

The Ultra Rare Diseases, Disorders and Disabilities Foundation

Northern Ireland · Charity number 102130

Details

Known as URDDAD Foundation

Status Overdue

Registered 2016-02-23

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

Contact

Address 86 Palmerston Road
Belfast
BT4 1qd
BT4 1QD

Phone +(44) 02890 650406

Email admin@urddad-foundation.org.uk

Website www.urddad-foundation.org.uk

Activities

Purposes: The Company is established to: 1. Support those people, their families, dependence and carers ("the beneficiaries") affected by or believe to be affected by Ultra rare diseases/Rare diseases or disorder and their disabilities caused by Ultra rare/rare Diseases in Northern Ireland and any part of the world ("the area of benefit") 2. advance the education of the public in all matters concerning rare diseases, disorders and disabilities.

What the charity does: The advancement of education, The advancement of health or the saving of lives, The relief of those in need by reason of youth, age, ill-health, disability, financial hardship or other disadvantage

How the charity works: Accommodation/housing, Advice/advocacy/information, Cross-border/cross-community, Disability, Education/training, General charitable purposes, Human rights/equality, Medical/health/sickness, Playgroup/after schools, Research/evaluation, Volunteer development, Welfare/benevolent, Youth development

Who the charity helps: Adult training, Carers, Children (5-13 year olds), Ethnic minorities, General public, Interface communities, Learning disabilities, Men, Mental health, Older people, Overseas/developing countries, Parents, Physical disabilities, Preschool (0-5 year olds), Sensory disabilities, Specific areas of deprivation, Tenants, Travellers, Unemployed/low income, Voluntary and community

sector,Volunteers,Women,Youth (14-25 year olds)

Finances

Period end	Income	Expenditure	Assets	Employees
2019-08-31	£11,234	£6,831	£0	0

Trustees

Name	Role	Appointed
Harry Scott		
Lorna Mcconnell		
Mr Terry Hoey		
Mrs Maureen Hoey		

The Ultra Rare Diseases, Disorders and Disabilities Foundation

Northern Ireland - Charity number 102130

Accounts

REGISTERED COMPANY NUMBER: NI617725 (Northern Ireland)
REGISTERED CHARITY NUMBER: NIC102130

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 AUGUST 2019
FOR
THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

M.B.McGrady & Co
Chartered Accountants
Suite 2B
Cadogan House
322 Lisburn Road
Belfast
Co. Antrim
BT9 6GH

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**CONTENTS OF THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 AUGUST 2019**

	Page
Reference and Administrative Details	1
Report of the Trustees	2
Independent Examiner's Report	3
Statement of Financial Activities	4
Balance Sheet	5
Notes to the Financial Statements	6 to 10
Detailed Statement of Financial Activities	11

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**REFERENCE AND ADMINISTRATIVE DETAILS
FOR THE YEAR ENDED 31 AUGUST 2019**

TRUSTEES

M Hoey
T Hoey
L McConnell
H C Scott

REGISTERED OFFICE

Suite 2B
Cadogan House
322 Lisburn Road
Belfast
Co. Antrim
BT9 6GH

**REGISTERED COMPANY
NUMBER**

NI617725 (Northern Ireland)

**REGISTERED CHARITY
NUMBER**

NIC102130

INDEPENDENT EXAMINER

M.B.McGrady & Co
Chartered Accountants
Suite 2B
Cadogan House
322 Lisburn Road
Belfast
Co. Antrim
BT9 6GH

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 AUGUST 2019**

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 2019. 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).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The aim of the charity is to be a centre of support, advice & help for children, adults and their families who have been diagnosed with a rare disease or an ultra rare disease. The future of the Foundation includes a dedicated team of volunteers, counsellors & medical staff. Their aims are high and with the help of funding and sponsorship and fundraising they hope to buy a large house that they can turn into a home from home, a place where the parents can bring their children to and a place of sanctuary for patients with special needs, also a home where the whole family can go to for support and understanding and with your help they can make this happen.

FINANCIAL REVIEW

The results for the year and the Charity's end of year position are shown in the attached accounts.

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.

Organisational structure

The board of Trustees administers and holds the legal responsibility for the good management of the company.

Approved by order of the board of trustees on 28 August 2020 and signed on its behalf by:

T Hoey - Trustee

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2019

		2019 Unrestricted fund £	2018 Total funds £
INCOME AND ENDOWMENTS FROM	Notes		
Donations and legacies		6,831	11,234
EXPENDITURE ON			
Raising funds	2	8,133	10,065
NET INCOME/(EXPENDITURE)		<u>(1,302)</u>	<u>1,169</u>
RECONCILIATION OF FUNDS			
Total funds brought forward		7,448	6,279
TOTAL FUNDS CARRIED FORWARD		<u><u>6,146</u></u>	<u><u>7,448</u></u>

The notes form part of these financial statements

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**BALANCE SHEET
31 AUGUST 2019**

		2019 Unrestricted fund £	2018 Total funds £
FIXED ASSETS	Notes		
Tangible assets	6	5,308	6,184
CURRENT ASSETS			
Cash at bank		1,558	1,984
CREDITORS			
Amounts falling due within one year	7	(720)	(720)
NET CURRENT ASSETS		<u>838</u>	<u>1,264</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>6,146</u>	<u>7,448</u>
NET ASSETS		<u>6,146</u>	<u>7,448</u>
FUNDS	8		
Unrestricted funds		<u>6,146</u>	<u>7,448</u>
TOTAL FUNDS		<u>6,146</u>	<u>7,448</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2019.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2019 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.

