



# Duchenne Research Fund

THE DUCHENNE RESEARCH FUND

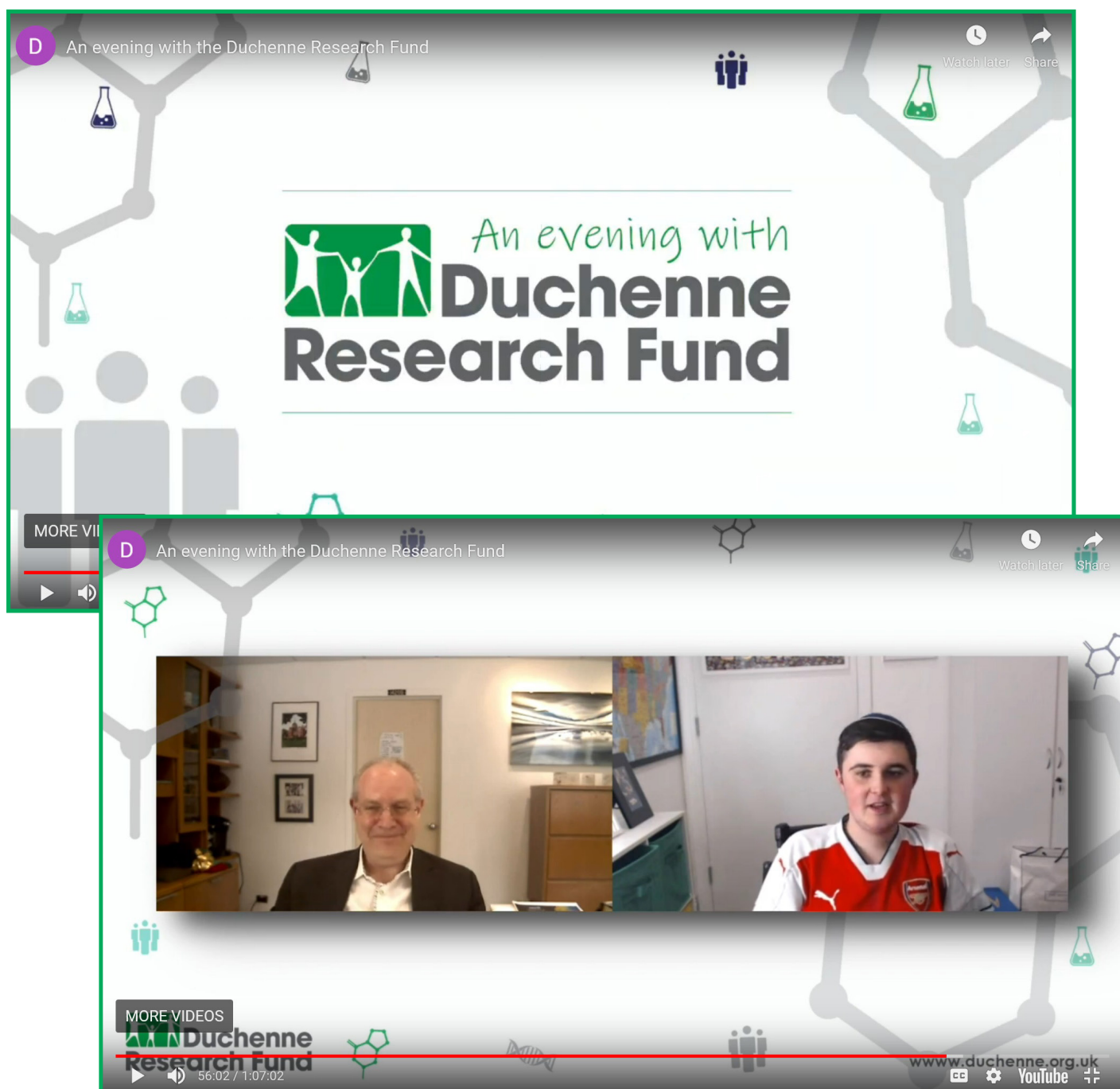
REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 DECEMBER 2021

Registered Charity No. 1119068

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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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## Reference and administrative details

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Trustees	Daniel Baum Simon Kanter Jeremy Shebson Sarah Shelley
Charity Registration Number	1119068
Principal Office	PO Box 77134 London N3 9GB
Key Management	Trustees
Banker	Bank of Scotland Teviot House 41 South Gyle Crescent Edinburgh EH12 9DR
Investment Managers	Canaccord Genuity Wealth Management 41 Lothbury London EC2R 7AE
Independent Examiner	M A Wilkes (FCA) Azets Audit Services Statutory Auditor Greytown House 221 – 227 High Street Orpington Kent BR6 0NZ

## Report of the trustees

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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](http://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)

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

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

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

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



## Report of the trustees (continued)

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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).

