

THE MADDI FOUNDATION

England & Wales · Charity number 1174374

Details

Status Registered

Legal form CIO

Registered 2017-08-24

Register [View on the Charity Commission register](#)

Contact

Address Tish Press Ltd
5 Rayleigh Road
Hutton
Brentwood
Essex
CM13 1AB

Phone 07557105306

Email info@themaddifoundation.com

Website www.themaddifoundation.com

Activities

Objects: FOR THE PUBLIC BENEFIT TO PROTECT AND PROMOTE THE HEALTH OF THE PUBLIC IN PARTICULAR BY RESEARCH INTO THE NATURE, CAUSES, DIAGNOSIS, PREVENTION, TREATMENT AND CURE OF HEREDITARY SPASTIC PARAPLEGIA TYPE 15 (SPG15) AND ASSOCIATED HEREDITARY SPASTIC PARAPLEGIAS, INCLUDING THE DEVELOPMENT OF RESEARCH INTO PRACTICAL APPLICATIONS FOR THE PREVENTION, TREATMENT AND CURE OF HEREDITARY SPASTIC PARAPLEGIA TYPE 15 (SPG15) AND ASSOCIATES HEREDITARY SPASTIC PARAPLEGIASAND TO PROVIDE INFORMATION AND RAISE PUBLIC UNDERSTANDING OF SUCH MATTERS.

Activities: We fund research to help develop treatments and hope ultimately to find a cure for Spastic Paraplegia Type 15 or SPG15. We aim to raise awareness of SPG15 disease by connecting clinicians, researchers and patients together and at Public Events.

Classification

- **How:** Makes Grants To Organisations
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-08-31	£12,728	£2,590	-	-
2023-08-31	£17,515	£1,691	-	-
2022-08-31	£10,879	£1,323	-	-
2021-08-31	£20,959	£46,026	-	-
2020-08-31	£29,197	£15,867	-	-

Trustees

Name	Role	Appointed
CARINA THURGOOD	Chair	2017-08-24
ALEXANDRA THURGOOD		2017-08-24
HARRY THURGOOD		2017-08-24
VICTORIA LEE BISSETT		2017-08-24

THE MADDI FOUNDATION

England & Wales - Charity number 1174374

Accounts

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 2024
FOR
THE MADDI FOUNDATION

Xeinadin South East Ltd
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 2024

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THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2024**

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 2024. 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

Xeinadin Southeast Limited
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 2024**

Trustees

FOR THE PERIOD 1 SEPTEMBER 2023 TO 31 AUGUST 2024

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 2023 to 31 August 2024. 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 2024.

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

Xeinadin South East Ltd

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

Introduction from the Trustees

The Trustees of The Maddi Foundation are pleased to present the charity's fourth annual review, covering the financial year ending 31 August 2024. We confirm that the Foundation has operated in full compliance with the Charities Act 2011 throughout the reporting period.

About the Foundation

The Maddi Foundation was founded in August 2017 by Carina and Alexandra Thurgood following the diagnosis of Carina's daughter and Alexandra's sister, Maddi, with SPG15, a rare, inherited neurodegenerative disorder, during the summer of 2016. At the time, there was no UK-based organisation dedicated to supporting medical research into SPG15, a complex subtype of Hereditary Spastic Paraplegia. The Foundation was created to fill this critical gap and to provide hope for Maddi and others affected by this ultra-rare condition.

Governance and Oversight

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2024**

The Board of Trustees meets annually at the end of each financial year to review the charity's activities, assess progress toward its strategic objectives, and consider any necessary updates to policies, procedures, or governance structures. This ongoing oversight ensures that the Foundation continues to operate effectively and transparently in line with its charitable objectives.

Our Focus and Activities

The Maddi Foundation is dedicated to funding high-impact medical research into SPG15 and related rare genetic conditions. Since our launch, we have primarily supported a long-term gene therapy research initiative in the UK, while also building connections with researchers in Europe and the United States to explore additional collaborative opportunities.

In parallel with our research efforts, we are committed to raising awareness of SPG15 through participation in rare disease networks, as well as via our website and social media platforms. By increasing visibility and engagement, we aim to reach more affected families, support knowledge-sharing, and strengthen the international effort to find effective treatments.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2024**

Our Mission and Grant-Making Approach

Since our establishment in 2017, our foundation has been committed to advancing research into treatments for SPG15, a rare and complex neurological condition. Through dedicated fundraising efforts, including community events, donor campaigns, and institutional grants, we have successfully raised the financial support necessary to drive forward scientific discovery. Based in the UK, we have built a strong international network of researchers, clinicians, and partner organisations, particularly across Europe and the United States. We believe that global collaboration is essential to accelerating progress and achieving meaningful breakthroughs in SPG15 research.

Our grant-making policy is firmly rooted in our mission to support innovative and impactful research. All research grants are funded through donations specifically earmarked for SPG15. In assessing potential grant allocations, we work closely with Professor Mimoun Azzouz, a leading expert in the field of gene therapy. Professor Azzouz heads the research team at the Sheffield Institute for Translational Neuroscience (SITraN) and serves as Director of the Gene Therapy Innovation and Manufacturing Centre (GTIMC). If Sheffield University is unable to secure alternative funding for SPG15 research, our foundation steps in to provide targeted financial support to his team's pioneering work.

Each funding decision is reviewed and approved by our Board of Trustees in consultation with our scientific advisory panel. This process ensures that all supported projects are scientifically sound and have the potential to meaningfully contribute to the development of effective treatments for SPG15. We remain deeply committed to ensuring that every grant we provide brings us closer to a future where those affected by SPG15 have access to viable therapies and improved quality of life.

What is SPG15?

SPG15, or Spastic Paraplegia Type 15, is a rare and progressive neurodegenerative disorder classified within the group of hereditary spastic paraplegias (HSPs). It is also considered a form of motor neuron disease, as it affects both the central and peripheral nervous systems. SPG15 is caused by mutations in the ZFYVE26 gene, which plays a critical role in the health and function of nerve cells.

Onset typically occurs in childhood or adolescence, with early symptoms often including stiffness (spasticity) in the legs and difficulty walking. As the condition progresses, it can lead to increasing paralysis of the lower and upper limbs, accompanied by severe muscle weakness and coordination difficulties. In many cases, individuals with SPG15 eventually become wheelchair dependent.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2024**

Beyond motor impairment, SPG15 also impacts the brain more broadly, causing a range of neurological and cognitive issues. These may include thinning of the corpus callosum (a vital brain structure that connects the two hemispheres), causing learning difficulties, speech and language delays. The disease can also affect vision through retinal degeneration, impair hearing, and lead to urinary incontinence. Some individuals may develop early-onset parkinsonism, a condition that mimics many features of Parkinson's disease.

SPG15 is inherited in an autosomal recessive pattern, meaning both parents must carry a copy of the faulty gene for a child to be affected. Due to its rarity, SPG15 is often underdiagnosed or misdiagnosed, and awareness among healthcare providers remains limited.

Currently, there is no cure or approved treatment for SPG15. Management is focused on relieving symptoms and maintaining mobility and quality of life through supportive care, including physiotherapy, occupational therapy, and assistive devices. Research is ongoing to better understand the underlying biology of the disease and to develop targeted therapies, including gene therapy.

Raising awareness and funding research are vital steps toward finding a cure and improving outcomes for individuals living with SPG15 and their families.

Report of the Trustees

For the year ending 31 August 2024

We present our report along with the financial statements of the Charity for the year ended 31 August 2024. 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 Maddi Foundation is fully committed to driving forward research into Hereditary Spastic Paraplegia Type 15 (SPG15), with the ultimate goal of identifying an effective treatment, and one day, a cure. Since our inception in 2017, we have worked closely with the researchers leading this vital work, ensuring that our efforts are strategically aligned with scientific developments. We believe collaboration is essential, and we actively engage with clinicians, scientists, and other rare disease organisations across the UK and internationally to accelerate progress.

