



# Duchenne Research Fund

**THE DUCHENNE RESEARCH FUND**

**REPORT AND FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 DECEMBER 2016**

**Registered Charity No. 1119068**

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**WILKINS KENNEDY LLP**  
**Chartered Accountants**  
**Greytown House**  
**221/227 High Street**  
**Orpington**  
**Kent BR6 0NZ**

*The time is now to cure Duchenne muscular dystrophy, the biggest genetic killer of children worldwide.*

*The Duchenne Research Fund partners with brilliant scientists and innovative biotech companies to accelerate treatments for this devastating disease.*

*Help us find a cure.*

*Gala dinner 2016*

*Image: Jeremy Coleman*

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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	Symal House 423 Edgware Road London NW9 0HU
Key Management	Daniel Buam Simon Kanter Jeremy Shebson Sarah Shelley Rachelle Rodney
Banker	Bank of Scotland Teviot House 41 South Gyle Crescent Edinburgh EH12 9DR
Statutory Auditor	Wilkins Kennedy LLP Statutory Auditor Chartered Accountants 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 2016.

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 and Republic of Ireland 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 (DMD).

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 Duchenne Research Fund 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 2016

#### THE TIME IS NOW: GALA DINNER

Following successful fundraising dinners in 2008 and 2013, on 5 May 2016 the Duchenne Research Fund hosted its third gala dinner, in the theme The Time Is Now, with the aim of raising more than £1m net of cost. Sponsors were secured to cover the costs of the evening.

Apart from the sponsorship, funds were raised via three separate avenues:

**Donations:** The voluntary dinner chairs and dinner committee helped to raise awareness of the event and attract table hosts, who in turn committed to invite guests to join their table. In February 2016 a no-obligation cocktail evening was held at the home of two of the dinner chairs, where supporters could find out more about the event, the charity and future funding plans, before committing to host a table. At the end of the dinner, guests received pledge cards to encourage them to donate following an appeal made by DRF co-founders Kerry & Doron Rosenfeld. In addition, many supporters who were unable to attend the event chose to make significant donations to mark the occasion.

**Brochure:** A voluntary brochure committee helped to secure advertisements and personal messages from a wide number of donors and supporters. The brochure was distributed at the gala dinner.

## REPORT OF THE TRUSTEES (CONTINUED)

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**Auction:** A voluntary auction committee sourced donations of merchandise, art and excursions that formed part of a “silent auction”. Supporters who were not at the dinner were able to bid on lots online, while attendees could place their bids on tablet devices available at the tables. Three lots were put up for a live auction at the end of the evening, which included exclusive meet-and-greet opportunities with celebrities.

The event drew more than 700 attendees and raised more than £1.3m, significantly exceeding expectations and previous fundraising dinner totals.

### OTHER FUNDRAISING ACTIVITY

The Duchenne Research Fund has always been reliant on fundraising to sustain its investment in research projects and to raise awareness of this life-threatening disease, and all donations are gratefully received. There have been several fundraising initiatives throughout the year undertaken by many of our supporters, including sponsored sporting events, 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 the various events and initiatives. We would particularly like to mention and thank the UCS Parents Guild, who have spearheaded a contribution from the school and its parents of more than £10,000 over the last year.

At the end of 2016 the DRF was preparing to launch a summer 2017 fundraising event: the Yorkshire Three Peaks Challenge, a 25 mile hike on Sunday 9 July 2017. A voluntary committee had already been formed to start publicising the event. Further information can be found at [www.duchenne.org.uk/y3p](http://www.duchenne.org.uk/y3p)

To find out how you can get involved in supporting or raising money for the charity, please visit [www.duchenne.org.uk/get-involved](http://www.duchenne.org.uk/get-involved), or contact [info@duchenne.org.uk](mailto:info@duchenne.org.uk)

### FUNDING STRATEGY IN 2016

The Duchenne Research Fund has its own Scientific Advisory Board, comprising three of the leading minds in the field of muscular dystrophy. This Scientific Advisory Board is spearheaded by Professor Ronald Cohn (Professor in Paediatrics, University of Toronto; Chief, Clinical and Metabolic Genetics, and Co-director, Centre for Genetic Medicine, the Hospital for Sick Children, Toronto). The other Scientific Advisors to the charity are Professor Victor Dubowitz (Emeritus Professor of Paediatrics, Imperial College London; and President of World Muscle Society), and Dr Kevin Campbell (Professor of Physiology and Biophysics at the University of Iowa). The charity has devised a robust two-tiered review process for any projects that it chooses to consider supporting.

