

Company number: 04899036

Registered charity number: 1101971

Registered charity number (Scotland): SC043852

ACTION DUCHENNE LIMITED
ANNUAL REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018



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ADMINISTRATIVE AND STATUTORY DETAILS

Board of Trustees	Mark Silverman Gary Fegan Sarah Colvin (Treasurer) Dr Tina Flatau Robert Laid Josephine Eames
Chief Executive Officer	Shelley Simmonds
Scientific Advisory Board	Dame Professor K Davies – Chair Dr M Wood – Vice Chair
Registered office	CAN Mezzanine 49-51 East Road Hoxton London N1 6AH
Auditors	Simpson Wreford LLP Wellesley House Duke of Wellington Avenue Royal Arsenal London SE18 6SS
Company number	04899036
Charity number	1101971 SC043852 (Scotland)
Solicitors	Morgan Cole Bradley Court Park Place Cardiff CF10 3DR
Banks	Barclays Bank PO Box 3 77 North Street, Keighley BD21 3SA The Co-operative Bank Plc PO Box 250 Skelmersdale N3 6WT

ACTION DUCHENNE LIMITED
REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 OCTOBER 2018

The Trustees present their report and audited financial statements for the year ended 31 October 2018 which have been prepared in accordance with accounting policies set out in the notes to the accounts and comply with the charity's governing document, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Act 2011, the Companies Act 2006, the Memorandum and Articles of Association 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 (FRS 102) (effective 1 January 2015).

Reference and administrative details

Action Duchenne Limited is registered under the Companies Act as a company limited by guarantee (company number 04899036). The charity registration number is 1101971 (England and Wales) and SC043852 (Scotland). The registered office address which is also the principal office address is CAN Mezzanine, 49-51 East Road, London N1 6AH.

The governing documents are the company's memorandum and articles of association. Each of the members has undertaken to contribute up to £1 in the event of dissolution. The board of Trustees manages the company on behalf of the members and the authority to appoint and remove Trustees is vested in the board.

The following persons were Directors and Trustees during the year:

Janet Bloor – resigned 1 January 2019
Shelley Simmonds – resigned 25 June 2018
Mark Silverman
Lesley Wegg – resigned 14 September 2018
Anupama Maakan – resigned 20 January 2019
Phillip Carroll – appointed 6 March 2018, resigned 20 December 2018
Gary Fegan
Sarah Colvin (Treasurer)
Dr Tina Flatau
Dr Karl Bettelheim – resigned 14 November 2017
Wayne Ebanks – resigned 15 November 2017
Josephine Eames – resigned 18 March 2019
Robert Laid – appointed 26 January 2019

The Board have agreed a process of Trustee Training and Induction, so that new and current Trustees are briefed with their legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the committee and decision-making processes, the business plan and recent financial performance of the charity and any changes therein. This includes the delivery of Charity Commission publications explaining their role.

The Trustees would like to thank Diana Ribeiro for her role as CEO, following her resignation during the year, and would like to welcome Shelley Simmonds into this role. Shelley Simmonds took over as CEO of the charitable company following her resignation as a Trustee. The Trustees would also like to thank all Trustees, past and present, who have given their time and energy to Action Duchenne.

Trustees' report

What is Duchenne?

Duchenne muscular dystrophy is a rare genetic condition caused by mutations in the dystrophin gene, which prevent production of a vital muscle protein called dystrophin. The lack of dystrophin makes muscles more susceptible to damage and leads to muscle wasting over time. People living with Duchenne experience progressive muscle weakness and typically need to use a powered wheelchair from their early teens. The heart and breathing muscles are eventually affected and most will require a ventilator in their twenties; life expectancy is around 30 years but has improved with palliative care developments. There is no cure.

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Objectives, aims and activities

The vision of Action Duchenne is a world where lives are no longer limited by Duchenne muscular dystrophy. We will work to deliver this through our three core objectives:

- Developing effective treatments for all by funding research, educating clinicians and researchers, supporting clinical trials and campaigning for access,
- Building a community by uniting families, educating about Duchenne and raising the profile of the condition to a wider audience,
- Striving for a more inclusive society by promoting the importance of human equality, day-to-day acceptance of disability and accessibility for those with Duchenne.

Building on the success of 2016/17, we have continued to be a crucial stakeholder for the Managed Access Agreement for Translarna, the first treatment available in England to treat an underlying genetic cause of Duchenne. This year, we have also campaigned for access to Raxone - a treatment believed to slow respiratory decline in people living with Duchenne who are 10 years old and over and not taking glucocorticoids (steroids). We have also started a campaign to secure access to suitable wheelchairs for everybody living with Duchenne.

The charity has continued with its proven track record in funding state-of-the art translational Duchenne research, funding a range of projects this financial year. We also published our three-year research strategy that identifies five key areas, where we will focus our investment in research going forward:

- **DMD Registry** – Strategically investing in both the capacity that underpins the UK DMD Registry, and in the database itself. With the aim of being at the forefront of facilitating clinical trials and other translational research.
- **Innovation** – We will be co-funding novel ideas by Duchenne healthcare professionals who apply and will publish their successful results.
- **Outcome measures** and natural history data.
- **Investing in tissue collection and biobanking** – Establish a viable platform and shared bank of biological specimens for the use of the community.
- **Standards of Care** – Continuing our long-standing involvement in supporting the best possible multidisciplinary standards of care, across the age spectrum.

Our international conference is growing both in attendee numbers and significance, becoming a global calendar event for both the patient and healthcare professional communities.

To find treatments to slow down the progression of Duchenne and Becker Muscular Dystrophy, with the ultimate goal of finding a cure

The Charity continued to seek innovative routes into finding treatments for Duchenne. A key example of this is a Clinical Research Fellow in Glasgow, that we jointly funded with the Chief Scientific Office (Scotland) and Muscular Dystrophy UK. This post enables young people living with Duchenne between the ages of 5 and 16 years to participate in a two-year comprehensive study of bone health. The study is progressing on schedule and already key personnel in this team are emerging as experts in bone management, and Glasgow as a specialist centre in Duchenne both in Scotland and nationally.