Our Defined Aims

1. Raise Awareness:

Increase public and professional awareness of SPG15 and related hereditary spastic paraplegias by providing accurate, accessible, and up-to-date information through our website, social media channels, and outreach initiatives.

2. Fund Research:

Generate and allocate funds to support cutting-edge scientific and clinical research into the causes, progression, and potential treatment of SPG15, with a focus on therapeutic innovation.

3. Provide Resources and Build Community:

Curate and share comprehensive resources, including peer-reviewed research papers, clinical trial updates, and educational materials. We are also dedicated to fostering a supportive network for families and individuals affected by SPG15, promoting knowledge-sharing and mutual support.

A Charitable Purpose with Public Benefit

When we established The Maddi Foundation, our first priority was to ensure that our aims clearly served the public interest. These objectives formed the foundation of our application to become a Charitable Incorporated Organisation (CIO), a status granted by the Charity Commission in recognition of our commitment to public benefit.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2024**

In planning and delivering our activities, we adhere strictly to the principles outlined in the Charities Act 2011. We have followed all relevant guidance from the Charity Commission, ensuring our operations consistently meet the standards of transparency, accountability, and impact expected of charitable organisations. The public benefit of the charity's activities is outlined under 'Our Aims and Objectives' and 'Achievements and Performance'.

Achievements and Performance

The Maddi Foundation is committed to funding cutting-edge medical research to develop effective treatments for SPG15, with the goal of halting the progression of this devastating disease. At present, many families affected by SPG15 have no treatment options to slow the disease or improve quality of life. We are determined to change that by supporting promising scientific advances and forging strong collaborations with world-leading experts in the field.

Our Progress So Far

Since 2017, the Maddi Foundation has focused its efforts on advancing gene therapy as a potential treatment for SPG15, a rare neurological condition caused by the absence or dysfunction of the SPG15 protein due to mutations in the ZFYVE26 gene. Gene therapy is an innovative and evolving area of medicine that seeks to replace or repair faulty genes rather than treat symptoms with traditional drugs. For SPG15, this approach holds immense promise, as it directly targets the root cause of the disease.

Our primary research collaboration is with the University of Sheffield, home to the Sheffield Institute for Translational Neuroscience (SITraN), where Professor Mimoun Azzouz and his team are pioneering gene replacement strategies specifically for SPG15. These researchers are currently testing several approaches to deliver functional copies of the SPG15 gene, working through the challenges of targeting the brain and spinal cord effectively. Preclinical studies using validated cell and animal models are underway to determine the most promising path forward.

We are also still proud to be collaborating with AskBio for another year, a global pharma biotech company specialising in gene therapy, to support and accelerate the research efforts at Sheffield. Together, we are moving closer to identifying a viable therapy that could change the lives of SPG15 patients.

As part of our growing partnership with the research community, we were recently invited to visit the Gene Therapy Innovation and Manufacturing Centre (GTIMC) in Sheffield, where we met with Professor Azzouz. GTIMC is one of three hubs in the UK that will soon be capable of manufacturing gene therapies for rare diseases like SPG15. These centres are crucial for translating laboratory breakthroughs into treatments that can be tested in clinical trials and eventually brought to patients.

It's important to note that because SPG15 is an ultra-rare condition, it would not have gained scientific attention without the dedicated efforts of our foundation and our supporters. With so few patients worldwide, large-scale commercial investment is unlikely, so we continue to fundraise and advocate to keep the momentum going. It is this continued support that allows world-class scientists to remain engaged in finding a cure for Maddi and others affected by this condition.

Global Collaboration

In addition to our work in the UK, we maintain close ties with international researchers. We recently travelled to Boston Children's Hospital to meet with the team leading the Natural History Study for SPG15, under the direction of Dr. Darius Ebrahimi-Fakhari. This important study is creating a global registry of SPG15 patients, which is critical for understanding the disease's progression over time and preparing for future clinical trials. Thanks to these efforts, many more patients have now been enrolled, expanding the data available to scientists worldwide.

Looking Ahead

The Maddi Foundation remains at the forefront of efforts to bring SPG15 from obscurity into the spotlight of cutting-edge research. Every step forward, from laboratory breakthroughs to international collaborations, brings us closer to real hope for affected families. With your continued support, we will keep pushing boundaries, funding life-changing science, and working tirelessly to reach the day when SPG15 is no longer untreatable.

Support and Global Outreach

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2024**

At the heart of The Maddi Foundation is our commitment to supporting families affected by SPG15 around the world. As awareness of SPG15 grows, more families are finding their way to us, often through referrals from neurologists and genetic specialists familiar with Hereditary Spastic Paraplegias. Our website consistently ranks highly in online searches for SPG15, making it a vital point of connection for those newly diagnosed or seeking guidance.

Each family's journey with SPG15 is unique, but they all share a common need: access to accurate information, emotional support, and opportunities to engage in research. When families reach out to us, we provide compassionate support and practical guidance based on our own experience and knowledge of the global research landscape.

One of the most important ways we help is by introducing families to the SPG15 patient registry and Natural History Study led by Dr. Darius Ebrahimi-Fakhari at Boston Children's Hospital. This international study plays a critical role in understanding how the disease progresses and prepares the groundwork for future clinical trials. Once families are connected, the Boston team follows up directly, either through in-person meetings or video consultations, to explain the study, answer questions, and offer support tailored to each family's circumstances.

By helping families participate in this research, we not only provide them with access to expert care and knowledge but also contribute to a growing global dataset that will be invaluable for developing and testing future treatments.

We believe that no family should face this diagnosis alone. Through continuous outreach, collaboration with healthcare professionals, and maintaining a strong online presence, The Maddi Foundation is building a supportive international community united by the shared goal of finding a cure for SPG15.

Raising Awareness

At The Maddi Foundation, raising awareness of SPG15 is a core part of our mission. Our website, [www.themaddifoundation.com], serves as a central hub of information for families, clinicians, and researchers. It provides accessible, up-to-date content about SPG15, including current research efforts, scientific resources, and support options. We strive to ensure it remains a trusted and valuable source for the global SPG15 community.

To further amplify awareness, we have grown our presence across major social media platforms, including Facebook, Instagram, and Twitter. These channels allow us to share updates on medical research, promote fundraising events, spotlight patient stories, and keep the public informed about our ongoing initiatives. Through digital outreach, we continue to connect with a broader audience and build a supportive online community.

We maintain a close and active partnership with the University of Sheffield, where leading researchers are working to develop a gene therapy treatment for SPG15. As progress is made, we share key updates from the research team with our supporters through our website and social media channels, ensuring transparency and engagement with those who make our work possible.

In addition to our UK partnerships, we collaborate with researchers worldwide who are dedicated to understanding and treating hereditary spastic paraplegias. As proud members of the European Organisation for Rare Diseases (EURORDIS), we regularly participate in international conferences and scientific meetings, including those focused on spastic paraplegias and gene therapy. When in-person attendance isn't possible, we engage through virtual platforms to stay connected with the broader research community.

Carina Thurgood, one of our co-founders, has served on the Board of Directors of the Spastic Paraplegia Foundation USA since 2019. Her role strengthens our transatlantic collaborations and helps unify global efforts to accelerate research and awareness for SPG15 and related conditions.

We remain dedicated to expanding our knowledge of SPG15 and forging new connections with medical researchers and institutions. By sharing information, advocating for patients, and supporting collaborative research, we aim to bring visibility to this rare condition and drive progress toward effective treatments.

