



# Duchenne Research Fund

THE DUCHENNE RESEARCH FUND

REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 DECEMBER 2023

Registered Charity No. 1119068

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AZETS AUDIT SERVICES  
River House  
1 Maidstone Road  
Sidcup  
Kent  
DA14 5RH

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## Reference and administrative details

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Trustees	Daniel Baum Simon Kanter Jeremy Shebson Sarah Shelley
Charity Registration Number	1119068
Principal Office	PO Box 77134 London N3 9GB
Key Management	Trustees
Banker	Bank of Scotland Teviot House 41 South Gyle Crescent Edinburgh EH12 9DR
Investment Managers	Canaccord Genuity Wealth Management 41 Lothbury London EC2R 7AE
Independent Examiner	M A Wilkes (FCA) Azets Audit Services River House 1 Maidstone Road Sidcup Kent DA14 5RH

## Report of the trustees

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The Trustees present their report and financial statements for the year ended 31 December 2023.

The financial statements have been prepared in accordance with 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 issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102), the Charities Act 2011 and UK Generally Accepted Accounting Practice.

### Objectives

The charity was founded to:

‘Promote the relief of persons suffering from and to promote research into the treatment, cure, care and welfare of those persons suffering from Duchenne muscular dystrophy in England, Wales and Overseas.’

### ABOUT THE DUCHENNE RESEARCH FUND

The Duchenne Research Fund (DRF) was founded with a clear and ambitious goal: that, through our work and the research we are funding, a cure will be found for Duchenne muscular dystrophy.

Duchenne muscular dystrophy is a severe and progressive fatal muscle wasting disease that almost exclusively affects boys. Young people with Duchenne lose the ability to walk, and are confined to a wheelchair by their early teens. By their early 20s they are left fighting for their lives as the muscles of their lungs and heart deteriorate. This devastating condition is fatal for all individuals with Duchenne, and there is currently no cure. It claims the lives of 100 young people every year in the UK alone.

The DRF identifies and funds research into potential treatments and cures, with the aim of improving the condition of all boys living with Duchenne – now and in the future. We focus on creating powerful collaborations between some of the world’s most brilliant scientists, proactive Duchenne charities, and innovative biotech companies to accelerate the development of therapies that are ripe for treating Duchenne. We aim to focus our efforts on research related to the pathogenesis and treatment of Duchenne muscular dystrophy for all boys regardless of mutation, as well as driving improved standards of care across the UK. We aim to improve quality of life for all those Duchenne, including through future exploration of palliative care research.

The DRF is particularly proud of the collaborative work undertaken with other prominent Duchenne charities in the UK and abroad. We have co-funded a vital research trial that has resulted in a newly approved treatment; and driven improvements in standards of care which have led to new UK-wide guidelines. These collaborations have achieved significant progress in the Duchenne arena.

For more information about Duchenne muscular dystrophy and the Duchenne Research Fund, please visit our website at [www.duchenne.org.uk](http://www.duchenne.org.uk)

### FUNDRAISING ACTIVITY

Since DRF’s inception, fundraising and donor support have enabled its ability to invest in research projects and to raise awareness of this life-threatening disease. In order to support future research, all donations are gratefully received. Fundraising initiatives are undertaken by many of our supporters, as well as birthday gifts and significant general donations from existing and new supporters. We are extremely grateful for the efforts of many who have given so much of their time and organised various initiatives. In 2023 our co-founder Doron Rosenfeld ran the Dead Sea marathon in aid of the DRF; the Alderman family, friends and supporters raised funds in memory of Jake; and several donors continued to support the DRF through the PayPal Giving Fund and other initiatives.

Please contact [info@duchenne.org.uk](mailto:info@duchenne.org.uk) with any suggestions or ideas for events or fundraising activities.

The DRF is committed to continuing to raise funds to tackle every aspect of this multi-faceted disease. We will continue to look for ways in which we can support Duchenne therapies moving to clinical trials as quickly and safely as possible, in the search for a cure. We will seek out complementary therapies and clinical research that aim to ensure as many boys and young men as possible will be eligible to receive curative treatments if and when they become available. We also want to ensure that all boys, whether ambulant or non-ambulant, are eligible to participate in clinical trials and get access to vital care and treatments.