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 28 August 2020 and were signed on its behalf by:

T Hoey - Trustee

The notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 AUGUST 2019

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 2015)', 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.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

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 ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2019**

2. RAISING FUNDS

Raising donations and legacies

	2019	2018
	£	£
Fundraising Costs	999	-
Support costs	7,134	10,065
	<u>8,133</u>	<u>10,065</u>

3. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2019	2018
	£	£
Depreciation - owned assets	876	906
	<u>876</u>	<u>906</u>

4. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2019 nor for the year ended 31 August 2018.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 August 2019 nor for the year ended 31 August 2018.

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	11,234
EXPENDITURE ON	
Raising funds	10,065
NET INCOME	<u>1,169</u>
RECONCILIATION OF FUNDS	
Total funds brought forward	6,279
TOTAL FUNDS CARRIED FORWARD	<u>7,448</u>

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2019

6. TANGIBLE FIXED ASSETS

	Office Building £	Fixtures and fittings £	Motor vehicles £	Computer equipment £	Totals £
COST					
At 1 September 2018 and 31 August 2019	3,634	382	3,995	268	8,279
DEPRECIATION					
At 1 September 2018	-	229	1,598	268	2,095
Charge for year	-	77	799	-	876
At 31 August 2019	-	306	2,397	268	2,971
NET BOOK VALUE					
At 31 August 2019	3,634	76	1,598	-	5,308
At 31 August 2018	3,634	153	2,397	-	6,184

7. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2019 £	2018 £
Accountancy	720	720

8. MOVEMENT IN FUNDS

	At 1/9/18 £	Net movement in funds £	At 31/8/19 £
Unrestricted funds			
General fund	7,448	(1,302)	6,146
TOTAL FUNDS	7,448	(1,302)	6,146

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	6,831	(8,133)	(1,302)
TOTAL FUNDS	6,831	(8,133)	(1,302)

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 AUGUST 2019**

8. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/9/17 £	Net movement in funds £	At 31/8/18 £
Unrestricted funds			
General fund	6,279	1,169	7,448
	<u>6,279</u>	<u>1,169</u>	<u>7,448</u>
TOTAL FUNDS	<u>6,279</u>	<u>1,169</u>	<u>7,448</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	11,234	(10,065)	1,169
	<u>11,234</u>	<u>(10,065)</u>	<u>1,169</u>
TOTAL FUNDS	<u>11,234</u>	<u>(10,065)</u>	<u>1,169</u>

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

	At 1/9/17 £	Net movement in funds £	At 31/8/19 £
Unrestricted funds			
General fund	6,279	(133)	6,146
	<u>6,279</u>	<u>(133)</u>	<u>6,146</u>
TOTAL FUNDS	<u>6,279</u>	<u>(133)</u>	<u>6,146</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	18,065	(18,198)	(133)
	<u>18,065</u>	<u>(18,198)</u>	<u>(133)</u>
TOTAL FUNDS	<u>18,065</u>	<u>(18,198)</u>	<u>(133)</u>

9. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2019.

10. VOLUNTARY INCOME

Voluntary Income includes £4,177 (2018: £8,623) received from trustees, Terry and Maureen Hoey, to cover expenditure incurred by the charity.

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2019**

	31/8/19 £	31/8/18 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	6,831	11,234
Total incoming resources	6,831	11,234
EXPENDITURE		
Raising donations and legacies		
Fundraising Costs	999	-
Support costs		
Management		
Insurance	223	-
Motor	205	976
Telephone	1,413	954
Postage and stationery	1,760	778
Advertising	312	408
Sundries	400	287
Office & computer	1,083	4,576
Membership fees	-	140
Fixtures and fittings	76	76
Motor vehicles	799	799
Computer equipment	-	31
	6,271	9,025
Finance		
Bank charges	34	107
Governance costs		
Accountancy and legal fees	829	933
Total resources expended	8,133	10,065
Net (expenditure)/income	(1,302)	1,169

This page does not form part of the statutory financial statements



From: Naomi Cameron <naomi.cameron@mbmcgrady.co.uk>
To: terryhoey <terryhoey@urddad-foundation.org.uk>
CC: Seamus McLernon <Seamus.McLernon@mbmcgrady.co.uk>
Subject: 2019 Accounts
Date: 2020-08-28, 13:09:11
Attachment: Ultra Rare Diseases, Disorders & Disabilities-Charities report2019.PDF

Hi Maureen & Terry,

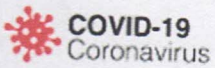
I hope you are both well.

