 |                             | Tom's Trust         | Total 2019/20 Contacts |
|------------------------|-----------------|-----------------------------|---------------------|------------------------|
| Occupational Therapist |                 |                             |                     | 64                     |
| Occupational Therapist | Physiotherapist |                             |                     | 34                     |
| Occupational Therapist | Physiotherapist | Speech and Language Therapy |                     | 6                      |
| Occupational Therapist | Physiotherapist | Speech and Language Therapy | Clinical Psychology | 5                      |
| Occupational Therapist | Physiotherapist |                             | Clinical Psychology | 0                      |
| Occupational Therapist |                 | Speech and Language Therapy | Clinical Psychology | 11                     |
| Occupational Therapist |                 | Speech and Language Therapy |                     | 24                     |
| Occupational Therapist |                 |                             | Clinical Psychology | 12                     |
|                        | Physiotherapist |                             |                     | 190                    |
|                        | Physiotherapist | Speech and Language Therapy | Clinical Psychology | 3                      |
|                        | Physiotherapist |                             | Clinical Psychology | 4                      |
|                        |                 | Speech and Language Therapy |                     | 189                    |
|                        |                 | Speech and Language Therapy | Clinical Psychology | 13                     |
|                        |                 |                             | Clinical Psychology | 257                    |



# 20 Brainbow Data continued

## School Visits

Unfortunately school visits could not take place during 2020/21 due to the pandemic, although Heather Mephem Joshua Tarrant Trust Specialist Teacher was able to perform one urgent classroom observation in December 2020.

## Joshua Tarrant Trust Specialist Teacher

The role of the Joshua Tarrant Specialist Teacher has always been difficult to capture as the IT system used at CUH (Epic) does not allow for non-clinical activity recording, therefore the work of the specialist teacher is unable to be recorded and therefore reported through Epic. In the past year, a system has been created in order to record Heather's activities and time spent working with families and schools. In total throughout 2020/21 The Joshua Tarrant Trust specialist teacher has worked with 76 individual families within the Brainbow service. Please see below a breakdown of the key activities this includes alongside an indicative indication of the time Heather spent in each activity in the year. As with the clinical team data above, the below does not include all the work Heather does in Brainbow, however this provides an overview of key activities.

| Activities  | Number of hours recorded |
|---|--------------------------|
| Child in need Meetings  | 2                        |
| Communication with school SENCo on specific cases                                 | 89                       |
| Education Health and Care Plan (EHCP) meetings                                    | 33                       |
| Local Authority Liaison   | 12                       |
| Attending and sometimes leading family Feedback Meetings following assessments    | 20                       |
| Other MDT Meetings including liaising with parents and schools following meetings | 77                       |
| Patient specific transition support   | 21                       |
| Writing patient reports   | 28                       |

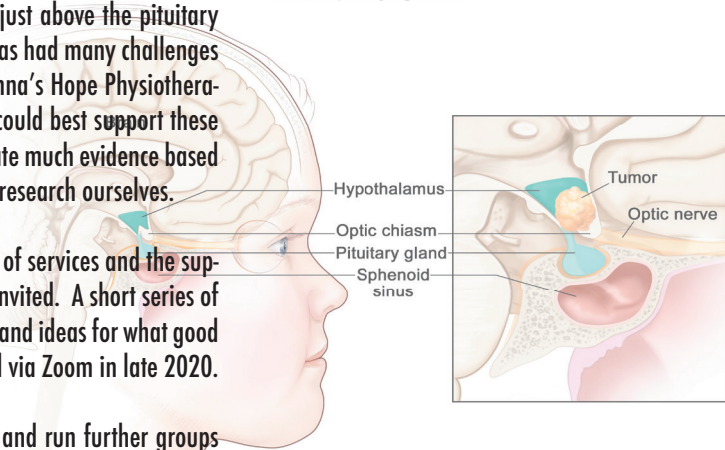
## Craniopharyngioma group

Craniopharyngiomas are brain tumours that usually grow near the base of the brain, just above the pituitary gland. Through Brainbow's work the team identified that children with Craniopharyngiomas had many challenges and multiple teams involved in their care. The Tom's Trust Clinical Psychologists and Anna's Hope Physiotherapist decided to take on a project thinking about how the multi-disciplinary team (MDT) could best support these families and what interventions would be most helpful. A literature search did not generate much evidence based practice for groups and MDT support, so we knew this was something we would need to research ourselves.