In order to ensure the Duchenne Research Fund 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. We are also considering future expansion of the Scientific Advisory Board as our research portfolio grows.

At the Duchenne Research Fund we aim to fund research related to the pathogenesis and treatment of Duchenne that includes minority mutations. We are highly committed to supporting the most promising research proposals that aim to find therapies and a cure. In light of numerous recent developments within global Duchenne research efforts, we have had a recent focus on gene therapy research, which has been shown to be an exciting candidate for tackling Duchenne for all boys. We are also committed to exploring viable complementary therapies and outcome measures so that future gene therapy treatments can be as efficient and safe as possible.

In addition, the wealth of research in recent years has created a bottleneck in getting new Duchenne treatments out of the laboratory and into clinical trial, so 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 2016 include:

### PROJECT 1: LTBP4 – Muscle fibrosis reduction

With the funds raised at the 2016 gala dinner, the DRF is tackling inflammation and fibrosis, which are two key problems for Duchenne boys. It is believed that the protein LTBP4 prevents the activation of a key biological pathway (called TGF-beta) that is an important contributor to these disease factors. In a natural history study of Duchenne patients, the presence of a modified version of this LTBP4 protein correlated with patients' ability to walk until later ages. Based on studies in the lab of Dr Beth McNally, currently at Northwestern University, Chicago, DRF is helping fund a potential therapy that aims to stabilise the LTBP4 protein to reduce signs of muscle disease and increase overall function. The project is being managed by Solid Biosciences.



### PROJECT 2: Howard Hughes Medical Institute Research Fellowship



As part of the DRF's partnership with the Howard Hughes Medical Institute to fund a medical student undertaking research in a field related to Duchenne muscular dystrophy, in 2016 the DRF funded Harvard Medical School student Kathy Wang (pictured), whose research is entitled: 'Intervening in Regulatory T Cell Signaling in Muscular Dystrophy via IL-33'.

### PROJECT 3: Paediatric expansion at Newcastle Clinical Research Facility

DRF together with Duchenne UK has funded the expansion of the clinical paediatric unit at the Newcastle NIHR Clinical Research Facility. This has enabled immediate expansion of Duchenne muscular dystrophy research activity at the facility.



### PROJECT 4: Non-invasive imaging biomarker

Biopsies have become a difficult necessity for Duchenne patients who are involved in clinical trials. In addition to the stress on patients, each muscle can present disease differently, making certain samples hard or inappropriate to analyse. DRF is helping fund the development of a platform technology that utilises classic imaging techniques to enable clinicians to measure changes in dystrophin expression in Duchenne patients without biopsies. These funds have enabled Solid Biosciences to form key collaborations with academic and biotechnology partners to perform necessary early development activities. If successful, this technology could be used as part of future clinical studies to evaluate disease correcting approaches.



### PROJECT 5: Blood-based biomarker

Although Duchenne has been studied for many years, classic measures of disease progression rely on basic observations of movement, such as the six-minute walk test. These measurements pose a significant challenge for researchers because incremental disease improvement may go unnoticed. In addition, these measures don't apply to non-ambulatory patients – like Gavriel Rosenfeld, son of DRF founders Kerry and Doron – who may benefit from new treatment candidates, and who are currently not eligible for clinical trials. Blood-based samples will be analysed with the aim of establishing molecular signatures that correlate with stages of Duchenne, which can then be measured through blood tests. If successful, this technique may provide an alternative, more informative measure of therapeutic efficacy in clinical trials.



## REPORT OF THE TRUSTEES (CONTINUED)

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### PROJECT 6: Newcastle University Clinical Research Fellow



The DRF and a consortium of seven UK Duchenne charities continue to fund a Fellowship for Dr Michela Guglieri 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: TREAT-NMD Programme Coordinator

The DRF jointly funds a programme coordinator post at the John Walton Muscular Dystrophy Research Centre at Newcastle University. The post was initially taken up by Kim Down, and is now held by Cathy Turner, who has worked with funders and key stakeholders to ensure the needs and input of the Duchenne community are addressed during the research and clinical process. The role is being funded by DRF together with Duchenne UK (formerly the Duchenne Children's Trust) and Joining Jack.



### PROJECT 8: The Duchenne Forum

The DRF continued to fund research projects as part of the Duchenne Forum, a collaboration between UK Duchenne charities to accelerate progress in the search for effective treatments and eventually cures. The partnership has supported nine pioneering Duchenne muscular dystrophy research projects, to which it hopes to contribute £840,000 between 2013 and 2017. Some of our unspent funds are earmarked for this project, and the ultimate amount contributed will be contingent on sufficient funds being available.