Action Duchenne continued to play a role in the consortium of charities: (which includes Alex's Wish, Duchenne Now and Harrison's Fund), to fund the project 'Repurposed Cancer Therapeutics as Treatments for DMD' at the University of Sheffield. This project assessed the long-term efficacy of cancer therapeutics in reducing the dystrophic pathophysiology in mdx mice (animal model for Duchenne). The study, which was successfully completed earlier this year, demonstrated potential benefit of the drugs in this model, suggesting that further work is warranted to move this work towards testing in clinical trials.

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We are co-funding a collaborative project - called UNITE-DMD - alongside Muscular Dystrophy UK and AFM Telethon. The project aims to develop and test in a clinical trial, a gene replacement therapy with the potential to be an effective treatment for most young people living with Duchenne, regardless of their mutation in the dystrophin gene. The gene therapy product has shown promising results in small and large animal models of Duchenne. The fundamental principle of gene therapy is to replace the faulty (mutated) gene with a healthy copy. However, the large dystrophin gene is challenging to deliver to cells, so a highly optimised micro- or mini- dystrophin gene - in effect, a smaller but still functional version of the gene - is used. The UNITE-DMD project includes 3 UK and 3 French research clinical teams, research and development organisation Genethon, and Sarepta Therapeutics from industry.

Also in the gene therapy area in April 2016 we provided funding for a project that will test AAV-U7 in a mouse model of Duchenne. AAV-U7 (adeno-associated virus) is a viral vector that carries a transgene (U7) to induce exon skipping in muscle cells. This study was successfully completed early this year, and publication of the results in a scientific journal is in progress.

Our annual conference in 2017 included updates on R&D for a variety of potential treatments, including timetabled focused sessions on Becker as well as Duchenne.

Increasing clinical trial capacity in the UK

Action Duchenne is delighted to report that the clinical lectureship we co-fund with a consortia of Duchenne charities (Alex's Wish, Duchenne UK, Duchenne Now, Duchenne Research Fund, Joining Jack and Harrison's Fund) at Newcastle University is progressing well. The post holder is the Chief or Principal Investigator on several prominent clinical trials, including FOR-DMD, which aims to evaluate the effectiveness and side-effects of different steroid regimes, and VISION-DMD, which aims to test the safety and effectiveness of vamorolone (also known as VBP15) - a drug designed to have the efficacy of a steroid, without the severe associated side effects.

As part of the Newcastle Plan - a plan agreed by several UK charities to increase clinical trial capacity in the UK - we are pleased to be funding the Neuromuscular Clinical Research Physiotherapist post at the Bristol Royal Hospital for Children. The post-holder has focused on establishing the centre as a clinical trial site for Duchenne studies and laying the foundations for the upcoming clinical trials.

We have also supported the National Hospital for Neurology and Neurosurgery in London with a clinical trial set-up fund. With a growing number of adult Duchenne patients attending the centre, this grant aims to increase the number of adult patients who are given the opportunity to participate in clinical trials.

Develop new outcome measures for Duchenne muscular dystrophy

It has been proposed that a novel wearable device called ActiMyo® could provide real-world data that could be used as an outcome measure in clinical trials. Importantly, the device could measure activity in both ambulant and non-ambulant people living with Duchenne. If validated successfully as an outcome measure, this type of data may lead to shorter trials or trials which require a reduced number of participants. ActiMyo® is a portable device that provides information on a body's specific force, angular rate, using a combination of sensors including an accelerometer, magnetometer and gyroscope. It is already being used experimentally in clinical trials and Action Duchenne is funding the further validation of ActiMyo® in a large sample including both patients and healthy volunteers. This will provide essential information about how the tool might work as a primary outcome measure in clinical trials.

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Campaigning for better standards of care available to all

The campaigns focus continued to be on access to medicines for Duchenne. This includes being an important stakeholder in the Managed Access Agreement for Translarna in England, also implemented in Wales and Northern Ireland. Action Duchenne was a key partner in developing this agreement and, legally, is a co-signatory with responsibility in ensuring patient participation. Part of being a stakeholder is explaining the terms of the agreement to families and young people who are eligible, but also to ensure the patient voice is represented in meetings with NICE and the pharmaceutical company.

The Medicines and Healthcare products Regulatory Agency (MHRA) gave Raxone a positive scientific opinion through the Early Access to Medicines Scheme (EAMS). Raxone is a treatment for Duchenne that has shown in clinical trials to slow the progression of respiratory decline. Those eligible are living with Duchenne who are 10 years old and over, who are not taking glucocorticoids (steroids) and through a series of tests are shown to be in a decline of respiratory function. The aim of the EAMS is to provide earlier availability of promising new unlicensed medicines to UK patients that have a high unmet clinical need. Action Duchenne has been directly involved in communication and working with all UK charities and other stakeholders in facilitating this scheme.

In January 2018 the new Standards of Care for Duchenne were published and detail a global consensus on the best clinical practice and care for those living with Duchenne. Action Duchenne together with other patient organisations from the UK and internationally have been working to develop a new Duchenne Guide for Families. This Guide will give patients, families and caregivers the information they need to work with their health care and support providers to ensure optimal care.

During the year, the charity continued with its Unplanned and Unexpected A&E campaign and via Freedom of Information requests, identified that unexpected deaths had occurred following hospital admissions. A likely cause of this is that patients are being recorded with the wrong ICD coding and we aim to address and highlight this by pushing for Duchenne to be recognised with its own ICD code to ensure correct reporting of the underlying condition of patients admitted to A&E.

A wheelchair campaign will commence in the next financial year with the aim of exploring how wheelchairs are currently obtained and funded by families. It is our understanding that many families self-fund their own wheelchairs and/or rely on charity donations because wheelchairs offered by the NHS do not meet a medical need. Ultimately, we want an outcome where no one with Duchenne has to self-fund a wheelchair to meet their medical need.

