

ASTRO BRAIN TUMOUR FUND

ACCOUNTS FOR THE YEAR ENDED

5<sup>th</sup> APRIL 2024

ASTRO BRAIN TUMOUR FUND

Legal and Administrative Information

Registered Charity Number	1133561
Trustees	Mrs M Burton Mrs L Rickford Mr R Burton Ms A Scrutton Mrs S Hopkins (resigned 22.1.24) Mr N Blatherwick Mrs D. Emerton (appointed 5.11.23) Mrs K. Phillips (appointed 1.4.24)
Independent Examiner	A Borland F.C.A. 75 Newnham Street Ely Cambs CB7 4PQ
Bankers	Barclays Bank
Correspondence address	15 Eastgate Holme Next the Sea Hunstanton Norfolk PE36 6LL

## ASTRO BRAIN TUMOUR FUND

Annual Report  
For the Year ended 5<sup>th</sup> April 2024

Astro Brain Tumour Fund has continued to raise money for research into low-grade glioma brain tumours. These may sound benign but this slow-growing, progressive group of tumours cause inevitable life-changing and life-limiting physical and psychological symptoms and can cause death depending upon the area of the brain affected. They may also become higher grade (faster growing) over time.

Without the fund-raising efforts of patients, their families, the trustees, and other supporters meeting the objectives of the charity would not be possible.

### **Research News**

As well as receiving reports from ongoing research that the charity is supporting, the trustees actively seek out information on new research into low-grade brain tumours. The thrust of much research is into higher grade tumours so it can be hard to find research initiatives that fit our brief. Although the trustees are not scientists, we screen potential projects to ensure that work we support is focussed on things that will move knowledge and/or treatments forward and have scientific rigour. One outcome that we look for is the intention to publish results of the research in accredited scientific journals as this necessitates strong scientific method in the way the research is organised, performed, recorded, and analysed.

The trustees obtained full funding for two PHD students working on research projects supervised by Prof. Stephen J. Price, BSc MBBS (Hons) PhD FRCS(Neuro Surg.) at Cambridge Biomedical Campus, over the next 3 years, this will utilise a large part of the reserves we are holding at present. One project is looking at developing artificial intelligence tools to monitor low grade gliomas (this project is scheduled to commence in 2024) and the other, which commenced in January 2023, is studying higher cognitive functions and return to work in low grade gliomas. The charity also extended the funding of “Molecular regulation of paediatric low-grade gliomas” for a further six months.

### **Projects funded in 2023/24:**

#### *Molecular regulation of paediatric low-grade gliomas:*

#### **Annual Report from Professor Denise Sheer, Blizard Institute, Queen Mary University of London. 23<sup>rd</sup> April 2023**

“Firstly, I’d like to thank the Trustees and the supporters of Astro Brain Tumour Fund for their generous funding. As reported previously, the aim of our research programme is to characterise the molecular changes that lead to the development of low-grade gliomas in children.

“Everything in the lab is going really well and we are so excited about the work. We have been culturing and analysing our new tumour models from Harvard and decided to do all of the molecular profiling in a single batch. This will allow us do proper comparisons between all the different genetic alterations that are found in children’s LGG (and in some adult tumours too), not just the BRAF changes. Our findings were presented to an international online committee on Thursday and the reviewers were very interested in what we showed. I’ve also been invited to a talk to a Cancer Research UK Paediatric Cancer Conference at Great Ormond Street Hospital”

#### *Higher cognitive functions and return to work in low grade gliomas:*

**Report from Jasmine Kennedy, PhD student who is executing the above project under the supervision of Professor Stephen J. Price BSc MBBS (Hons) PhD FRCS (Neuro Surg.)  
Clinical Professor of Neurosurgical Oncology, Hon. Consultant Neurosurgeon,  
Department of Clinical Neuroscience, Cambridge**

“We’re very happy to report another successful meeting with the trustees of Astro Brain Tumour Fund at Addenbrookes Hospital, Cambridge in April 2024. The aims of the meeting were to:

1. Present the results of the first stage of our project, a service questionnaire, to the trustees.
2. Begin planning of the next stages of the project, which includes one-to-one interviews.

A total of 47 participants (aged 22-59 years, 31 females and 16 males) with low grade glioma responded to our questionnaire. Participants were asked questions about their work status prior to their diagnosis and currently, their experiences of receiving certain clinical services (for example, vocational rehabilitation) and their opinions on whether their cognitive functions (for example, attention, memory, decision making) had gotten better or worse since before their diagnosis.