### PROJECT 9: Activity monitoring

The DRF has also committed to explore activity monitoring in 2017. One of the major challenges in Duchenne drug development is linking measurable clinical trial endpoints with actual quality of life benefits. While there is a measurable and predictable decline in function during the course of the disease, each boy declines in a unique way, which can be hard to measure through classic functional tests like the six-minute walk test. DRF is supporting the exploration of activity monitoring devices. This entails employing sensors to monitor normal, daily activities of both ambulant and non-ambulant Duchenne patients. 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.

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



## 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 £1,370,532 (2015: £274,278). Total expenditure for the year was £756,610 (2015: £764,090). Of this, £426,987 (2015: £700,924) was provided as grants payable towards research into Duchenne muscular dystrophy.

The funds at 31 December 2016 were a surplus of £609,857 (2015 deficit: £4,066) of which £30,000 (2015: £30,000) were restricted.

### 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 success of the fundraising dinner, and the Trustees and Scientific Advisory Board are now evaluating and considering additional research projects. 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. From 2008 the surplus funds are placed in a high interest account and utilised for general purposes as a contingency fund as authorised by the Trustees.

### 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.

## REPORT OF THE TRUSTEES (CONTINUED)

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### STATEMENT OF TRUSTEES' RESPONSIBILITIES

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

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

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

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

Approved by the Trustees and signed on their behalf:

Simon Kanter – Chairman  
Trustee

Date: 29/08/17

## INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES

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We have audited the financial statements of The Duchenne Research Fund for the year ended 31 December 2016 which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows and the related notes. The financial reporting framework that has been applied to their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

This report is made solely to the Trustees, as a body, in accordance with Section 154 of the Charities Act 2011. Our audit work has been undertaken so that we might state to the 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.

### RESPECTIVE RESPONSIBILITIES OF THE TRUSTEES AND THE AUDITORS

As explained more fully in the Trustees' Responsibilities Statement set out on page 5, the Trustees are responsible for the preparation of financial statements which give a true and fair view.

We have been appointed as auditor under section 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that act. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's (APB's) Ethical Standards for Auditors.

### SCOPE OF THE AUDIT OF THE FINANCIAL STATEMENTS

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charity's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the Trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Trustees' Report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

### OPINION ON FINANCIAL STATEMENTS

In our opinion the financial statements:-

- give a true and fair view of the state of the charity's affairs as at 31 December 2016 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.

### MATTERS ON WHICH WE ARE REQUIRED TO REPORT BY EXCEPTION

We have nothing to report in respect of the following matters where the Charities Act 2011 requires us to report to you if, in our opinion:-

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

Michelle Wilkes (Senior Statutory Auditor)  
For and on behalf of Wilkins Kennedy LLP  
Statutory Auditor  
Chartered Accountants  
Greytown House  
221-227 High Street  
Orpington BR6 0NZ

11/09/17

## STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2016

	Notes	Unrestricted funds £	Restricted funds £	Total 2016 £	Total 2015 £
<b>INCOME FROM:</b>					
Donations	<b>2</b>	1,216,591	-	1,216,591	268,176
Investment income		260	-	260	5,962
Other	<b>3</b>	153,681	-	153,681	140
<b>Total income</b>		<b>1,370,532</b>	<b>-</b>	<b>1,370,532</b>	<b>274,278</b>
<b>EXPENDITURE ON:</b>					
Raising funds	<b>5</b>	273,430	-	273,430	9,052
Charitable activities	<b>6</b>	483,179	-	483,179	755,038
<b>Total resources expended</b>	<b>4</b>	<b>756,609</b>	<b>-</b>	<b>756,609</b>	<b>764,090</b>
<b>Net movements in funds</b>		<b>613,923</b>	<b>-</b>	<b>613,923</b>	<b>(489,812)</b>
<b>Fund balances brought forward 1 January 2016</b>		<b>(34,066)</b>	<b>30,000</b>	<b>(4,066)</b>	<b>485,746</b>
<b>Fund balance carried forward 31 December 2016</b>		<b>579,857</b>	<b>30,000</b>	<b>609,857</b>	<b>(4,066)</b>

► All transactions are derived from continuing activities.

## STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2016

COMPARATIVE SOFA 31 DECEMBER 2015	Notes	Unrestricted funds £	Restricted funds £	Total 2015 £
<b>INCOME FROM:</b>				
Donations	2	81,195	186,981	268,176
Investment income		5,962	-	5,962
Other	3	140	-	140
<b>Total income</b>		<b>87,297</b>	<b>186,981</b>	<b>274,278</b>
<b>EXPENDITURE ON:</b>				
Raising funds	5	9,052	-	9,052
Charitable activities	6	598,057	156,981	755,038
<b>Total resources expended</b>	<b>4</b>	<b>607,109</b>	<b>156,981</b>	<b>764,090</b>
<b>Net movements in funds</b>		<b>(519,812)</b>	<b>30,000</b>	<b>(489,812)</b>
<b>Fund balances brought forward 1 January 2015</b>		<b>485,746</b>	<b>-</b>	<b>485,746</b>
<b>Fund balance carried forward 31 December 2015</b>		<b>(34,066)</b>	<b>30,000</b>	<b>(4,066)</b>

► All transactions are derived from continuing activities.

## BALANCE SHEET AS AT 31 DECEMBER 2016

	Notes	2016 £	2015 £
<b>Fixed assets</b>			
Tangible fixed assets	10	287	1,174
<b>Current assets</b>			
Debtors	12	70,394	24,273
Cash at bank and in hand		862,008	352,237
		932,689	376,510
<b>Creditors:</b> Amounts falling due within one year	13	(322,832)	(381,750)
<b>Net current assets</b>		609,857	(5,240)
<b>Net assets</b>		<b>609,857</b>	<b>(4,066)</b>
<b>FUNDS</b>			
Restricted funds	14	30,000	30,000
Unrestricted general funds		579,857	(34,066)
	16	<b>609,857</b>	<b>(4,066)</b>

The financial statements were approved on 29/08/17 and signed on behalf of the Board by:

Simon Kanter - Chairman  
Trustee

Daniel Baum - Treasurer  
Trustee



## STATEMENT OF CASH FLOWS AS AT 31 DECEMBER 2016

	Notes	2016 £	2015 £
<b>Cash flow from operating activities</b>	<b>17</b>	509,511	(151,569)
<b>Net cash flow from operating activities</b>		509,511	(151,569)
<b>Cash flow from investing activities</b>			
Sale of investment			50,000
Interest received		260	5,962
<b>Net cash flow from investing activities</b>		260	55,962
<b>Net increase in cash and cash equivalents</b>		509,771	(95,607)
<b>Cash and cash equivalents at 01 January 2016</b>		352,237	447,844
<b>Cash and cash equivalents at 31 December 2016</b>		<b>862,008</b>	<b>352,237</b>
<b>Cash and cash equivalents consists of:</b>			
Cash at bank and in hand		862,088	352,237
<b>Cash and cash equivalent at 31 December 2016</b>		<b>862,088</b>	<b>352,237</b>

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2016

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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 2016**

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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. Premises overheads have been allocated on an insert detail basis and other overheads have been allocated on an insert detail basis.

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

The analysis of these costs is included in note 4.

### **1.5 Funds**

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

Designated funds comprise unrestricted funds that have been set aside by the trustees for particular purposes. The aim and use of each designated fund is set out in the notes to the financial statements.

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 Loans**

Loans are initially recognised at the transaction price including transaction costs. Subsequently, they are measured at amortised cost using the effective interest rate method, less impairment. If an arrangement constitutes a finance transaction it is measured at present value.

### **1.9 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.

### **1.10 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.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2016

### 1.11 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.

### 1.12 Going concern

The financial statements have been prepared on a going concern basis as the trustees believe that no material uncertainties exist. The trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern.

### 1.13 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 10 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

	2016 £	2015 £
<b>Restricted funds:</b>		
Donations	-	186,981
<b>Unrestricted funds:</b>		
Donations	69,881	69,695
Dinner income 2013	1,500	11,500
Dinner income 2016	1,145,210	-
	<b>1,216,591</b>	<b>268,176</b>

## 3. OTHER INCOME

	2016 £	2015 £
<b>Unrestricted funds:</b>		
Dinner sponsorship	153,681	-
Other	-	140
	<b>153,681</b>	<b>140</b>

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2016

<b>4. ANALYSIS OF EXPENDITURE</b>	Staff costs £	Direct costs £	Support costs £	Total 2016 £	Total 2015 £
Raising funds	-	273,430	-	273,430	9,052
Charitable activities	30,146	412,713	40,320	483,179	755,038
<b>Total resources expended</b>	<b>30,146</b>	<b>686,143</b>	<b>40,320</b>	<b>756,609</b>	<b>764,090</b>

Support costs have all been allocated against charitable activities.