Provide information and support to families living in the UK

The registry continued to grow, with more than 2,000 participants, including over 1,000 guardians. Significant outcomes of the registry have been featured publications, but also a number of enquiries from pharmaceutical companies. The registry also featured in a number of different UK and EU-led surveys on key topics such as clinical trial participation.

Action Duchenne continues to support the Accident and Emergency (A&E) mobile phone app, whilst providing the pocket guide (A&E) to those without access to the app. Information can be entered via the website or directly via the app. These will both be updated with the revised standards of care.

The conference in 2017 was hugely successful with over 500 delegates attending from at least 20 countries. The involvement of young people and adults living with Duchenne was invaluable with the breadth of sessions ranging from independent living for adults, education and support, standards of care, translational research and advances in clinical trials in Duchenne. Half a day at the 2017 conference focused solely on Becker Muscular Dystrophy with around 15 attendees.

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Financial Review

To a reasonable extent, the charity budgets according to the predicted donation environment. In 2017/18 the Charity had a net deficit for the year of £205,026 following a surplus of £165,902 in the previous year. The year has been characterised by a challenging environment across the whole charity sector. For Action Duchenne this materialised as a reduction in donations and legacies received, down 38.3% from a previous £397,007 to £245,084. Scientific research and grants payable increased by 26.8% from £494,825 to £627,228 which compounded the deficit for the year.

Income was £775,993 in 2017 and £538,956 in 2018, a reduction of 30.5% overall. All sources of income showed corresponding drop from 2017 with amounts generated from donations and legacies falling 38.3%, income from other trading activities falling 13.3% and a reduction in income from charitable activities reducing 50.3%.

Expenditure on charitable activities was £666,171 in the year (2016/17: £534,076), including allocated support costs. This represents 89.5% of total expenditure, compared to 87.5% in the previous year. Of this, £627,228 was spent on research and grants payable (2016/17: £494,825). The institutions receiving research funding during the year were CHU Outcome Measures, the CSO, Sheffield University, UPPMD membership, Genetic Alliance UK membership, University Hospitals Bristol NHS Foundation and the Royal Holloway University – Gene Therapy.

Operational costs continue to be managed tightly and the Board of Trustees have initiated a focused programme of work to correct the fall in charitable income in particular.

Reserves

The Finance Committee, on behalf of the Board of Trustees, monitors the level of unrestricted reserves in the general fund, which is compared to the minimum level of required reserves calculated in accordance with the reserves policy. This is based on three months of charity expenditure, which is aimed at providing cover in the event of a sudden reduction in income:

- To allow time for reorganisation in the event of a downturn in income.
- To protect ongoing work programme.
- To allow the Charity to meet its objectives.
- To ensure the General funds are allocated to meet the Charity's Aims and Objectives.

Unrestricted reserves are £57,288 down from £191,846 in October 2017 and restricted reserves are £79,278 (2017: £149,746). The unrestricted reserves exceed the minimum required under the policy.

Grant Making Policy

The Charity has a programme of grant making to provide funds for new research towards finding viable treatments and ultimately curing Duchenne Muscular Dystrophy. The rapidly changing developments in international research demand a constant updating of the Charity's grant making policy. The Charity has secured a Scientific Advisory Board (SAB) to peer review grant applications as part of a two-stage review process and to advise Action Duchenne on the most effective way to fund research to meet our objectives. The Charity systematically reviews and agrees its research and grant making policy during the development of its annual business plan.

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Investment Policy

The Charity's assets will be invested in accordance with the Trustee Act 2000 and the trust instrument. Any investments will be managed prudently and in such a way as to provide sufficient income to enable the charity to carry out its purposes effectively both in the short term and over the longer term. In order to spread the level of risk, no single investment or account should exceed 50% of the total funds held by the charity without the agreement of the Finance Committee.

While the Charity's overall investment policy has been set by the Board of Trustees as a whole, responsibility for ongoing investment matters has been delegated to the Finance Committee.

Plans for the future

Action Duchenne continues to be the longest-standing organisation in the UK for the wider Duchenne community and was the first patient organisation to publish a Duchenne research strategy. We will build on the success of Translarna and the momentum of other campaigns, to ensure that access to medicines and improved standards of care, as well as a more inclusive society, can benefit the entire Duchenne population.

We will support those who wish to fundraise for us and those who are at different and difficult periods in their Duchenne journey. In doing so we will continue to fund innovative translational research for the wider Duchenne population. By supporting new treatment avenues and by working with the experts and informing the families we will also ensure international standards of care guidelines are adopted as widely as possible.

Internal control and processes

The systems of internal control, put in place by the Trustees, are designed to provide reasonable but not absolute assurance against material misstatement or loss and include:

- The Charity's Finance Manager produces monthly financial information for the CEO and Board of Trustees.
- Financial reports are reviewed at the quarterly Board meetings as part of measures to ensure that the resources of the Charity are effectively allocated and utilised.
- Expenditure approval limits beyond which approval must be sought by the Finance Manager from the CEO and then the Finance Committee and/or the board of Trustees.
- The Finance Committee prepares a business plan with internally audited yearly accounts and projections of budget expenditure at the end of each year. This is fully discussed at a specially convened meeting of all the Charity's Trustees
- The Finance Committee is responsible for overseeing the annual audit of the accounts by Simpson Wreford LLP
- Regular consideration by the Trustees of financial results, variances from budgets, forecasts and performance indicators
- Chain of command overseen by the CEO, delegation of authority and segregation of duties
- Ensuring that the Charity submits Annual Reports to the Charity Commission and Companies House in line with current standard reporting procedures
- Trustees are encouraged to undertake Trustee and governance training by accredited providers of education to the charity sector
- The Board maintains a forward programme of process/policy update and creation, this includes policies for:
 - Identification and management of risk
 - Reviewing and updating the Staff Handbook to ensure that the Charity complies with changes in HR and Government legislation
 - Introduction of a Trustee roles and responsibilities document

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- Monitoring and reviewing the Charities child protection policies and procedures
- Monitoring and reviewing the Charities Equal opportunities Policies
- Introduction of a code of practice for social media and digital / electronic communications

The Board of Trustees of Action Duchenne Limited meet face to face or via remote conferencing at least four times a year. The Board can have up to 15 members and 3 of the longest serving Trustees must stand for re-appointment or resign every three years at the Annual General Meeting.

