

THE DUCHENNE RESEARCH FUND

England & Wales · Charity number 1119068

Details

Other names THE GAVRIEL MEIR TRUST

Status Registered

Legal form Trust

Registered 2007-05-03

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

Contact

Address The Duchenne Research Fund
PO Box 77134
London
N3 9GB

Phone 020 7724 8824

Email info@duchenne.org.uk

Website www.duchenne.org.uk

Activities

Objects: 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 AND/OR WALES AND OVERSEAS.

Activities: 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.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, People With Disabilities, Other Charities Or Voluntary Bodies, Other Defined Groups

Geography

- **Area of benefit:** NOT DEFINED IN PRACTICE NATIONAL AND OVERSEAS
- Throughout England

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£37,788	£129,302	-	-
2023-12-31	£57,929	£322,538	-	-
2022-12-31	£37,067	£284,290	-	-
2021-12-31	£142,376	£350,299	-	-
2020-12-31	£48,904	£220,988	-	-

Trustees

Name	Role	Appointed
DANIEL IAN BAUM		2012-10-26
Dr SARAH SHELLEY		2011-04-11
JEREMY SHEBSON		
SIMON KANTER		2011-04-11

THE DUCHENNE RESEARCH FUND

England & Wales - Charity number 1119068

Accounts



Duchenne Research Fund

THE DUCHENNE RESEARCH FUND

REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2024

Registered Charity No. 1119068

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

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Reference and administrative details

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

The Trustees present their report and financial statements for the year ended 31 December 2024.

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 is proud to help drive global endeavours to identify and fund research into potential cures and treatments, and raise standards of care, with the aim of improving the condition of all boys living with Duchenne – now and in the future. We aim to impact quality of life for all boys regardless of their mutation type, age, or stage of Duchenne. We focus on creating powerful collaborations between some of the world’s most brilliant scientists, proactive Duchenne charities, innovative biotech companies, and leading clinicians and hospitals, to accelerate the development of therapies and care standards for Duchenne.

We were one of the first charities to invest in gene therapy for Duchenne, which is now making significant progress in the clinic. We were also an early funder of vamorolone, the steroid alternative treatment for Duchenne that has recently been approved in the US, UK and EU, and became available on the NHS for all Duchenne patients in 2024.



The DRF is particularly proud of the collaborative work undertaken with other prominent Duchenne charities in the UK and abroad, achieving significant progress in the Duchenne arena.

We have co-funded both gene therapy and vamorolone, and driven improvements in standards of care that have led to new UK-wide care guidelines. Through DMD Care UK, we are also working with NICE (the National Institute for Health and Care Excellence) to ensure our care guidelines reach a wide audience across the UK.

Some of the key people behind the development of vamorolone – Sheli Rodney (Director of Operations, Duchenne Research Fund), Emily Reuben OBE (Co-founder and Chief Executive of Duchenne UK), Professor Katie Bushby (Newcastle University), Professor Michela Guglieri (Newcastle University), Alex Johnson OBE (Co-founder of Duchenne UK and Chief Executive of Joining Jack), Professor Eric Hoffman (Binghamton University, New York)

For more information about Duchenne muscular dystrophy and the Duchenne Research Fund, please visit www.duchenne.org.uk

Report of the trustees (continued)

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 condition. We are extremely grateful for the efforts of many who have given so much of their time and organised various initiatives, which have enabled us to significantly impact the Duchenne arena.

During 2024 we have not been actively fundraising but concentrating our efforts on driving progress in ongoing research programmes and clinical care standards, as well as seeking out suitable new projects to invest in. We are committed to ensuring that the funds raised previously and any investment income made as a result of previous projects is put to the most beneficial use for the Duchenne community.

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

FUNDING STRATEGY IN 2024

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.

The DRF is continuously seeking to expand our research portfolio, as and when recommended by the Scientific Advisory Board, and we welcome all 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.

The DRF is committed to tackling every aspect of this multi-faceted condition. Guided by our Scientific Advisory Board, 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 disease-modifying treatments. 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 disease-modifying 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 the best possible standards of care and treatments – for both physical and mental health.

As the Duchenne research landscape continues to evolve, we have expanded beyond drug-based research – for example, we have funded a specialist physiotherapist and a dietitian at Great Ormond Street, to ensure young people who are no longer able to walk still receive dedicated upper-body and respiratory physiotherapy, as well as vital dietary support. We also fund specialist psychologists and psychiatrists across the UK as part of our drive to improve mental health research, care and treatment for Duchenne.

We continue to nurture and sponsor emerging talent in the Duchenne research field to ensure the pipeline of science and treatments continues to evolve, and up-and-coming researchers are encouraged to continue their work in the Duchenne arena.

Please see our website www.duchenne.org.uk for further details on how to apply for a grant or contact research@duchenne.org.uk

Report of the trustees (continued)

Some of the research projects that the Duchenne Research Fund has funded in 2024 include:

PROJECT 1: DMD Care UK

Following the unprecedented progress of Phase 1 of the DMD Care UK programme in 2020-23, the Duchenne Research Fund was pleased to extend its funding towards the £1m Phase 2 that is now under way until 2026. The project is funded in partnership with Duchenne UK and Joining Jack, and aims to ensure everyone living with Duchenne in the UK has access to the best care. DMD Care UK has expanded into 13 working groups and now has more than 130 expert clinician advisors and 25 patient representatives.



Many of these stakeholders, as well as other clinicians from across the UK, convened in London on 29 February 2024 – Rare Disease Day – for a DMD Care UK national meeting. Guidelines were presented and discussed, and workshops were held to evaluate next steps for several of the working groups.

DRF's director of operations took part in a steering committee meeting to progress the future of the whole project, as well as a meeting to progress and evaluate funding options for DECRI – the proposed education platform where all DMD Care UK guidance will be disseminated and managed. The next national meeting was scheduled for March 2025.



DRF participates in the 2024 DMD Care UK national meeting

DMD Care UK was launched by Duchenne UK 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.

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

Recommendations to clinicians have been published and disseminated on bone and endocrine care, endorsed by the British Society for Paediatric Endocrinology and Diabetes (BSPED); on cardiac care, published by the BMJ Open Heart journal and endorsed by the British Cardiovascular Society (BCS); on physiotherapy and occupational therapy, endorsed by the Neuromuscular Group of Association of Paediatric Chartered Physiotherapists; on respiratory care, endorsed by the British Thoracic Society; as well as guidance on corticosteroids, and a summary of evidence so far on vamorolone. 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, a diagnosis working group, a nutrition working 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.

Read more at www.duchenne.org.uk/our-projects

Report of the trustees (continued)

PROJECT 2: DMD Care UK Psychosocial Programme

DRF continues to drive 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 towards publication of guidelines, 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.

We are pleased that in November 2024, Dr Bouquillon was promoted to a permanent post at the trust, and will continue to be involved with the project. DRF funds have now made possible the recruitment of psychologist Dr Catherine Bonney-Murrell to join the expert team, as well as Dr Talia Eilon, psychiatry senior clinical fellow, who joined in early 2025. 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.

On 29 February 2024, the expert team presented their work and aims at the national DMD Care UK meeting, and planned to do so again in 2025.



Dr Chloe Geagan

paediatric clinical psychologist



Dr Linda Bouquillon

adult clinical psychologist



Dr Dot Bindman

adult neuropsychiatrist



Dr Rory Conn

paediatric liaison psychiatrist



Dr Talia Eilon

neuropsychiatry
clinical fellow

Our psychology and psychiatry specialists 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. They are striving 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).

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. Trustees confirmed support of a proposal by GOSH for DRF to fund a dietitian to add a further layer of vital support for young people with Duchenne attending the clinic. The post was advertised and recruitment was ongoing in 2024.

In 2025 the post was filled by paediatric dietitian and researcher Melis Sevim. Physiotherapy remains of enormous importance and benefit for upper-body and respiratory function even after loss of ambulation. DRF proposed to support a non-ambulant clinic at GOSH, and 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.

Read more at www.duchenne.org.uk/our-projects

Report of the trustees (continued)

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 29th congress in October 2024, held in Prague, was Rebecca Willcocks, research assistant professor at the Department of Physical Therapy, University of Florida, Gainesville. She presented two pieces of research relating to her work using MRI. In one she examines bone alterations in young people with Duchenne who have been treated with steroids, while in the other she uses MRI to assess the effects of gene therapy.



Read more at www.duchenne.org.uk/our-projects

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 £37,788 (2023: £57,929). Total expenditure for the year was £129,302 (2023: £322,538). Of this, £52,193 (2023: £249,274) was provided as grants payable towards research into Duchenne Muscular Dystrophy. The result for the year was net expenditure of £91,514 before gains on investments of £29,792 (2023: net expenditure of £264,609 before gains on investments of £16,744).

Total funds at the year end totalled £1,013,405 (2023: £1,075,127).

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. This is used to cover medical research and other charitable expenditure, as and when projects arise, and as agreed upon as suitable by the Trustees on the advice of the Scientific Advisory Board. Previously 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. The trustees regularly review the funds held and try to ensure they are being invested in the most beneficial way for the charity.

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)

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: 21/08/2025

Independent examiner's report to the trustees

I report to the Trustees on my examination of the financial statements of The Duchenne Research Fund for the year ended 31 December 2024 which are set out on pages 9 to 17.