I have attached a PDF copy of The Ultra Rare Diseases, Disorders and Disabilities Foundation 2019 accounts for your approval. If you are happy with the accounts, please print, sign and scan them back to us for submission by close of play today.

If you have any queries please do not hesitate to get in touch.

Kind regards,
Naomi

Naomi Cameron
M B McGrady & Co



Covid-19 Important Notice: As a practice, we are conscientiously following government guidelines and our offices are now open by appointment to the public.

We have taken the relevant precautionary steps to insure the safety of staff and clients and if visiting our offices please follow the onsite safety guidance. Where possible, we encourage clients to continue to engage with us remotely but we appreciate this is not always possible.

Offices in:

Downpatrick:	52 St. Patricks Avenue DOWNPATRICK BT30 6DS	t. 028 4461 6321
Belfast:	2B Cadogan House 322 Lisburn Road BELFAST BT9 6GH	t. 028 9031 6950
Newtownards:	27 Frances Street NEWTOWNARDS BT23 7DW	t. 028 9181 4557

This email is confidential and may be privileged; it is for the use of the named recipient only.

If you have received it in error please do not copy or disclose its contents to any person or body, and delete it from your computer system.

M B McGrady & Co is authorised to carry on Investment Business in the ROI and regulated for a range of investment business in the UK. The firm is registered to carry on audit work by the Institute of Chartered Accountants in Ireland.

Directors - MBT McGrady FCA, Conaill McGrady FCA, Seamus McLernon FCA.

MB McGrady & Co is the trading name of Rathmore House Ltd, a company registered in Northern Ireland, registration number NI 601538. Our Downpatrick office is our registered address.

The Ultra Rare Diseases, Disorders and Disabilities Foundation

Northern Ireland - Charity number 102130

Accounts

REGISTERED COMPANY NUMBER: NI617725 (Northern Ireland)
REGISTERED CHARITY NUMBER: NIC102130

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS FOR
THE YEAR ENDED 31 AUGUST 2018
FOR**

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

M.B.McGrady & Co
Chartered Accountants
Suite 2B
Cadogan House
322 Lisburn Road
Belfast
Co. Antrim
BT9 6GH

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**CONTENTS OF THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 AUGUST 2018**

	Page
Reference and Administrative Details	1
Report of the Trustees	2
Independent Examiner's Report	3
Statement of Financial Activities	4
Balance Sheet	5 to 6
Notes to the Financial Statements	7 to 11
Detailed Statement of Financial Activities	12

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**REFERENCE AND ADMINISTRATIVE DETAILS
FOR THE YEAR ENDED 31 AUGUST 2018**

TRUSTEES

M Hoey (Director)
T Hoey (Director)

REGISTERED OFFICE

Suite 2B
Cadogan House
322 Lisburn Road
Belfast
Co. Antrim
BT9 6GH

REGISTERED COMPANY NUMBER

NI617725 (Northern Ireland)

REGISTERED CHARITY NUMBER

NIC102130

INDEPENDENT EXAMINER

M.B.McGrady & Co
Chartered Accountants
Suite 2B
Cadogan House
322 Lisburn Road
Belfast
Co. Antrim
BT9 6GH

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 AUGUST 2018**

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 2018. 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).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The aim of the charity is to be a centre of support, advice & help for children, adults and their families who have been diagnosed with a rare disease or an ultra rare disease. The future of the Foundation includes a dedicated team of volunteers, counsellors & medical staff. Their aims are high and with the help of funding and sponsorship and fundraising they hope to buy a large house that they can turn into a home from home, a place where the parents can bring their children to and a place of sanctuary for patients with special needs, also a home where the whole family can go to for support and understanding and with your help they can make this happen.

FINANCIAL REVIEW

The results for the year and the Charity's end of year position are shown in the attached accounts.

STRUCTURE, GOVERNANCE AND MANAGEMENT

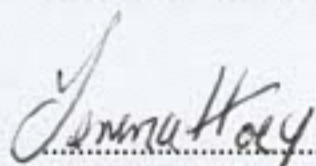
Governing document

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.

Organisational structure

The board of Trustees administers and holds the legal responsibility for the good management of the company.

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


.....
T Hoey - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

I report on the accounts of the company for the year ended 31 August 2018, which are set out on pages four to eleven.

Respective responsibilities of charity trustees and examiner

As the charity's trustees (and also the 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.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under Section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Basis of the independent examiner's report

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters.

My role is to state whether any material matters have come to my attention giving me cause to believe:

1. That accounting records were not kept in accordance with section 386 of the Companies Act 2006
2. That the accounts do not accord with those accounting records
3. That the accounts do not comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the 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
4. That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.