Of the 47 participants, 28 (59.6%) had returned to work, 15 (31.9%) had not returned to work and four (8.5%) were on sick leave. Seven participants did not take time off work after receiving their low grade glioma diagnosis. Participants who had not returned to work reporting that their working memory (i.e., the small amount of information that can be held in mind and used in the execution of cognitive tasks) had gotten significantly worse since before their diagnosis. Most participants (57.4%) reported that they often experience fatigue. Only seven participants (14.9%) received vocational rehabilitation after completing treatment for their LGG; three participants were very satisfied, four participants were satisfied, and one participant was very unsatisfied with this service.

We are now focusing on the next stages of the project. This will include semi-structured interviews, neuropsychological assessment, and evaluation of a simple screening tool. This screening tool could possibly be used in clinical settings to screen for deficits in higher cognitive function. We will further investigate some of the issues collected from the service questionnaire on a deeper level during the interview stage”.

### ***Developing artificial intelligence tools to monitor low grade gliomas***

**Prof. Stephen J. Price, BSc MBBS (Hons) PhD FRCS(Neuro Surg.) at Cambridge Biomedical Campus**

Prof Price is in the process of interviewing PHD students to carry out this work and it is hoped that the project will commence within the next few months.

### **Attendance at Houses of Parliament and Conferences**

We continue to support the All-Party Parliamentary Group (APPG) for Brain Tumours which seeks to raise awareness of the issues facing the brain tumour community to improve research, diagnosis, information, support, treatment and care outcomes.

In late 2023, we supported the Emerton family in bringing to the APPG’s attention their and the LGG community’s frustrations in being unable to access the new drug, Vorasidenib in the UK (see below). As a direct result, the APPG took action to further establish the main issues and solutions, and engaging with the manufacturers, Servier, at the highest level in the UK in early 2024. Vorasidenib is now available in the UK under the early access scheme on a named patient basis.

At the APPG on 14<sup>th</sup> November 2023, Mr Kismet Hossain-Ibrahim of Dundee University did a presentation on Sonic Dynamic Therapy - ABTF trustees have engaged with him to try to understand the obstacles he is facing in getting this into a clinical trial in the UK and continue to pursue this. Also, Dr Kathreena Kurian of North Bristol NHS Trust presented a talk on the importance of genetic whole genome sequencing - which ABTF pursued by presenting information to LGG patients in order for them to understand more about this and also how they might access it

### **Fundraising and Donations**

The trustees are enormously grateful to everyone who has supported the charity either with donations or holding fundraising events.

Our biggest fundraiser, the Norfolk Family Walk, was held at Holkham Hall, North Norfolk on Sunday 24th September 2023. Around 150 adults, children and dogs walked one, three, six or ten miles.

We were a small team of helpers this year but had some assistance with the preparation.

It was lovely to see so many walkers who return every year to meet up with family and friends, supporting loved ones with brain tumours or remembering those who have sadly passed away from this cruel disease. Not forgetting, of course, brain tumour patients themselves walking with their families. Adrian Flux Insurance Services once again generously sponsored all the expenses of the event, with the owners of Holkham Hall allowing us to use the park and facilities free of charge.

The 2024 walk is scheduled to take place on Sunday, 22<sup>th</sup> September.

**Support**

The Astro Brain Tumour Fund Low Grade Glioma support group continues to grow steadily and has reached over 600 in number. There are members from all parts of the planet including the UK, the United States, Mexico, Poland, South Africa, the Middle and the Far East, and so many more...a really widespread community. The members are so supportive of each other and are always keen to share experiences, tips, recommendations, support, pool their knowledge and share, as well as their fears, their hopes and celebrations. As is often mentioned by members themselves, it is a very much valued asset of the charity.

This global spread reflects the fact that the focus on low grade tumours support is uncommon and that there is a real need for it. Each year, we send informative leaflets to all Neuro-oncology units around the whole of the United Kingdom, so that information about Astro Brain Tumour Fund, and the support we can offer, can be shared with all newly diagnosed patients.

## ASTRO BRAIN TUMOUR FUND

### Trustees' Annual Report For the Year ended 5<sup>th</sup> April 2024

In accordance with statutory requirements and the Charities Statement of Recommended Practice (second edition – Oct 2019) 'Accounting and Reporting by Charities' (FRS102), the Trustees submit their report for the year ended 5<sup>th</sup> April 2024. These financial statements have been prepared in accordance with accounting policies set out on page 12 and comply with the charity's governing document, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice edition II applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland - October 2019.

#### **Trustees**

The trustees named on page 1 served throughout the financial year, with the exception of Sam who resigned in January 2024 due to personal circumstances and Dawn who joined us in November 2023 and Katie in April 2024. Appointment of trustees is governed by the Trust Deed of the charity.