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: 09/09/2025

Statement of financial activities for the year ended 31 December 2024

	Notes	Unrestricted funds	
		Total 2024 £	Total 2023 £
INCOME FROM			
Donations	2	11,938	27,490
Investment income	3	25,850	30,439
Total income		37,788	57,929
EXPENDITURE ON			
Raising funds including:	4		
Website marketing		251	731
Investment manager's fee		13,456	12,142
Charitable activities	5	115,595	309,665
Total expenditure	5	129,302	322,538
Net expenditure		(91,514)	(264,609)
Gain on investments	10,11	29,792	16,744
Net movements in funds		(61,722)	(247,865)
Fund balances brought forward 1 January 2024		1,075,127	1,322,992
Fund balance carried forward 31 December 2024		1,013,405	1,075,127

- ▶ All transactions are derived from continuing activities.
- ▶ All transactions in 2024 and 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 2024

	Notes	2024 £	2023 £
FIXED ASSETS			
Investments	10	858,403	997,616
Programme Related Investments	11	36,972	55,796
		895,375	1,053,412
CURRENT ASSETS			
Debtors	12	31,313	115
Cash at bank and in hand		191,861	47,036
		223,174	47,151
Creditors: Amounts falling due within one year	13	(105,144)	(25,436)
Net current assets		118,030	21,715
Net assets		1,013,405	1,075,127
FUNDS			
Unrestricted general funds		1,013,405	1,075,127
		1,013,405	1,075,127

The financial statements were approved on 21/08/2025 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 2024

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 2024

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 2024

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.

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	2024 £	2023 £
Donations	11,938	12,976
Dead Sea Marathon	-	14,514
	11,938	27,490

3. INVESTMENT INCOME	2024 £	2023 £
Interest	374	1,477
Investment dividends	25,476	28,962
	25,850	30,439

Notes to the financial statements for the year ended 31 December 2024

4. RAISING FUNDS	2024	2023
	£	£
Website marketing	251	731
Investment manager fee	13,456	12,142

	13,707	12,873
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5. ANALYSIS OF EXPENDITURE	Staff costs	Direct costs	Support costs	Total 2024	Total 2023
	£	£	£	£	£
Raising funds	-	13,707	-	13,707	12,873
Charitable activities	53,767	52,193	9,635	115,595	309,665

Total expenditure	53,767	65,900	9,635	129,302	322,538
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6. DIRECT CHARITABLE EXPENDITURE	2024	2023
	£	£
DMD Care UK	46,858	22,245
DMD Care UK Physiotherapy Research	4,000	-
DMD Care UK Psychosocial Programme	-	215,087
GOSH Dietitian	30,989	-
Little Steps	-	7,515
New River Trust	-	3,927
University of Florida	(30,154)	-
World Muscle Society	500	500

	52,193	249,274
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Notes to the financial statements for the year ended 31 December 2024

7. SUPPORT COSTS	2024	2023
	£	£
Bank charges	340	342
Postage, stationery and telephone	351	354
Administration	-	945
Travel	212	-
Rent and service costs	2,036	1,910
Insurance	603	609
Governance:		
Independent examination	3,240	2,820
Audit of DRIL accounts	2,853	-
	9,635	6,980

8. STAFF COSTS AND TRUSTEE REMUNERATION	2024	2023
	£	£
Wages and salaries	52,599	52,200
Pension Costs	1,168	1,211
	53,767	53,411

Two members of staff (head count) were employed during 2024 (2023: Two). No employees earned over £60,000 per annum.

No benefits are received by key management personnel (2023: £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 £121 (2023: £122) was paid for Trustee Indemnity Insurance.

Notes to the financial statements for the year ended 31 December 2024

9. TANGIBLE FIXED ASSETS		Furniture and equipment £
Cost:		
At 1 January 2024 & 31 December 2024		3,548
Depreciation:		
At 1 January 2024 & 31 December 2024		(3,548)
Net book value:		
At 1 January 2024 & 31 December 2024		-
10. FIXED ASSET INVESTMENTS	2024 £	2023 £
Market value at 1 January 2024	965,481	918,189
Additions – cost	30,004	496,973
Disposal proceeds	(229,564)	(462,137)
Change in value in the year	48,616	12,456
	814,537	965,481
Cash held within investment portfolio	43,866	32,135
Market value at 31 December 2024	858,403	997,616
Historical cost at 31 December 2024	720,264	946,283
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	384,477	465,676
Equities	349,542	406,229
Infrastructure	80,518	93,576
Cash	43,866	32,135
	858,403	997,616

Notes to the financial statements for the year ended 31 December 2024

11. PROGRAMME RELATED INVESTMENTS	2024	2023
	£	£
Market value of investment at 1 January 2024	55,796	51,508
(Loss) / gain on investment	(18,824)	4,288
	36,972	55,796

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 2024.

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

12. DEBTORS	2024	2023
	£	£
Gift Aid receivable	159	115
Other debtors	30,154	
Prepayments	1,000	
	31,313	115

13. CREDITORS	2024	2023
Amounts falling due within one year	£	£
Other taxes and social security	1,769	2,164
Grants payable	93,675	16,613
Other creditors	407	464
Accruals	9,293	6,195
	105,144	25,436

14. RELATED PARTY TRANSACTIONS

There were no related party transactions during the year (2023 – None).

THE DUCHENNE RESEARCH FUND

England & Wales - Charity number 1119068

Accounts



Duchenne Research Fund

THE DUCHENNE RESEARCH FUND

REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2023

Registered Charity No. 1119068

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

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Reference and administrative details

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

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

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 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, or sign up for our newsletter via the homepage.

Report of the trustees (continued)

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 for further details on how to apply for a grant or contact research@duchenne.org.uk

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)

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.

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

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)

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

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)

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

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

	Notes	Total 2023 £	Unrestricted funds Total 2022 £
INCOME FROM			
Donations	2	27,490	16,371
Investment income	3	30,439	20,696
Total income		57,929	37,067
EXPENDITURE ON			
Raising funds	4	12,873	12,812
Charitable activities	5	309,665	271,478
Total expenditure	5	322,538	284,290
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 £
FIXED ASSETS			
Investments	10	997,616	968,340
Programme Related Investments	11	55,796	51,508
		1,053,412	1,019,848
CURRENT ASSETS			
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		1,075,127	1,322,992
FUNDS			
Unrestricted general funds		1,075,127	1,322,992
		1,075,127	1,322,992

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

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

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

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	-
	27,490	16,371

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

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
		12,873	12,812

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
Total expenditure	53,411	262,147	6,980	322,538	284,290

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	-
		249,274	213,396

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

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

6,980	3,924
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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

53,411	54,158
---------------	---------------

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)
	55,796	51,508

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
	115	380

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
	25,436	24,950

14. RELATED PARTY TRANSACTIONS

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

THE DUCHENNE RESEARCH FUND

England & Wales - Charity number 1119068

Accounts



Duchenne Research Fund

THE DUCHENNE RESEARCH FUND

REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022

Registered Charity No. 1119068

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

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Reference and administrative details

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

The Trustees present their report and financial statements for the year ended 31 December 2022.

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. Sufferers lose the ability to walk, and are confined to a wheelchair by their early teens. By their early 20s these boys are left fighting for their lives as the muscles of their lungs and heart deteriorate. This devastating condition is fatal for all sufferers, 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 specifically focus our efforts on research related to the pathogenesis and treatment of Duchenne muscular dystrophy for all boys regardless of mutation.

[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, 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 2022 we continued to receive donations towards Yoni Leaf’s Helvellyn climb. At the end of 2022 our co-founder Doron Rosenfeld announced he would be running a marathon in aid of the DRF in early 2023.

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

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, or sign up for our newsletter via the homepage.](http://www.duchenne.org.uk/news)

Report of the trustees (continued)

FUNDING STRATEGY IN 2022

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. For many years we have worked with other Duchenne charities both in the UK and abroad in order to fund large scale and other projects.

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 for further details on how to apply for a grant or contact research@duchenne.org.uk

Some of the research projects that the Duchenne Research Fund has funded in 2022 include:

PROJECT 1: DMD Care UK Psychosocial Programme

In 2021 DRF approved funding of a three-year grant for a vital psychosocial care and research as part of the DMD Care UK programme. The project is now under way, and in 2022 the grant funded the hiring of 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; as well as appointing Dr Dorothea Bindman, consultant neuropsychiatrist at Queens Square, one day a week to support the project. Joining Jack has also collaborated on this project, funding the appointment of Dr Rory Conn, consultant paediatric and adolescent psychiatrist at Devon Partnership Trust in Exeter, one day a week to support the project. DRF's grant also funds administrative staff to support the clinicians employed as part of the project. This project, called the DMD Care UK Psychosocial Programme, has 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 will address the 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 in October 2020 by Duchenne UK and Newcastle University to improve standards of care in all aspects of Duchenne muscular dystrophy across the UK (see Project 2, overleaf).



Dr Chloe Geagan
paediatric clinical
psychologist



Dr Linda Bouquillon
adult clinical psychologist



Dr Dot Bindman
adult neuropsychiatrist



Dr Rory Conn
paediatric liaison
psychiatrist



Report of the trustees (continued)

PROJECT 2: DMD Care UK

The Duchenne Research Fund has partnered with Duchenne UK and Joining Jack to fund the DMD Care UK initiative, which aims to ensure everyone living with Duchenne in the UK has access to the best care. The project 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, DMD Care UK has broken down the project into various working groups including bone and endocrine care, cardiac care, psychosocial care, and endocrine care, which covers puberty, adrenal suppression and steroids. As well as being a funding partner, Duchenne Research Fund staff also participate in the working groups and 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. 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.