<b>5. RAISING FUNDS</b>	2016 £	2015 £
Website marketing	-	4,655
Dinner costs	271,517	-
Other	1,913	4,397
	<b>273,430</b>	<b>9,052</b>

<b>6. DIRECT CHARITABLE EXPENDITURE</b>	2016 £	2015 £
<b>Restricted expenditure:</b>		
Solid GT	-	156,981
<b>Unrestricted expenditure:</b>		
Blood-based biomarker	140,040	-
Non-invasive imaging biomarker	108,035	-
LTBP4 - muscle fibrosis reduction	70,015	-
Treat-NMD Programme Co-ordinator	31,532	-
HHMI Fellowship	28,330	-
Muscular Dystrophy Campaign	15,012	20,937
Paediatric expansion at Newcastle Clinical Research Facility	12,606	-
Newcastle University Clinical Research Fellowship (administered by Action Duchenne)	7,143	7,143
Solid GT	-	388,116
ReveraGen BioPharma, Inc	-	82,747
Royal Veterinary College	-	45,000
Staff costs	30,146	25,530
Support costs	40,320	28,584
	<b>483,179</b>	<b>755,038</b>

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2016

<b>7. SUPPORT COSTS</b>	2016 £	2015 £
Legal costs	343	82
Bank charges	2,375	564
Postage, stationery and telephone	828	1,988
Administration	5,110	3,888
Rent and service costs	9,408	8,236
Travel costs	248	1,400
Insurance	1,921	1,344
Depreciation	887	887
Consultancy	14,274	5,000
Other	606	501
Governance	4,320	4,694

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	<b>40,320</b>	<b>28,584</b>
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<b>8. GOVERNANCE COSTS</b>	2016 £	2015 £
Auditors' remuneration - for audit	4,320	4,034
Accountancy fees	-	660

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	<b>4,320</b>	<b>4,694</b>
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<b>9. STAFF COSTS AND TRUSTEE REMUNERATION</b>	2015 £	2014 £
Wages and salaries	29,797	25,141
Social Security costs	349	389

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	<b>30,146</b>	<b>25,530</b>
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Two members of staff (head count) were employed during 2016 (2015: One). No employees earned over £60,000 per annum.

The total amount of employee benefits received by key management personnel is £11,629 (2015: £25,290). 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 £1,330 (2015: £773) was paid for Trustee Indemnity Insurance.



## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2016

### 10. TANGIBLE FIXED ASSETS

	Furniture and equipment £
<b>Cost:</b>	
At 1 January 2016	3,547
Additions	-
At 31 December 2016	3,547
<b>Depreciation:</b>	
At 1 January 2016	2,373
Charge for the year	887
At 31 December 2016	3,260
<b>Net book value:</b>	
At 31 December 2016	287
At 31 December 2015	1,174

### 11. FIXED ASSET INVESTMENTS

	2016 £	2015 £
Cost at 1 January 2016	-	50,000
Disposals	-	(50,000)
Cost at 31 December 2016	-	-

The investment was made up of 500 Blue Coast Property Preference shares.

### 12. DEBTORS

	2016 £	2015 £
Prepayments	-	21,737
Gift Aid debtor	59,506	-
Other debtors	10,888	2,536
	<b>70,394</b>	<b>24,273</b>

### 13. CREDITORS Amounts falling due within one year

	2016 £	2015 £
Accruals	322,725	29,327
Loan	-	350,000
Other taxes and social security	107	2,423
	<b>322,832</b>	<b>381,750</b>

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2016

### 14. RESTRICTED FUNDS

	Balance at 1.01.16 £	Incoming resources £	Resources expended £	Balance at 31.12.16 £
Research grants	30,000	-	-	30,000
	<b>30,000</b>	<b>-</b>	<b>-</b>	<b>30,000</b>

### 15. RELATED PARTY TRANSACTIONS

There were no related party transactions during the year.

### 16. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Restricted £	Unrestricted £	Total £
Fixed assets	-	287	287
Current assets	30,000	902,402	932,402
Current liabilities	-	(322,832)	(322,832)
	<b>30,000</b>	<b>579,857</b>	<b>609,857</b>

### 17. RECONCILIATION OF NET INCOME TO CASH FLOW FROM OPERATING ACTIVITIES

	2016 £	2015 £
Net income for 31 December 2016	613,923	(489,812)
Interest received	(260)	(5,962)
Depreciation	887	887
(Increase) / Decrease in debtors	46,121	(9,299)
Increase / (Decrease) in creditors	(58,918)	352,617
<b>Net cash flow from operating activities</b>	<b>509,511</b>	<b>(151,569)</b>