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### 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)

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### 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

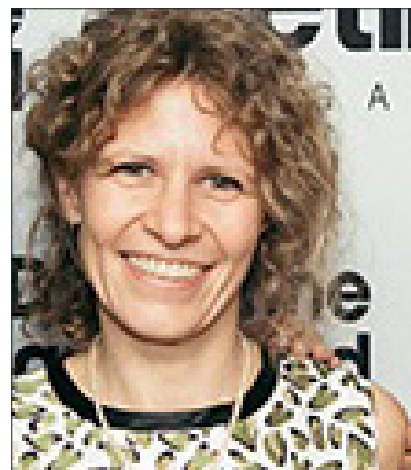
DRF had been aware for several years that there was a distinct lack of physiotherapy provision for boys and young men with Duchenne at Great Ormond Street Hospital (GOSH) once they were no longer ambulant (able to walk). Despite loss of ambulation, physiotherapy remains of enormous importance and benefit 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)

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### PUBLIC BENEFIT

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

### FINANCIAL REVIEW

Total income for the year was £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)

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### STRUCTURE, GOVERNANCE AND MANAGEMENT

#### Constitution

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

#### Trustees

The following Trustees have served during the year to date:

Daniel Baum  
Simon Kanter  
Sarah Shelley  
Jeremy Shebson

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

### STATEMENT OF TRUSTEES' RESPONSIBILITIES

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

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

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

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

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

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I report to the Trustees on my examination of the financial statements of The Duchenne Research Fund for the year ended 31 December 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 £
<b>INCOME FROM</b>			
Donations	2	65,199	24,819
Investment income	3	77,177	16,820
Other	4	-	7,265
<b>Total income</b>		<b>142,376</b>	<b>48,904</b>
<b>EXPENDITURE ON</b>			
Raising funds	5	18,274	13,223
Charitable activities	6	332,025	207,765
<b>Total expenditure</b>	<b>6</b>	<b>350,299</b>	<b>220,988</b>
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 £
<b>FIXED ASSETS</b>			
Investments	12	1,070,555	994,545
Programme Related Investments	13	87,581	962,497
		1,158,136	1,957,042
<b>CURRENT ASSETS</b>			
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		<b>1,720,054</b>	<b>2,732,744</b>
<b>FUNDS</b>			
Unrestricted general funds		1,720,054	2,732,744
		<b>1,720,054</b>	<b>2,732,744</b>

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

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## 1. ACCOUNTING POLICIES

### 1.1 Basis of preparation

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

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK (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

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### 1.4 Support costs allocation

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

The analysis of these costs is included in note 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	-
	<b>65,199</b>	<b>24,819</b>

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

## 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
					-	<b>7,265</b>
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)
					<b>18,274</b>	<b>13,223</b>
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	<b>53,936</b>	<b>285,616</b>	<b>10,747</b>	<b>350,299</b>	<b>220,988</b>
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	-
					<b>267,342</b>	<b>144,262</b>

## 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

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

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	<b>2,400</b>	<b>4,680</b>
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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

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	<b>53,936</b>	<b>44,975</b>
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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	<b>1,070,555</b>	<b>994,545</b>
Historic cost at 31 December 2021	<b>973,650</b>	<b>963,956</b>

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
	<b>1,070,555</b>	<b>994,545</b>

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
	<b>87,581</b>	<b>962,497</b>

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

The purpose of DRIL is to invest in SOLID GT LLC, a limited liability corporation incorporated on 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	-
	<b>61,493</b>	<b>564</b>

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
	<b>42,661</b>	<b>149,351</b>

## 16. RELATED PARTY TRANSACTIONS

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