Our Future Goals

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 AUGUST 2024

Looking ahead, The Maddi Foundation remains steadfast in its commitment to accelerating research and expanding global awareness of SPG15. Our goals reflect our long-term vision to not only find a treatment but ultimately a cure for this devastating condition.

o Strengthening Medical Research

We will continue to prioritise and fund high-quality medical research, while actively expanding our network of scientists working on Hereditary Spastic Paraplegias and other rare neurodegenerative diseases. Building strong collaborations across academic and clinical communities remains central to our strategy.

o Advancing Gene Therapy for SPG15

A key objective is to support the next phase of the gene therapy research programme currently underway at the University of Sheffield. Should their approach continue to show positive results in SPG15 cell and animal models, we are prepared to fund further development in partnership with the research team. This programme remains our most promising avenue toward a targeted treatment.

o Welcoming New Research Proposals

We are actively seeking to engage additional researchers interested in tackling SPG15. All new project proposals will be carefully reviewed in consultation with our scientific advisory board. Proposals that demonstrate scientific merit and potential for real-world impact will be considered for funding. Our goal is to support innovative, forward-thinking research that could lead to transformative breakthroughs for individuals living with SPG15.

As a foundation focused on an ultra-rare condition, it can be challenging to find long-term trustees who are both passionate and committed. We are pleased to report that all current members of The Maddi Foundation Board of Trustees have chosen to remain in post for another year. Their continued support reflects a shared dedication to our mission and to the families we serve. The trustees are proud to be part of this vital work and are fully committed to seeing our vision through.

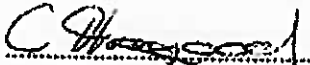
Together, with our supporters, researchers, and families, we move forward with determination and hope, driven by the belief that a cure for SPG15 is within reach.

Company Secretary

Independent Examiner

Michael Lomotey
Xeinadin South East Ltd
Create Business Hub
Ground Floor
5 Rayleigh Road
Hutton, Brentwood.
Essex
CM13 1AB

Approved by order of the board of trustees on²⁸⁻⁰⁵⁻²⁰²⁵ 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 2024.

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').

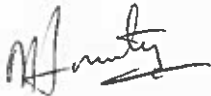
Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act').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



Michael Lomotey . FCCA .

Xeinadin South East Ltd
Create Business Hub
Ground Floor
5 Rayleigh Road
Hutton, Brentwood.
Essex
CM13 1AB

Date: 28-05-2025

THE MADDI FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2024

	Notes	2024 Unrestricted fund £	2023 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		12,728	17,515
EXPENDITURE ON			
Raising funds	2	2,590	1,691
NET INCOME		10,138	15,824
RECONCILIATION OF FUNDS			
Total funds brought forward		59,167	43,343
TOTAL FUNDS CARRIED FORWARD		69,305	59,167

The notes form part of these financial statements

THE MADDI FOUNDATION

BALANCE SHEET
31 AUGUST 2024

	Notes	2024 Unrestricted fund £	2023 Total funds £
CURRENT ASSETS			
Cash at bank		69,305	59,167
NET CURRENT ASSETS		<u>69,305</u>	<u>59,167</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		69,305	59,167
NET ASSETS		<u>69,305</u>	<u>59,167</u>
FUNDS			
Unrestricted funds	5	69,305	59,167
TOTAL FUNDS		<u>69,305</u>	<u>59,167</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2024 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 notes form part of these financial statements

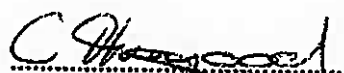
THE MADDI FOUNDATION

BALANCE SHEET - continued
31 AUGUST 2024

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 MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 AUGUST 2024

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

	2024	2023
	£	£
Fundraising costs	1,563	1,022
Subscriptions	37	85
Support costs	-	584
	<u>1,600</u>	<u>1,691</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2024

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2024 nor for the year ended 31 August 2023.

Trustees' expenses

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

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM Donations and legacies	17,515
EXPENDITURE ON Raising funds	1,691
NET INCOME	15,824
RECONCILIATION OF FUNDS Total funds brought forward	43,343
TOTAL FUNDS CARRIED FORWARD	<u>59,167</u>

5. MOVEMENT IN FUNDS

	At 1.9.23 £	Net movement in funds £	At 31.8.24 £
Unrestricted funds General fund	59,167	10,138	69,305
TOTAL FUNDS	<u>59,167</u>	<u>10,138</u>	<u>69,305</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds General fund	12,728	(2,590)	10,138
TOTAL FUNDS	<u>12,728</u>	<u>(2,590)</u>	<u>10,138</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2024

5. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

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

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

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

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

	At 1.9.22 £	Net movement in funds £	At 31.8.24 £
Unrestricted funds			
General fund	43,343	25,962	69,305
TOTAL FUNDS	<u>43,343</u>	<u>25,962</u>	<u>69,305</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 £
Unrestricted funds			
General fund	30,243	(4,281)	25,962
TOTAL FUNDS	<u>30,243</u>	<u>(4,281)</u>	<u>25,962</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2024

6. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2024.

THE MADDI FOUNDATION

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2024

	2024 £	2023 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	12,728	17,515
Total incoming resources	<u>12,728</u>	<u>17,515</u>
EXPENDITURE		
Raising donations and legacies		
Fundraising costs	1,563	1,022
Subscriptions	37	85
	<u>1,600</u>	<u>1,107</u>
Support costs		
Finance		
Bank charges	216	216
Information technology		
Website expenses	101	302
Other		
Sundries	673	66
Total resources expended	<u>2,590</u>	<u>1,691</u>
Net income	<u><u>10,138</u></u>	<u><u>15,824</u></u>

This page does not form part of the statutory financial statements

THE MADDI FOUNDATION

England & Wales - Charity number 1174374

Accounts

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], 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
Date:

THE MADDI FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2023

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

The notes form part of these financial statements

THE MADDI FOUNDATION

BALANCE SHEET

31 AUGUST 2023

	Notes	2023 Unrestricted fund £	2022 Total funds £
CURRENT ASSETS			
Cash at bank		59,167	43,343
NET CURRENT ASSETS		<u>59,167</u>	<u>43,343</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		59,167	43,343
NET ASSETS		<u>59,167</u>	<u>43,343</u>
FUNDS	5		
Unrestricted funds		<u>59,167</u>	<u>43,343</u>
TOTAL FUNDS		<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 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 £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	10,879
	<hr/>
EXPENDITURE ON	
Raising funds	1,323
	<hr/>
NET INCOME	9,556
	<hr/>
RECONCILIATION OF FUNDS	
Total funds brought forward	33,787
	<hr/>
TOTAL FUNDS CARRIED FORWARD	<u>43,343</u>

5. MOVEMENT IN FUNDS

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

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

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

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 £
Unrestricted funds			
General fund	33,787	9,556	43,343
TOTAL FUNDS	<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 £
Unrestricted funds			
General fund	10,879	(1,323)	9,556
TOTAL FUNDS	<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 £
Unrestricted funds			
General fund	33,787	25,380	59,167
TOTAL FUNDS	<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 £
Unrestricted funds			
General fund	28,394	(3,014)	25,380
TOTAL FUNDS	<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 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	17,515	10,879
Total incoming resources	17,515	10,879
EXPENDITURE		
Raising donations and legacies		
Fundraising costs	1,022	89
Subscriptions	85	80
	1,107	169
Support costs		
Finance		
Bank charges	216	231
Information technology		
Website expenses	302	873
Other		
Sundries	66	50
Total resources expended	1,691	1,323
Net income	15,824	9,556

THE MADDI FOUNDATION

England & Wales - Charity number 1174374

Accounts

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 2022
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 2022**

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THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2022**

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 2022. 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 2022**

Trustees

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 2020 to 31 August 2021. 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 2022.

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 2022. We are confirming that we comply with the requirements of the Charities Act 2011.