The Charity aims to involve parents and those living with Duchenne Muscular Dystrophy as key members of the Board of Trustees. A balance, however, is sought by recruiting non-family members who have other scientific, business and professional expertise. The Board is divided into sub committees, with specific terms of reference for, research, finance and fundraising and for campaigns.

The remit of the Finance Committee is to monitor the annual budget in line with the agreed annual business plan and oversee the audit of accounts. The business plan was prepared and discussed at a special meeting of all Trustees. The finance committee oversees the Charity's reserves policy and investments.

A DMD Registry Steering Committee remains in operation, meeting on at least an annual basis. At the year ending 31 October 2018, the membership was as follows:

- Chair: Dr Jo McCauley (molecular geneticist), Guys Hospital
- Prof. Hanns Lochmuller (TREAT-NMD Activity Leader for Registries)
- Prof. Kate Bushby (clinician), John Walton Centre, Newcastle, International Centre for Life
- Dr Michela Guglieri (TREAT-NMD Institute of Human Genetics, Newcastle University)
- Dr. Stephen Abbs (molecular geneticist), Guy's Hospital
- Dr. Emma Ashton (molecular geneticist), GOSH
- Dr. Anne-Marie Childs (clinician), Leeds General Infirmary
- Dr. Ros Quinlivan (clinician), UCL, Queen's Square
- Nick Catlin, Parent representative
- Jack Bosanquet, Patient representative
- Neil Bennett (Head of Research), Action Duchenne
- Shelley Simmonds (CEO), Action Duchenne
- Angela Stringer, Action Duchenne, as Secretariat

The Chair, who is a molecular geneticist at Guy's and St Thomas' NHS Foundation Trust, reviews and audits the information in the registry and alongside the DMD Registry Curator ensures compliance with GDP.

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Trustees' Responsibilities

The Trustees (who are also Directors of the charity for the purposes of company law) 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).

Company law 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 charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company 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;
- make judgments and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- there is no relevant audit information of which the charitable company'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.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Auditors

Simpson Wreford LLP were reappointed as Independent Auditors during the year and have expressed their willingness to continue in that capacity.

The above report has been prepared in accordance with the special provisions of Section 419(2) of the Companies Act 2006 relating to small companies.

Signed on behalf of the Board of Directors.



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Sarah Colvin
Treasurer

Date: 25 July 2019

INDEPENDENT AUDITORS' REPORT
TO THE TRUSTEES OF ACTION DUCHENNE LIMITED
FOR THE YEAR ENDED 31 OCTOBER 2018

Opinion

We have audited the financial statements of Action Duchenne Limited for the year ended 31 October 2018 which comprise the Statement of Financial Activities, Balance Sheet, Cash Flow Statement and the related 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 and Republic of Ireland (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 October 2018 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;
- have been prepared in accordance with the requirements of the Charities Act 2011 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

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

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the Charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

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, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

INDEPENDENT AUDITORS' REPORT

TO THE TRUSTEES OF ACTION DUCHENNE LIMITED FOR THE YEAR ENDED 31 OCTOBER 2018

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

In the light of the knowledge and understanding of the Charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report. We have nothing to report in respect of the following matters in relation to which the Charities Accounts (Scotland) Regulations 2006 and the Charities Act 2011 requires us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us;
- the financial statements are not in agreement with the accounting records and returns;
- certain disclosures of Trustees' remuneration specified by law are not made;
- we have not obtained all the information and explanations necessary for the purposes of our audit;
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemption in preparing the Trustees' report and take advantage of the small companies' exemption from the requirement to prepare a strategic report.

Responsibilities of the Trustees

As explained more fully in the Trustees' responsibilities statement set out on pages 3-10, the Trustees (who are also the directors of the charitable company for the purposes of company law) 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 they 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.

INDEPENDENT AUDITORS' REPORT
TO THE TRUSTEES OF ACTION DUCHENNE LIMITED
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Our responsibilities for the audit of the financial statements

The Trustees have elected for the financial statements to be audited in accordance with the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Act 2011 rather than the Companies Act 2006. Accordingly, we have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and 144 of the Charities Act 2011 and report in accordance with regulations made under section 154 of that Act.

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

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

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 and Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. 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's Trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Simpson Wreford LLP
Statutory Auditor
Wellesley House
Duke of Wellington Avenue
London
SE18 6SS