The group started with the idea of an initial focus group to explore parents' experiences of services and the support available. All families supported by Brainbow with a child with this diagnosis were invited. A short series of open questions were circulated to allow those who signed up to explore their experiences and ideas for what good support would look like. Seven parents agreed to attend and two focus groups were held via Zoom in late 2020.

Overall the families found the groups helpful and Brainbow hope to take this forward and run further groups with other parents and children. The team are currently in the process of reviewing the transcripts to help plan future pathways for this patient group. In time we would really like to extend this to children with other diagnoses.

Craniopharyngioma



# 2 | case study - Sophie

## Background

Sophie is a teenager who was diagnosed with a brain tumour when she was very young. She has needed lots of treatment over the years and as a result of her tumour she finds it very difficult to walk or use her hands. Sophie also has great difficulty with fatigue and becomes incredibly tired completing everyday activities. Until recently Sophie has predominantly remained indoors and she hasn't been able to get outside to see her friends or participate in the social activities which many of her peers enjoy without her mother pushing her in her wheelchair. Sophie understandably wants to be able to start having some independence and to spend time with her friends by herself.

## Brainbow Input

The Anna's Hope Occupational Therapist picked this up when having a discussion with Sophie's mother. Referrals were made locally for Sophie to have some Physiotherapy input and for an Occupational Therapist to assess the family home to see if there were any adaptations which could help her to more easily access the kitchen and take part in activities in her house. The Anna's Hope Occupational Therapist also discussed Sophie's goal with the local Wheelchair Service as it was felt that an add-on power pack to her existing chair would enable her to drive her own wheelchair but still mean her wheelchair would fit in the family car. This is not an option normally provided but Brainbow advocated for this for Sophie as it worked better with her and her family's specific needs. The Wheelchair Service were also keen to be flexible and Sophie's family approached charities for the additional funding with supporting information from Brainbow.

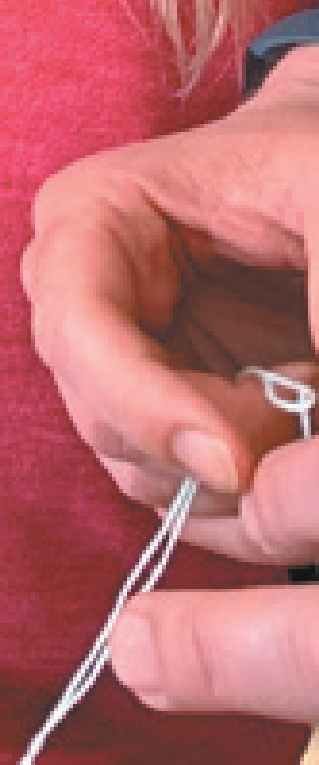
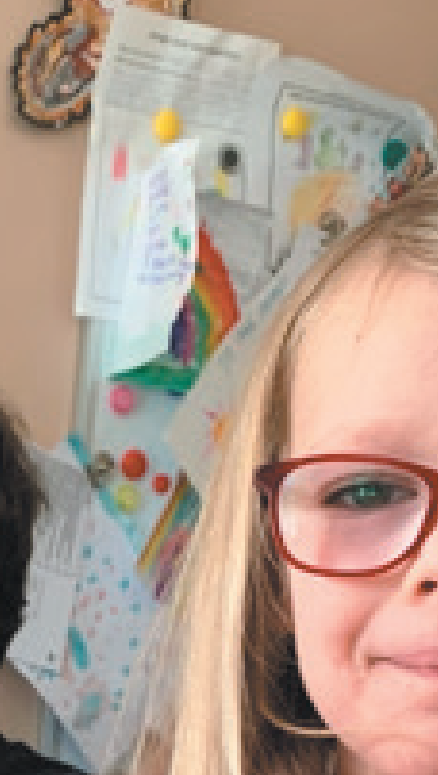
## Impact