The Maddi Foundation was established in August 2017 by Carina and Alexandra Thurgood. Maddi is the daughter of Carina and sister of Alexandra; she was diagnosed with SPG15 in the summer of 2016. At the time there was no other UK based Charity dedicated to medical research of SPG15, a complicated and rare type of Hereditary Spastic Paraplegia.

The trustees meet at the end of each financial year to determine whether any changes are required or if new policies and procedures are required.

The Maddi Foundation's focus is funding medical research for a potential treatment or cure for SPG15 and other related rare conditions. The Charity has continued to fund a Gene Therapy research project based in the UK which began in 2017; and other research avenues are being explored throughout Europe and USA. The Foundation continues to raise awareness of the disease through rare disease groups and charities, through our up to-date website, and the use of social media.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2022

Since the Charity was founded in 2017, we have worked hard in gathering donations through fundraising events and receiving some grants from other institutions to enable work to continue in medical research towards a treatment for SPG15. As well as being based in the UK, the Foundation has and continues to build links with many researchers and clinicians worldwide. We believe collaboration with our European and US counterparts aids the process to further research.

The Foundation's grant making policy is based on donations received towards the research into a potential treatment for SPG15. In order for the charity to make a grant, we take advice from Professor Mimoun Azzouz who leads the research team at SITraN (Sheffield University). He is also the Director of Gene Therapy Innovation and Manufacturing Centre. There has been an arrangement that the Foundation will help provide grants to his work if Sheffield University are unable to obtain funding from other sources.

The research grants will be reviewed by the Foundation's trustees and scientific advisors to determine if the work being undertaken will have a positive effect for a 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 where the first symptom often starts as leg stiffness. It is known to cause paralysis in the lower and upper limbs with neurological impairment causing abnormalities in the brain. In addition, it affects the peripheral nervous system impairing vision and hearing it can also bring on early juvenile parkinsonism. The disease is progressive and has devastating effects of Motor Neuron Disease.

At present there is no known treatment or cure for SPG15.

Report of the Trustees

For the year ending 31 August 2022

We present our report with the financial statements of the Charity for the year ended 31 August 2022. 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 committed to finding a way to treat SPG15 effectively and potentially halt the disease. Therefore, the trustees are actively involved with the team leading the research into a potential treatment. Collaboration is especially important through our counterparts. We are there as a voice to engage with other researchers and clinicians from around the globe.

Our defined aims are

- 1 Raise awareness of SPG15 (Hereditary Spastic Paraplegia 15) and associated Spastic Paraplegias to the public by providing relevant information on our website and on social media.
- 2 To raise and provide funds for further research into the disease for any potential treatment.
- 3 Aim to provide as much information for resources on published research papers, potential treatment research and other relevant medical research that may benefit. Continue to build a network of families affected by the disease.

Our first task established as a Charity in 2017 was to decide the aims for The Maddi Foundation. We were aware that the aims had to be a public benefit for us to be recognised as a Charitable Incorporated Organisation by the Charity Commission.

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

Achievements and Performance

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2022

Research

Through funding medical research, The Maddi Foundation aims to find a way to treat SPG15 effectively and potentially halt the disease. Many families have no treatment options to stabilise the disease and there are limited options to improve the quality of life. The Maddi Foundation hopes to change this.

What we have achieved so far

The focus of our research has been to develop gene therapeutic approaches for diseases of the brain and spinal cord such as SPG15. Gene therapy is a rapidly evolving field that uses genes, instead of drugs, to treat diseases. When genetic mutations cause a protein to be faulty or absent, (in most cases of SPG15 the protein is absent) gene therapy aims to provide a normal copy of the gene to restore the protein and its functions.

As hereditary spastic paraplegia (HSP) type 15 is caused by the lack of SPG15 protein, it classifies as an ideal candidate for gene therapy. We have one Gene Therapy research program at Sheffield University that has been running for since 2017 and remains to be our first hope for a potential treatment towards SPG15.

Sheffield University have a team of scientists who have been actively working on different strategies for a gene replacement for SPG15, they are trying to overcome challenges with this gene replacement. The prediction is that at least one of the strategies the University are working on will be amendable for gene therapy. Studies on validated cell and animal models will tell which strategy can be a practical approach to treating SPG15.

The National History Study based at Boston Children's Hospital with Dr Darius Ebrahimi-Fakhari is continuing and he has successfully added many more SPG15 patients to the registry.

Support

We are continuing to connect with families from all over the world. These families have managed to find our Charity through introductions from their clinicians who are familiar with Hereditary Spastic Paraplegia's, and by using an internet search looking for SPG15 our website comes up top of the google page which allows patients families to reach out to us.

We make introductions with SPG15 families who have reached out to us, to take part in the registry and natural history study with Boston Children's Hospital. The hospital has connected with all families if not in person but through video consultations as introductions to the families worldwide.

Awareness

Our website www.themaddifoundation.com offers detailed information about SPG15 and we try to keep up to date with research resources through our research section. We hope that this continues to be a useful resource for both families and researchers.

Social media is increasingly popular and we have extended our Facebook, Instagram and Twitter pages to promote awareness of the disease. We generally promote fundraising campaigns, events and updates on our research and patient wellbeing. However, events have been slower this year due to the results from covid.

We continue to work in partnership with Sheffield University whilst they are working on their research into a treatment for SPG15 and when we receive any updates from the University, we share appropriate information through The Maddi Foundation.

We continue to work closely with researchers worldwide within the hereditary spastic paraplegia community. We are a member of the European Organisation for rare diseases and have attended the annual spastic paraplegia conferences previously, as well as many other conferences involving scientists working in this field, and gene therapy meetings. Many of these meetings take place via videoconferencing if unable to attend in person.

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

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2022**

We continue to offer our helping hand to acquire any knowledge of the disease and continue to connect with more medical researchers to push for ongoing studies and projects.

Plans for the Future

What we hope to achieve by going forward:

The Maddi Foundation has always had a strong focus on medical research, and we will continue to support and build our network of scientists who are working on Hereditary Spastic Paraplegia's and rare diseases.

We are continuing the focus of the next steps for the research program we are involved in for a Gene Therapy for SPG15. We will continue to fund and work with Sheffield University in taking this forward if their strategy is successful in SPG15 cells and animal models.

We will continue to engage other researchers who are interested in working on SPG15 and review their project proposals with our scientific board. We will accept new proposals that appear to be promising and supported by our board. We are committed to funding innovative research into treatments for SPG15 which may lead to breakthroughs in this area.

In terms of awareness, we will keep promoting the Foundation through our media outputs nationally (and internationally), to keep the momentum going by sharing stories of the SPG15 disease and how it affects families across the world.

Re appointed Charity Trustees

At present all our Trustees are happy to continue

We met at the end of the last financial year to discuss re appointing of Trustees. With SPG15 being an extremely rare disease and there is not enough knowledge and interest involving the condition, it can prove very difficult to engage others to work on an ultra-rare disease. As we had reached the three years at our last year-end report, we decided that all four Trustees were reappointed by a vote from each of our current Trustees as stated in our governing document.

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 26/6/2023 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 2022.

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:29-06-2023.....