Seamus McLernon FCA
M.B.McGrady & Co
Chartered Accountants
Suite 2B
Cadogan House
322 Lisburn Road
Belfast
Co. Antrim
BT9 6GH

Date:

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2018**

	Notes	2018 Unrestricted fund £	2017 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		<u>11,231</u>	<u>12,975</u>
Total		11,231	12,975
EXPENDITURE ON			
Raising funds	2	<u>10,062</u>	<u>8,294</u>
NET INCOME		1,169	4,681
RECONCILIATION OF FUNDS			
Total funds brought forward		<u>6,279</u>	<u>1,598</u>
TOTAL FUNDS CARRIED FORWARD		<u>7,448</u>	<u>6,279</u>

The notes form part of these financial statements

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**BALANCE SHEET
AT 31 AUGUST 2018**

	Notes	2018 Unrestricted fund £	2017 Total funds £
FIXED ASSETS			
Tangible assets	6	6,184	7,090
CURRENT ASSETS			
Cash at bank		1,984	-
CREDITORS			
Amounts falling due within one year	7	(720)	(811)
NET CURRENT ASSETS/(LIABILITIES)		<u>1,264</u>	<u>(811)</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		7,448	6,279
NET ASSETS		<u>7,448</u>	<u>6,279</u>
FUNDS	9		
Unrestricted funds		7,448	6,279
TOTAL FUNDS		<u>7,448</u>	<u>6,279</u>

The notes form part of these financial statements

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**BALANCE SHEET - CONTINUED
AT 31 AUGUST 2018**

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2018.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2018 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.

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to charitable small companies.

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

.....
T Hoey -Trustee

The notes form part of these financial statements

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 2015)', 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.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

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

	2018	2017
	£	£
Support costs	<u>10,065</u>	<u>8,294</u>

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 AUGUST 2018**

3. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2018	2017
	£	£
Depreciation - owned assets	<u>906</u>	<u>929</u>

4. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2018 nor for the year ended 31 August 2017.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 August 2018 nor for the year ended 31 August 2017.

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	<u>12,975</u>
Total	<u>12,975</u>
EXPENDITURE ON	
Raising funds	<u>8,294</u>
Total	<u>8,294</u>
NET INCOME	<u>4,681</u>
RECONCILIATION OF FUNDS	
Total funds brought forward	<u>1,598</u>
TOTAL FUNDS CARRIED FORWARD	<u><u>6,279</u></u>

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 AUGUST 2018**

6. TANGIBLE FIXED ASSETS

	Office Building £	Fixtures and fittings £	Motor vehicles £	Computer equipment £	Totals £
COST					
At 1 September 2017 and 31 August 2018	3,634	382	3,995	268	8,279
DEPRECIATION					
At 1 September 2017	-	153	799	237	1,189
Charge for year	-	76	799	31	906
At 31 August 2018	-	229	1,598	268	2,095
NET BOOK VALUE					
At 31 August 2018	3,634	153	2,397	-	6,184
At 31 August 2017	3,634	229	3,196	31	7,090

7. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2018 £	2017 £
Bank loans and overdrafts (see note 8)	-	91
Accountancy	720	720
	<u>720</u>	<u>811</u>

8. LOANS

An analysis of the maturity of loans is given below:

	2018 £	2017 £
Amounts falling due within one year on demand:		
Bank overdraft	-	91
	<u>-</u>	<u>91</u>

9. MOVEMENT IN FUNDS

	At 1/9/17 £	Net movement in funds £	At 31/8/18 £
Unrestricted funds			
General fund	6,279	1,169	7,448
TOTAL FUNDS	<u>6,279</u>	<u>1,169</u>	<u>7,448</u>

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 AUGUST 2018**

9. 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	11,231	(10,062)	1,169
	<u>11,231</u>	<u>(10,062)</u>	<u>1,169</u>
TOTAL FUNDS	<u><u>11,231</u></u>	<u><u>(10,062)</u></u>	<u><u>1,169</u></u>

Comparatives for movement in funds

	At 1/9/16 £	Net movement in funds £	At 31/8/17 £
Unrestricted Funds			
General fund	1,598	4,681	6,279
	<u>1,598</u>	<u>4,681</u>	<u>6,279</u>
TOTAL FUNDS	<u><u>1,598</u></u>	<u><u>4,681</u></u>	<u><u>6,279</u></u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	12,975	(8,294)	4,681
	<u>12,975</u>	<u>(8,294)</u>	<u>4,681</u>
TOTAL FUNDS	<u><u>12,975</u></u>	<u><u>(8,294)</u></u>	<u><u>4,681</u></u>

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

	At 1/9/16 £	Net movement in funds £	At 31/8/18 £
Unrestricted funds			
General fund	1,598	5,850	7,448
	<u>1,598</u>	<u>5,850</u>	<u>7,448</u>
TOTAL FUNDS	<u><u>1,598</u></u>	<u><u>5,850</u></u>	<u><u>7,448</u></u>

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 AUGUST 2018**

9. 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	24,206	(18,356)	5,850
TOTAL FUNDS	<u>24,206</u>	<u>(18,356)</u>	<u>5,850</u>

10. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2018.