Present Trustees Mary (Treasurer), Linda (Support Group Moderator), Robbie, Angela, Neal, Dawn and Katie have been committed to carrying on the invaluable work of the charity. Mary has been treasurer/trustee since the charity was registered in 2009, looks after the daily administration of the charity and with husband Robbie are very active fundraisers and prime organisers of the annual Holkham Hall walk. Linda, as well as fundraising, is support co-ordinator and moderates the Facebook page, Sam has focussed on the website and has agreed to carry on with this invaluable work. Angela and Dawn represent the charity at All-Party Parliamentary Group meetings at Westminster and on related calls instigated by BTR. Neal and his family are prolific fundraisers for the charity.

#### **Supply of Vorasidenib to UK LGG patients**

Trial of this drug took place in several countries (including the UK) and proved very successful in delaying further treatment to patients after they underwent surgery for LGGs.

Trustee Dawn was instrumental in instigating a campaign for the drug to become available for all patients who qualified for this drug in the UK. Dawn, Mary and Angela worked together and began a petition which gained over 10,000 signatures. There were numerous email exchanges with Servier (the suppliers of vorasidenib), MPs, patients and other brain tumour charity representatives and it is gratifying to report that the drug has just become available, through an early access scheme, via patients' oncologists who are required to liaise with Servier in order to arrange treatment.

#### **Investment powers**

The Trust Deed authorises the trustees to make and hold investments.

#### **Constitution, Objects and Policies**

The charity's constitution is embodied in the Trust Deed. The object of the charity is to raise funds for low grade glioma research. The work of the charity is for the public benefit seeking to improve scientific knowledge, treatments, outcomes, and support in this area. To ensure that this is at the forefront of what we do the trustees have due regard to the public benefit guidance issued by the Charity Commission when exercising their responsibilities, for example when making funding decisions. The charity has appropriate policies in place to cover e.g., management of the Facebook support group, data protection and safeguarding, recognition of fund raisers/supporters etc. The charity has no employees and therefore no policies in relation to employment.

#### **Developments, activities, and achievements**

The trustees report that the performance of the charity for the past year has been challenging, with income down from previous years. However, we have full funding in place for the research projects we are committed to. In the year we invested a further £30,000 in research being run by Professor Denise Sheer into molecular regulation of paediatric low-grade gliomas. With Professor Stephen Price, we have begun funding one of two new research projects, the second one will hopefully begin later in 2024.

Our Facebook Support Group page has been a source of strong support and information. Members are actively interacting and providing support both emotional and practical both to existing members facing periodic scans/procedures and waits for results; and also, as new patients and their families seek knowledge from those who have already been through certain treatments/tests/processes.

## **Financial review**

The Fund derives its income from donations, grants from charitable trusts, fund-raising events run by the trustees and the charity's supporters, and interest on money held on deposit. Administrative expenses are small as the charity is run by volunteers and where possible the trustees seek sponsorship to cover administrative costs for larger events such as the Norfolk Family Walk.

## **Risk management**

The trustees review the major risks that the charity faces on a regular basis and are mindful of risks such as reputational risk or mandate related risks when discussing day to day business of the charity or when considering research funding possibilities. The trustees have also examined other operational risks faced by the Charity and confirm that they have established systems to mitigate the significant risks. The trustees reserve policy is to aim for its resources to be distributed to suitable research projects as soon as practical to meet commitments made. Where specific grants have been received amounts may be held as restricted reserves until such time as the activity supported by the grant is completed. At the end of the financial year reserves were £198,967 (prior year £130,539) of which £38,000 were restricted reserves. The trustees believe that maintaining reserves at current levels, combined with an annual review of the controls over key financial systems, will provide sufficient resources for the future.

The Trustees are responsible for preparing the report and accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to Trustees in England and Wales requires Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the income resources and application of resources of the charity for that period. In preparing these financial statements, the Trustees are required to:

- Observe the methods and principles in the Charities' SORP second edition – Oct 2019 (FRS102);
- Select suitable accounting standards and then apply them consistently;
- Make judgements and estimates that are reasonable and prudent;
- State whether applicable accounting standards and statements of recommended practice have been followed, subject to any departure disclosed and explained in the financial statements;
- Prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping accounting records which disclose with reasonable accuracy at any time the financial position of the charity, and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the Trust Deed. They are also responsible for safeguarding the assets of the charity and for taking reasonable steps for the prevention and detection of fraud and other irregularities.

## **Approval**

This report was approved by the trustees on \_\_\_\_\_ 2024 and signed on their behalf.