To stay up to date with our latest news, visit [www.duchenne.org.uk/news](http://www.duchenne.org.uk/news), or sign up for our newsletter via the homepage.

## Report of the trustees (continued)

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### FUNDING STRATEGY IN 2023

The DRF has its own Scientific Advisory Board, comprising some of the leading minds in the field of muscular dystrophy. This board is spearheaded by Dr Ronald Cohn (Paediatrics, University of Toronto; President and CEO of the Hospital for Sick Children, Toronto, where he is also Chief of Clinical and Metabolic Genetics and Co-director of the Centre for Genetic Medicine. He is joined on the board by Dr Kevin Campbell (Professor of Physiology and Biophysics at the University of Iowa), Dr James Dowling (Senior Scientist at the Hospital for Sick Children, Toronto, and Associate Professor of Paediatrics and Molecular Genetics at University of Toronto) and Prof Madeleine Durbeej-Hjalt (Professor and Vice Chair of the Department of Experimental Medical Science at Lund University, Sweden). Professor Dubowitz (Emeritus Professor of Paediatrics, Imperial College London; and President of World Muscle Society) is our honorary scientific patron. To the extent that any member of the Scientific Advisory Board has any interest in the receipt of a grant he/she is excluded from the review and recommendation to the Trustees.

In order to ensure the DRF is exploring every avenue that could help cure, treat or support all people with Duchenne, we are continuously seeking to expand our research portfolio, as and when recommended by the Scientific Advisory Board, and we are anxious for scientists to submit relevant research proposals for our Scientific Advisory Board to consider. The charity has devised a robust two-tiered review process for any projects that it chooses to consider supporting.

In order to ensure new Duchenne treatments are successful in moving out of the laboratory and into clinical trial as quickly and safely as possible, the DRF continues to provide grants for clinical and administrative posts to help accelerate the clinical trial pipeline for Duchenne muscular dystrophy. The DRF also continues to nurture and sponsor emerging talent in the Duchenne research field to ensure the pipeline of science and treatments continues to evolve.

Please see our website [www.duchenne.org.uk](http://www.duchenne.org.uk) for further details on how to apply for a grant or contact [research@duchenne.org.uk](mailto:research@duchenne.org.uk)

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Some of the research projects that the Duchenne Research Fund has funded in 2023 include:

#### PROJECT 1: DMD Care UK

The Duchenne Research Fund funds the DMD Care UK initiative, in partnership with Duchenne UK and Joining Jack, which aims to ensure everyone living with Duchenne in the UK has access to the best care. DRF helped fund Phase 1 of the DMD Care UK programme in 2020-22.



Due to the project's significant expansion across 13 working groups and with more than 70 expert clinician advisors, Duchenne UK and Newcastle University worked together in 2023 to devise a strategy for a £1m Phase 2 of the project in 2023-26. Following consultation across the steering committee and working groups, and submission of a proposal, DRF has agreed to continue its funding through Phase 2 of the project.

DMD Care UK was launched in October 2020 in collaboration with Dr Michela Guglieri and Cathy Turner from Newcastle University. Leading Duchenne muscular dystrophy experts in the UK are working in collaboration with the Duchenne community to review current Standards of Care (published in the Lancet in 2018), and agree and publish recommendations for every area of care that can and should be delivered within the NHS.

Because Duchenne is a complex disease and covers many areas of medicine, the DMD Care UK project functions across a range of working groups including respiratory care, cardiac care, psychosocial care, and bone and endocrine care, which covers puberty, adrenal suppression and steroids. As well as being a funding partner, Duchenne Research Fund's director of operations participates in some of the working groups and sits on the main steering committee.

Significant progress has been made across several working groups: patient information guides have been published on adrenal insufficiency; puberty and testosterone; and cardiac care, and webinars have been created that can be re-watched on demand, regarding: preparing for emergencies; steroid stress dosing; and adrenal, bone and puberty.