DRF funds supporting this project were granted in 2020 for 2020/21 and in 2021 for 2021/22. At the end of 2022, due to the project's significant expansion across ten working groups and with 70 expert clinician advisors, Duchenne UK and Newcastle University began to consult on plans to administer the next three years of the project. Strategy and personnel needs will be finalised in early 2023 and DUK and Newcastle plan to submit an application to the DRF for funding relating to 2023-2026.

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

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 Great Ormond Street Hospital (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 pleased that after years of lobbying by the charity together with key clinicians at GOSH, a dedicated clinic was established in 2019 and DRF awarded a two-year grant spanning 2019-21 to support the post of Senior Physiotherapist Nicola Burnett. DRF extended this by a further six months in 2021, with the funds granted in 2021 still continuing to support the post into 2022. In August 2022 DRF was delighted to receive confirmation that Nicola Burnett's position would be made permanent by the Trust following an extensive business case put forward by the clinical team.

In addition, DRF was pleased to fund a post for a Clinical Nurse Specialist in 2020 to support the clinic and ensure all boys and young men receive dedicated care. Funds granted in 2020/21 were still continuing to support the post into 2022. At the end of 2022 the team submitted an application to DRF to fund the vital support of a nutritionist to the clinic to add a further dimension of support to young people with Duchenne attending the clinic. Following the usual review process, Trustees confirmed support of this proposal in early 2023 and will administer the new tranche of this project in due course.



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

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 27th congress in Halifax, Canada, in October 2022 was Dr Juan M. Fernández-Costa, a senior researcher at the Institute for Bioengineering of Catalonia in Barcelona, for his work on a new approach of using human bioengineered organoids to advance research – rather than relying on traditional cell cultures and animal models.

Report of the trustees (continued)

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 £37,067 (2021: £142,376). Total expenditure for the year was £284,290 (2021: £350,299). Of this, £213,396 (2021: £267,342) was provided as grants payable towards research into Duchenne Muscular Dystrophy. The result for the year was net expenditure of £247,223 before gains and losses (2021: Net expenditure of £207,923).

The unrestricted funds at 31 December 2022 totalled £1,322,992 (2021: £1,720,054).

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 interest rates have now increased considerably and returns on investments have been limited as a result of the general poor market conditions, the Trustees are carefully considering a change in strategy for these funds in future.

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)

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 on 17 October 2023 and signed on their behalf by:

Simon Kanter – Chairman
Trustee

Date: 17 October 2023

Independent examiner's report to the trustees

I report to the Trustees on my examination of the financial statements of The Duchenne Research Fund for the year ended 31 December 2022 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

19 October 2023

Statement of financial activities for the year ended 31 December 2022

	Notes	Total 2022 £	Unrestricted funds Total 2021 £
INCOME FROM			
Donations	2	16,371	65,199
Investment income	3	20,696	77,177
Total income		37,067	142,376
EXPENDITURE ON			
Raising funds	4	12,812	18,274
Charitable activities	5	271,478	332,025
Total expenditure	5	284,290	350,299
Net expenditure		(247,223)	(207,923)
(Loss)/Gain on investments	10,11	(149,839)	(804,767)
Net movements in funds		(397,062)	(1,012,690)
Fund balances brought forward 1 January 2022		1,720,054	2,732,744
Fund balance carried forward 31 December 2022		1,322,992	1,720,054

- ▶ All transactions are derived from continuing activities.
- ▶ All transactions in 2021 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 2022

	Notes	2022 £	2021 £
FIXED ASSETS			
Investments	10	968,340	1,070,555
Programme Related Investments	11	51,508	87,581
		1,019,848	1,158,136
CURRENT ASSETS			
Debtors	12	380	61,493
Cash at bank and in hand		327,714	543,086
		328,094	604,579
Creditors: Amounts falling due within one year	13	(24,950)	(42,661)
Net current assets		303,144	561,918
Net assets		1,322,992	1,720,054
FUNDS			
Unrestricted general funds		1,322,992	1,720,054
		1,322,992	1,720,054

The financial statements were approved on 17 October 2023 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 2022

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 2022

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 2022

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	2022 £	2021 £
Donations	16,091	21,809
London Marathon	280	30,721
Virtual Event – An Evening with the Duchenne Research Fund	-	12,669
	16,371	65,199

3. INVESTMENT INCOME	2022 £	2021 £
Interest	172	77
Milestone payment from ReveraGen Biopharma, Inc.	-	59,032
Investment dividends	20,524	18,068
	20,696	77,177

Notes to the financial statements for the year ended 31 December 2022

4. RAISING FUNDS		2022	2021
		£	£
Website marketing		488	813
London Marathon		-	349
Virtual Event – An Evening with the Duchenne Research Fund		-	3,600
Investment manager fee		12,280	12,777
Other costs		44	735
		12,812	18,274

5. ANALYSIS OF EXPENDITURE	Staff costs	Direct costs	Support costs	Total 2022	Total 2021
	£	£	£	£	£
Raising funds	-	12,812	-	12,812	18,274
Charitable activities	54,158	213,396	3,924	271,478	332,025
Total expenditure	54,158	226,205	3,924	284,290	350,299

6. DIRECT CHARITABLE EXPENDITURE		2022	2021
		£	£
HHMI Fellowship		-	(2,885)
World Muscle Society		500	500
Great Ormond Street Hospital Physiotherapist		-	26,321
Great Ormond Street Hospital Specialist Nurse		-	12,686
DMD Care UK		-	20,000
DMD Care UK Psychosocial Programme		212,896	210,720
		213,396	267,342

Notes to the financial statements for the year ended 31 December 2022

7. SUPPORT COSTS	2022	2021
	£	£
Legal costs	-	874
Bank charges	335	352
Postage, stationery and telephone	157	123
Administration	2,070	2,790
Rent and service costs	1,761	1,792
Travel costs	-	6
Insurance	546	2,162
Foreign exchange variance	(3,585)	(367)
Other	-	615
Governance - Independent examination	2,640	2,400

3,924	10,747
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8. STAFF COSTS AND TRUSTEE REMUNERATION	2022	2021
	£	£
Wages and salaries	52,500	51,975
Social Security costs	766	770
Pension Costs	1,192	1,191

54,158	53,936
---------------	---------------

Two members of staff (head count) were employed during 2022 (2021: Two). No employees earned over £60,000 per annum.

No benefits are received by key management personnel (2021: £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 £516 (2021: £1,023) was paid for Trustee Indemnity Insurance.

Notes to the financial statements for the year ended 31 December 2022

9. TANGIBLE FIXED ASSETS	Furniture and equipment £
Cost:	
At 1 January 2022 & 31 December 2022	3,547
Depreciation:	
At 1 January 2022 & 31 December 2022	3,547
Net book value:	
At 1 January 2022 & 31 December 2022	-

10. FIXED ASSET INVESTMENTS	2022 £	2021 £
Market value at 1 January 2022	1,070,555	994,545
Additions	236,677	322,259
Disposals	(228,711)	(316,765)
Foreign exchange variance	3,585	367
Change in value in the year	(113,766)	70,149
Market value at 31 December 2022	968,340	1,070,555
Historic cost at 31 December 2022	975,250	973,650

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	374,586	337,758
Equities	376,681	442,366
Infrastructure	166,923	183,843
Cash	50,150	106,588

968,340	1,070,555
----------------	------------------

The following investments are significant holdings within the investment portfolio:

Ishares III PLC CORE GBL AGGRG	54,664	27,814
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Notes to the financial statements for the year ended 31 December 2022

11. PROGRAMME RELATED INVESTMENTS	2022	2021
	£	£
Market value of investment at 1 January 2022	87,581	962,497
(Loss)/Gain on investment	(36,073)	(874,916)
	51,508	87,581

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 5th August 2014 in Delaware, USA. During March 2017 SOLID GT LLC merged with Solid Bioscience 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 the 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.

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 2022.

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

12. DEBTORS	2022	2021
	£	£
Gift Aid receivable	380	2,461
Other debtors	-	59,032
	380	61,493

13. CREDITORS	2022	2021
Amounts falling due within one year	£	£
Accruals	9,072	7,032
Other taxes and social security	2,192	2,443
Grants payable	13,686	33,186
	24,950	42,661

14. RELATED PARTY TRANSACTIONS

There were no related party transactions during the year (2021 – None).