Mary Burton (Trustee)

## ASTRO BRAIN TUMOUR FUND

### Independent Examiner's Report to the Trustees of The Astro Brain Tumour Fund

Charity Number – 1133561

We report on the accounts of the Association for the year ended 5<sup>th</sup> April 2024, on pages 5-6.

Respective responsibilities of trustees and examiner.

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.

It is my responsibility to:-

- examine the accounts under section 145 of the Charities Act.
- 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
- to state whether particular matters have come to my attention.

Basis of independent examiner's report.

My examination was carried out in accordance with the 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 you as 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.

Independent examiner's statement.

In connection with my examination, no matter has come to my attention: -

1. which gives me reasonable cause to believe that in, any material respect, the requirements: -

- to keep accounting records in accordance with section 130 of the Charities Act.
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or

2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

A Borland F.C.A.  
75 Newnham Street  
Ely Cambs CB7 4PQ

Dated \_\_\_\_\_



ASTRO BRAIN TUMOUR FUND

STATEMENT OF FINANCIAL ACTIVITIES

FOR THE YEAR ENDED 5<sup>TH</sup> APRIL 2024

	<u>2024</u>	Total <u>2023</u>
<u>Incoming Resources:-</u>		
Donations and Grants	32,127	42,981
Restricted Grants	0	38,000
Gift Aid repayments	4,773	4,080
Interest Received	<u>962</u>	<u>100</u>
Total Income	<u>37,862</u>	<u>85,161</u>
<u>Expenditure:-</u>		
Research Funding	52,500	15,000
Fundraising	1,016	562
Restricted expenses (note 2)	30,452	651
Website hosting	300	300
Insurance	185	185
Publicity	167	-
Printing, Postage and Stationery	-	-
Miscellaneous	<u>35</u>	<u>35</u>
Total Expenditure	<u>84,655</u>	<u>16,733</u>
Net Incoming Resources	(46,793)	68,428
Fund Balances b/fwd	<u>198,967</u>	<u>130,539</u>
Fund Balances c/fwd	<u>£152,174</u>	<u>£198,967</u>

ASTRO BRAIN TUMOUR FUND

BALANCE SHEET AS AT 5<sup>TH</sup> APRIL 2024

	<u>2024</u>	2023
<u>Current Assets</u>		
Barclays Bank	22,164	128,957
Cambridge & Counties Bank	<u>130,010</u>	<u>70,010</u>
NET CURRENT ASSETS	<u>£152,174</u>	<u>£198,967</u>
<u>Funds</u>		
Fund Reserves	144,626	160,967
Restricted Reserves (note 2)	<u>7,548</u>	<u>38,000</u>
	<u>£152,174</u>	<u>£198,967</u>

Approved by the Board of Trustees on \_\_\_\_\_ and signed on their behalf

Mary Burton  
Trustee

## ASTRO BRAIN TUMOUR FUND

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### Notes to the Accounts For the Year ended 5<sup>th</sup> April 2024

#### 1 Accounting Policies

##### 1.1 Statement of compliance

The financial statements have been prepared in accordance with applicable UK accounting standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the United Kingdom and the Republic of Ireland' (FRS 102). Additionally, they comply with the Statement of Recommended Practice 'Accounting and Reporting by Charities' second edition – October 2019 in all material aspects. The Charity meets the definition of a public benefit entity under FRS 102.

##### 1.2 Basis of Preparation

The financial statements have been prepared on a going concern basis under the historical cost convention. The functional currency of the Charity is considered to be Pounds Sterling because that is the currency of the primary economic environment in which the charity operates.

##### 1.3 Going concern

The trustees have assessed whether the use of the going concern assumption is appropriate in preparing these financial statements. The trustees have made this assessment in respect to a period of one year from the date of approval of these financial statements.

The trustees of the charity have concluded that there are no material uncertainties related to events or conditions that may cast significant doubt on the ability of the charity to continue as a going concern. There is no specific threat or relevance to Astro Brain Tumour Fund from most government policies. The charity benefits from our supporters being very active fundraisers and the annual Holkham Walk being a well-supported event. We also received some significant donations in the year which resulted in receipts being £14,151 up on the previous year. In addition, the charity has small, fixed overheads. The trustees are of the opinion that the charity will have sufficient resources to meet funding obligations that will be tailored to fit resources and reserve policies. The charity does not take on funding commitments beyond the available reserves.

#### 2 Restricted Reserves and Expenses

In 2022 two grants were received - £15,000 from Mazars Charitable Trust and £23,000 (Anon). These grants are being treated as restricted and will be used towards the project of 'Higher Cognitive Functions and Return to work' being carried out at Cambridge by Prof Stephen Price and his PHD student, Jasmine Kennedy.