11. VOLUNTARY INCOME

Voluntary Income includes £8,623 received from the trustees, Terry and Maureen Hoey, to cover expenditure incurred by the charity.

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2018**

	2018 £	2017 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	11,231	12,975
Total incoming resources	11,231	12,975
EXPENDITURE		
Other trading activities		
Exceptional items	(3)	-
Support costs		
Management		
Insurance	-	80
Motor	976	299
Telephone	954	220
Postage and stationery	778	444
Advertising	408	228
Sundries	287	360
Office & computer	4,576	4,236
Membership fees	140	690
	8,119	6,557
Finance		
Bank charges	107	114
Fixtures and fittings	76	76
Motor vehicles	799	799
Computer equipment	31	54
	1,013	1,043
Governance costs		
Accountancy and legal fees	933	694
Total resources expended	10,062	8,294
Net income	1,169	4,681

This page does not form part of the statutory financial statements

The Ultra Rare Diseases, Disorders and Disabilities Foundation

Northern Ireland - Charity number 102130

Annual report

THE ULTRA RARE DISEASE, DISORDER AND
DISABILITIES FOUNDATION

DIRECTOR'S REPORT

2017 TO 2018

Founder/Directors: Terence Hoey
Maureen Hoey

2017-2018

DIRECTOR'S REPORT

Introduction

The Ultra Rare Disease, Disorders and Disabilities Foundation (URDDAD Foundation) is a charity set up by two Directors, Terence Hoey and Maureen Hoey.

The Background of the charity is they are the grandparents of Cavan Tommy Hoey. Their grandson Cavan was a five year old child who took ill, his parents thought he had a childhood illness, the Doctor's thought he had glandular fever. He was not getting better after six weeks and his weight plummeted, his Doctor and his parents admitted him to the Cornwall Hospital. He remained there for a further six weeks and they carried out tests on Cavan, but the tests came back blank. The family became very worried and demanded that further tests be done. His bloods were sent to all major hospitals within England.

His parents did not have to wait long until his results started coming back with various diseases. It was Bristol Children's Hospital who came back with definite diagnosis of HLH and Cavan had to be rushed to Bristol. The Doctors told his parents it was urgent, he got there following a four-hour journey by ambulance. When he arrived Cavan took a major seizure and Doctors gave him 48-hours to live. They carried out further tests and they found Cavan had another disease called XLP, they were told that this was a very rare disease and that there were only 100 children in the world with it.

Cavan got through the 48 hours and managed to fight back, he remained in hospital for one year as Doctors tried to fight the HLH and XLP. In that time his grandparents set up the Cavan Tommy Hoey Trust, and Terence Hoey spent his time researching into XLP and HLH. At that time he went on the web but could not find much information and he decided to set up a website for Cavan. He blogged day and night telling the story about his grandson and his work went viral.

He started getting results from all over the world. He realised very quickly that HLH was a rare disease that seemed to affect people in America. He found that XLP was ultra-rare. He started to blog about rare diseases and with the help of Google Rare Disease, it went viral. Every drug manufacturing companies started to set up sites for rare diseases. They, for the first time, started to take notice of Terence Hoey blog sites and the media started taking notice. Terry and Maureen started holding Rare Disease days and they put about raising awareness of ultra-rare disease. They followed the same plan as rare disorders and they found that drug manufacturers called ultra-rare disease as orphan diseases, so they started out to change the name "orphan" to "ultra" as it was a name that would cause a bigger impact on the web. They set out to blog day and night about ultra-rare disease, it set a fire on the web that drug companies and Doctors started to take notice. This was when Terry and Maureen set up the Foundation, they also found how having a child with a rare and an ultra-rare disease affects the family circle.

The Foundation is moving from strength to strength. It had to go through a very lean time due to fundraising, the Foundation has found it very hard to raise funds due to being a small charity and because of the bigger charities starting their TV ad campaigns, although the Foundation is holding its own and it's fundraising is now showing an increase.

The Foundation is happy to report that due to it bringing on two new volunteers it has greatly improved the work the charity can do, and it frees up time for the Directors to do other work. They

are involved in setting up a client base of good fund raisers and also setting up road shows to raise awareness. The Foundation is also raising awareness of the web.

We are glad to report that the Foundation is building up its client base on the web and is now making inroads on building a bigger and stronger base with other groups all over the globe, from America, South Africa, Australia, India, Pakistan, Ireland and United Kingdom. This work is vital to the Foundation. In Northern Ireland it is running road shows and is trying to break through the hold that much bigger charities has on Northern Ireland. We have been building on our client base and working to increase this client base in Northern Ireland. The Foundation is also building a client base in Europe, this is vital to be prepared for Brexit. The Foundation is building this base in readiness of a "No Deal" Brexit, we take this work as vital to the Foundation and the European plan on Rare Disease.

Funding

We are adding to our client base daily, we depend on raising our funds through collection boxes. The Foundation is setting its sights on raising funds in Northern Ireland and it is increasing its numbers of clients within the area and is at present increasing its supply of charity boxes throughout the Province. Its main area is Belfast, we are seeking to expand on this.