THE DUCHENNE RESEARCH FUND

England & Wales - Charity number 1119068

Accounts



Duchenne Research Fund

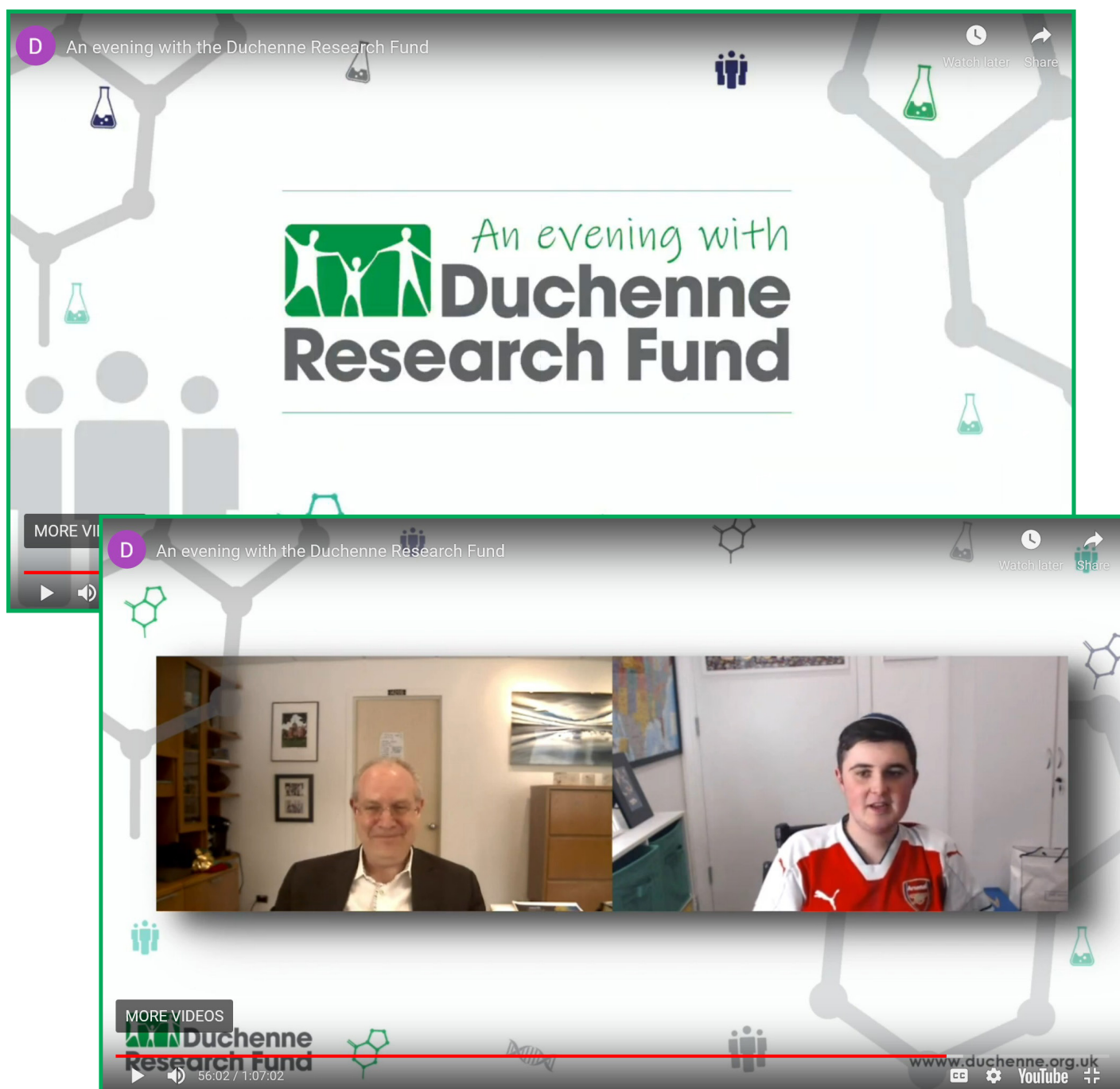
THE DUCHENNE RESEARCH FUND

REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2021

Registered Charity No. 1119068

AZETS AUDIT SERVICES
Greytown House
221/227 High Street
Orpington
Kent BR6 0NZ

*The Duchenne Research Fund partners with brilliant scientists and innovative biotech companies to accelerate treatments for Duchenne muscular dystrophy.
Help us find a cure for this devastating disease.*



In March 2021 more than 400 people watched the DRF's virtual donor event which featured scientific advisory board chair Dr Ronni Cohn in conversation with Gavriel Rosenfeld about living with Duchenne

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Statement of Financial Activities	9
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Reference and administrative details

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 Statutory Auditor Greytown House 221 – 227 High Street Orpington Kent BR6 0NZ

Report of the trustees

The Trustees present their report and financial statements for the year ended 31 December 2021.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's trust deed, the Charities Act 2011 and 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 published on 16 July 2014.

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. Sufferers lose the ability to walk, and are confined to a wheelchair by their early teens. By their early 20s these boys are left fighting for their lives as the muscles of their lungs and heart deteriorate. This devastating condition is fatal for all sufferers, 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 specifically focus our efforts on research related to the pathogenesis and treatment of Duchenne muscular dystrophy for all boys regardless of mutation.

For more information about Duchenne muscular dystrophy and the Duchenne Research Fund, please visit our website at www.duchenne.org.uk

FUNDRAISING IN 2021

Due to the Covid-19 pandemic, it was not possible to hold any in-person events in the first half of 2021.

On 17 March DRF held a virtual event that was streamed via a video platform, to update all donors and supporters on new and existing research projects that have been made possible by their generosity. Researchers from four different projects across the UK, US and Canada presented their latest work, and Gavriel Rosenfeld, son of the DRF's founders, spoke about his experiences of living with Duchenne. The event was viewed by more than 400 supporters and received excellent feedback regarding both content and format. Although the evening was a free informational event for donors, and not part of a specific appeal, it nonetheless drew donations of more than £11,000.

DRF will consider opportunities for future virtual events, depending on the availability of researchers, and research updates that can be made public to donors.

Following the cancellation of the Prudential RideLondon-Surrey event that had been scheduled for August 2020, the organisers converted DRF's 10 event places that had already been paid for, into five London Marathon places for 2021. The 2021 London Marathon was held on 3 October 2021. Five supporters took up the marathon places and DRF worked with them to support their fundraising efforts. Together they raised £27,000. Unfortunately one participant was unable to take part on the day due to recovering from Covid-19 illness. The event organisers have indicated that his place can be carried forward into the 2022 London Marathon. In addition, three supporters participated in the Virtual London Marathon and together raised more than £4,000.

DRF will continue to seek out suitable sporting events in 2022.

Report of the trustees (continued)

OTHER FUNDRAISING ACTIVITY

Since DRF's inception, fundraising and donor support has 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. There have been several fundraising initiatives throughout the year undertaken by many of our supporters, including Yoni Leaf's Helvellyn climb, birthday gifts and significant general donations from existing and new supporters. In addition, a feature highlighting Duchenne muscular dystrophy on Good Morning Britain at the end of 2020 continued to prompt donations into early 2021. We are extremely grateful for the efforts of many who have given so much of their time and organised various initiatives.

Please contact 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 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, or sign up for our newsletter via the homepage.

FUNDING STRATEGY IN 2021

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 treat or cure 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.

For many years we have worked with other Duchenne charities both in the UK and abroad in order to fund large scale and other projects.

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 for further details on how to apply for a grant or contact research@duchenne.org.uk

Report of the trustees (continued)

Some of the research projects that the Duchenne Research Fund has funded in 2021 include:

PROJECT 1: DMD Care UK Psychosocial Programme

In 2021 the Duchenne Research Fund approved funding of a three-year grant for a vital psychosocial care and research as part of the DMD Care UK programme. The grant will fund the posts of two research clinical psychologists, a neuropsychiatrist and additional support staff over the next three years at Newcastle University and the National Hospital for Neurology and Neurosurgery in Queens Square, London, with an aim to dramatically increase psychosocial standards of care for children and young adults with Duchenne, and their families.

This project, called the DMD Care UK Psychosocial Programme, has 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 will address the 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 in October 2020 by Duchenne UK and Newcastle University to improve standards of care in all aspects of Duchenne muscular dystrophy across the UK (see Project 2, right).



PROJECT 2: DMD Care UK

The Duchenne Research Fund has partnered with Duchenne UK and Joining Jack to fund the DMD Care UK initiative, which aims to ensure everyone living with Duchenne in the UK has access to the best care.



The project was launched in October 2020 in collaboration with Dr Michela Guglieri and Cathy Turner (pictured) 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, DMD Care UK has broken down the project into various working groups including bone and endocrine care, cardiac care, psychosocial care, and endocrine care, which covers puberty, adrenal suppression and steroids. As well as being a funding partner, Duchenne Research Fund staff also participate in the working groups and the main steering committee.

In 2021 DMD Care UK has already seen excellent progression in several working groups. Recommendations have already been published and disseminated by the bone and endocrine group, an app has been released by the emergency care group to ensure Duchenne patients get the right care when attending A&E, and recommendations from other groups are due to be published pending approval by various key journals. In addition, the DRF approved significant funding for the psychosocial arm of the project (see Project 1, left).

PROJECT 3: Neurobehavioural issues in Duchenne



Although the physical challenges of Duchenne have been investigated extensively, the neurobehavioural and psychosocial issues that can result from the diagnosis are under-explored, despite their significant impact on everyday life for many people living with Duchenne and their families.

DRF has awarded a grant to Parent Project Muscular Dystrophy (PPMD) to support its research into neurobehavioural issues in Duchenne – focusing on key areas such as learning, behaviour, depression and anxiety. The term “neurobehavioural” relates to the way the brain affects emotion, behaviour and learning. Neurobehavioral and cognitive diagnoses are not uncommon in those living with Duchenne, but access to timely assessment, diagnosis and treatment can be difficult to obtain and varied in experience and outcome. The work funded by DRF is part of PPMD’s new Brain Initiative, which aims to ensure all people living with Duchenne have access to appropriate neurobehavioural care.

