

**REGISTERED COMPANY NUMBER: CE010848 (England and Wales)**  
**REGISTERED CHARITY NUMBER: 1174374**

**REPORT OF THE TRUSTEES AND**  
**UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 AUGUST 2023**  
**FOR**  
**THE MADDI FOUNDATION**

Tish Press & Company  
Create Business Hub  
Ground Floor  
5 Rayleigh Road  
Hutton, Brentwood.  
Essex  
CM13 1AB

**THE MADDI FOUNDATION**

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**FOR THE YEAR ENDED 31 AUGUST 2023**

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## **THE MADDI FOUNDATION**

### **REPORT OF THE TRUSTEES** **FOR THE YEAR ENDED 31 AUGUST 2023**

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 August 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **Governing document**

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

#### **REFERENCE AND ADMINISTRATIVE DETAILS**

##### **Registered Company number**

CE010848 (England and Wales)

##### **Registered Charity number**

1174374

##### **Registered office**

Tish Press and Co KGE Ltd  
Create Business Hub  
Ground Floor, 5 Rayleigh Road  
Shenfield  
Brentwood  
CM13 1AB

## **THE MADDI FOUNDATION**

### **REPORT OF THE TRUSTEES** **FOR THE YEAR ENDED 31 AUGUST 2023**

#### **Trustees**

FOR THE PERIOD 1 SEPTEMBER 2022 TO 31 AUGUST 2023

The trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the period 1 September 2022 to 31 August 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

#### **INCORPORATION**

The charitable company was incorporated on 24 August 2017.

#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **Governing document**

The charity is controlled by its governing document, a Deed of Trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

The organisational structure of the charity and how decisions are made.

The board of trustees consists of 4 individuals as of 31st August 2023.

Carina Thurgood is CEO and is responsible for the day to day organisation of the charity, working closely with other trustees and management on decision making matters.

#### **REFERENCE AND ADMINISTRATIVE DETAILS**

Registered Company number CE010848 (England and Wales)

Registered Charity number 1174374

Registered office

Tish Press & Co

Create Business Hub

5 Rayleigh Road

Shenfield

Brentwood

Essex

CM13 1AB

#### **THE TRUSTEES**

Mrs Carina Thurgood

Miss Alexandra Thurgood

Miss Victoria Bissett

Mr Harry Thurgood

#### **Reference and Administration details**

#### **Trustees introducing The Maddi Foundation**

The Trustees of The Maddi Foundation are pleased to present the fourth annual review of the charity for the year ending 31 August 2023. We confirm our compliance with the Charities Act 2011.

The Maddi Foundation was established in August 2017 by Carina and Alexandra Thurgood. Maddi, Carina's daughter and Alexandra's sister, was diagnosed with SPG15 in the summer of 2016. At that time, there was no UK-based charity dedicated to medical research of SPG15, a rare and complex form of Hereditary Spastic Paraplegia.

The trustees meet at the end of each financial year to assess the need for any changes or the introduction of new policies and procedures.

The Maddi Foundation focuses on funding medical research for potential treatments or cures for SPG15 and related rare conditions. Since 2017, we have supported a gene therapy research project in the UK and are exploring other research avenues in Europe and the USA. We continue to raise awareness of SPG15 through rare disease groups, our website, and social media.

## **THE MADDI FOUNDATION**

### **REPORT OF THE TRUSTEES** **FOR THE YEAR ENDED 31 AUGUST 2023**

Since our founding in 2017, we have actively raised funds through events and grants from various institutions, enabling ongoing research into treatments for SPG15. Our foundation, based in the UK, has also built strong connections with researchers and clinicians worldwide. We believe that collaboration with our European and US counterparts enhances research efforts.

Our grant-making policy is based on donations received for SPG15 research. To determine grants, we consult with Professor Azzouz, who leads the research team at SITraN (Sheffield University) and is the Director of the Gene Therapy Innovation and Manufacturing Centre. The foundation provides grants to his work if Sheffield University cannot secure funding from other sources.

The foundation's trustees and scientific advisors review research grants to ensure that the work undertaken will positively impact the potential treatment of SPG15.