(Continued overleaf)

## Report of the trustees (continued)

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Recommendations to clinicians have been published and disseminated on bone and endocrine care, endorsed by the British Society for Paediatric Endocrinology and Diabetes (BSPED); and on cardiac care, published by the BMJ Open Heart journal and endorsed by the British Cardiovascular Society (BCS). Feedback from families shows that the Duchenne Emergency Care app, designed to ensure Duchenne patients get the right care when attending A&E, has already proven vital to Duchenne patients in emergency situations.

More recent additions to the project include a family focus group, and a working group to address the transition from paediatric to adult care, which can be a particularly challenging time for young people living with Duchenne and their families. A working group focused on diagnosis, and another on nutrition, are also in the pipeline.

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### PROJECT 2: DMD Care UK Psychosocial Programme

DRF continues to fund the DMD Care UK Psychosocial Programme, which pursues vital psychosocial care and research for those living with Duchenne and their families.

The psychosocial project has made significant strides during the first half of the grant, thanks to the expert team that has been assembled with DRF's funds: Dr Chloe Geagan, paediatric clinical psychologist at Newcastle University; Dr Linda Bouquillon, clinical psychologist at the National Hospital for Neurology and Neurosurgery in Queens Square; and Dr Dorothea Bindman, consultant neuropsychiatrist at Queens Square. This project is in collaboration with Joining Jack, which funds Dr Rory Conn, consultant paediatric and adolescent psychiatrist at Royal Devon and Exeter NHS Trust. DRF's grant also funds administrative staff to support the clinicians employed as part of the project.

The expert team have the ambitious aim of working towards a 'new normal': namely that the appropriate psychosocial evaluation, care and treatment be fully integrated throughout every Duchenne patient's life, across the UK. It strives to address current lack of understanding of, provision for and consensus around psychosocial care and needs, in order to generate clear evidence and expert-opinion-based recommendations for psychosocial care in Duchenne across the UK. This Psychosocial programme is a crucial component of the wider DMD Care UK programme that was launched by Duchenne UK and Newcastle University to improve standards of care in all aspects of Duchenne muscular dystrophy across the UK (see project 1, above).



**Dr Chloe Geagan**  
paediatric clinical  
psychologist



**Dr Linda Bouquillon**  
adult clinical psychologist



**Dr Dot Bindman**  
adult neuropsychiatrist



**Dr Rory Conn**  
paediatric liaison  
psychiatrist



**DMD  
CARE UK**  
Best care for all

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### PROJECT 3: Extension of non-ambulant clinic at Great Ormond Street Hospital

Since 2019, DRF has been pleased to support a dedicated non-ambulant clinic at Great Ormond Street Hospital (GOSH). DRF funded a senior physiotherapist post over several years, which has now been made permanent by the Trust, and a Clinical Nurse Specialist post to further enhance the clinic and ensure all boys and young men received dedicated care. In 2023, Trustees confirmed support of a proposal by GOSH for DRF to fund a nutritionist to add a further layer of vital support for young people with Duchenne attending the clinic. Following agreement of scope and terms of the role in 2023, the nutritionist post is due to be advertised and filled in 2024.

DRF had been aware dating back to 2016 that there was a distinct lack of physiotherapy provision for boys and young men with Duchenne at GOSH once they were no longer ambulant (able to walk). Despite loss of ambulation, physiotherapy remains of enormous importance and benefit for upper body function in these patients. DRF proposed to support a dedicated non-ambulant clinic at GOSH, however such a clinic required a business case from medical consultants and a financial commitment at the hospital Trust level, as a consultant would need to be allocated to oversee the clinic. DRF was delighted that after years of lobbying the Trust together with key clinicians at GOSH, a dedicated clinic was established in 2019. The clinic has since been able to offer support to hundreds of patients, including throughout the Covid-19 pandemic.



## Report of the trustees (continued)

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### PROJECT 4: International World Muscle Society Congress – Duchenne Research Prize

The DRF continues to fund the Duchenne Research Prize for an up-and-coming researcher at the International World Muscle Society's annual symposium. The winner at the 28th congress in October 2023, held in Charleston, South Carolina, US, was Dr Stefan Nicolau, a research fellow at the Center for Gene Therapy at Nationwide Children's Hospital in Ohio, for his work entitled: "Clinical spectrum and molecular features of asymptomatic and paucisymptomatic DMD mutations."