Report of the trustees (continued)

PROJECT 4: 'KineDMD' extension

DRF previously awarded a grant Dr Aldo Faisal's team at Imperial College London to develop a novel biomarker to track the progression of Duchenne. The study is called 'KineDMD'. As part of the study, both ambulant and non-ambulant Duchenne patients wear sensor devices on each wrist and ankle to monitor their daily activities and movements outside a clinical setting.



Imperial College London

The aim is for this approach to complement or even replace classic clinical endpoints, more sensitively capturing functional changes, and increasing the number of boys eligible for clinical trials. Following successful recruitment of patients in the first round and promising early data captured and analysed from the sensor devices, the DRF agreed to fund an extension of the study to include more patients for a longer period 2019-22, and to gather more extensive data to be analysed. This study is currently being carried out as a clinical natural history study at the Clinical Research Facility of Great Ormond Street Hospital Trust, overseen by Professor Thomas Voit and Dr Valeria Ricotti.

PROJECT 5: Extension of dedicated non-ambulant clinic at Great Ormond Street Hospital

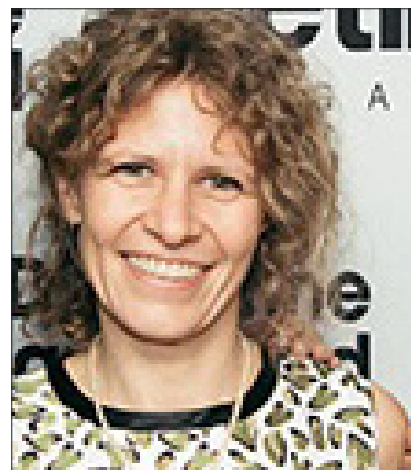
DRF had been aware for several years that there was a distinct lack of physiotherapy provision for boys and young men with Duchenne at Great Ormond Street Hospital (GOSH) once they were no longer ambulant (able to walk). Despite loss of ambulation, physiotherapy remains of enormous importance and benefit for upper body function in these patients. DRF proposed to support a dedicated non-ambulant physiotherapy 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 is pleased that after years of lobbying by the charity together with key clinicians at GOSH, a dedicated clinic was established in 2019 and DRF has awarded a two-year grant spanning 2019-21 to support the post of Senior Physiotherapist Nicola Burnett (pictured).

In addition, in 2020 DRF was pleased to fund a post for a Clinical Nurse Specialist Victoria Crook to support the clinic and ensure all boys and young men receive dedicated care.

PROJECT 6: Newcastle University Clinical Research Fellow



DRF and a consortium of seven UK Duchenne charities funds a Fellowship for Dr Michela Guglieri (pictured) in partnership with Newcastle University and Newcastle University Teaching Hospital, to develop and advance the clinical trial agenda for Duchenne muscular dystrophy. The award of £250,000 over five years is being matched by Newcastle University to enable Dr Guglieri to develop the clinical trial capacity for Duchenne at the John Walton Muscular Dystrophy Research Centre and nationally.

PROJECT 7: International World Muscle Society Congress – Duchenne Research Prize

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 25th congress in October 2020, held virtually, was Eleonora Maino, a PhD candidate from the Hospital for Sick Children in Toronto for her work on targeted genome editing in vivo in a novel mouse model to correct a Duchenne muscular dystrophy duplication.



Report of the trustees (continued)

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 £142,376 (2020: £48,904). Total expenditure for the year was £350,299 (2020: £220,988). Of this, £267,342 (2020: £144,262) was provided as grants payable towards research into Duchenne Muscular Dystrophy. The result for the year was net expenditure of £207,923 before gains and losses (2020: Net expenditure of £172,084).

The unrestricted funds at 31 December 2021 totalled £1,720,054 (2020: £2,732,744).

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 Duchenne Research Fund were extremely fortunate to have surplus funds due to the sale of shares in Solid Biosciences by DRIL in 2018 which the Duchenne Research Fund has a third shareholding in.

The value of the Programme Related Investment has fallen further since the year end and the value in the accounts has been written down to reflect this (see note 13 of the Financial Statements). The value is principally affected by the stage and success of research which can change but the Trustees consider it prudent for this to be viewed as a permanent diminution in value.

The Trustees felt it was prudent to revisit the charity's investment strategy. The Trustees use a current account with limited funds held 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 current 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 a million pounds with a wealth management fund, Canaccord Genuity Financial Planning Limited, which is authorised and regulated by the Financial Conduct Authority (registered number 154608) which receive fees for managing the funds.

GOING CONCERN

The ongoing Covid-19 pandemic has altered the DRF's operations. Administrative costs are kept to a minimum as the charity no longer has a permanent office and employees work from home. Employees now aim as much as possible to store only digital records, and a Dropbox business subscription has been taken out to provide a larger storage space for this purpose. It was not possible to hold any in-person donor or fundraising events in the first half of 2021. However, a successful virtual event was held in the first half of 2021, and DRF supporters were able to take part in the London Marathon in the second half of 2021 as restrictions eased.

All support, correspondence and tranche payments for existing grantees; administration of new grants; receipt and acknowledgement of donations and individual fundraising efforts; and general administrative work have continued as before. Following continued government guidance to work from home wherever possible, all staff continue to work from home. At times when schools were closed or running reduced provision, work was carried out on a flexible basis. As restrictions began to ease, in the event that employee decided to meet in person, a risk assessment was undertaken, social distancing was adhered to as much as possible, and masks were worn where appropriate.

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)

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.

In so far as the Trustees are aware:

- ▶ there is no relevant information of which the charity's examiner is unaware; and
- ▶ the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant information and to establish that the examiner is aware of that information.

Approved by the Trustees on 3 October 2022 and signed on their behalf by:

Simon Kanter – Chairman
Trustee

Date: 3 October 2022

Independent examiner's report to the trustees

I report to the Trustees on my examination of the financial statements of The Duchenne Research Fund for the year ended 31 December 2021 which are set out on pages 9 to 17.

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
Greytown House
221-227 High Street
Orpington
Kent BR6 0NZ

7 October 2022

Statement of financial activities for the year ended 31 December 2021

		Unrestricted funds	
	Notes	Total 2021 £	Total 2020 £
INCOME FROM			
Donations	2	65,199	24,819
Investment income	3	77,177	16,820
Other	4	-	7,265
Total income		142,376	48,904
EXPENDITURE ON			
Raising funds	5	18,274	13,223
Charitable activities	6	332,025	207,765
Total expenditure	6	350,299	220,988
Net expenditure		(207,923)	(172,084)
(Loss)/Gain on investments	12,13	(804,767)	372,074
Net movements in funds		(1,012,690)	199,990
Fund balances brought forward 1 January 2021		2,732,744	2,532,754
Fund balance carried forward 31 December 2021		1,720,054	2,732,744

- ▶ All transactions are derived from continuing activities.
- ▶ All transactions in 2020 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 2021

	Notes	2021 £	2020 £
FIXED ASSETS			
Investments	12	1,070,555	994,545
Programme Related Investments	13	87,581	962,497
		1,158,136	1,957,042
CURRENT ASSETS			
Debtors	14	61,493	564
Cash at bank and in hand		543,086	924,489
		604,579	925,053
Creditors: Amounts falling due within one year	15	(42,661)	(149,351)
Net current assets		561,918	775,702
Net assets		1,720,054	2,732,744
FUNDS			
Unrestricted general funds		1,720,054	2,732,744
		1,720,054	2,732,744

The financial statements were approved on 3 October 2022 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 2021

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 (FRS 102) issued on 16 July 2014 and updated by Bulletin 1, the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

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 2021

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 8.

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 5.

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 2021

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 11 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	2021 £	2020 £
Donations	21,809	14,819
Yorkshire Three Peaks Challenge	-	10,000
London Marathon	30,721	-
Virtual Event – An Evening with the Duchenne Research Fund	12,669	-
	65,199	24,819

3. INVESTMENT INCOME	2021 £	2020 £
Interest	77	329
Milestone payment from ReveraGen Biopharma, Inc.	59,032	-
Investment dividends	18,068	16,491
	77,177	16,820

Notes to the financial statements for the year ended 31 December 2021

4. OTHER INCOME				2021	2020
				£	£
Rental income				-	600
Job retention scheme				-	6,665
				-	7,265
5. RAISING FUNDS				2021	2020
				£	£
Website marketing				813	114
London Marathon				349	-
Virtual Event – An Evening with the Duchenne Research Fund				3,600	-
Investment manager fee				12,777	13,294
Other costs				735	(185)
				18,274	13,223
6. ANALYSIS OF EXPENDITURE	Staff costs	Direct costs	Support costs	Total 2021	Total 2020
	£	£	£	£	£
Raising funds	-	18,274	-	18,274	13,223
Charitable activities	53,936	267,342	10,747	332,025	207,765
Total expenditure	53,936	285,616	10,747	350,299	220,988
7. DIRECT CHARITABLE EXPENDITURE				2021	2020
				£	£
Treat-NMD Programme Co-ordinator				-	17,363
HHMI Fellowship				(2,885)	-
World Muscle Society				500	500
Great Ormond Street Hospital Physiotherapist				26,321	17,547
Great Ormond Street Hospital Specialist Nurse				12,686	12,340
Neurobehavioural Issues in Duchenne – PPMD				-	76,512
DMD Care UK				20,000	20,000
DMD Care UK Psychosocial Programme				210,720	-
				267,342	144,262

Notes to the financial statements for the year ended 31 December 2021

8. SUPPORT COSTS	2021	2020
	£	£
Legal costs	874	330
Bank charges	352	565
Postage, stationery and telephone	123	119
Administration	2,790	2,670
Rent and service costs	1,792	7,696
Travel costs	6	-
Insurance	2,162	2,184
Foreign exchange variance	(367)	90
Other	615	194
Governance	2,400	4,680

10,747	18,528
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9. GOVERNANCE COSTS	2021	2020
	£	£
Auditors' remuneration	-	4,680
Independent examination	2,400	-

2,400	4,680
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10. STAFF COSTS AND TRUSTEE REMUNERATION	2021	2020
	£	£
Wages and salaries	51,975	43,268
Social Security costs	770	743
Pension Costs	1,191	964

53,936	44,975
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Two members of staff (head count) were employed during 2021 (2020: Two). No employees earned over £60,000 per annum.