THE MADDI FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2022

	Notes	2022 Unrestricted fund £	2021 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		<u>10,879</u>	<u>20,959</u>
EXPENDITURE ON			
Raising funds	2	1,323	68
Charitable activities			
Sheffield University		-	45,449
Other		-	509
Total		<u>1,323</u>	<u>46,026</u>
NET INCOME/(EXPENDITURE)		9,556	(25,067)
RECONCILIATION OF FUNDS			
Total funds brought forward		33,787	58,854
TOTAL FUNDS CARRIED FORWARD		<u>43,343</u>	<u>33,787</u>

THE MADDI FOUNDATION

BALANCE SHEET
31 AUGUST 2022

	Notes	2022 Unrestricted fund £	2021 Total funds £
CURRENT ASSETS			
Cash at bank		43,343	33,787
NET CURRENT ASSETS		<u>43,343</u>	<u>33,787</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		43,343	33,787
NET ASSETS		<u>43,343</u>	<u>33,787</u>
FUNDS	5		
Unrestricted funds		<u>43,343</u>	<u>33,787</u>
TOTAL FUNDS		<u>43,343</u>	<u>33,787</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2022.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2022 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 2022

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 26/6/2023 and were signed on its behalf by: [£]


H. Thurgood - Trustee


Mrs C. Thurgood - Trustee


A. Thurgood - Trustee


Mrs V.L. Bissett - Trustee

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 AUGUST 2022

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.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

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

	2022	2021
	£	£
Fundraising costs	89	23
Subscriptions	80	45
Support costs	1,154	-
	<u>1,323</u>	<u>68</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued FOR THE YEAR ENDED 31 AUGUST 2022

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2022 nor for the year ended 31 August 2021.

Trustees' expenses

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

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	20,959
EXPENDITURE ON	
Raising funds	68
Charitable activities	
Sheffield University	45,449
Other	509
Total	<u>46,026</u>
NET INCOME/(EXPENDITURE)	(25,067)
RECONCILIATION OF FUNDS	
Total funds brought forward	58,854
TOTAL FUNDS CARRIED FORWARD	<u><u>33,787</u></u>

5. MOVEMENT IN FUNDS

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

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2022

5. MOVEMENT IN FUNDS - continued

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

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

Comparatives for movement in funds

	At 1.9.20 £	Net movement in funds £	At 31.8.21 £
Unrestricted funds			
General fund	58,854	(25,067)	33,787
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>58,854</u>	<u>(25,067)</u>	<u>33,787</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	20,959	(46,026)	(25,067)
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>20,959</u>	<u>(46,026)</u>	<u>(25,067)</u>

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

	At 1.9.20 £	Net movement in funds £	At 31.8.22 £
Unrestricted funds			
General fund	58,854	(15,511)	43,343
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>58,854</u>	<u>(15,511)</u>	<u>43,343</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2022

5. MOVEMENT IN FUNDS - continued

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 £
Unrestricted funds			
General fund	31,838	(47,349)	(15,511)
TOTAL FUNDS	<u>31,838</u>	<u>(47,349)</u>	<u>(15,511)</u>

6. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2022.

THE MADDI FOUNDATION

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2022

	2022 £	2021 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	10,879	20,959
Total incoming resources	10,879	20,959
EXPENDITURE		
Raising donations and legacies		
Fundraising costs	89	23
Subscriptions	80	45
	169	68
Charitable activities		
Grants to institutions	-	45,449
Support costs		
Management		
Postage and stationery	-	15
Finance		
Bank charges	231	-
Information technology		
Website expenses	873	259
Other		
Sundries	50	19
Governance costs		
Legal & professional fees	-	216
Total resources expended	1,323	46,026
Net income/(expenditure)	9,556	(25,067)

This page does not form part of the statutory financial statements

THE MADDI FOUNDATION

England & Wales - Charity number 1174374

Accounts

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 2021
FOR
THE MADDI FOUNDATION

Tish Press & Company
Cambridge House
27 Cambridge Park
Wanstead
London
E11 2PU

THE MADDI FOUNDATION

**CONTENTS OF THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 AUGUST 2021**

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THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2021**

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 2021. 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
Cambridge House
27 Cambridge Park
Wanstead
London
E11 2PU

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2021

Trustees

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES

FOR THE PERIOD 1 SEPTEMBER 2020 TO 31 AUGUST 2021

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 2020 to 31 August 2021. 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 at 31st August 2021.

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

Cambridge House

27 Cambridge Park

Wanstead

Essex

E11 2PU

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 2021. We are confirming that we comply with the requirements of the Charities Act 2011.

The Maddi Foundation was established in August 2017 by Carina and Alexandra Thurgood. Maddi is the daughter of Carina and sister of Alexandra; she was diagnosed with SPG15 in the summer of 2016. At the time there was no other UK based Charity dedicated to medical research of SPG15, a complicated and rare type of Hereditary Spastic Paraplegia.

The trustees meet at the end of each financial year to determine whether any changes are required or if new policies and procedures are required.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2021

The Maddi Foundation's focus is funding medical research for a potential treatment or cure for SPG15 and other related rare conditions. The Charity has continued to fund a Gene Therapy research project based in the UK which began in 2017; and other research avenues are being explored throughout Europe and USA. The Foundation continues to raise awareness of the disease through rare disease groups and charities, through our up to-date website, and the use of social media.

Since the Charity was founded in 2017, we have worked hard in gathering donations through many fundraising events and receiving grants from other institutions to enable work to continue in medical research for a treatment for SPG15. As well as being based in the UK, the Foundation has and continues to build links with many researchers and clinicians worldwide. We believe collaboration with our European and US counterparts aids the process to further research.

The Foundation's grant making policy is based on donations received towards the research into a potential treatment for SPG15. In order for the charity to make a grant, we take advice from Professor Mimoun Azzouz who leads the research team at SITraN (Sheffield University). There has been an arrangement that the Foundation will help provide grants to his work if Sheffield University are unable to obtain funding from other sources.

The research grants will be reviewed by the Foundation's trustees and scientific advisors to determine if the work being undertaken will have a positive effect for a 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 where the first symptom often starts as leg stiffness. It is known to cause paralysis in the lower and upper limbs with neurological impairment causing abnormalities in the brain. In addition, it affects the peripheral nervous system impairing vision and hearing it can also bring on early juvenile parkinsonism. The disease is progressive and has devastating effects of Motor Neuron Disease.

At present there is no known treatment or cure for SPG15.

Report of the Trustees

For the year ending 31 August 2021

We present our report with the financial statements of the Charity for the year ended 31 August 2021. 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 committed to finding a way to treat SPG15 effectively and potentially halt the disease. Therefore, the trustees are actively involved with the team leading the research into a potential treatment. Collaboration is especially important through our counterparts. We are there as a voice to engage with other researchers and clinicians from around the globe.

Our defined aims are

- 1 Raise awareness of SPG15 (Hereditary Spastic Paraplegia 15) and associated Spastic Paraplegias to the public by providing relevant information on our website and on social media.
- 2 To raise and provide funds for further research into the disease for any potential treatment.
- 3 Aim to provide as much information for resources on published research papers, potential treatment research and other relevant medical research that may benefit. Continue to build a network of families affected by the disease.

Our first task established as a Charity in 2017 was to decide the aims for The Maddi Foundation. We were aware that the aims had to be a public benefit for us to be recognised as a Charitable Incorporated Organisation by the Charity Commission.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2021

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

Achievements and Performance

Research

Through funding medical research, The Maddi Foundation aims to find a way to treat SPG15 effectively and potentially halt the disease. Many families have no treatment options to stabilise the disease and there are limited options to improve the quality of life. The Maddi Foundation hopes to change this.

What we have achieved so far

The focus of our research has been to develop gene therapeutic approaches for diseases of the brain and spinal cord such as SPG15. Gene therapy is a rapidly evolving field that uses genes, instead of drugs, to treat diseases. When genetic mutations cause a protein to be faulty or absent, (in most cases of SPG15 the protein is absent) gene therapy aims to provide a normal copy of the gene to restore the protein and its functions.

As hereditary spastic paraplegia (HSP) type 15 is caused by the lack of SPG15 protein, it classifies as an ideal candidate for gene therapy. We have one Gene Therapy research program at Sheffield University that has been running for since 2017 and remains to be our first hope for a potential treatment towards SPG15.