Read more at [www.duchenne.org.uk/our-projects](http://www.duchenne.org.uk/our-projects)

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### PUBLIC BENEFIT

The Trustees confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Fund's aim and objectives and in planning future activities and setting the grant making policy for the year.

### FINANCIAL REVIEW

Total income for the year was £57,929 (2022: £37,067). Total expenditure for the year was £322,538 (2022: £284,290). Of this, £249,274 (2022: £213,396) was provided as grants payable towards research into Duchenne Muscular Dystrophy. The result for the year was net expenditure of £264,609 before gains on investments of £16,744 (2022: net expenditure of £247,223 before losses on investments of £149,839).

Total funds at the year end totalled £1,075,127 (2022: £1,322,992).

### RESERVES POLICY

On an ongoing basis the Trustees aim to hold minimal reserves as the general cost base is low and before commencing any project the Trustees aim to raise the majority of the required income pertaining to each project. However the trustees are conscious that new development and research is dynamic and projects worthy of funding may arise at any time and believe it prudent to maintain some reserve for such eventuality. Considerable reserves are currently being held due to the sale of shares in Solid Biosciences in 2018 by DRIL and the Trustees and Scientific Advisory Board are evaluating and considering additional research projects on an ongoing basis. The reserve policy will be reviewed on an annual basis.

### INVESTMENT PERFORMANCE

The Trust Deed authorises the Trustees to make and hold investments, using the general funds of the charity.

The Trustees use a current account with limited funds to cover running costs. Additional funds are held in a deposit account which is accessible, and this is used to cover medical research and other charitable expenditure as projects arise and are agreed upon as suitable by the Trustees.

However, whilst considering future projects the Trustees felt that due to the historical low rates of interest the funds held in the deposit account were generating very low returns. After deliberation, in the hope that greater returns could be achieved for the charity, the Trustees invested £1 million with a wealth management fund, Canaccord Genuity Financial Planning Limited, which is authorised and regulated by the Financial Conduct Authority (registered number 154608) and which receives fees for managing the funds. Canaccord has no relationship with any of the Trustees or their families and is totally independent. As required the investment will be drawn down to meet the charity's commitments.

The Duchenne Research Fund also has a one-third shareholding in Duchenne Research (UK) Investment Limited ('DRIL') which holds shares in Solid Biosciences, a US listed research company dedicated to investigating gene therapy as a means of curing Muscular Dystrophy.

### GOING CONCERN

The financial statements have been prepared on a going concern basis as the charity has sufficient funds to cover running costs for the next 12 months and all existing research commitments.

## Report of the trustees (continued)

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### STRUCTURE, GOVERNANCE AND MANAGEMENT

#### Constitution

The Charity is an unincorporated entity, governed by a Declaration of Trust dated 25 March 2007. It is a registered charity, number 1119068. The charity received charitable status on 3 May 2007 and started operating on 17 May 2007.

#### Trustees

The following Trustees have served during the year to date:

Daniel Baum  
Simon Kanter  
Sarah Shelley  
Jeremy Shebson

At all times there shall be at least three Trustees holding office. Under the provisions of the Trust Deed, new Trustees are appointed by a resolution of the Trustees passed at a special meeting. The Board of Trustees is authorised to appoint new Trustees to fill vacancies arising because of resignation or the demise of an existing Trustee.

### STATEMENT OF TRUSTEES' RESPONSIBILITIES

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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

- ▶ select suitable accounting policies and then apply them consistently;
- ▶ observe the methods and principles in the Charities SORP 2015 (FRS 102);
- ▶ make judgements and estimates that are reasonable and prudent;
- ▶ state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- ▶ prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

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

Approved by the Trustees and signed on their behalf:

Simon Kanter – Chairman  
Trustee

Date: 08/10/2024



## Independent examiner's report to the trustees

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I report to the Trustees on my examination of the financial statements of The Duchenne Research Fund for the year ended 31 December 2023 which are set out on pages 8 to 16.

### Respective responsibilities of Trustees and Examiner

As the Charity's Trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

### Independent examiner's statement

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

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable accounting requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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.