#### What is SPG15

SPG15 is classified as a type of motor neuron disease and is an exceedingly rare neurodegenerative illness. Onset generally occurs in childhood or adolescence, often beginning with leg stiffness. It progresses to cause paralysis in the lower and upper limbs, along with neurological impairment leading to brain abnormalities. Additionally, SPG15 affects the peripheral nervous system, impairing vision and hearing, and can trigger early juvenile parkinsonism. The disease is progressive and has devastating effects similar to other motor neuron diseases.

Currently, there is no known treatment or cure for SPG15.

#### Report of the Trustees

For the year ending 31 August 2023

We present our report along with the financial statements of the Charity for the year ended 31 August 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

#### Our Aims and Objectives

The Foundation is dedicated to finding an effective treatment and potential cure for SPG15. The trustees are actively involved with the team leading this critical research. Collaboration is key, and we engage with researchers and clinicians worldwide to further our mission.

#### Our defined aims

1. Raise awareness of SPG15 (Hereditary Spastic Paraplegia 15) and related Spastic Paraplegias by providing relevant information on our website and social media platforms.
2. Raise and provide funds for further research into the disease to explore potential treatments.
3. Offer comprehensive resources on published research papers, potential treatment research, and other relevant medical studies. Continue to build a network of families affected by the disease.

When we established The Maddi Foundation in 2017, our first task was to define its aims. We recognised that these aims needed to provide public benefit to be recognised as a Charitable Incorporated Organisation by the Charity Commission.

In planning our activities, we have complied with the duties set out by the Charities Act 2011, taking due regard of the guidance published by the Charity Commission in relation to public benefit. The public benefit of the charity's activities is outlined under 'Our Aims and Objectives' and 'Achievements and Performance'.

#### Achievements and Performance

##### Research

## **THE MADDI FOUNDATION**

### **REPORT OF THE TRUSTEES** **FOR THE YEAR ENDED 31 AUGUST 2023**

The Maddi Foundation is dedicated to funding medical research to develop effective treatments for SPG15, aiming to halt the disease's progression. Many families currently have no treatment options to stabilise the disease, and there are limited means to improve the quality of life. The Maddi Foundation is determined to change this.

#### **What We Have Achieved So Far**

Our research has focused on developing gene therapeutic approaches for diseases of the brain and spinal cord, such as SPG15. Gene therapy is an evolving field that uses genes, instead of drugs, to treat diseases. In cases where genetic mutations result in a faulty or absent protein, as with most SPG15 cases, gene therapy aims to provide a normal copy of the gene to restore the protein and its functions.

SPG15, caused by the absence of the SPG15 protein, is an ideal candidate for gene therapy. Since 2017, our primary hope for a potential treatment has been a Gene Therapy research program at Sheffield University.

The team of scientists at Sheffield University is actively working on different strategies for gene replacement for SPG15, aiming to overcome challenges associated with this approach. Their prediction is that at least one of these strategies will be amenable to gene therapy. Studies on validated cell and animal models will help determine which strategy can be a practical approach to treating SPG15. We are also collaborating with AskBio, a pharmaceutical company, to aid the gene therapy research at Sheffield University.

Additionally, the Natural History Study based at Boston Children's Hospital, led by Dr. Darius Ebrahimi-Fakhari, is ongoing and has successfully added many more SPG15 patients to the registry.

#### **Support**

We continue to connect with families from around the world. Many of these families have found our Charity through introductions from their clinicians who are familiar with Hereditary Spastic Paraplegias. Our website ranks high on internet searches for SPG15, allowing patients' families to reach out to us.

We introduce SPG15 families who contact us to the registry and natural history study at Boston Children's Hospital. The hospital connects with all families, either in person or through video consultations, to introduce them to the study and provide support.

#### **Awareness**

Our website, [[www.themaddifoundation.com](http://www.themaddifoundation.com)], provides comprehensive information about SPG15, including up-to-date research resources. We strive to make this a valuable resource for both families and researchers.

To increase awareness of the disease, we have expanded our presence on social media platforms like Facebook, Instagram, and Twitter. We use these channels to promote fundraising campaigns, events, and updates on our research and patient well-being.