Sheffield University have a team of scientists who have been actively working on different strategies for a gene replacement for SPG15, they are trying to overcome challenges with this gene replacement. The prediction is that at least one of the strategies the University are working on will be amendable for gene therapy. Studies on validated cell and animal models will tell which strategy can be a practical approach to treating SPG15.

Since March 2020 with the arrival of covid19, the research came to a standstill whilst the UK lockdown was put in place. The research did not begin again remotely until the later part of the year so has caused many delays in this gene therapy study.

On the 1st October 2020 we were contacted by Dr Darius Ebrahimi-Fakhari from Boston Children's Hospital, USA who had been working on the AP-4 registry and natural history study. After having previous discussions and correspondence with Carina Thurgood, Trustee, Dr Fakhari decided to enrol SPG15 onto this study. This is very good news for the SPG15 community to aid any future studies and clinical trials.

Due to Covid19 our plan to attend the Spastic Paraplegia Annual conference 2020 did not take place.

Support

We are continuing to connect with families from all over the world. These families have managed to find our Charity through introductions from their clinicians who are familiar with Hereditary Spastic Paraplegia's, and by using an internet search looking for SPG15 our website comes up top of the page which allows patients families to reach out to us.

We have since made introductions for SPG15 families to take part in the registry and natural history study with Boston Children's Hospital. The hospital is eager to connect with all families and arrange video meetings as introductions to the families along with translators if required.

Awareness

We continue to improve and update our website www.themaddifoundation.com offering detailed information about SPG15 and any up to research sources through our research section. We hope that this continues to be a useful resource for both families and researchers.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2021**

Social media has become increasingly popular and we have extended our Facebook, Instagram and Twitter pages to promote awareness of the disease. We generally promote fundraising campaigns, events and updates on our research and patient wellbeing. However, sadly the arrival of Covid19 made a huge impact to our fundraising campaigns and events with us not being able to fundraise in the same manner. Our events came to a halt this year.

We continue to work in partnership with Sheffield University whilst they are working on their research into a treatment for SPG15 and when we receive any updates from the University, we share appropriate information through The Maddi Foundation.

We continue to work closely with researchers worldwide within the hereditary spastic paraplegia community. We are a member of the European Organisation for rare diseases and have attended the annual spastic paraplegia conferences, as well as many other conferences involving scientists working in this field, and gene therapy meetings.

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

We continue to offer our helping hand to acquire any knowledge of the disease and continue to connect with more medical researchers to push for ongoing studies and projects.

Plans for the Future

What we hope to achieve by going forward:

The Maddi Foundation has always had a strong focus on medical research, and we will continue to support and build our network of scientists who are working on Hereditary Spastic Paraplegia's and rare diseases.

We are continuing the focus of the next steps for the research program we are involved in for a Gene Therapy for SPG15. We will continue to fund and work with Sheffield University in taking this forward if their strategy is successful in SPG15 cells and animal models.

We will continue to engage other researchers who are interested in working on SPG15 and review their project proposals with our scientific board. We will accept new proposals that appear to be promising and supported by our board. We are committed to funding innovative research into treatments for SPG15 which may lead to breakthroughs in this area.

In terms of awareness, we will keep promoting the Foundation through our media outputs nationally (and internationally), to keep the momentum going by sharing stories of the SPG15 disease and how it affects families across the world.

Over the next year we will continue to organise and take part in fundraiser events, if permitted, once the current situation with Covid19 and ongoing lockdowns cease to exist.

Re appointed Charity Trustees

We met at the end of the last financial year to discuss re appointing of Trustees. With SPG15 being an extremely rare disease and there is not enough knowledge and interest involving the condition, it can prove very difficult to engage others to work on an ultra-rare disease. As we had reached the three years at our last year-end report, we decided that all four Trustees were reappointed by a vote from each of our current Trustees as stated in our governing document.

Company Secretary

THE MADDI FOUNDATION

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 AUGUST 2021**

REFERENCE AND ADMINISTRATIVE DETAILS

Company Secretary

Independent Examiner

Tayla McArthur
Tish Press & Company
Cambridge House
27 Cambridge Park
Wanstead
London
E11 2PU

Approved by order of the board of trustees on 24.6.22 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 2021.

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
Cambridge House
27 Cambridge Park
Wanstead
London
E11 2PU

Date:29/06/22.....

THE MADDI FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2021

	Notes	2021 Unrestricted fund £	2020 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		20,959	29,197
EXPENDITURE ON			
Raising funds	2	68	11,473
Charitable activities			
Sheffield University		45,449	-
Berlin University		-	4,394
Other		509	-
Total		46,026	15,867
NET INCOME/(EXPENDITURE)		(25,067)	13,330
RECONCILIATION OF FUNDS			
Total funds brought forward		58,854	45,524
TOTAL FUNDS CARRIED FORWARD		33,787	58,854

THE MADDI FOUNDATION

BALANCE SHEET
31 AUGUST 2021

	Notes	2021 Unrestricted fund £	2020 Total funds £
CURRENT ASSETS			
Cash at bank		33,787	60,697
CREDITORS			
Amounts falling due within one year	5	-	(1,843)
NET CURRENT ASSETS		<u>33,787</u>	<u>58,854</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		33,787	58,854
NET ASSETS		<u>33,787</u>	<u>58,854</u>
FUNDS	6		
Unrestricted funds		<u>33,787</u>	<u>58,854</u>
TOTAL FUNDS		<u>33,787</u>	<u>58,854</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2021.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2021 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 2021

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 24.6.22 and were signed on its behalf by:


H Thurgood - Trustee


Mrs C Thurgood - Trustee


A Thurgood - Trustee


Mrs V L Bisson - Trustee

The notes form part of these financial statements

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 AUGUST 2021

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.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

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

	2021	2020
	£	£
Fundraising costs	23	10,092
Subscriptions	45	136
Support costs	-	1,245
	<u>68</u>	<u>11,473</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2021

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2021 nor for the year ended 31 August 2020.

Trustees' expenses

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

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	29,197
EXPENDITURE ON	
Raising funds	11,473
Charitable activities	
Berlin University	4,394
Total	<u>15,867</u>
NET INCOME	<u>13,330</u>
RECONCILIATION OF FUNDS	
Total funds brought forward	45,524
TOTAL FUNDS CARRIED FORWARD	<u><u>58,854</u></u>

5. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021 £	2020 £
Other creditors	-	1,843

6. MOVEMENT IN FUNDS

	At 1.9.20 £	Net movement in funds £	At 31.8.21 £
Unrestricted funds			
General fund	58,854	(25,067)	33,787
TOTAL FUNDS	<u><u>58,854</u></u>	<u><u>(25,067)</u></u>	<u><u>33,787</u></u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2021

6. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	20,959	(46,026)	(25,067)
TOTAL FUNDS	<u>20,959</u>	<u>(46,026)</u>	<u>(25,067)</u>

Comparatives for movement in funds

	At 1.9.19 £	Net movement in funds £	At 31.8.20 £
Unrestricted funds			
General fund	45,524	13,330	58,854
TOTAL FUNDS	<u>45,524</u>	<u>13,330</u>	<u>58,854</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	29,197	(15,867)	13,330
TOTAL FUNDS	<u>29,197</u>	<u>(15,867)</u>	<u>13,330</u>

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

	At 1.9.19 £	Net movement in funds £	At 31.8.21 £
Unrestricted funds			
General fund	45,524	(11,737)	33,787
TOTAL FUNDS	<u>45,524</u>	<u>(11,737)</u>	<u>33,787</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2021

6. MOVEMENT IN FUNDS - continued

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 £
Unrestricted funds			
General fund	50,156	(61,893)	(11,737)
TOTAL FUNDS	<u>50,156</u>	<u>(61,893)</u>	<u>(11,737)</u>

7. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2021.