### **M A Wilkes (FCA)**

For and on behalf of Azets Audit Services  
River House  
1 Maidstone Road  
Sidcup  
Kent  
DA14 5RH

Date: 15 October 2024

## Statement of financial activities for the year ended 31 December 2023

		Unrestricted funds	
	Notes	Total 2023 £	Total 2022 £
<b>INCOME FROM</b>			
Donations	2	27,490	16,371
Investment income	3	30,439	20,696
<b>Total income</b>		<b>57,929</b>	<b>37,067</b>
<b>EXPENDITURE ON</b>			
Raising funds	4	12,873	12,812
Charitable activities	5	309,665	271,478
<b>Total expenditure</b>	<b>5</b>	<b>322,538</b>	<b>284,290</b>
Net expenditure		(264,609)	(247,223)
Gain/(loss) on investments	10,11	16,744	(149,839)
Net movements in funds		(247,865)	(397,062)
Fund balances brought forward 1 January 2023		1,322,992	1,720,054
Fund balance carried forward 31 December 2023		1,075,127	1,322,992

- ▶ All transactions are derived from continuing activities.
- ▶ All transactions in 2023 related to unrestricted income and expenditure.
- ▶ All recognised gains and losses are included in the Statement of Financial Activities.

## Balance sheet as at 31 December 2023

	Notes	2023 £	2022 £
<b>FIXED ASSETS</b>			
Investments	10	997,616	968,340
Programme Related Investments	11	55,796	51,508
		1,053,412	1,019,848
<b>CURRENT ASSETS</b>			
Debtors	12	115	380
Cash at bank and in hand		47,036	327,714
		47,151	328,094
Creditors: Amounts falling due within one year	13	(25,436)	(24,950)
Net current assets		21,715	303,144
Net assets		<b>1,075,127</b>	<b>1,322,992</b>
<b>FUNDS</b>			
Unrestricted general funds		1,075,127	1,322,992
		<b>1,075,127</b>	<b>1,322,992</b>

The financial statements were approved on **08/10/2024** and signed on behalf of the Board by:

Simon Kanter – Chairman  
Trustee

Daniel Baum – Treasurer  
Trustee

# Notes to the financial statements for the year ended 31 December 2023

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## 1. ACCOUNTING POLICIES

### 1.1 Basis of preparation

The Duchenne Research Fund is a company limited by guarantee in the United Kingdom. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 1 of these financial statements. The nature of the charity's operations and principal activities are set out on page 2.

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with 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 issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102), the Charities Act 2011 and UK Generally Accepted Accounting Practice.

The financial statements are prepared on a going concern basis under the historical cost convention, modified to include certain items at fair value. The financial statements are prepared in sterling which is the functional currency of the charity.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

### 1.2 Income

All income is included in the Statement of Financial Activities (SoFA) when the charity is legally entitled to the income after any performance conditions have been met, the amount can be measured reliably and it is probable that the income will be received.

For donations to be recognised the charity will have been notified of the amounts and the settlement date in writing. If there are conditions attached to the donation and this requires a level of performance before entitlement can be obtained then income is deferred until those conditions are fully met or the fulfilment of those conditions is within the control of the charity and it is probable that they will be fulfilled.

Investment income is earned through holding assets for investment purposes such as shares. It includes dividends and interest. Where it is not practicable to identify investment management costs incurred within a scheme with reasonable accuracy the investment income is reported net of these costs. It is included when the amount can be measured reliably. Interest income is recognised using the effective interest method and dividend and rent income is recognised as the charity's right to receive payment is established.

### 1.3 Expenditure

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Expenditure is recognised where there is a legal or constructive obligation to make payments to third parties, it is probable that the settlement will be required and the amount of the obligation can be measured reliably. It is categorised under the following headings:

- ▶ Costs of raising funds includes those costs incurred by the charity when marketing and fundraising to raise fund for the charity; and
- ▶ Expenditure on charitable activities comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs allocated directly to such activities and those costs of an indirect nature necessary to support them.

## Notes to the financial statements for the year ended 31 December 2023

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### 1.4 Support costs allocation

Support costs are those that assist the work of the charity but do not directly represent charitable activities and include office costs, governance costs, administrative payroll costs. They are incurred directly in support of expenditure on the objects of the charity and include project management carried out at Headquarters. Where support costs cannot be directly attributed to particular headings they have been allocated to cost of raising funds and expenditure on charitable activities on a basis consistent with use of the resources.