No benefits are received by key management personnel (2020: £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 £1,023 (2020: £1,574) was paid for Trustee Indemnity Insurance.

Notes to the financial statements for the year ended 31 December 2021

11. TANGIBLE FIXED ASSETS	Furniture and equipment £
Cost:	
At 1 January 2021 & 31 December 2021	3,547
Depreciation:	
At 1 January 2021 & 31 December 2021	3,547
Net book value:	
At 1 January 2021 & 31 December 2021	-

12. FIXED ASSET INVESTMENTS	2021 £	2020 £
Market value at 1 January 2021	994,545	996,942
Additions	322,259	315,099
Disposals	(316,765)	(308,867)
Foreign exchange variance	367	-
Change in value in the year	70,149	(8,629)
Market value at 31 December 2021	1,070,555	994,545
Historic cost at 31 December 2021	973,650	963,956

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	337,758	310,296
Equities	442,366	376,908
Infrastructure	183,843	179,852
Cash	106,588	127,489

1,070,555	994,545
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The following investments are significant holdings within the investment portfolio:

Ishares II PLC CORE UK Gilts	50,090	53,168
Ishares III PLC UK Gilts	49,556	50,531

Notes to the financial statements for the year ended 31 December 2021

13. PROGRAMME RELATED INVESTMENTS	2021	2020
	£	£
Market value of investment at 1 January 2021	962,497	581,794
(Loss)/Gain on investment	(874,916)	380,703
	87,581	962,497

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 5th August 2014 in Delaware, USA. During March 2017 SOLID GT LLC merged with Solid Bioscience 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 the 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.

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 2021.

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

14. DEBTORS	2021	2020
	£	£
Gift Aid receivable	2,461	564
Other debtors	59,032	-
	61,493	564

15. CREDITORS	2021	2020
Amounts falling due within one year	£	£
Accruals	7,032	11,956
Other taxes and social security	2,443	2,353
Grants payable	33,186	135,042
	42,661	149,351

16. RELATED PARTY TRANSACTIONS

There were no related party transactions during the year (2020 – None).

THE DUCHENNE RESEARCH FUND

England & Wales - Charity number 1119068

Accounts



Duchenne Research Fund

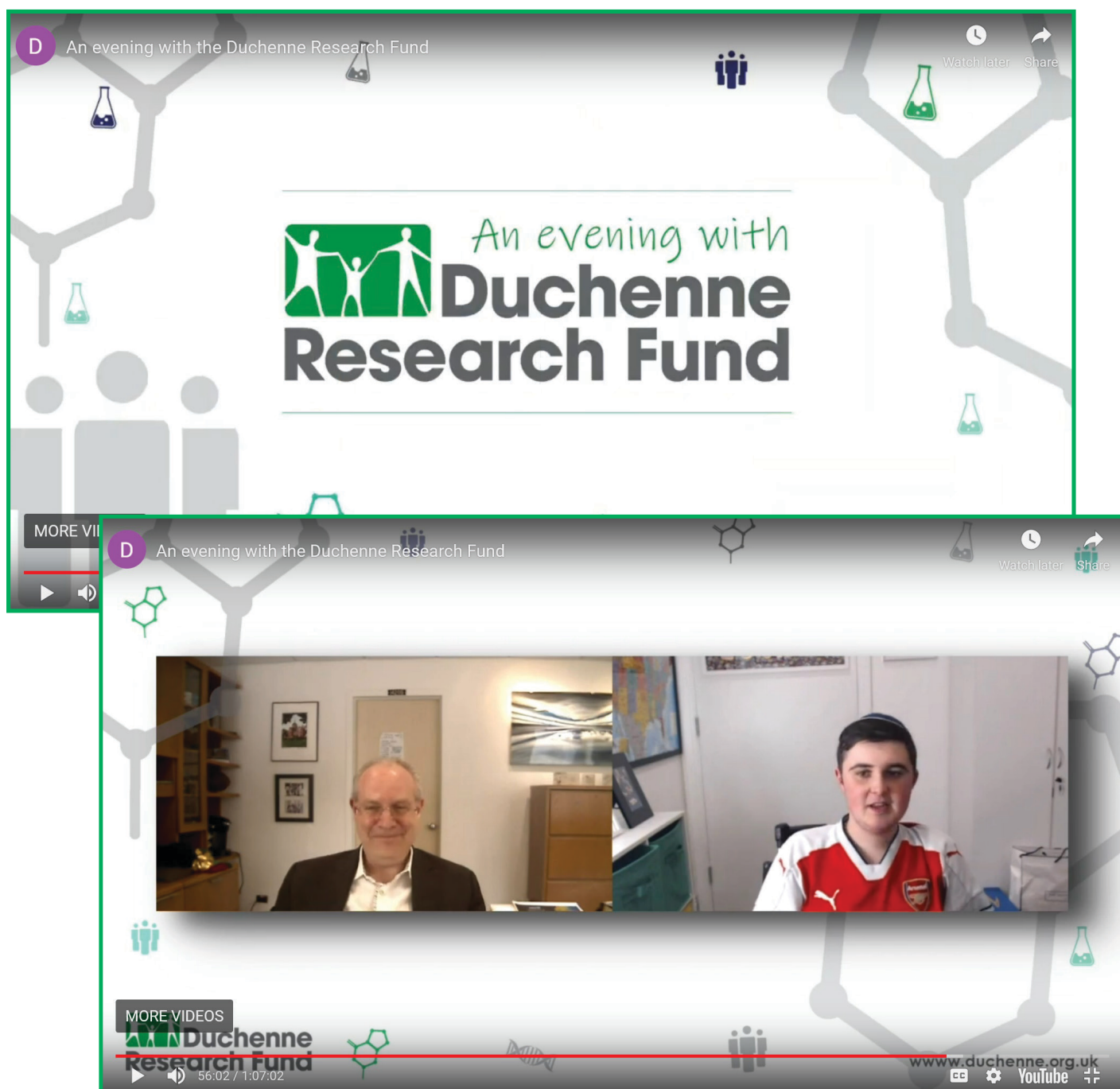
THE DUCHENNE RESEARCH FUND

**REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2020**

Registered Charity No. 1119068

**AZETS AUDIT SERVICES
Greytown House
221/227 High Street
Orpington
Kent BR6 0NZ**

The Duchenne Research Fund partners with brilliant scientists and innovative biotech companies to accelerate treatments for Duchenne muscular dystrophy. Help us find a cure for this devastating disease.



During the pandemic the DRF held its first virtual donor event which featured scientific advisory board chair Dr Ronni Cohn in conversation with Gavriel Rosenfeld about living with Duchenne

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REFERENCE AND ADMINISTRATIVE DETAILS

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
Statutory Auditor	Azets Audit Services Statutory Auditor Greytown House 221 – 227 High Street Orpington Kent BR6 0NZ

REPORT OF THE TRUSTEES

The Trustees present their report and audited financial statements for the year ended 31 December 2020.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's trust deed, the Charities Act 2011 and 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 published on 16 July 2014.

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. Sufferers lose the ability to walk, and are confined to a wheelchair by their early teens. By their early 20s these boys are left fighting for their lives as the muscles of their lungs and heart deteriorate. This devastating condition is fatal for all sufferers, 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 specifically focus our efforts on research related to the pathogenesis and treatment of Duchenne muscular dystrophy for all boys regardless of mutation.

For more information about Duchenne muscular dystrophy and the Duchenne Research Fund, please visit our website at www.duchenne.org.uk

FUNDRAISING IN 2020

Due to the Covid-19 pandemic, it was not possible to hold any in-person events in 2020.

The Prudential RideLondon-Surrey event scheduled for August 2020 was cancelled. The organisers have confirmed that the DRF's 10 event places already paid for will be converted to five London Marathon places for 2021. The 2021 London Marathon is scheduled for October 2021. The DRF has already garnered significant interest from supporters who wish to take up the marathon places and is working with them to support their fundraising efforts.

The Hackney Half Marathon scheduled for May 2020 was cancelled. The places that had been reserved by the DRF for its supporters have since been refunded. The DRF will continue to seek out suitable sporting events in 2021 and beyond that may appeal to its supporters.

In addition, DRF held a virtual event in the first quarter of 2021, to update all donors and supporters on new and existing research projects that have been made possible by their generosity. Researchers from four different projects across the UK, US and Canada presented their latest work, and Gavriel Rosenfeld, son of the DRF's founders, spoke about his experiences of living with Duchenne.