Dated: 26 July 2019

Simpson Wreford LLP is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

ACTION DUCHENNE LIMITED

**STATEMENT OF FINANCIAL ACTIVITIES
(including statement of income and expenditure)
FOR THE YEAR ENDED 31 OCTOBER 2018**

	Notes	2018 Unrestricted funds	2018 Restricted funds	2018 Total funds	2017 Total funds
Income and endowments from:	4				
Donations and legacies		245,084	-	245,084	397,007
Charitable activities		2,956	42,857	45,813	92,094
Other trading activities		247,492	-	247,492	285,591
Investments		<u>567</u>	<u>-</u>	<u>567</u>	<u>1,301</u>
Total income		<u>496,099</u>	<u>42,857</u>	<u>538,956</u>	<u>775,993</u>
 Expenditure on:	 16				
Raising funds:					
Cost of events and general fundraising		77,811	-	77,811	76,015
Charitable activities:					
Campaigning and education		26,331	-	26,331	27,453
Scientific and clinical research and grants payable		472,359	154,869	627,228	494,825
Improved management and medical care		<u>12,612</u>	<u>-</u>	<u>12,612</u>	<u>11,798</u>
Total expenditure		<u>589,113</u>	<u>154,869</u>	<u>743,982</u>	<u>610,091</u>
Net income/(expenditure)		(93,014)	(112,012)	(205,026)	165,902
Transfers between funds		<u>(41,544)</u>	<u>41,544</u>	<u>-</u>	<u>-</u>
Net movement in funds		<u>(134,558)</u>	<u>(70,468)</u>	<u>(205,026)</u>	<u>165,902</u>
 Reconciliation of funds					
Balance at 1 November 2017		<u>191,846</u>	<u>149,746</u>	<u>341,592</u>	<u>175,690</u>
Balance at 31 October 2018		<u>57,288</u>	<u>79,278</u>	<u>136,566</u>	<u>341,592</u>

The notes on pages 17 to 27 form part of these financial statements.

ACTION DUCHENNE LIMITED

**BALANCE SHEET
AS AT 31 OCTOBER 2018**

	Notes	2018		2017	
		£	£	£	£
Fixed assets					
Tangible assets	5		1,513		2,018
Investments	6		<u>2</u>		<u>1</u>
			1,515		2,019
Current assets					
Debtors	7	84,474		52,539	
Cash at bank and in hand		<u>185,256</u>		<u>426,546</u>	
		269,730		479,085	
Current liabilities					
Creditors due within one year	8	<u>(134,679)</u>		<u>(139,512)</u>	
Net current assets			<u>135,051</u>		<u>339,573</u>
Net assets			<u>136,566</u>		<u>341,592</u>
Represented by:					
Restricted funds	12		79,278		149,746
Unrestricted funds	13		<u>57,288</u>		<u>191,846</u>
			<u>136,566</u>		<u>341,592</u>

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 October 2018, although an audit has been carried out under section 144 of the Charities Act 2011. No member of the company has deposited a notice, pursuant to section 476, requiring an audit of these accounts under the requirements of the Companies Act 2006.

These accounts have been prepared in accordance with the provisions applicable to company's subject to the small companies' regime.

The financial statements on pages 14 to 27 were approved by the Trustees on 25 July 2019 and signed on their behalf by:



.....
Sarah Colvin – **Trustee/Treasurer**

Registered charity number – 1101971

Registered charity – SC043852 (Scotland)

ACTION DUCHENNE LIMITED

STATEMENT OF CASHFLOWS
FOR THE YEAR ENDED 31 OCTOBER 2018

	Notes	2018 Total £	2017 Total £
Cashflows from operating activities:			
Net cash (used in) provided by operating activities	18	<u>(241,856)</u>	<u>27,013</u>
Cashflows from investing activities:			
Dividends, interest and rents from investments		567	1,301
Purchase of investments		(1)	-
Purchase of property plant and equipment		<u>-</u>	<u>(500)</u>
Net cash provided by (used in) investing activities		<u>566</u>	<u>801</u>
Change in cash and cash equivalents in the reporting period		(241,290)	27,814
Cash and cash equivalents as at 1 November 2017	19	<u>426,546</u>	<u>398,732</u>
Cash and cash equivalents as at 31 October 2018	19	<u>185,256</u>	<u>426,546</u>

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018

1. Accounting policies

- a) Company information – Action Duchenne Limited is a company limited by guarantee, incorporated in England and Wales and registered as a charity with the Charities Commission and in Scotland. The principal and registered office is CAN Mezzanine, 49-51 East Road, Hoxton, London, N1 6AH.
- b) The financial statements have been prepared in accordance with accounting policies set out in the notes to the accounts and comply with the charity's governing document, 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 (FRS 102) (effective 1 January 2015) - (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Action Duchenne Limited meets the definition of a public benefit entity under FRS102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

The financial statements are prepared in sterling, which is the functional currency of the company. Monetary amounts in the financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation long-term leasehold property and certain financial instruments at fair value or amortised cost. The principal accounting policies are set out below.

The effects of events relating to the year ended 31 October 2018 which occurred before the date of approval of the financial statements by the Trustees has been included in the financial statements to the extent required to show a true and fair view of the state of affairs as at 31 October 2018 and the results for the year ended on that date.

- c) Going Concern – at the time of approving the financial statements, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.
- d) Donations and legacies are accounted for when receivable by the Charity. Revenue grants are credited to the Statement of Financial Activities (SOFA) when the Charity is considered to have entitlement to the assets. It is probable that the resources will be received, and the monetary value of incoming resources can be measured with sufficient reliability. If grants are related to a future donor-imposed period, the income is deferred until that period. Other income is accounted for on an accrual basis.
- e) Direct charitable expenditure includes the direct costs of the activities. Support costs are allocated per note 16 on the basis of time spent.
- f) Fundraising costs are the direct costs of obtaining funds, and attributable allocated support costs.
- g) Governance costs include those costs incurred in the governance of the Charity, such as audit fees.
- h) Programme related investments are included in the accounts at cost less amounts written off as grants payable.

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018**

1. Accounting policies (continued)

- i) Fixed assets are only capitalised where their values exceeds £500. Fixed assets are stated at cost and depreciation is calculated so as to write off the cost of an asset, less its estimated residual value, over the useful economic life of that asset at a rate of 25% reducing balance.
- j) Impairment of fixed assets - at each reporting date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).
- k) Debtors – trade and other debtors are recognised at the settlement amount due after trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.
- l) Cash and cash equivalents – include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.
- m) Financial instruments – the charity only has financial assets and liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.
- n) Creditors and provisions – are recognised at the point where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discount due. All expenditure is accounted for on an accruals basis and includes irrecoverable Value Added Tax.

Grants payable are payments made to third parties in the furtherance of the Charity's objectives. Single or multi-year grants are recognised as resources expended when a grant commitment is made without condition, or when the condition will not in practice allow the Charity to avoid the liability.