The analysis of these costs is included in note 7.

Fund-raising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of the charitable activities.

The analysis of these costs is included in note 4.

### 1.5 Funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

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

### 1.6 Investments

Investments are recognised initially at their transaction value which is normally the transaction price less transaction costs. Subsequently, they are measured at fair value with changes recognised in 'net gains / (losses) on investments' in the SoFA if the shares are publicly traded or their fair value can otherwise be measured reliably.

### 1.7 Debtors and creditors receivable / payable within one year

Debtors and creditors with no stated interest rate and receivable or payable within one year are recorded at transaction price. Any losses arising from impairment are recognised in expenditure.

### 1.8 Foreign currencies

Assets and liabilities in foreign currencies are translated into Sterling at the rates of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into Sterling at the rate of exchange ruling at the date of transaction. Exchange differences are taken into account in arriving at the operating result.

### 1.9 Tangible fixed assets

Tangible fixed assets are stated at cost (or deemed cost) or valuation less accumulated depreciation and accumulated impairment losses. Assets costing less than £500 are written off in the period of acquisition. All other assets are capitalised.

### 1.10 Depreciation

Depreciation is provided on a straight line basis on the cost of tangible fixed assets, to write them down to their estimated residual values over their expected useful lives. Assets are depreciated over 4 years but this commences the year after acquisition.

## Notes to the financial statements for the year ended 31 December 2023

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### 1.11 Going concern

The financial statements have been prepared on a going concern basis as the trustees believe that no material uncertainties exist. The trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern. This included consideration of the effect of the Covid-19 virus on the Charity's operations.

### 1.12 Judgements and key sources of estimation uncertainty

Accounting estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

The following judgements (apart from those involving estimates) have been made in the process of applying the above accounting policies that have had the most significant effect on amounts recognised in the financial statements:

#### *Useful economic lives of tangible assets*

The annual depreciation charge for tangible assets is sensitive to changes in the estimated useful economic lives and residual values of the assets. The useful economic lives and residual values are re-assessed annually. They are amended when necessary to reflect current estimates, based on technological advancement, future investments, economic utilisation and the physical condition of the assets. See note 9 for the carrying amount of the property plant and equipment, and note 1.10 for the useful economic lives for each class of assets.

There are no key assumptions concerning the future and other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

2. DONATIONS	2023 £	2022 £
Donations	12,976	16,091
London Marathon	-	280
Dead Sea Marathon	14,514	-
	<b>27,490</b>	<b>16,371</b>

3. INVESTMENT INCOME	2023 £	2022 £
Interest	1,477	172
Investment dividends	28,962	20,524
	<b>30,439</b>	<b>20,696</b>



## Notes to the financial statements for the year ended 31 December 2023

4. RAISING FUNDS	2023 £	2022 £
Website marketing	731	488
Investment manager fee	12,142	12,280
Other costs	-	44

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	<b>12,873</b>	<b>12,812</b>
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5. ANALYSIS OF EXPENDITURE	Staff costs £	Direct costs £	Support costs £	Total 2023 £	Total 2022 £
Raising funds	-	12,873	-	12,873	12,812
Charitable activities	53,411	249,274	6,980	309,665	271,478

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Total expenditure	<b>53,411</b>	<b>262,147</b>	<b>6,980</b>	<b>322,538</b>	<b>284,290</b>
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6. DIRECT CHARITABLE EXPENDITURE	2023 £	2022 £
World Muscle Society	500	500
DMD Care UK	22,245	-
DMD Care UK Psychosocial Programme	215,087	212,896
New River Trust	3,927	-
Little Steps	7,515	-

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	<b>249,274</b>	<b>213,396</b>
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## Notes to the financial statements for the year ended 31 December 2023

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7. SUPPORT COSTS	2023 £	2022 £
Bank charges	342	335
Postage, stationery and telephone	354	157
Administration	945	2,070
Rent and service costs	1,910	1,761
Insurance	609	546
Foreign exchange variance	-	(3,585)
Governance - Independent examination	2,820	2,640

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	<b>6,980</b>	<b>3,924</b>
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8. STAFF COSTS AND TRUSTEE REMUNERATION	2023 £	2022 £
Wages and salaries	52,200	52,200
Social Security costs	-	766
Pension Costs	1,211	1,192

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	<b>53,411</b>	<b>54,158</b>
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Two members of staff (head count) were employed during 2023 (2022: Two). No employees earned over £60,000 per annum.