THE MADDI FOUNDATION

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2021

	2021 £	2020 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	20,959	29,197
Total incoming resources	20,959	29,197
EXPENDITURE		
Raising donations and legacies		
Fundraising costs	23	10,092
Subscriptions	45	136
	68	10,228
Charitable activities		
Grants to institutions	45,449	4,366
Support costs		
Management		
Postage and stationery	15	103
Finance		
Bank charges	-	28
Information technology		
Website expenses	259	482
Other		
Sundries	19	130
Governance costs		
Legal & professional fees	216	530
Total resources expended	46,026	15,867
Net (expenditure)/income	(25,067)	13,330

THE MADDI FOUNDATION

England & Wales - Charity number 1174374

Accounts

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 2020
FOR
THE MADDI FOUNDATION

Tish Press & Company
Cambridge House
27 Cambridge Park
Wanstead
London
E11 2PU

THE MADDI FOUNDATION

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FOR THE YEAR ENDED 31 AUGUST 2020

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THE MADDI FOUNDATION

REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 AUGUST 2020**

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 2020. 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

Cambridge House
27 Cambridge Park
Wanstead
Essex
E11 2PU

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2020

Trustees

REPORT OF THE TRUSTEES
FOR THE PERIOD 1 SEPTEMBER 2019 TO 31 AUGUST 2020

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 2019 to 31 August 2020. 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 at 31st August 2020.

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

Cambridge House

27 Cambridge Park

Wanstead

Essex

E11 2PU

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 third annual review of the charity for the year ending 31 August 2020. We are confirming that we comply with the requirements of the Charities Act 2011.

The Maddi Foundation was established in August 2017 by Carina and Alexandra Thurgood. Maddi is the daughter of Carina and sister of Alexandra; she was diagnosed with SPG15 in the summer of 2016. At the time there was no other UK based Charity dedicated to medical research of SPG15, a complicated and rare type of Hereditary Spastic Paraplegia.

The trustees meet at the end of each financial year to determine whether any changes are required or if new policies and procedures are required.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2020

The Maddi Foundation's focus is funding medical research for a potential treatment or cure for SPG15 and other related rare conditions. The Charity is helping to fund a current Gene Therapy research project based in the UK; and other research avenues are also being explored throughout Europe and USA. The Foundation continues to raise awareness of the disease through rare disease groups and charities, through our up to-date website, and the use of social media.

Since the Charity was founded in 2017, we have worked hard in gathering donations through many fundraising events and receiving grants from other institutions to enable work to continue in medical research for a treatment for SPG15. As well as being based in the UK, the Foundation has and continues to build links with many researchers and clinicians worldwide. We believe collaboration with our European and US counterparts aids the process to further research.

The Foundation's grant making policy is based on donations received towards the research into a potential treatment for SPG15. In order for the charity to make a grant, we take advice from Professor Mimoun Azzouz who leads the team at SITraN (Sheffield University). There is an agreement that the Foundation will help provide grants to his work if Sheffield University are unable to get funding from other sources.

The research grants will be reviewed by the Foundation's trustees and scientific advisors to determine if the work being undertaken will have a positive effect for a 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 where the first symptom often starts as leg stiffness. It is known to cause paralysis in the lower and upper limbs with neurological impairment causing abnormalities in the brain. In addition, it affects the peripheral nervous system impairing vision and hearing it can also bring on early juvenile parkinsonism. The disease is progressive and has devastating effects of Motor Neuron Disease.

At present there is no known treatment or cure for SPG15.

Report of the Trustees

For the year ending 31 August 2020

We present our report with the financial statements of the Charity for the year ended 31 August 2020. 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 committed to finding a way to treat SPG15 effectively and potentially halt the disease. Therefore, the trustees are actively involved with the team leading the research into a potential treatment. Collaboration is especially important through their counterparts. We are there as a voice to engage with other researchers and clinicians from around the globe.

Our defined aims are

- 1 Raise awareness of SPG15 (Hereditary Spastic Paraplegia 15) and associated Spastic Paraplegias to the public by providing relevant information on our website and on social media.
- 2 To raise and provide funds for further research into the disease for any potential treatment.
- 3 Aim to provide as much information for resources on published research papers, potential treatment research and other relevant medical research that may benefit. Continue to build a network of families affected by the disease.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2020

Our first task established as a Charity in 2017 was to decide the aims for The Maddi Foundation. We were aware that the aims had to be a public benefit for us to be recognised as a Charitable Incorporated Organisation by the Charity Commission.

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

Achievements and Performance

Research

Through funding research, The Maddi Foundation aims to find a way to treat SPG15 effectively and potentially halt the disease. Many families have no treatment options to stabilise the disease and there are limited options to improve the quality of life. The Maddi Foundation hopes to change this.

What we have achieved so far

The focus of our research has been to develop gene therapeutic approaches for diseases of the brain and spinal cord such as SPG15. Gene therapy is a rapidly evolving field that uses genes, instead of drugs, to treat diseases. More precisely, when genetic mutations cause a protein to be faulty or absent, (in most cases of SPG15 the protein is absent) gene therapy aims to provide a normal copy of the gene to restore the protein and its functions.

As hereditary spastic paraplegia (HSP) type 15 is caused by the lack of SPG15 protein, it classifies as an ideal candidate for gene therapy. We have one Gene Therapy research program at Sheffield University that has been running for three years and remains to be our first hope for a potential treatment towards SPG15. The University have been actively working on gene therapy strategies for SPG15.

Last year an additional scientist joined the team at Sheffield University, to continue working on ways to overcome the challenges with this gene. The prediction is that at least one of the strategies the University are working on will be amendable for gene therapy. Studies on validated cell and animal models will tell whether this strategy can be a practical approach to treating SPG15. However, since March 2020 with the arrival of covid19, the research came to a standstill whilst the UK lockdown was put in place.

In February 2020, Spatax - (The network of Hereditary forms of Spastic paraplegias and cerebellar Ataxias) reached out to us and announced the beginning of their Registry and Natural History Study for SPG11 and SPG15. Spatax are based at ICM Institute in Paris. This proves to be positive news for the SPG15 community to aid any future studies and clinical trials.

We also joined together, in 2018, with University College London Hospital to encourage testing patient cell lines that have a loss of function with SPG15 patient cells. This is with a view to test compounds which are used for other diseases that are caused by loss of function in cells. We have collaborated with French and Italian scientists to share their appropriate cells to complete this project and are awaiting the outcome of these testing results.

In 2019 we approved a grant to Doctor Amir Jahic, Charite University of Medicine in Berlin along with other partners, ie Tom Wahlig Foundation. The grant was to assist a project titled "A Proof of concept: Somatic gene repair as a potential therapeutic approach for hereditary spastic paraplegia type SPG15". The goal of the project is to examine the molecular requirements for therapeutic interventions in SPG15 with the generation of a novel SPG15 rescue-knockout mouse model. This research is ongoing and is also supported by third party Foundations.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 31 AUGUST 2020

We have created presentation awareness posters to explain the disease and display potential treatment strategies that the researchers are working on. The posters can be presented at rare disease events, medical research conferences and multi stakeholder gatherings covering research, healthcare, and public health policies.

Support

We continue to connect with families from all over the world. These families have managed to find our Charity through introductions from their clinicians who are familiar with Hereditary Spastic Paraplegia's, and by using an internet search they have found our website to reach out to us.

When we have connected with other SPG15 and SPG11 families, we have introduced them to the neurology team at University College London Hospital from whom we have a relationship with and recently with the Spatax group who are now working on the registry and natural history study for SPG11 and SPG15.

Awareness

We continue to improve and update our website www.themaddifoundation.com which offers detailed information about SPG15 and any research sources through our research section. We hope that this continues to be a useful resource for both families and researchers.

Social media has become increasingly popular and we have extended our Facebook, Instagram and Twitter pages to promote awareness of the disease. We promote fundraising campaigns, events and updates on our research and patient wellbeing.