Brainbow have just heard from Sophie's mother that her power pack has been fitted. The very next day, Sophie asked if she could independently go home from school in her wheelchair rather than being picked up in the car.... And she did!! Everyone is incredibly proud of her adventurous spirit and determination to achieve her goals. As her mother said, "she loves it and it's literally changed everything".



# 22 Brainbow Objectives

| Brainbow Objectives   | Progress   |
|---|--|
| <p>To develop a specialist core team at Addenbrooke's who can provide neuro-rehabilitation assessment and some therapy for children with brain tumours living in the East of England.</p> <p>The core team will include Occupational Therapist, Physiotherapist and Speech and Language Therapist funded by Anna's Hope, and a Clinical Psychologist funded by Tom's Trust.</p> | <p>The staffing model has been updated to now include an assistant clinical psychologist, specialist teacher and speech and language therapy assistant.</p> <p>These additional posts have enabled Brainbow to provide more functional assessment, more MDT working and provide more focus on the educational needs of the patients.</p>   |
| <p>To ensure that all children with brain tumours in the East of England receive a clear programme of rehabilitation intervention based on standardised needs assessment.</p>   | <p>Brainbow has standardised the patient pathway to ensure every patient has equal opportunities. Each patient receives a clear rehabilitation plan that is goal based.</p>  |
| <p>To demonstrate and report on improved outcomes for children with brain tumours as a result of coordinated rehabilitation assessment and therapy.</p>   | <p>Functional measures are on-going and this will take several years to achieve.</p>   |
| <p>To gain a better understanding of how children treated for brain tumours can reach their maximum potential following treatment and to maximise opportunities to share this learning.</p>   | <p>Brainbow is on the cusp of leading pioneering research in the feasibility study of functional Magnetic Resonance Imaging (fMRI) in children with brain tumours.</p>   |
| <p>To embrace new ways of working including joint therapy sessions.</p>   | <p>Joint therapy sessions are embedded into the Brainbow service. These have been translated to and supported by the use of virtual appointments.</p>  |
| <p>To improve the experience for families in terms of better coordination of rehabilitation services.</p>   | <p>Feedback from families has shown that the work done by Brainbow has significantly aided the co-ordination of care outside of the hospital, in the community and at school.</p>  |
| <p>For the Brainbow service team to work collaboratively with families, charities, and existing teams within CUH and across the East of England to improve rehabilitation therapy provision.</p>  | <p>Brainbow works collaboratively with a wide range of teams within CUH, the community, Tadworth, families and charities to improve rehabilitation therapy provision.</p>  |
| <p>To develop a service that will be sustainable in the East of England after the three-year charitable funding period.</p>   | <p>Brainbow will be fully NHS funded by April 2023.</p> <p>We are delighted that Anna's Hope, Joshua Tarrant Trust and Tom's Trust have agreed to fund 62.5% of 2021/2022 and 50% of 2022/23.</p>  |
| <p>To develop a sustainable model of care – an optimal rehabilitation package – which can be rolled out across the East of England, and beyond of 2022/23.</p>  | <p>In the new Children's Hospital Rehabilitation facility, Brainbow will be instrumental in the roll out of paediatric rehabilitation across services within the East of England.</p>  |
| <p>To develop a system to record the rehabilitation needs and treatment results of all children with brain tumours across the East of England.</p>  | <p>With CUH's introduction of Epic, a new way to record data was introduced. Brainbow requirements have been built into Epic and reports have been created from the data collected.</p> <p>Within the East of England's Childrens Hospital, the integration of mental and physical health will greatly aid the aim for more detailed data recording. Advances are being made in the electronic recording of data from psychological assessments, which have huge potential when combined with the physical health data stored via patient records.</p> |





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