Directors

Mr Terence Hoey had a kidney transplant in June 2017. He had a lot of infections to get over but we are glad to report he is getting back to fitness again.

Report ends.

Signed by Directors:

Founder/Director:

Terence Hoey

Founder/Director:

Maurice Hoey

Date:

28th May 2019

The Ultra Rare Diseases, Disorders and Disabilities Foundation

Northern Ireland - Charity number 102130

Annual return

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

I report on the accounts of the company for the year ended 31 August 2018, which are set out on pages four to eleven.

Respective responsibilities of charity trustees and examiner

As the charity's trustees (and also the 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.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under Section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Basis of the independent examiner's report

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters.

My role is to state whether any material matters have come to my attention giving me cause to believe:

1. That accounting records were not kept in accordance with section 386 of the Companies Act 2006
2. That the accounts do not accord with those accounting records
3. That the accounts do not comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the 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
4. That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.

Seamus McLernon FCA
M.B.McGrady & Co
Chartered Accountants
Suite 2B
Cadogan House
322 Lisburn Road
Belfast
Co. Antrim
BT9 6GH

Date:

The Ultra Rare Diseases, Disorders and Disabilities Foundation

Northern Ireland - Charity number 102130

Accounts

REGISTERED COMPANY NUMBER: NI617725 (Northern Ireland)
REGISTERED CHARITY NUMBER: NIC102130

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS FOR
THE YEAR ENDED 31 AUGUST 2017
FOR

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

M.B.McGrady & Co
Chartered Accountants
85 University Street
Belfast
Co. Antrim
BT7 1HP

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

CONTENTS OF THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 AUGUST 2017

	Page
Reference and Administrative Details	1
Report of the Trustees	2
Independent Examiner's Report	3
Statement of Financial Activities	4
Balance Sheet	5
Notes to the Financial Statements	6 to 9
Detailed Statement of Financial Activities	10

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

REFERENCE AND ADMINISTRATIVE DETAILS
FOR THE YEAR ENDED 31 AUGUST 2017

TRUSTEES	M Hoey (Director) T Hoey (Director)
REGISTERED OFFICE	86 Palmerston Road Sydenham Belfast Co. Antrim BT4 1QD
REGISTERED COMPANY NUMBER	NI617725 (Northern Ireland)
REGISTERED CHARITY NUMBER	NIC102130
INDEPENDENT EXAMINER	M.B.McGrady & Co Chartered Accountants 85 University Street Belfast Co. Antrim BT7 1HP

**THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

**REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 AUGUST 2017**

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 2017. 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).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The aim of the charity is to be a centre of support, advice & help for children, adults and their families who have been diagnosed with a rare disease or an ultra rare disease. The future of the Foundation includes a dedicated team of volunteers, counsellors & medical staff. Their aims are high and with the help of funding and sponsorship and fundraising they hope to buy a large house that they can turn into a home from home, a place where the parents can bring their children to and a place of sanctuary for patients with special needs, also a home where the whole family can go to for support and understanding and with your help they can make this happen.

FINANCIAL REVIEW

The results for the year and the Charity's end of year position are shown in the attached accounts.

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.

Organisational structure

The board of Trustees administers and holds the legal responsibility for the good management of the company.

Approved by order of the board of trustees on 20 June 2018 and signed on its behalf by:

T Hoey - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

I report on the accounts of the company for the year ended 31 August 2017, which are set out on pages four to nine.

Respective responsibilities of charity trustees and examiner

As the charity's trustees (and also the 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.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under Section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Basis of the independent examiner's report

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters.

My role is to state whether any material matters have come to my attention giving me cause to believe:

1. That accounting records were not kept in accordance with section 386 of the Companies Act 2006
2. That the accounts do not accord with those accounting records
3. That the accounts do not comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the 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
4. That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.

Seamus McLernon FCA
M.B.McGrady & Co
Chartered Accountants
85 University Street
Belfast
Co. Antrim
BT7 1HP

20 June 2018

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2017

		2017 Unrestricted fund £	2016 Total funds £
INCOME AND ENDOWMENTS FROM	Notes		
Donations and legacies		12,975	10,888
Investment income	2	-	1
Total		<u>12,975</u>	<u>10,889</u>
EXPENDITURE ON			
Raising funds	3	<u>8,294</u>	<u>8,717</u>
NET INCOME		4,681	2,172
RECONCILIATION OF FUNDS			
Total funds brought forward		1,598	(574)
TOTAL FUNDS CARRIED FORWARD		<u><u>6,279</u></u>	<u><u>1,598</u></u>

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

The notes form part of these financial statements

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

BALANCE SHEET
AT 31 AUGUST 2017

		2017 Unrestricted fund £	2016 Total funds £
FIXED ASSETS	Notes		
Tangible assets	7	7,090	2,259
CREDITORS			
Amounts falling due within one year	8	(811)	(661)
NET CURRENT ASSETS/(LIABILITIES)		<u>(811)</u>	<u>(661)</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		6,279	1,598
NET ASSETS		<u>6,279</u>	<u>1,598</u>
FUNDS	10		
Unrestricted funds		<u>6,279</u>	<u>1,598</u>
TOTAL FUNDS		<u>6,279</u>	<u>1,598</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2017.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2017 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.