We continue to work in partnership with Sheffield University whilst they are working on their research into a treatment for SPG15 and when we receive any updates from the University, we share appropriate information through The Maddi Foundation.

We continue to work closely with researchers worldwide within the hereditary spastic paraplegia community. We are a member of the European Organisation for rare diseases and have attended the annual spastic paraplegia conferences, as well as many other conferences involving scientists working in this field, and gene therapy meetings. In September 2019 Carina made a live speech and presented some slides at the Rare Summit 19 at the Wellcome Genome Campus, Cambridge to talk about patient groups partnering with drug development and raising awareness for The Maddi Foundation.

In February 2020, Carina attended the House of Commons to join Rare Disease UK for their annual Westminster Reception. Carina was able to highlight and raise awareness of the struggles of being an ultra-rare disease Charity. Dr Jenny Harries - Deputy Chief Medical Officer for England was talking about early diagnosis, coordinating care and early access to new medicines.

In March 2019, Carina was elected to join the Board of Directors for the Spastic Paraplegia Foundation USA as the first European Board Member, she continues to be on the Board for a second year running.

We continue to offer our helping hand to acquire any knowledge of the disease and continue to connect with more medical researchers to push for ongoing studies and projects.

Plans for the Future

What we hope to achieve by going forward:

The Maddi Foundation has always had a strong focus on medical research, and we will continue to support and build our network of scientists who are working on Hereditary Spastic Paraplegia's and rare diseases.

THE MADDI FOUNDATION

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 AUGUST 2020

We are continuing the focus of the next steps for the research program we are involved in for a Gene Therapy for SPG15. We will continue to fund and work with Sheffield University in taking this forward if their strategy is successful in SPG15 cells and animal models.

We will continue to engage other researchers who are interested in working on SPG15 and review their project proposals with our scientific board. We will accept new proposals that appear to be promising and supported by our board. We are committed to funding innovative research into treatments for SPG15 which may lead to breakthroughs in this area.

In terms of awareness, we will keep promoting the Foundation through our media outputs nationally (and internationally), to keep the momentum going by sharing stories of the SPG15 disease and how it affects families across the world.


Over the next year we will continue to organise and take part in fundraiser events, if permitted, once the current situation with Covid19 and ongoing lockdowns cease to exist.

Company Secretary

Independent Examiner

Tayla McArthur
Tish Press & Company
Cambridge House
27 Cambridge Park
Wanstead
London
E11 2PU

Approved by order of the board of trustees on 7/5/2021 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 2020.

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
Cambridge House
27 Cambridge Park
Wanstead
London
E11 2PU

Date: 11/05/2021

THE MADDI FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2020

	Notes	2020 Unrestricted fund £	2019 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		29,197	43,725
EXPENDITURE ON			
Raising funds	2	11,473	8,928
Charitable activities			
Sheffield University		-	44,392
Berlin University		4,394	-
Other		<u>-</u>	<u>5,299</u>
Total		<u>15,867</u>	<u>58,619</u>
NET INCOME/(EXPENDITURE)		<u>13,330</u>	<u>(14,894)</u>
RECONCILIATION OF FUNDS			
Total funds brought forward		<u>45,524</u>	<u>60,418</u>
TOTAL FUNDS CARRIED FORWARD		<u><u>58,854</u></u>	<u><u>45,524</u></u>

The notes form part of these financial statements

THE MADDI FOUNDATION

BALANCE SHEET
31 AUGUST 2020

	Notes	2020 Unrestricted fund £	2019 Total funds £
CURRENT ASSETS			
Cash at bank		60,697	47,367
CREDITORS			
Amounts falling due within one year	5	(1,843)	(1,843)
NET CURRENT ASSETS		<u>58,854</u>	<u>45,524</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>58,854</u>	<u>45,524</u>
NET ASSETS		<u>58,854</u>	<u>45,524</u>
FUNDS	6		
Unrestricted funds		<u>58,854</u>	<u>45,524</u>
TOTAL FUNDS		<u>58,854</u>	<u>45,524</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2020.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2020 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 notes form part of these financial statements


THE MADDI FOUNDATION

BALANCE SHEET - continued
31 AUGUST 2020

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 7/5/2021 and were signed on its behalf by:


H Thurgood -Trustee


Mrs C Thurgood -Trustee


A Thurgood -Trustee


Mrs V L Bissott -Trustee

The notes form part of these financial statements

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 AUGUST 2020

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.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

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.

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2020

2. RAISING FUNDS

Raising donations and legacies

	2020	2019
	£	£
Fundraising costs	10,092	8,768
Subscriptions	136	158
Support costs	<u>1,245</u>	<u>2</u>
	<u>11,473</u>	<u>8,928</u>

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2020 nor for the year ended 31 August 2019.

Trustees' expenses

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

4. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	43,725
EXPENDITURE ON	
Raising funds	8,928
Charitable activities	
Sheffield University	44,392
Other	<u>5,299</u>
Total	<u>58,619</u>
NET INCOME/(EXPENDITURE)	<u>(14,894)</u>
RECONCILIATION OF FUNDS	
Total funds brought forward	<u>60,418</u>
TOTAL FUNDS CARRIED FORWARD	<u>45,524</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2020

5. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2020	2019
	£	£
Other creditors	<u>1,843</u>	<u>1,843</u>

6. MOVEMENT IN FUNDS

	At 1.9.19	Net movement in funds	At 31.8.20
	£	£	£
Unrestricted funds			
General fund	45,524	13,330	58,854
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>45,524</u>	<u>13,330</u>	<u>58,854</u>

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

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	29,197	(15,867)	13,330
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>29,197</u>	<u>(15,867)</u>	<u>13,330</u>

Comparatives for movement in funds

	At 1.9.18	Net movement in funds	At 31.8.19
	£	£	£
Unrestricted funds			
General fund	60,418	(14,894)	45,524
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>60,418</u>	<u>(14,894)</u>	<u>45,524</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2020

6. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	43,725	(58,619)	(14,894)
	<u>43,725</u>	<u>(58,619)</u>	<u>(14,894)</u>
TOTAL FUNDS	<u>43,725</u>	<u>(58,619)</u>	<u>(14,894)</u>

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

	At 1.9.18 £	Net movement in funds £	At 31.8.20 £
Unrestricted funds			
General fund	60,418	(1,564)	58,854
	<u>60,418</u>	<u>(1,564)</u>	<u>58,854</u>
TOTAL FUNDS	<u>60,418</u>	<u>(1,564)</u>	<u>58,854</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 £
Unrestricted funds			
General fund	72,922	(74,486)	(1,564)
	<u>72,922</u>	<u>(74,486)</u>	<u>(1,564)</u>
TOTAL FUNDS	<u>72,922</u>	<u>(74,486)</u>	<u>(1,564)</u>

THE MADDI FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2020

7. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2020.

THE MADDI FOUNDATION

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2020

	2020 £	2019 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	<u>29,197</u>	<u>43,725</u>
Total incoming resources	29,197	43,725
EXPENDITURE		
Raising donations and legacies		
Fundraising costs	10,092	8,768
Subscriptions	<u>136</u>	<u>158</u>
	10,228	8,926
Charitable activities		
Grants to institutions	4,366	44,392
Support costs		
Management		
Postage and stationery	103	117
Advertising & PR	<u>-</u>	<u>2,137</u>
	103	2,254
Finance		
Bank charges	28	237
Information technology		
Website expenses	482	287
Other		
Sundries	130	220
Governance costs		
Legal & professional fees	<u>530</u>	<u>2,303</u>
Total resources expended	<u>15,867</u>	<u>58,619</u>
Net income/(expenditure)	<u>13,330</u>	<u>(14,894)</u>

This page does not form part of the statutory financial statements