

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
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THE MADDI FOUNDATION

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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
E31 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 notes form part of these financial statements

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
	<hr/>	<hr/>
	68	11,473
	<hr/>	<hr/>

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	15,867
NET INCOME	13,330
RECONCILIATION OF FUNDS	
Total funds brought forward	45,524
TOTAL FUNDS CARRIED FORWARD	58,854

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	58,854	(25,067)	33,787

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