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to charitable small companies.

The financial statements were approved by the Board of Trustees on 20 June 2018 and were signed on its behalf by:

T Hoey -Trustee

The notes form part of these financial statements

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 2015)', 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.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

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. INVESTMENT INCOME

	2017	2016
	£	£
Interest receivable	-	1
	<u> </u>	<u> </u>

3. RAISING FUNDS

Raising donations and legacies

	2017	2016
	£	£
Support costs	8,294	8,717
	<u> </u>	<u> </u>

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 AUGUST 2017

4. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2017	2016
	£	£
Depreciation - owned assets	<u>929</u>	<u>130</u>

5. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2017 nor for the year ended 31 August 2016.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 August 2017 nor for the year ended 31 August 2016.

6. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	10,888
Investment income	1
Total	<u>10,889</u>
EXPENDITURE ON	
Raising funds	8,717
Total	<u>8,717</u>
NET INCOME	2,172
RECONCILIATION OF FUNDS	
Total funds brought forward	(574)
TOTAL FUNDS CARRIED FORWARD	<u><u>1,598</u></u>

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 AUGUST 2017

7. TANGIBLE FIXED ASSETS

	Office Building £	Fixtures and fittings £	Motor vehicles £	Computer equipment £	Totals £
COST					
At 1 September 2016	1,869	382	-	268	2,519
Additions	1,765	-	3,995	-	5,760
At 31 August 2017	<u>3,634</u>	<u>382</u>	<u>3,995</u>	<u>268</u>	<u>8,279</u>
DEPRECIATION					
At 1 September 2016	-	153	-	107	260
Charge for year	-	-	799	130	929
At 31 August 2017	<u>-</u>	<u>153</u>	<u>799</u>	<u>237</u>	<u>1,189</u>
NET BOOK VALUE					
At 31 August 2017	<u>3,634</u>	<u>229</u>	<u>3,196</u>	<u>31</u>	<u>7,090</u>
At 31 August 2016	<u>1,869</u>	<u>229</u>	<u>-</u>	<u>161</u>	<u>2,259</u>

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2017 £	2016 £
Bank loans and overdrafts (see note 9)	91	1
Accountancy	720	660
	<u>811</u>	<u>661</u>

9. LOANS

An analysis of the maturity of loans is given below:

	2017 £	2016 £
Amounts falling due within one year on demand:		
Bank overdraft	<u>91</u>	<u>1</u>

10. MOVEMENT IN FUNDS

	At 1/9/16 £	Net movement in funds £	At 31/8/17 £
Unrestricted funds			
General fund	1,598	4,681	6,279
TOTAL FUNDS	<u>1,598</u>	<u>4,681</u>	<u>6,279</u>

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
FOR THE YEAR ENDED 31 AUGUST 2017

10. 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	12,975	(8,294)	4,681
	<u>12,975</u>	<u>(8,294)</u>	<u>4,681</u>
TOTAL FUNDS	<u>12,975</u>	<u>(8,294)</u>	<u>4,681</u>

Comparatives for movement in funds

	At 1/9/15 £	Net movement in funds £	At 31/8/16 £
Unrestricted Funds			
General fund	(574)	2,172	1,598
	<u>(574)</u>	<u>2,172</u>	<u>1,598</u>
TOTAL FUNDS	<u>(574)</u>	<u>2,172</u>	<u>1,598</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	10,889	(8,717)	2,172
	<u>10,889</u>	<u>(8,717)</u>	<u>2,172</u>
TOTAL FUNDS	<u>10,889</u>	<u>(8,717)</u>	<u>2,172</u>

11. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2017.

12. VOLUNTARY INCOME

Voluntary Income includes £ 11,044 received from the trustees, Terry and Maureen Hoey, to cover expenditure incurred by the charity.

THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 AUGUST 2017

	2017 £	2016 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	12,975	10,888
Investment income		
Interest receivable	-	1
Total incoming resources	<u>12,975</u>	<u>10,889</u>
EXPENDITURE		
Support costs		
Management		
Insurance	80	235
Motor	299	216
Telephone	220	1,430
Postage and stationery	444	1,048
Advertising	228	1,535
Sundries	360	31
Office & computer	4,236	3,191
Membership fees	690	192
	<u>6,557</u>	<u>7,878</u>
Finance		
Bank charges	114	326
Fixtures and fittings	76	76
Motor vehicles	799	-
Computer equipment	54	54
	<u>1,043</u>	<u>456</u>
Governance costs		
Accountancy and legal fees	694	383
Total resources expended	<u>8,294</u>	<u>8,717</u>
Net income	<u><u>4,681</u></u>	<u><u>2,172</u></u>

