



# Duchenne Research Fund

**THE DUCHENNE RESEARCH FUND**

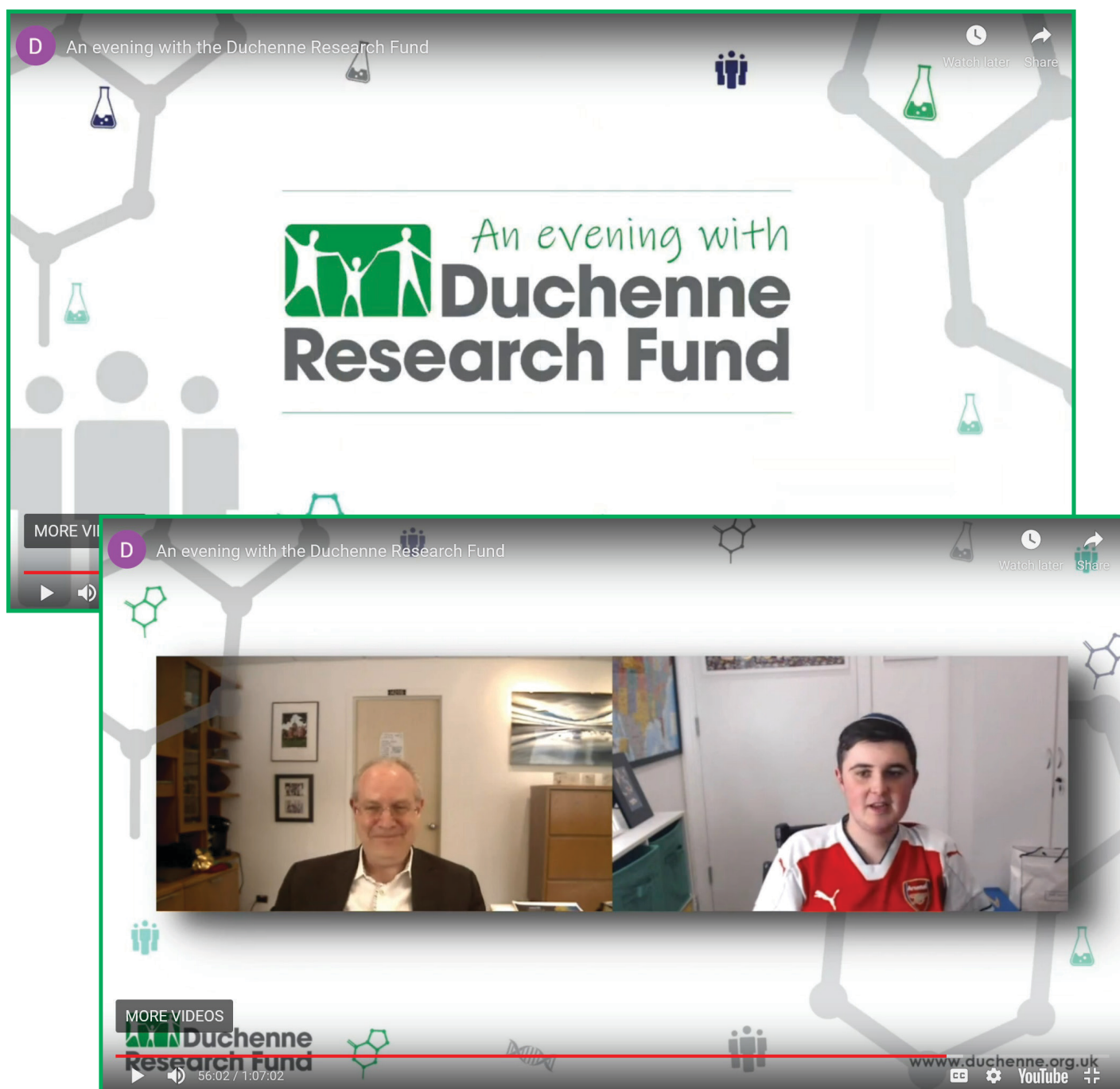
**REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 DECEMBER 2020**

**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.*



*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

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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
Statutory Auditor	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 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](http://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)

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### 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](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 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](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 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.



**DMD  
CARE UK**  
Best care for all

## REPORT OF THE TRUSTEES (CONTINUED)

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### 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)**

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### **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)

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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.

#### 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

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### 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)**

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### **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](http://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)**

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### **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

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

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

► All transactions are derived from continuing activities.

## BALANCE SHEET AS AT 31 DECEMBER 2020

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

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

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## 1. ACCOUNTING POLICIES

### 1.1 Basis of preparation

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

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

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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.

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 £
<b>Unrestricted funds:</b>		
Donations	14,819	32,401
Yorkshire Three Peaks Challenge	10,000	10,000
Prudential RideLondon-Surrey	-	7,877
	<b>24,819</b>	<b>50,278</b>

## 3. INVESTMENT INCOME

	2020 £	2019 £
Interest	329	884
Programme Related Investment dividend receivable	-	315,338
Investment dividends	16,491	5,350
	<b>16,820</b>	<b>321,572</b>

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

<b>4. OTHER INCOME</b>				2020 £	2019 £
<b>Unrestricted funds:</b>					
Rental income				600	1,200
Job retention scheme				6,665	-
				<b>7,265</b>	<b>1,200</b>
<b>5. RAISING FUNDS</b>				2020 £	2019 £
Website marketing				114	627
Prudential RideLondon-Surrey				-	2,814
Investment manager fee				13,294	6,900
Other costs				(185)	3,497
				<b>13,223</b>	<b>13,838</b>
<b>6. ANALYSIS OF EXPENDITURE</b>					
	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
<b>Total expenditure</b>	<b>44,975</b>	<b>157,485</b>	<b>18,528</b>	<b>220,988</b>	<b>548,265</b>
Support costs have all been allocated against charitable activities.					
<b>7. DIRECT CHARITABLE EXPENDITURE</b>				2020 £	2019 £
<b>Restricted expenditure:</b>					
KineDMD – Imperial College London				-	520
<b>Unrestricted expenditure:</b>					
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	-
				<b>144,262</b>	<b>467,720</b>

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

<b>8. SUPPORT COSTS</b>	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

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

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

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	<b>44,975</b>	<b>41,017</b>
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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)
	<b>962,497</b>	<b>581,794</b>

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

The purpose of DRIL is to invest in SOLID GT LLC, a limited liability corporation incorporated on 5 August 2014 in Delaware, USA.

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
	<b>564</b>	<b>3,015</b>

### 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
	<b>149,351</b>	<b>28,503</b>



## 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)	-
	<b>520</b>	-	<b>(520)</b>	-

### 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).