We maintain a strong partnership with Sheffield University as they work on developing a treatment for SPG15. When we receive updates from the University, we share relevant information through The Maddi Foundation.

We also collaborate with researchers worldwide in the hereditary spastic paraplegia community. As members of the European Organisation for Rare Diseases, we have attended annual spastic paraplegia conferences and other related scientific meetings, including those focused on gene therapy. Many of these meetings now take place via videoconferencing when in-person attendance is not possible.

Carina, a member of the Board of Directors for the Spastic Paraplegia Foundation USA, has continued her role since 2019.

We are dedicated to acquiring knowledge about the disease and connecting with more medical researchers to drive ongoing studies and projects.

#### **Plans for the Future**

## **THE MADDI FOUNDATION**

### **REPORT OF THE TRUSTEES** **FOR THE YEAR ENDED 31 AUGUST 2023**

Our future goals include:

- Continuing our strong focus on medical research and expanding our network of scientists working on Hereditary Spastic Paraplegias and rare diseases.
- Advancing the next steps in our gene therapy research program for SPG15. We will continue to fund and collaborate with Sheffield University if their strategy proves successful in SPG15 cells and animal models. We hope our partnership with AskBio will further strengthen our gene therapy research with Sheffield University.
- Engaging with other researchers interested in working on SPG15 and reviewing their project proposals with our scientific board. We will accept new proposals that appear promising and are supported by our board. We remain committed to funding innovative research into treatments for SPG15, potentially leading to significant breakthroughs in this area.


The Board of Trustees have all decided to stay for another year. The Trustees are eager to stay part of The Maddi Foundation to continue supporting the mission to find a cure for SPG15.

#### **Company Secretary**

#### **Independent Examiner**

Tayla McArthur  
Tish Press & Company  
Create Business Hub  
Ground Floor  
5 Rayleigh Road  
Hutton, Brentwood.  
Essex  
CM13 1AB

Approved by order of the board of trustees on ..... and signed on its behalf by:

  
Mrs C Thurgood -Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF  
THE MADDI FOUNDATION**

**Independent examiner's report to the trustees of THE MADDI FOUNDATION ('the Company')**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 August 2023.

**Responsibilities and basis of report**

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

**Independent examiner's statement**

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Tayla McArthur

Tish Press & Company  
Create Business Hub  
Ground Floor  
5 Rayleigh Road  
Hutton, Brentwood.  
Essex  
CM13 1AB

Date: 28/6/2024



**THE MADDI FOUNDATION**

**STATEMENT OF FINANCIAL ACTIVITIES**  
**FOR THE YEAR ENDED 31 AUGUST 2023**

	Notes	2023 Unrestricted fund £	2022 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies		17,515	10,879
		<hr/>	<hr/>
<b>EXPENDITURE ON</b>			
Raising funds	2	1,691	1,323
		<hr/>	<hr/>
<b>NET INCOME</b>		15,824	9,556
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward		43,343	33,787
		<hr/>	<hr/>
<b>TOTAL FUNDS CARRIED FORWARD</b>		59,167	43,343
		<hr/> <hr/>	<hr/> <hr/>

The notes form part of these financial statements

**THE MADDI FOUNDATION**

**BALANCE SHEET**  
**31 AUGUST 2023**

	Notes	2023 Unrestricted fund £	2022 Total funds £
<b>CURRENT ASSETS</b>			
Cash at bank		59,167	43,343
<b>NET CURRENT ASSETS</b>		<u>59,167</u>	<u>43,343</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		59,167	43,343
<b>NET ASSETS</b>		<u>59,167</u>	<u>43,343</u>
<b>FUNDS</b>	5		
Unrestricted funds		59,167	43,343
<b>TOTAL FUNDS</b>		<u>59,167</u>	<u>43,343</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2023.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

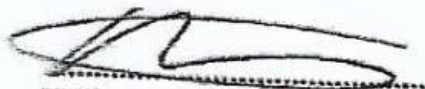
**THE MADDI FOUNDATION**

**BALANCE SHEET - continued**


**31 AUGUST 2023**

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on ..... and were signed on its behalf by:



H Thurgood -Trustee



Mrs C Thurgood -Trustee



A Thurgood -Trustee



Mrs V L Bissett -Trustee

The notes form part of these financial statements

## **THE MADDI FOUNDATION**

### **NOTES TO THE FINANCIAL STATEMENTS** **FOR THE YEAR ENDED 31 AUGUST 2023**

#### **1. ACCOUNTING POLICIES**

##### **Basis of preparing the financial statements**

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

##### **Income**

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

##### **Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

##### **Taxation**

The charity is exempt from corporation tax on its charitable activities.