This page does not form part of the statutory financial statements

The Ultra Rare Diseases, Disorders and Disabilities Foundation

Northern Ireland - Charity number 102130

Annual report

Report of The Trustees for The Period

Dated 31 August 2017

The Ultra Rare Disease Disorders and Disabilities Foundation

Registered Company Number N1617725 (Northern Ireland

Registered Charity Number NIC 102130

Directors Mr Terence Hoey

Mrs Maureen Hoey

This is a short statement compiled by the Directors of The Ultra Rare Disease Disorders and Disabilities Foundation Ltd year ending 31 August 2017

We welcome this opportunity to supply our short statement on the Ultra-Rare Disease Disorders and Disabilities Foundation the charity was set up to help families and patients with rare and ultra-rare disease we work to raise awareness of rare and ultra-rare diseases within Northern Ireland and Ireland we do this by our web sites and social media. Our aim is to help families deal with the effects that ultra-rare and rare disease brings with it the foundation works to help with everyday problems like claiming benefits and housing issues and advice.

The Foundation works as a backup to families and patients signposting them to other agencies and also guiding new families to Hospitals within Northern Ireland and Ireland and the United Kingdom who can help with a diagnosis a genetic, rare or an ultra-rare disease the foundation knows only too well how important it is to get the correct diagnosis and it also knows that if a correct diagnosis is not carried out that patients may be treated with the wrong medication plan.

Diagnosis with a rare or an ultra-rare disease is very complex and it needs to be carried out by hospitals designated to diagnosis genetic, rare and ultra-rare disease these Hospitals are known as centres of excellence we have had the experience of patients having blood tests carried out and the bloods having to be sent to hospitals in the United Kingdom such as Liverpool Children's Hospital Bristol Children's university teaching Hospital or Great Ormond Street Hospital to name a few.

The foundation helps to guide and support families who have recently had a child diagnosed with a genetic, rare or ultra-rare disease it helps in many ways like filling out benefit forms or problems with housing, The foundation also helps with day to day problems that arise like debt problems and siblings being bullied at school, We also find that guilt issues also arise caused by the demand of care it takes dealing with a young child who has had a diagnosis of a genetic, rare or ultra-rare disease the pressure it put on the family unit is immense.

The foundation had only four volunteers in 2017 the foundation like other charities has found it hard to bring on volunteers due to people finding full time work the demand for volunteers is huge we at the foundation has witnessed charity shops closing or being temporarily closed due to having no volunteers to run them, The foundation mainly has worked on research of genetic, rare and ultra-rare disease it depends a lot on experience and that is very hard to find due to the nature of the research that the foundation carries out.

We have found that due to the very nature of the work we do it is hard to recruit people who can deal with the pressures it takes to be able to work with families with a child who has a genetic, rare disease, ultra-rare disease, and the problems it brings with it we also have to train our volunteers up on the effects that a diagnosis can cause and the complete devastation it brings to a family due to so many issues that can arise. The foundation knows just how vital training is and just how important it is to meet the standards that we expect of our volunteers.

Due to the shortage of volunteers we at the foundation know just how important it is to bring on people who has experience in fields like book keeping, fundraising, dealing with website design and social media, and sourcing new sites for our charity boxes, and financial standards to deal with HMRC and Funding regulations.

The foundation has had a very tough year caused by lack of funding that it needs to bring in full time staff although the foundation is now bringing on volunteers that have a background of fundraising, and social media, websites, and accounting the foundation has also seen its Director having to take time out to deal with kidney problems in 2017 and 2018 when he had to have a kidney transplant and also deal with infections that rendered him unable to carry out any sort of work for the foundation.

We are very pleased to report that he is now back to his duties and the foundation has learnt that the need for volunteers is vital in the smooth running of the foundation.

The Directors and Trustees

The Ultra Rare Disease Disorders And Disabilities Foundation

The Ultra Rare Diseases, Disorders and Disabilities Foundation

Northern Ireland - Charity number 102130

Annual return

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
THE ULTRA RARE DISEASES, DISORDERS AND
DISABILITIES FOUNDATION**

I report on the accounts of the company for the year ended 31 August 2017, which are set out on pages four to nine.

Respective responsibilities of charity trustees and examiner

As the charity's trustees (and also the 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.

Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under Section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Basis of the independent examiner's report

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters.

My role is to state whether any material matters have come to my attention giving me cause to believe:

1. That accounting records were not kept in accordance with section 386 of the Companies Act 2006
2. That the accounts do not accord with those accounting records
3. That the accounts do not comply with the accounting requirements of section 396 of the Companies Act 2006 and with the methods and principles of the 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
4. That there is further information needed for a proper understanding of the accounts to be reached.

Independent examiner's statement

I have completed my examination and have no concerns in respect of the matters (1) to (4) listed above and, in connection with following the Directions of the Charity Commission for Northern Ireland, I have found no matters that require drawing to your attention.

Seamus McLernon FCA
M.B.McGrady & Co
Chartered Accountants
85 University Street
Belfast
Co. Antrim
BT7 1HP

20 June 2018