Performance related grants are charged to SOFA as performance conditions are met.

- o) Operating lease commitments – rentals paid under operating leases are charged on a straight-line basis over the lease term.
- p) Employee benefits – the cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.
- q) Pension scheme – the charity provides a defined contribution scheme for all new employees, the assets of which are held separately from those of the company in an independently administered fund. Contributions to this scheme are charged to the income and expenditure account as they become payable.
- r) Fund accounting – General funds are unrestricted funds which 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 made to the charity are to be used in accordance with specific restrictions imposed by donors. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018

2. Employees

Costs to the company were as follows:

	2018	2017
	£	£
Gross wages:		
- projects	35,000	38,285
- non-projects	182,644	173,481
Staff pension	2,527	1,640
Employer's NI contributions	<u>16,180</u>	<u>10,102</u>
	<u>236,351</u>	<u>223,508</u>

The average number of full-time employees during the year was 8 (2017 - 9) analysed as follows:

	2018	2017
	Number	Number
Management	1	2
Research	1	1
Fundraising	4	4
Projects	<u>2</u>	<u>2</u>
	<u>8</u>	<u>9</u>

There were no employees at Action Duchenne Limited whose remuneration exceeded £60,000.

3. Net incoming resources is stated after charging

	2018	2017
	£	£
Audit and accountancy fees	7,380	7,949
Depreciation	<u>505</u>	<u>672</u>

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018**

4. Analysis of income and endowments

	Unrestricted funds £	Restricted funds £	2018 Total £	2017 Total £
Donations and legacies				
- Grants of a general nature	101	-	101	144,278
- Membership subscriptions	43,805	-	43,805	43,365
- Fundraising income	168,210	-	168,210	165,096
- Gift Aid	27,672	-	27,672	38,780
- Other	5,296	-	5,296	5,488
Charitable activities				
- Performance related grants	-	42,857	42,857	88,208
- Other	2,956	-	2,956	3,886
Other trading activities				
- Fundraising events	82,444	-	82,444	140,201
- Non-charitable trading activities	164,906	-	164,906	144,625
- Shop income	142	-	142	765
Investments	<u>567</u>	<u>-</u>	<u>567</u>	<u>1,301</u>
	<u>496,099</u>	<u>42,857</u>	<u>538,956</u>	<u>775,993</u>

5. Tangible assets

	Computer Equipment £	Fixtures & fittings £	Office equipment £	Total £
Cost				
At 1 November 2017	25,147	1,098	6,839	33,084
Additions	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
31 October 2018	<u>25,147</u>	<u>1,098</u>	<u>6,839</u>	<u>33,084</u>
Depreciation				
At 1 November 2017	23,394	1,071	6,601	31,066
Charge for the year	<u>438</u>	<u>7</u>	<u>60</u>	<u>505</u>
At 31 October 2018	<u>23,832</u>	<u>1,078</u>	<u>6,661</u>	<u>31,571</u>
Net book value				
At 31 October 2018	<u>1,315</u>	<u>20</u>	<u>178</u>	<u>1,513</u>
At 31 October 2017	<u>1,753</u>	<u>27</u>	<u>238</u>	<u>2,018</u>

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018**

6. Investments

	2018 £	2017 £
Programme related investments		
Convertible loan note in Halo Therapeutics LLC	225,000	225,000
Less: treated as grant paid 2012	<u>(224,999)</u>	<u>(224,999)</u>
	<u>1</u>	<u>1</u>

Halo Therapeutics is a clinical-stage biopharmaceutical firm focused on developing innovative therapies for rare fibrotic diseases such as Duchenne Muscular Dystrophy. The programme has now merged with DART to ensure IP protection in anticipation of FDA approval. 2014 saw an application being made to the US regulatory body that included nonclinical study reports, pharmacokinetics, human safety and biomarker data from the DMD clinical program, and a comprehensive analysis and summary of the year's activity.

	2018 £	2017 £
Other investments		
1,371 Ordinary shares of £0.001	<u>1</u>	<u>-</u>

Pepgen Limited (company number 11170794) is a company focused on biotech research and development, to improve the delivery and effectiveness of exon skipping drugs as a way of restoring dystrophin. In April 2018, Action Duchenne was donated a number of shares in the company in recognition of previous support and funding to the University of Oxford, which amounted to a grant of £48,000 in April 2017. These shares are currently held at nominal value in the balance sheet on the absence of any reliable valuation information.

7. Debtors

	2018 £	2017 £
Other debtors	40,636	10,439
Prepayments	<u>43,838</u>	<u>42,100</u>
	<u>84,474</u>	<u>52,539</u>

ACTION DUCHENNE LIMITED

STATEMENT OF CASHFLOWS

FOR THE YEAR ENDED 31 OCTOBER 2018

8. Creditors due within one year

	2018	2017
	£	£
Trade creditors	1,909	1,959
Accruals and deferred income	127,078	132,174
Tax and social security	<u>5,692</u>	<u>5,379</u>
	<u>134,679</u>	<u>139,512</u>

Deferred income included above relates to corporate sponsorship income £88,455 (2017 - £63,500), Registration fee income for annual conference event £12,821 (2017 - £14,994) and Newcastle CRF income received in advance of £14,286 (2017 - £28,571). These have been deferred as they relate to the 2018/19 year and will be recognised as income in that period.

9. Trustees' expenses and indemnity insurance

A Trustee may receive reimbursement of reasonable out-of-pocket expenses actually incurred in running the charity. In 2018, the total out-of-pocket expenses reimbursed was £3,660 (2017 - £409) for travel and accommodation.

No indemnity insurance was paid by the company on behalf of the Trustees.

No Trustees received any remuneration from the Charity during the year.

10. Control relationships

The company is limited by guarantee with the liability of the members limited to £1 each in the event of a winding up. Consequently, no Trustee or group of Trustees has overall control of the company.