##### **Fund accounting**

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

#### **2. RAISING FUNDS**

##### **Raising donations and legacies**

	2023	2022
	£	£
Fundraising costs	1,022	89
Subscriptions	85	80
Support costs	584	1,154
	<u>1,691</u>	<u>1,323</u>

**THE MADDI FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 31 AUGUST 2023**

**3. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 August 2023 nor for the year ended 31 August 2022.

**Trustees' expenses**

Trustees were reimbursed for reasonable expenses properly incurred while serving as trustees.

**4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES**

	Unrestricted fund £
<b>INCOME AND ENDOWMENTS FROM</b>	
Donations and legacies	10,879
	<hr/>
<b>EXPENDITURE ON</b>	
Raising funds	1,323
	<hr/>
<b>NET INCOME</b>	9,556
<b>RECONCILIATION OF FUNDS</b>	
Total funds brought forward	33,787
	<hr/>
<b>TOTAL FUNDS CARRIED FORWARD</b>	43,343
	<hr/>

**5. MOVEMENT IN FUNDS**

	At 1.9.22 £	Net movement in funds £	At 31.8.23 £
<b>Unrestricted funds</b>			
General fund	43,343	15,824	59,167
	<hr/>	<hr/>	<hr/>
<b>TOTAL FUNDS</b>	43,343	15,824	59,167
	<hr/>	<hr/>	<hr/>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	17,515	(1,691)	15,824
	<hr/>	<hr/>	<hr/>
<b>TOTAL FUNDS</b>	17,515	(1,691)	15,824
	<hr/>	<hr/>	<hr/>

**THE MADDI FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 31 AUGUST 2023**

**5. MOVEMENT IN FUNDS - continued**

**Comparatives for movement in funds**

	At 1.9.21 £	Net movement in funds £	At 31.8.22 £
<b>Unrestricted funds</b>			
General fund	33,787	9,556	43,343
	<hr/>	<hr/>	<hr/>
<b>TOTAL FUNDS</b>	<u>33,787</u>	<u>9,556</u>	<u>43,343</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	10,879	(1,323)	9,556
	<hr/>	<hr/>	<hr/>
<b>TOTAL FUNDS</b>	<u>10,879</u>	<u>(1,323)</u>	<u>9,556</u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.9.21 £	Net movement in funds £	At 31.8.23 £
<b>Unrestricted funds</b>			
General fund	33,787	25,380	59,167
	<hr/>	<hr/>	<hr/>
<b>TOTAL FUNDS</b>	<u>33,787</u>	<u>25,380</u>	<u>59,167</u>

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	28,394	(3,014)	25,380
	<hr/>	<hr/>	<hr/>
<b>TOTAL FUNDS</b>	<u>28,394</u>	<u>(3,014)</u>	<u>25,380</u>

**THE MADDI FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**FOR THE YEAR ENDED 31 AUGUST 2023**

**6. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 31 August 2023.

**THE MADDI FOUNDATION****DETAILED STATEMENT OF FINANCIAL ACTIVITIES**  
**FOR THE YEAR ENDED 31 AUGUST 2023**

	2023 £	2022 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations	17,515	10,879
<b>Total incoming resources</b>	17,515	10,879
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Fundraising costs	1,022	89
Subscriptions	85	80
	1,107	169
<b>Support costs</b>		
<b>Finance</b>		
Bank charges	216	231
<b>Information technology</b>		
Website expenses	302	873
<b>Other</b>		
Sundries	66	50
<b>Total resources expended</b>	1,691	1,323
<b>Net income</b>	15,824	9,556