REPORT OF THE TRUSTEES (CONTINUED)

OTHER FUNDRAISING ACTIVITY

Since the DRF's inception, fundraising and donor support has 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. There have been several fundraising initiatives throughout the year undertaken by many of our supporters, including 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.

Please contact 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 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, or sign up for our newsletter via the homepage.

FUNDING STRATEGY IN 2020

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 Duchenne sufferers survive, 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 for further details on how to apply for a grant or contact research@duchenne.org.uk

REPORT OF THE TRUSTEES (CONTINUED)

Some of the research projects that the Duchenne Research Fund has funded in 2020 include:

PROJECT 1: Neurobehavioural issues in Duchenne

Although the physical challenges of Duchenne have been investigated extensively, the neurobehavioural and psychosocial issues that can result from the diagnosis are under-explored, despite their significant impact on everyday life for many people living with Duchenne and their families.



The DRF has awarded a grant to Parent Project Muscular Dystrophy (PPMD) to support its research into neurobehavioural issues in Duchenne – focusing on key areas such as learning, behaviour, depression and anxiety. The term “neurobehavioural” relates to the way the brain affects emotion, behaviour and learning. Neurobehavioral and cognitive diagnoses are not uncommon in those living with Duchenne, but access to timely assessment, diagnosis and treatment can be difficult to obtain and varied in experience and outcome. The work funded by DRF is part of PPMD’s new Brain Initiative, which aims to ensure all people living with Duchenne have access to appropriate neurobehavioural care.

PROJECT 2: ‘KineDMD’ extension

DRF previously awarded a grant to the team of Dr Aldo Faisal (pictured) at Imperial College London to develop a novel biomarker to track the progression of Duchenne. The study is called ‘KineDMD’. As part of the study, both ambulant and non-ambulant Duchenne patients wear sensor devices on each wrist and ankle to monitor their daily activities and movements outside a clinical setting.



The aim is for this approach to complement or even replace classic clinical endpoints, more sensitively capturing functional changes, and increasing the number of boys eligible for clinical trials. Following successful recruitment of patients in the first round and promising early data captured and analysed from the sensor devices, the DRF agreed to fund an extension of the study to include more patients for a longer period 2019-22, and to gather more extensive data to be analysed. This study is currently being carried out as a clinical natural history study at the Clinical Research Facility of Great Ormond Street Hospital Trust, overseen by Professor Thomas Voit and Dr Valeria Ricotti.

**Imperial College
London**

PROJECT 3: DMD Care UK

The Duchenne Research Fund has partnered with Duchenne UK and Joining Jack to fund the DMD Care UK initiative, which aims to ensure everyone living with Duchenne in the UK has access to the best care. The project was launched in October 2020 in collaboration with Dr Michela Guglieri and Cathy Turner (pictured) 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, DMD Care UK will break down the project into various working groups such as bone care, cardiac care, psychosocial care, and endocrine care, which covers puberty, adrenal suppression and steroids. As well as being a funding partner, Duchenne Research Fund staff will also participate in the working groups.

The logo for DMD Care UK features a stylized blue hexagon with three horizontal lines inside, resembling an eye or a bridge. To the right of the hexagon, the text 'DMD CARE UK' is written in a bold, dark blue font, with 'Best care for all' in a smaller, lighter blue font below it.

**DMD
CARE UK**
Best care for all

REPORT OF THE TRUSTEES (CONTINUED)

PROJECT 4: Dedicated non-ambulant clinic at Great Ormond Street Hospital

DRF had been aware for several years that there was a distinct lack of physiotherapy provision for boys and young men with Duchenne at Great Ormond Street Hospital (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 physiotherapy 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 is pleased that after years of lobbying by the charity together with key clinicians at GOSH, a dedicated clinic was established in 2019 and DRF has awarded a two-year grant spanning 2019-21 to support the post of Senior Physiotherapist Nicola Burnett (pictured). In addition, in 2020 DRF was pleased to fund a post for a Clinical Nurse Specialist to support the clinic and ensure all boys and young men receive dedicated care.



PROJECT 5: Newcastle University Clinical Research Fellow

The DRF and a consortium of seven UK Duchenne charities continue to fund a Fellowship for Dr Michela Guglieri (pictured) in partnership with Newcastle University and Newcastle University Teaching Hospital, to develop and advance the clinical trial agenda for Duchenne muscular dystrophy. The award of £250,000 over five years is being matched by Newcastle University to enable Dr Guglieri to develop the clinical trial capacity for Duchenne at the John Walton Muscular Dystrophy Research Centre and nationally.



The Newcastle upon Tyne Hospitals 
NHS Foundation Trust



PROJECT 6: 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 25th congress in October 2020, held virtually, was Eleonora Maino, a PhD candidate from the Hospital for Sick Children in Toronto for her work on targeted genome editing in vivo in a novel mouse model to correct a Duchenne muscular dystrophy duplication.



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

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 £48,904 (2019: £373,050). Total expenditure for the year was £220,988 (2019: £548,265). Of this, £144,262 (2019: £467,720) was provided as grants payable towards research into Duchenne muscular dystrophy. The result for the year was a loss of £172,084 before gains and losses (2019: loss £175,215).

The unrestricted funds at 31 December 2020 totalled £2,734,381 (2019: £2,532,754). Restricted funds totalled £nil at 31 December 2020 (2019: £nil).

REPORT OF THE TRUSTEES (CONTINUED)

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 and the Trustees and Scientific Advisory Board are evaluating and considering additional research projects on an ongoing basis. The reserves 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 Duchenne Research Fund were extremely fortunate to have surplus funds due to the sale of shares in Solid Biosciences by DRIL in 2018 which the Duchenne Research Fund has a third shareholding in. The Trustees felt it was prudent to revisit the charity's investment strategy. The Trustees use a current account with limited funds held 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 current 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 a million pounds with a wealth management fund, Canaccord Genuity Financial Planning Limited, which is authorised and regulated by the Financial Conduct Authority (registered number 154608) which receives fees for managing the funds.

GOING CONCERN REVIEW

The advent of the Covid-19 pandemic impacted the DRF's operations. There was less work for DRF staff to undertake in the first half of 2020, as the closure of universities and the circumstances of clinicians working against the backdrop of the crisis meant new research projects were unable to be reviewed and agreed in 2020. It was also not possible to hold any in-person donor or fundraising events. The decision was taken to furlough the Donor & Fundraising Manager until the end of August 2020. During this time, the charity covered 20% of the employee's salary to make up the shortfall from the government furlough scheme.

Ongoing support, correspondence and tranche payments for existing grantees; administration of grants that were close to being agreed before the start of the pandemic; receipt and acknowledgement of donations and individual fundraising efforts; and general administrative work all continued as before. Following government guidance to work from home wherever possible, the Director of Operations worked from home, as did the Donor & Fundraising Manager upon return from furlough in September 2020. At times when schools were closed or running reduced provision, work was carried out on a flexible basis. In the event that employee(s) needed to attend the office a risk assessment was undertaken, social distancing was adhered to as much as possible, masks were worn, and a cleaning schedule was implemented.

In the fourth quarter of 2020, the lease was due to expire on the DRF's office space at Symal House NW9. After deliberation and review of all relevant costings, the Trustees took the decision not to renew the lease and to convert the charity's operations to permanent remote working. Paper records are now stored in a secure storage unit, a PO Box has been set up as the charity's correspondence address, and employees now work from home on a permanent basis. Going forward employees aim as much as possible to store only digital records, and a Dropbox business subscription has been taken out to provide a larger storage space for this purpose.

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.

Fees that have already been paid for participation in external fundraising events will either be refunded or carried over to 2021. In the case of the Prudential RideLondon-Surrey, the 10 places already paid for will be converted to five London Marathon places for the October 2021 race.

REPORT OF THE TRUSTEES (CONTINUED)

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.

Auditor

In so far as the Trustees are aware:

- there is no relevant audit information of which the charity's auditor is unaware; and
- the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

Approved by the Trustees and signed on their behalf:

Simon Kanter – Chairman
Trustee

Date: 25/10/21

INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES

OPINION

We have audited the financial statements of The Duchenne Research Fund (the 'charity') for the year ended 31 December 2019 which comprise the Statement of Financial Activities, Balance Sheet, Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2020 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

BASIS FOR OPINION

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

CONCLUSIONS RELATING TO GOING CONCERN

In auditing the financial statements, we have concluded that the Trustee's use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the Trustees with respect to going concern are described in the relevant sections of this report.

OTHER INFORMATION

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

MATTERS ON WHICH WE ARE REQUIRED TO REPORT BY EXCEPTION

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the trustees' report; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES (CONTINUED)

RESPONSIBILITIES OF TRUSTEES

As explained more fully in the trustees' responsibilities statement, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error. In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

AUDITOR'S RESPONSIBILITIES FOR THE AUDIT OF THE FINANCIAL STATEMENTS

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

EXTENT TO WHICH THE AUDIT WAS CONSIDERED CAPABLE OF DETECTING IRREGULARITIES, INCLUDING FRAUD

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above and on the Financial Reporting Council's website, to detect material misstatements in respect of irregularities, including fraud.

We obtain and update our understanding of the entity, its activities, its control environment, and likely future developments, including in relation to the legal and regulatory framework applicable and how the entity is complying with that framework. Based on this understanding, we identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. This includes consideration of the risk of acts by the entity that were contrary to applicable laws and regulations, including fraud.