11. Other professional services provided by the auditors

In common with many other businesses of our size and nature, we use our auditors to assist with the preparation of the financial statements.

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018

12. Restricted funds

The Charity has a number of restricted funds which are for future use.

The movements for the year are as follows:

	Newman's Own Foundation	De Laszlo Foundation	Newcastle CRF	Steve Winder Foundation	Godfrey Adams	Total
At 1 November 2017	29,278	10,000	-	60,468	50,000	149,746
Donations / legacies / grants	-	-	42,857	-	-	42,857
Grants payable and research costs	-	(44,401)	-	(60,468)	(50,000)	(154,869)
Transfers from unrestricted funds	-	<u>34,401</u>	<u>7,143</u>	-	-	<u>41,544</u>
As at 31 October 2018	<u>29,278</u>	-	<u>50,000</u>	-	-	<u>79,278</u>

Details of funds

Newman's Own Foundation – support programmes creating awareness and improving the quality of life of Duchenne patients.

De Laszlo Foundation – grant received to further medical research.

Newcastle CRF – a consortia of 5 UK Duchenne charities that funds a senior lectureship at Newcastle University.

Steve Winder Foundation – a consortia of 4 charities that funds the University of Sheffield for the “repurposed cancer therapeutics as treatment for DMD” medical research project.

Godfrey Adams Funding – grant received to further medical research.

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018**

13. Unrestricted funds

	General fund £
At 1 November 2017	191,846
Income	496,099
Expenditure	(589,113)
Transfer	<u>(41,544)</u>
At 31 October 2018	<u>57,288</u>

The General Fund – Funds allocated to pursue the Charity’s aim of finding a cure for Duchenne, bring new medicines for Duchenne to the market and to enable us to continue to campaign for greater standards of care for those with Duchenne.

14. Analysis of net assets between funds

	Fixed assets £	Current assets £	Current liabilities £	Total £
Restricted fund	-	93,564	(14,286)	79,278
Unrestricted funds	<u>1,515</u>	<u>176,166</u>	<u>(120,393)</u>	<u>57,288</u>
	<u>1,515</u>	<u>269,730</u>	<u>(134,679)</u>	<u>136,566</u>

15. Fund Transfers

Funds have been transferred from unrestricted reserves as this relates to Action Duchenne Limited’s annual consortium committed payment of £7,143 to Newcastle CRF. Transfer to De Laszlo Foundation restricted fund from unrestricted reserves of £34,401 relates to the balancing contribution of the Charity towards CHU Outcome Measures after satisfying the conditions attached to the donation.

ACTION DUCHENNE LIMITED
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018

16. Analysis of resources expended

	2018	2017
	£	£
Support costs:		
Bank charges and interest	1,843	2,041
Insurance	1,260	810
Wages and salaries	236,351	223,508
Printing, postage and stationery	8,623	8,726
Training, recruitment and other staff costs	1,319	-
Rent and rates	17,730	19,754
Computer costs	24,275	19,532
Storage	884	884
Telephone and internet costs	11,476	10,662
Depreciation	505	672
Trustees' meetings	3,660	409
Governance costs	<u>7,380</u>	<u>7,949</u>
	<u>315,306</u>	<u>294,947</u>

Grants totalling £209,505 were payable to 6 medical research institutions, as described in note 17.

Support and governance costs are allocated as follows:

	Support and governance £	Direct costs £	Total £
Scientific and clinical research and grants payable 80%	252,245	374,983	627,228
Fundraising 10%	31,531	46,280	77,811
Campaigning and education 6%	18,918	7,413	26,331
Improved management and medical care 4%	<u>12,612</u>	<u>-</u>	<u>12,612</u>
	<u>315,306</u>	<u>428,676</u>	<u>743,982</u>

The allocation has been determined on the basis of time spent by staff.

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018**

17. Grants paid and future commitments

The following institutional grants, in respect of research projects in furtherance of the charitable activities, were treated as grants payable during the year:

	2018	2017
	£	£
Grant – CHU Outcome Measures	44,401	-
Grant – The University of Newcastle	-	50,000
Grant – CSO	24,726	24,726
Grant – University of Oxford	-	48,000
Grant – Sheffield University	60,468	-
Grant – AAV France	-	10,004
Grant – UPPMD membership	905	910
Grant – University Hospitals Bristol NHS Foundation	29,005	17,583
Grant – Royal Holloway University – Gene Therapy	<u>50,000</u>	<u>50,000</u>
	<u>209,505</u>	<u>201,223</u>

The following payments in respect of research projects have been committed to but not provided for in the accounts:

	2018	2017
	£	£
Grant to Steve Winder Foundation	-	60,468
Grant to The Chief Scientist Office	9,064	33,790
Grant to The University of Newcastle	100,000	100,000
Grant to University Hospitals Bristol NHS Foundation	12,260	41,265
Grant to Muscular Dystrophy UK	<u>100,000</u>	<u>350,000</u>
	<u>221,324</u>	<u>585,523</u>

ACTION DUCHENNE LIMITED

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 OCTOBER 2018**

18. Reconciliation of net income / (expenditure) to net cashflow from operating activities

	2018	2017
	Total	Total
	£	£
Net income / (expenditure) for the reporting period	(205,026)	165,902
Adjustments for:		
Depreciation charges	505	672
Dividends, interest and rents from investments	(567)	(1,301)
(Increase) / decrease in debtors	(31,935)	(29,516)
Increase / (decrease) in creditors	<u>(4,833)</u>	<u>(108,744)</u>
Net cash provided by (used in) operating activities	<u>(241,856)</u>	<u>27,013</u>

19. Analysis of cash and cash equivalents

	2018	2017
	£	£
Cash in hand	<u>185,256</u>	<u>426,546</u>
Total cash and cash equivalents	<u>185,256</u>	<u>426,546</u>

20. Commitments under operating leases

The Charity had annual commitments under non-cancellable leases as set out below:

	2018	2017
	£	£
Operating leases which expire: within two to five years	<u>23,671</u>	<u>15,821</u>

LETTER OF REPRESENTATION

CAN Mezzanine
49-51 East Road
Hoxton
London
N1 6AH

Company number 04899036
Charity number – 1101971
Charity number (Scotland) –
SC043852

Simpson Wreford LLP
Wellesley House
Duke of Wellington Avenue
Royal Arsenal
London
SE18 6SS

Date 25 July 2019

Dear Sirs

Action Duchenne Limited

We confirm, to the best of our knowledge and belief, the following representations of this charity's financial statements for the year ended 31 October 2018.