No benefits are received by key management personnel (2022: £Nil). The Trust considers its key management personnel to comprise those individuals listed on page 1.

None of the Trustees received any remuneration or expenses during the year. During the year £122 (2022: £516) was paid for Trustee Indemnity Insurance.

# Notes to the financial statements for the year ended 31 December 2023

## 9. TANGIBLE FIXED ASSETS

Furniture and  
equipment  
£

Cost:

At 1 January 2023 & 31 December 2023

3,547

Depreciation:

At 1 January 2023 & 31 December 2023

(3,547)

Net book value:

At 1 January 2023 & 31 December 2023

-

## 10. FIXED ASSET INVESTMENTS

2023  
£

2022  
£

Market value at 1 January 2023

918,189

963,967

Additions – cost

496,973

142,070

Disposal proceeds

(462,137)

(74,082)

Change in value in the year

12,456

(113,766)

**965,481**

**918,189**

Cash held within investment portfolio

32,135

50,151

Market value at 31 December 2023

**997,616**

**968,340**

Historical cost at 31 December 2023

**946,283**

**975,250**

The fair value of listed investments is determined by reference to the mid-market value of one share in the Fund at the Balance Sheet date.

This balance is made up of:

Debt and fixed interest

465,676

374,586

Equities

406,229

376,681

Infrastructure

93,576

166,923

Cash

32,135

50,150

**997,616**

**968,340**

The following investments are significant holdings within the investment portfolio:

Ishares III PLC CORE GBL AGGRG

-

54,664

Microsoft Corp

53,076

27,808

## Notes to the financial statements for the year ended 31 December 2023

11. PROGRAMME RELATED INVESTMENTS	2023 £	2022 £
Market value of investment at 1 January 2023	51,508	87,581
Gain / (loss) on investment	4,288	(36,073)
	<b>55,796</b>	<b>51,508</b>

Duchenne Research Fund is a shareholder in Duchenne Research (UK) Investment Ltd ("DRIL") a company incorporated in the UK as a company limited by shares on 9 December 2014.

The purpose of DRIL is to invest in SOLID GT LLC, a limited liability corporation incorporated on 5 August 2014 in Delaware, USA. During March 2017 SOLID GT LLC merged with Solid Biosciences Inc.

The Trustees hold the investment in SOLID GT LLC as part of their long term strategy. The market value at the year end will be dependent upon prevailing market conditions and is taken at a fixed date. The valuation of the investment has fallen further since the year end and the Trustees consider it is prudent for this to be viewed as a permanent diminution in value and have impaired the value accordingly.

The purpose of SOLID GT LLC is to undertake gene therapy-based research in Duchenne Muscular Dystrophy and drug development and treatments in connection therewith. On 26 January 2018 Solid Biosciences was listed on the Nasdaq and the Common C Stock was converted to 520,477 ordinary shares at a conversion rate of 0.8485 per C stock.

On 27 October 2022 Solid Biosciences Inc. implemented a 1-for-15 reverse split of its common stock.

The charity's investment in DRIL has been adjusted to its share (one third) of the value Solid Biosciences shares held by DRIL at 31 December 2023.

One director of DRIL, Sarah Shelley, was a Trustee of Duchenne Research Fund during the year.

12. DEBTORS	2023 £	2022 £
Gift Aid receivable	115	380
	<b>115</b>	<b>380</b>

13. CREDITORS	2023 £	2022 £
Amounts falling due within one year		
Other taxes and social security	2,164	2,192
Grants payable	16,613	13,686
Other creditors	464	232
Accruals	6,195	8,840
	<b>25,436</b>	<b>24,950</b>

## 14. RELATED PARTY TRANSACTIONS

There were no related party transactions during the year (2022 – None).