In response to the risk of irregularities and non-compliance with laws and regulations, including fraud, we designed procedures which included:

- Enquiry of management and those charged with governance around actual and potential litigation and claims as well as actual, suspected and alleged fraud;
- Reviewing minutes of meetings of those charged with governance;
- Assessing the extent of compliance with the laws and regulations considered to have a direct material effect on the financial statements or the operations of the entity through enquiry and inspection;
- Reviewing financial statement disclosures and testing to supporting documentation to assess compliance with applicable laws and regulations;
- Performing audit work over the risk of management bias and override of controls, including testing of journal entries and other adjustments for appropriateness, evaluating the business rationale of significant transactions outside the normal course of business and reviewing accounting estimates for indicators of potential bias.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES (CONTINUED)

OTHER MATTERS

Your attention is drawn to the fact that the charity has prepared financial statements 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 (FRS 102)" (as amended) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn. This has been done in order for the financial statements to provide a true and fair view in accordance with current Generally Accepted Accounting Practice.

USE OF OUR REPORT

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Azets Audit Services
Statutory Auditor
Greytown House
221-227 High Street
Orpington BR6 0NZ

25/10/21

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2020

	Notes	Unrestricted funds	
		Total 2020 £	Total 2019 £
INCOME FROM:			
Donations	2	24,819	50,278
Investment income	3	16,820	321,572
Other	4	7,265	1,200
Total income		48,904	373,050
EXPENDITURE ON:			
Raising funds	5	13,223	13,838
Charitable activities	6	207,765	534,427
Total expenditure	5	220,988	548,265
Net expenditure/income		(172,084)	(175,215)
Gain on investments	12,13	372,074	(3,063,113)
Net movements in funds		199,990	(3,238,328)
Fund balances brought forward 1 January 2020		2,532,754	5,771,082
Fund balance carried forward 31 December 2020		2,732,744	2,532,754

► All transactions are derived from continuing activities.

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2020

COMPARATIVE 31 DECEMBER 2019		Unrestricted funds	Restricted funds	Total 2019
	Notes	£	£	£
INCOME FROM:				
Donations	2	50,278	-	50,278
Investment income		321,572	-	321,572
Other	3	1,200	-	1,200
Total income		373,050	-	373,050
EXPENDITURE ON:				
Raising funds	5	13,838	-	13,838
Charitable activities	6	533,907	520	534,427
Total expenditure	5	547,745	520	548,265
Net expenditure/income		(174,695)	(520)	(175,215)
Loss on investments	12,13	(3,063,113)	-	(3,063,113)
Net movements in funds		(3,237,808)	(520)	(3,238,328)
Fund balances brought forward 1 January 2019		5,770,562	520	5,771,082
Fund balance carried forward 31 December 2019		2,532,754	-	2,532,754

► All transactions are derived from continuing activities.

BALANCE SHEET AS AT 31 DECEMBER 2020

	Notes	2020 £	2019 £
Fixed assets			
Investments	12	994,545	996,942
Programme Related Investments	13	962,497	581,794
		1,957,042	1,578,736
Current assets			
Debtors	14	564	3,015
Cash at bank and in hand		924,489	979,506
		925,053	982,521
Creditors: Amounts falling due within one year	15	(149,351)	(28,503)
Net current assets		775,702	954,018
Net assets		2,732,744	2,532,754
FUNDS			
Restricted funds	16	-	-
Unrestricted general funds		2,732,744	2,532,754
		2,732,744	2,532,754

The financial statements were approved on 25/10/21 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 2020

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 (FRS 102) issued on 16 July 2014, the Charities Act 2011 and UK Generally Accepted Practice as it applies from 1 January 2015.

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 2020

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.

Fundraising 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 5.

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 2020

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 12 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	2020 £	2019 £
Unrestricted funds:		
Donations	14,819	32,401
Yorkshire Three Peaks Challenge	10,000	10,000
Prudential RideLondon-Surrey	-	7,877
	24,819	50,278

3. INVESTMENT INCOME	2020 £	2019 £
Interest	329	884
Programme Related Investment dividend receivable	-	315,338
Investment dividends	16,491	5,350
	16,820	321,572

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

4. OTHER INCOME	2020 £	2019 £
Unrestricted funds:		
Rental income	600	1,200
Job retention scheme	6,665	-
	7,265	1,200

5. RAISING FUNDS	2020 £	2019 £
Website marketing	114	627
Prudential RideLondon-Surrey	-	2,814
Investment manager fee	13,294	6,900
Other costs	(185)	3,497
	13,223	13,838

6. ANALYSIS OF EXPENDITURE	Staff costs £	Direct costs £	Support costs £	Total 2020 £	Total 2019 £
Raising funds	-	13,223	-	13,223	13,838
Charitable activities	44,975	144,262	18,528	207,765	534,427
Total expenditure	44,975	157,485	18,528	220,988	548,265

Support costs have all been allocated against charitable activities.

7. DIRECT CHARITABLE EXPENDITURE	2020 £	2019 £
Restricted expenditure:		
KineDMD – Imperial College London	-	520
Unrestricted expenditure:		
KineDMD – Imperial College London	-	233,191
Treat-NMD Programme Co-ordinator	17,363	15,328
Management of AAV Pre-Immunity – University of Florida	-	84,552
Newcastle University Clinical Research Fellowship (administered by Action Duchenne)	-	7,143
World Muscle Society	500	500
Gene therapy for Becker – UCL	-	27,047
CRISPR for Duplications – Hospital for Sick Children, Toronto	-	99,439
Great Ormond Street Hospital Physiotherapist	17,547	-
Great Ormond Street Hospital Specialist Nurse	12,340	-
Neurobehavioural Issues in Duchenne – PPMD	76,512	-
DMD Care UK	20,000	-
	144,262	467,720

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

8. SUPPORT COSTS	2020	2019
	£	£
Legal costs	330	362
Bank charges	565	712
Postage, stationery and telephone	119	184
Administration	2,670	2,776
Rent and service costs	7,696	7,122
Travel costs	-	2,002
Insurance	2,184	2,182
Foreign exchange variance	90	4,802
Other	194	388
Governance	4,680	5,160

	18,528	25,690
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9. GOVERNANCE COSTS	2020	2019
	£	£
Auditors' remuneration - current year	4,680	5,160

	4,680	5,160
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10. STAFF COSTS AND TRUSTEE REMUNERATION	2020	2019
	£	£
Wages and salaries	43,268	39,577
Social Security costs	743	534
Pension Costs	964	906

	44,975	41,017
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Two members of staff (head count) were employed during 2020 (2019: Two). No employees earned over £60,000 per annum.

No benefits are received by key management personnel (2019: £Nil). The Trust considers its key management personnel to comprise those individuals listed on page 1.

None of the Trustees received any remuneration or reimbursed expenses during the year. During the year £1,578 (2019: £1,987) was paid for Trustee Indemnity Insurance.

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

11. TANGIBLE FIXED ASSETS	Furniture and equipment £
Cost:	
At 1 January 2020 & 31 December 2020	3,547
Depreciation:	
At 1 January 2020 & 31 December 2020	3,547
Net book value:	
At 1 January 2020 & 31 December 2020	-

12. FIXED ASSET INVESTMENTS	2020 £	2019 £
Market value at 1 January 2020	996,942	-
Additions	315,099	1,000,000
Disposals	(308,867)	(1,550)
Change in value in the year	(8,629)	(1,508)
Market value at 31 December 2020	994,545	996,942
Historic cost at 31 December 2020	963,956	998,207

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	310,296	327,232
Equities	376,908	266,762
Infrastructure	179,852	177,462
Cash	127,489	225,486
	994,545	996,942

The following investments are significant holdings within the investment portfolio:

Ishares II PLC CORE UK Gilts	53,168	49,666
Ishares III PLC UK Gilts	50,531	50,057

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

13. PROGRAMME RELATED INVESTMENTS

	2020 £	2019 £
Market value of investment at 1 January 2020	581,794	3,643,399
(Loss)/gain on investment	380,703	(3,061,605)
	962,497	581,794

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.

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 Trustees do not consider this to be a permanent diminution in value.

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. During March 2017 SOLID GT LLC merged with Solid Biosciences Inc. 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.

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 2020.

During the year DRIL declared a dividend to Duchenne Research Fund of £nil (2019: £315,338).

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

14. DEBTORS

	2020 £	2019 £
Gift Aid receivable	564	944
Other debtors	-	2,071
	564	3,015

15. CREDITORS

Amounts falling due within one year	2020 £	2019 £
Accruals	11,956	5,032
Other taxes and social security	2,353	-
Grants payable	135,042	23,471
	149,351	28,503

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

16. RESTRICTED FUNDS

	Balance at 1.01.20	Income	Expenditure	Balance at 31.12.20
2020	£	£	£	£
Research grants	-	-	-	-
	-	-	-	-

	Balance at 1.01.19	Income	Expenditure	Balance at 31.12.19
2019	£	£	£	£
Research grants	520	-	(520)	-
	520	-	(520)	-

17. RELATED PARTY TRANSACTIONS

One trustee, Sarah Shelley, was a director of Duchenne Research (UK) Investment Ltd (“DRIL”). During the year, dividends totalling £nil were receivable (2019: £315,338).