1. Responsibility

We have fulfilled our responsibilities as directors/trustees under the Companies Act 2006 for preparing financial statements, in accordance with FRS 102, that give a true and fair view and for making accurate representations to you as auditors.

We confirm that all the accounting records have been made available to you for the purpose of your audit, in accordance with your terms of engagement, and that all the transactions undertaken by the charity have been properly reflected and recorded in the accounting records. All other records and related information, including minutes of all management meetings, have been made available to you. We have given you unrestricted access to persons within the Charity in order to obtain audit evidence and have provided any additional information that you have requested for the purposes of your audit.

We confirm that significant assumptions used by us in making accounting estimates, including those measured at fair value, are reasonable.

We confirm that all known or possible litigation and claims whose effects should be considered when preparing the financial statements.

We acknowledge our responsibility for the design and implementation of internal controls to prevent and detect fraud. We confirm that we have disclosed to you the results of our own risk assessment that the financial statements may be misstated as a result of fraud.

We confirm that there have been no actual or suspected instances of fraud involving management or employees who have a central role in internal control of that could have a material effect on the financial statements. We also confirm that we are not aware of any allegations of fraud by former employees, regulators or others.

We confirm that we are not aware of any possible or actual instance of non-compliance with those laws and regulations which provide a legal framework within which the charity conducts its activities and which are central to the charity's ability to conduct its activity.

2. Current assets

All current assets are considered to have a value on realisation in the ordinary course of the charity's activity at least equal to the amounts at which they are stated in the Balance Sheet.

3. Fixed assets and capital commitments

The value of fixed assets shown in the Balance Sheet is arrived at after including all capital expenditure, but excluding revenue expenditure, and making adequate, but not excessive, provision for depreciation and obsolescence. The basis of such provision remained unchanged since the previous year. All such assets are currently used or required for use in the charity's activity. We confirm that the charity has not contracted for any capital expenditure other than disclosed in the financial statements.

4. Ownership of assets

- a. All tangible assets owned by the charity are included in the Balance Sheet.
- b. All the assets recorded in the charity's books and shown in the accounts are owned by the charity and are free from any charges exercisable by third parties.

5. Matters having a material effect on financial statements

There have been no matters that could have a material effect on the financial statements in the nature of:-

- a. Irregularities involving management or employees, or
- b. Communications from regulatory agencies concerning non-compliance with or deficiencies in financial reporting practices.

Also, there are no plans or intentions that may materially affect the present book value or classifications of assets and liabilities.

6. Liabilities and provisions

All established liabilities at the Balance Sheet date are included in the accounts and there were no known contingent liabilities at that date.

7. Trustee loans and securities

We confirm that the charity has had, at no time during the year, any arrangement, transaction or agreement to provide credit facilities (including loans, quasi-loans or credit transactions) for trustees, nor to guarantee nor provide security for such matters.

8. Subsequent events

We confirm that there have been no events since the balance sheet date which require disclosing or which would materially affect the amounts in the financial statements, other than those already disclosed or included in the financial statements.

10. Accounting policies

The basis of accounting used in preparing the accounts is consistent with that used in the previous period and acceptable under current UK GAAP.

11. Related parties

We confirm that we are aware that a related party of the charity is a person or organisation which either (directly or indirectly) controls, has joint control of, or significantly influences the charity or vice versa and as a result will include: trustees/directors, other key management, close family and other activity interests of the previous. We confirm that there are no further related party disclosures necessary to be made in the accounts.

12. Future cash requirements

In our opinion, the charity will have adequate cash resources available to finance operations during the course of the twelve months following the foregoing Balance Sheet date.

We confirm that having considered our expectations and intentions for the next 12 months and the availability of working capital, the charity is a going concern.

13. We confirm that we are not aware of any matters of material significance that should be reported to the Charity Commission.

15. We confirm that all grants, donations and other income, including those subject to special terms or conditions or received for restricted purposes, have been notified to you. There have been no breaches of terms or conditions during the period regarding

the application of such income. The balances on restricted funds carried forward at 31 October 2018 are £79,278.

16. **Fund Transfers**

We confirm that the following fund transfers have been approved by us and are appropriate.

Transfers to restricted funds

De-Laszlo Foundation	34,401
Newcastle CRF	7,143

Transfers from unrestricted funds

Unrestricted funds	(41,544)
--------------------	----------

17. **Unadjusted errors**

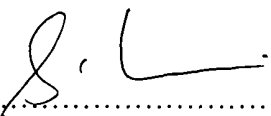
We confirm that the effects of unadjusted misstatements are immaterial, both individually and in aggregate, to the financial statements as a whole. A list of unadjusted misstatements is attached to this letter as Appendix 1.

We acknowledge our legal responsibilities regarding disclosure of information to you as auditors and confirm that:

- So far as each trustee is aware, there is no relevant audit information of which you as auditors are unaware; and
- Each trustee has taken all the steps that they ought to have taken as a trustee to make themselves aware of any relevant audit information and to establish that you are aware of that information

We confirm that the above representations are made on the basis of enquiries of management and staff with relevant knowledge and expertise, sufficient to satisfy ourselves that we can properly make these representations to you and that the best of our knowledge and belief they accurately reflect the representations made to you by the trustees during the course of your audit.

Yours faithfully
For and on behalf of
Action Duchenne Limited



.....

25 July 2019